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The Experience of "Doing Well" in Older Nursing Home Residents: Bringing the Past to the Present

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THE EXPERIENCE OF “DOING WELL” IN OLDER NURSING HOME RESIDENTS: BRINGING THE PAST TO THE PRESENT

by

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[redacted]

To the memory of my father,
Joseph P. Walent, Sr.

and

To my mother,
Virginia E. Walent,
with gratitude for her continued loving presence.

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THE EXPERIENCE OF "DOING WELL" IN OLDER NURSING HOME RESIDENTS: BRINGING THE PAST TO THE PRESENT

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ABSTRACT

Though discussions of well-being and quality of life for older adults in American nursing homes have flourished over the past decade, relatively few studies have explored these notions from the perspective of older residents themselves. The purpose of this research is to understand experiences and perceptions of "doing well" in older nursing home residents.

Using interview, observational and interpretive methods, this qualitative study explored the phenomenon of "doing well" from the perspective of frail older adults (>=65 years old) living in two nursing homes, one private for-profit and the other government sponsored. Data were collected in three overlapping phases: (a) initial interviews exploring the participants' experiences and perceptions of how well they are doing, (b) participant observation focusing on daily activities and experiences of residents and the environment of the nursing home, and (c) follow-up interviews to clarify understandings of doing well that surfaced during the initial interview and observation phases.

Data analysis resulted in identification of an over arching theme, *bringing the past to the present,* and three sub themes: (a) *familiar territory*, (b) *family bonds*, and (c) *settled in.* Major factors that facilitated doing well included *advocacy, control of discomfort,* and *breaking the routine*. Findings prompted fusion of reinterpreted concepts from the life course capital (LCC) discourse with Kayser-Jones' nursing home environment framework to develop a heuristic for understanding biographically informed resources that residents rely on to do well.

This study is a first step in understanding what it means for residents to “do well” in a structured long-term care setting. Discerning factors related to the experience of doing well may provide a foundation for development of health care policies and direct caregiver approaches that support the transition and adjustment of older adults to congregate living environments and contribute to subjective quality of life.

TABLE OF CONTENTS

Chapter One

Chapter Two

Chapter Three
ACCESSING EXPERIENCE, AUTOBIOGRAPHY AND ENVIRONMENT: METHODOLOGY FOR A STUDY OF DOING WELL IN A NURSING HOME.. 68

Chapter Four
LIVES IN CONTEXT: OVERVIEW OF STUDY SITES AND PARTICIPANTS…. 83

Chapter Five

Chapter Six

Chapter Seven

LIST OF TABLES

LIST OF FIGURES

Chapter One

QUALITY OF LIFE AND RELATED STATES OF WELL-BEING AMONG OLDER NURSING HOME RESIDENTS

Introduction

Situating the Issue

Epidemiological forecasts, though controversial, suggest that despite advances in biomedical treatment modalities and delivery systems, the number of frail elders transitioning to care in supportive settings such as nursing homes, group homes or assisted living environments is likely to increase by as much as 25% during the first half of this century (Edlund, Lufkin, & Franklin, 2003; Harrington, Chapman, Miller, Miller, & Newcomer, 2005; Lakdawalla, Bhattacharya, & Goldman, 2003; Lakdawalla, Goldman et al., 2003; Manton, 2003; Williamson, 2003). Though there is disagreement on the numbers of various types of supportive settings that will be needed, it is unlikely that nursing homes will be disappearing in the near future. Given these projections, and despite reports of modest improvement in nationally aggregated quality outcomes related to pressure sore incidence, prevalence of urinary catheters and restraint use (Zhang & Grabowski, 2004), it is distressing that many American nursing homes have continued to suffer from the same deficits in quality care that were identified in the mid 1960's (Bates-Jensen, Schnelle, Alessi, Al-Samarrai, & Levy-Storms, 2004; Diamond, 1992; Gass, 2004; Gubrium, 1975; Harrington, Carrillo, & Crawford, C. 2005; Henry, 1963; Kayser-Jones, 1981; Kayser-Jones & Schell, 1997; Kayser-Jones, Schell, Porter, Barbaccia, & Shaw, 1999; Schnelle, Bates-Jensen, Chu, & Simmons, 2004; Schnelle et al., 2003; Wunderlich & Kohler, 2001).

On the positive side, in the midst of continuing quality problems in the nursing home industry, innovative approaches and demonstration projects to revamp prevailing systems of care delivery and enhance quality outcomes have periodically emerged (Baker, 2005; Lustbader, 2001; Rabig, Thomas, Kane, Cutler, & McAlilly, 2006; Thomas, 1996). Unfortunately, in many cases efforts to gauge the relative success of innovations in care delivery have been hampered by inadequate facility quality improvement infrastructures (Adams-Wendling & Lee, 2005) and a lack of sound methods for evaluating the effectiveness of evolving models of care, especially from the standpoint of direct recipients of services (R. A. Kane et al., 2003; Wunderlich & Kohler, 2001).

Correspondingly, tailoring individualized interventions and ways of caring to support older adults transitioning to nursing homes and to sustain their well-being requires attention to the constituents of quality at the caregiver-resident interface. Yet reports indicate that many caregivers lack an adequate understanding of the numerous intersecting factors that contribute to a resident’s doing well (Katz & Gurland, 2001). This mode of interpersonal competence requires sensitivity not only to quality indicators as defined by regulators and researchers but, more importantly, to each resident’s lived understanding of a quality life.

Facets of Nursing Home Quality.

In attempting to refine the notion of nursing home quality, research and commentary to date have focused mainly on empirical outcomes related to quality of care (QOC), with much less attention paid to the status of resident quality of life (QOL). In contrast to QOC, the QOL construct and related concepts elude discrete regulatory and operational definition hindering the construction of integrated datasets useful for regulatory activities (R. L. Kane, 2001). Nonetheless, several quantitative studies (reviewed below) have explored discrete variables associated with a resident's sense of well-being, life-satisfaction or morale. In particular, factors related to control, choice, self-determination and social interaction have emerged as areas of focus. Only recently, has government funding been earmarked to support investigation and development of quantitative QOL assessment strategies aimed at identifying, gauging and aggregating variables related to well-being among nursing home residents (R. A. Kane et al., 2004; Wunderlich & Kohler, 2001).

Turning to qualitative research, several outstanding works have examined issues of resident well-being in the context of principal investigators' major interests (Diamond, 1992; Gubrium, 1975, 1993; R. L. Kane, 2001; Kayser-Jones, 1981; Savishinsky, 1991; Shield, 1988). Ethnographic and other qualitative approaches have provided insight into facility, caregiver, and resident factors that bear on a resident's doing well, and in many cases have stimulated the process of policy change (Kayser-Jones, 2003a).

Overview of Goals and Direction

On the whole, well-being among older nursing home residents has proven to be an elusive concept. Some have characterized well-being and QOL (Kahn & Juster, 2002) as comparable terms; others have identified well-being in terms of life satisfaction, morale or happiness (Stock, Okun, & Benin, 1986). Acknowledging the close correspondence among these concepts, the following review summarizes and critiques site specific research on life satisfaction, morale and other QOL related terms used to described subjective well-being. A final goal is to identify controversies and gaps in the present understanding of QOL (or here, what it means to "do well") as a nursing home resident, and to propose directions for future research.

For the purpose of this discussion, "doing well" is a broadly cast term used to describe a generally positive disposition toward one's lived experience. The theoretical underpinnings of this description will be articulated in chapter two. Perceptions and characteristics of "doing well" will be further elaborated in subsequent findings and discussion chapters.

Review of the Literature

Quality of Life and Well-Being: Framing the Review

Assumptions

Investigators agree the construct "quality of life" remains elusive and ill defined (Rapley 2003). Consequently, sorting out nursing home QOL and its allied concepts requires taking a stance on generic QOL issues that remain open for debate. Therefore, forgoing an extended discussion of the controversies that surround QOL research in general, review and critique will be framed by the following assumptions.

First, QOL is conceived of as a "measurable" or describable "aspect of individual subjective experience," rather than a broader measure of "the well-being of whole populations" (Rapley, 2003, p. 3). In Rapley's initial mention of "measurable" aspects of QOL, it is possible to infer preeminence of quantitative methodologies. Including the term "describable" clarifies the scope of review, ensuring inclusion of research from a broad range of qualitative traditions. "Description" includes insight into QOL, well-being and ancillary concepts conveyed directly by residents or others in the nursing home environment (emic standpoint). Situating the construct in the subjective realm supports a review that is clearly centered on the individual’s report of QOL and its constituents, regardless of the issue of measurability (R. A. Kane, 2001).

Second, critique is based on the premise that the constellation of concepts that comprise QOL designates a maintainable “state”—albeit a potentially mutable state—rather than a “process” (Rapley, 2003). Justification for this approach hinges on theoretical work on successful aging by Baltes (1994) who characterizes “successful aging as the process(es) of reaching the criteria or goals, which in turn, then ensure *maintenance of quality of life* [italics added].” (p. 186).

Third, this review will not address disease specific or heath related quality of life (HRQOL) measures and research. Unlike more global concepts of QOL, research in HRQOL typically requires that respondents rate quality of life in the context of identified disease or disability. The focus is on how health status related domains affect quality of life, a strategy that, while helpful in determining the effects of disease and treatment on an identified population, tends to overlook the complex interplay of social and environmental factors essential for a comprehensive QOL construct (Rapley, 2003; Stewart & King, 1994)

Fourth, recognizing both the variability in prevailing definitions of QOL and well-being and their multi-dimensional natures, this review may refer to differing theoretical frameworks but will not attempt to reconcile underlying conceptual differences between these frameworks.

Search Strategy

Several complementary approaches were used to identify literature appropriate for review. Initially, searches of PubMed, CINAHL and PsychINFO databases focused on combinations of the umbrella terms “nursing homes” and “aged” with the terms “quality of life,” “life satisfaction,” “morale” and “well-being.” Results were screened to include only English language research in peer-reviewed journals. Available articles that included a tool or strategy involving resident self-report of some aspect of well-being and that dealt with life in a United States (US) nursing home were retained for in-depth critique. Studies that focused on HRQOL constructs related to specific disease states (e.g., arthritis, cancer, dementia) were eliminated. Exceptionally strong research undertaken in countries with nursing home cultures similar to those found in the US (e.g., Australia and Canada) was included. Reference lists from the selected works were searched for additional reports germane to the review, providing leads to book length nursing home ethnographies and other qualitative works that employed interview methods. A check of references, endnotes, and bibliographies to capture works that might have been overlooked completed the search strategy. Throughout the process only literature that provided insight into a resident’s subjective state of well-being was retained. This strategy resulted in 29 quantitative research reports and 12 book-length ethnographies or qualitative reports that provide the basis for this review.

Quantitative Approaches: Defining and Measuring Well-Being

Correlates, and Predictors of Well-being and Related States

Comparative studies. Research on well-being in nursing homes has focused mainly on the constraining effects of the environment and issues of choice, control or autonomy. Several studies have relied on designs that compared the life satisfaction or morale of nursing home residents with that of older adults in other settings. In comparing residents in a retirement (nursing) home with those in a retirement village, Wolk and

Telleen (1976) found that the more constraining environment of the retirement (nursing) home was associated with lower life satisfaction and lower developmental task accomplishment. In this setting, satisfaction was related to level of perceived health and resident resolution of Havinghurst's (1972) developmental tasks. Notably, though perceived level of autonomy and self-acceptance were significantly associated with self-satisfaction in the less constraining setting of the retirement village (housing), there was no such correlation in the more restrictive retirement home environment. Successful developmental task accomplishment predicted life satisfaction in both settings. The authors speculate that greater opportunity and need to exert oneself in a less restrictive setting may provide the impetus for perceived autonomy to emerge as a significant correlate of satisfaction. Researcher commentary indicates that given the size (n = 129) and homogeneity of the sample (100% Caucasian from 2 sites), and the restricted number of variables entered into regression models, findings are too limited to apply extensively. Nevertheless, the study called into question the importance of perceived autonomy for nursing home residents, suggesting a need for further investigation.

Queen and Freitag (1978) explored the differences in control, anxiety and life satisfaction between 20 active community dwelling older adults (aged 67 to 86) and 20 nursing home residents (aged 60 to 95). Active older adults were significantly less anxious, expressed higher life satisfaction and displayed a more internal locus of control than nursing home residents. The strength of the study is difficult to assess since the characteristics and psychometrics of the life satisfaction instrument were not presented, the study sample was small and inadequately described, and the analytic approach vague and incompletely developed. Despite the shortcomings of the report, findings concur with research supporting the association of an internal locus of control with increased life satisfaction.

In a longitudinal study, Oktay and Volland (1987) found that while frail elders receiving foster home care (n = 24) demonstrated greater improvement in activities of daily living (ADL) function and better cognitive scores than those in nursing homes (n =21), nursing home residents scored higher on the Life Satisfaction Index-Z (LSI-Z) and displayed greater participation in social and recreational activities. Though randomized, the study was small and the interpretation of confidence interval data questionable. In addition, the LSI-Z demonstrated poor interrater reliability (.52). Commenting on the respondents' appraisals of life satisfaction, the authors posit that in rating LSI-Z items the foster home group may have been using the healthy caregiver as a reference point for response, whereas those in the nursing home may have been using fellow residents for comparison. This may have contributed to lower scores in the foster home group. Though the study lacks generalizability, commentary on life satisfaction appraisal suggests the need for further investigation of how the dynamics of comparison influence subject responses to life satisfaction items.

Given and Range (1990) compared nursing home residents and public housing residents using the Philadelphia Geriatric Center Morale Scale (PGCMS) and a measure of death anxiety and found no statistically significant difference, despite more frequent reports by nursing home residents that they expected to be dead within the next five years. As with many of the aforementioned comparative studies, the sample size was small (n = 50), the settings represented were limited (a single nursing home and two public housing sites), and possible confounding variables were either not identified or not well controlled. Salamon (1987) reported similar results in a study of life satisfaction in 241 older adults from six different types of heath care settings. Responding to a researcher-developed instrument based on the LSI, residents living in residential intermediate care or nursing home settings reported higher life satisfaction than older adults receiving health-related services in clinics, physician's offices, senior centers or hospitals. Results may have been affected by a convenience sampling strategy that favored selection of higher functioning individuals from the residential settings. Even discounting the effect of methodological problems in these studies, the use of a simple comparative design, though appropriate for describing similarities and differences, provides little insight into the underlying reasons for variations between groups.

Moving beyond prevailing basic nursing home versus non nursing home study designs, Vallerand, O'Connor and Blais (1989) used four groups to examine associations between life satisfaction and control and self-determination in Canadian community dwelling older adults and nursing home residents, all aged 65 or older. Subjects were randomly chosen from senior centers and randomly selected nursing homes from across greater Montreal. Nursing homes were categorized as providing high or low self determination based on amount of resident choice regarding mealtimes, level of involvement of staff in personal care, residents' freedom to personalize their rooms, permission to have or care for pets and the degree to which staff encouraged resident initiative. The study sample was divided into four comparison groups: residents in regular community housing (n = 50), in low-cost community housing (n = 50), in high self-determination nursing homes (n = 52) and in low-self determination nursing homes (n = 52). Data were collected on age, sex, education, income and self-rated health. The outcome measure, a French translation of the Satisfaction With Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985), demonstrated an acceptable level of internal consistency in this study (Cronbach's alpha = .80).

Results indicate that residents in low self-determination nursing homes reported significantly lower life satisfaction than those in other settings. Correlation and analysis of covariance showed no significant effects related to demographics or other variables. The study supports a relationship between resident life satisfaction and environmental factors that inhibit or foster self-determination. Though findings are not generalizable to residence alternatives available to older adults in the US, they do highlight the need to consider the influence of environmental characteristics on self-determination as a correlate of life satisfaction. Particularly noteworthy is use of a research design that moves beyond earlier simple comparisons between community settings and nursing homes as discrete homogenous environments. The methodological shift to examine internal characteristics of each setting and subsequent findings underscore the need for further investigation of how specific environmental features affect a resident's experience of well-being.

Control and well-being. A significant body of work has examined the relationship between control and well-being among nursing home residents. Puzzled by earlier findings of Felton and Kahana (1974) that suggested a positive association between *external* locus of control and increased morale (PGCMS) in institutionalized older adults, Fawcett, Stoner and Zepelin (1980) studied 56 female residents, aged 67 to 95, of two proprietary nursing homes and arrived at an opposite conclusion: belief in an *internal* locus of control (personal influence) was found to be associated with increased life satisfaction (LSI-Z) and inversely related to the perception of environmental constraint. In their critique of the earlier study the authors suggest that differences in measures of locus of control may have led to the contradictory findings. Making a case for the comparability of the well-being measures used in these studies (PGCMS versus LSI-Z) the authors suggest that the earlier Felton-Kahana measure of perceived locus of control may not have adequately reflected the control construct. Contradictory findings suggest a need for further refinement and testing of key concepts such as locus of control and outcome measures of well-being, especially in nursing home residents.

Using the PGCMS as an outcome criterion, Chang (1978) investigated locus of control, perception of control and well-being in 30 cognitively intact skilled nursing home residents aged 65 to 96. Results suggest that higher perceived situational control of daily activities (SCDA) was related to increased morale regardless of locus of control orientation (internal, external associated with a powerful other, external associated with chance). Residents with self-determined SCDA scored higher in morale than those with other-determined SCDA. Despite study limitations related to small sample size and single setting, this examination of the interplay between locus of control (as a generalized expectancy related to previous life experiences) and situational perception of control and their relationship to morale intimates that appreciation of the tension between life long orientations and present situations may be central to an understanding of a resident's experience of subjective well-being.

Ryden (1984) examined causal relationships between perceived control (SCDA) and morale (PGCMS), and explored direct and indirect effects of socioeconomic status, functional dependency and length of institutionalization on morale in randomly selected, older, intermediate care residents (n = 59) and skilled care residents (n = 54) from four proprietary urban nursing homes. Results indicated that residents at the intermediate care level experienced less functional dependency, and saw themselves as more in control of their daily activities than those receiving skilled care. Path analysis of causal models developed from relationships supported by prior research suggested that perceived control was significantly related to morale for both groups of residents, though functional dependency, socioeconomic status and self-rated health demonstrated direct effects on morale only among intermediate care residents. These results suggest the possibility that interventions aimed at increasing perceived control may have a beneficial effect on the morale for residents in both settings.

Rooted in social learning theory, a later study by Bowsher and Gerlach (1990) explored predictors of psychological well-being among a convenience sample of 302 cognitively intact nursing home residents aged 65 years or older. Independent variables included expectancy of control, reinforcement value, self rated health, functional health, socioeconomic status, length of stay and age. According to social learning theory, “personal control is the expectancy (EC) that a particular reinforcement (RV) will occur as the result of one’s own behavior (BP) within a specific psychological situation (S)” (Bowsher & Gerlach, 1990, p. 92). Thirty-three percent of the variance in psychological well-being (operationalized through a composite score derived from LSI-A and the Bradburn Affect Balance Scale) was explained by expectancy for control (19%), reinforcement value (11%) and self rated health (4%) supporting the significance of personal control for life satisfaction. The authors recommended fostering situations and activities in the nursing home in which resident’s expectancy of control has already been established, as well as conditions that promote reinforcement value or outcomes desired by the resident. Results support previous findings of a relationship between a sense of personal control and psychological well-being.

Additional studies of the relationship between control and well-being have produced conflicting results. In a study evaluating differences in control beliefs between homebound elders (n = 37, mean age = 84.2) and nursing home residents (n = 37, mean age = 82.4), Crain (2001) found that both groups had similar high levels of life satisfaction (LSI) despite lower perceived internal control scores in the nursing home group. In addition, life satisfaction showed no relationship to length of stay or to level of perceived control among nursing facility residents. Crain theorizes that results may be explained by nursing home resident accommodation to a more controlling environment. In contrast, exploring the effects of relocation on nursing home residents, Tickle (1993) found a significant relationship between internal control (as perceived control of health) and life satisfaction (LSI). One possible explanation for these differences is that these studies, as is the case with much nursing home research on well-being, are based on relatively small samples drawn from settings that may vary greatly despite the uniform label "nursing home." Likewise, facility admission criteria that consciously or unconsciously screened for particular resident characteristics may have contributed to variability between sampled groups. Nonetheless, despite their small sizes, limited sampling scopes and other methodological shortcomings, these studies suggest potential benefits from continued investigation into the relationship between residents' perceptions of control and well-being.

Social relationship factors. Exploring other potential correlates of well-being among nursing home residents has uncovered additional factors worthy of consideration for inclusion in multidimensional QOL constructs. One particularly productive research thread has examined resident social interaction, intimacy and privacy.

In researching the relationship between facility size and resident isolation and life satisfaction (LSI), Curry and Ratliff (1973) studied 200 elderly nursing home residents in 26 Ohio nursing homes stratified according to size: small (49 or fewer beds), intermediate (50 to 99 beds) and large (100 or more beds). Residents' per month number of contacts with family and friends were tallied and rated on a one to four scale as a measure of isolation. Researchers reported that demographic and background profiles of the three study groups were comparable. Results revealed residents in smaller homes had significantly more friends within the home and more contacts with those friends, whereas those in intermediate and large homes had more contact with visiting relatives. Neither nursing home size nor level of isolation (contact with friends or relatives) proved to be significantly related to life satisfaction. The authors speculate that this finding may be explained by the number and complexity of potential factors contributing to life satisfaction, stating that though "isolated residents may be very lonesome and unhappy with their current isolation, they may still be relatively satisfied with other areas of their life." (p. 298). It is possible that confounding effects of staff interaction, social activities and environmental characteristics (e.g. constraint) may have influenced results. In any case, study findings and commentary underscore the need for an integrated multidimensional approach to advance investigation of life-satisfaction and other well-being related constructs.

In a carefully crafted study focusing on interpersonal relationships of 332 residents (mean age = 83.47, SD =7.38) from 54 Wisconsin nursing homes, Bitzan and Kruzich (1990) discovered that 95% of the residents reported having significant relationships, 58% reported having someone close within the facility, and around 90% indicated having a close person outside the facility. About 36% of all residents identified another resident as someone they were close to. Residents with difficulty hearing or ambulating were less likely to identify a friend within the facility. While no significant relationship was demonstrated between having someone close outside the home and life satisfaction (LSI) or level of satisfaction with nursing home life, being close to one's roommate was significantly related to satisfaction with the nursing home, life satisfaction (LSI), affect and social support (ANOVA, $p < .01$). In addition to the main results on life satisfaction, findings related to the effect of hearing and ambulation on resident intra-facility relationships support the need to identify and address the direct or indirect effects of resident characteristics (e.g., function, capacity) on well-being.

Kovach and Robinson (1996), examined peer relationships among 50 older residents (age $\geq$ 75 years) in Southwest Ohio nursing homes and found that 20 of these residents did not talk to their roommates. A simple regression on data from residents who did talk to their roommates indicated that rapport with roommates explained 23% of the variance in life satisfaction. Not surprising, no relationship between rapport and life satisfaction was discovered for residents who did not talk to their roommates. The study corroborates findings by Bitzan and Kruzich (1990) and reiterates the importance of support for resident relationships in promoting resident well-being.

In a study of intimacy in 45 male veterans home residents (mean age = 70 years, SD = 10.5), life satisfaction (LSI-Z) was found to be significantly related to the level of importance respondents attached to intellectual intimacy, non-sexual physical intimacy, and social intimacy and to current experiences of intimacy but not to reported importance of sexual-physical intimacy (Bullard-Poe, Powell, & Mulligan, 1994). Reliance on a convenience sample of small size and the use of an untested tool to evaluate intimacy may have compromised validity and seriously limited the generalizability of these findings. Results warrant further investigation of intimacy as significant component of a social relations dimension of resident well-being.

Additional Factors Related to Well-Being. Though most well-being research among nursing home residents has concentrated on control and social relations, studies have also identified significant associations between reports of subjective QOL and factors such as environmental intrusiveness (Firestone, Lichtman, & Evans, 1980), cherished possessions (Sherman & Newman, 1977), meaningful task participation (MacDonald & Settin, 1978), and religious coping and intrinsic religious activity (Ayele, Mulligan, Gheorghiu, & Reyes-Ortiz, 1999). Due to small size, sampling strategies, and the issue of controlling for potential covariates and confounds, many of the findings in these studies have limited generalizability and tentative validity. Nevertheless, viewed as a whole, this research demonstrates the range and complexity of possible factors associated with the well-being construct.

Examinations of multiple correlates. In attempting to probe the issue of complexity, several studies have investigated constellations of factors and their relationship to nursing home residents’ well-being or QOL. Harel and Noelker (1982) examined the relationship between social integration, demographic variables, self rated health, mobility, feelings about entry and desired residence, and “well-being.” Well-being was operationalized using three self-report measures: morale (PGCMS), life satisfaction and satisfaction with treatment (care). The study examined 125 resident interviews from 14 Cleveland nursing homes representing public (n = 30), proprietary (n = 51), and non-profit (n = 44) sectors. Most residents rated their health as good or fair, and most were ambulatory, relatively high functioning and interviewable. Social integration was measured using ten questions that probed the type, quality and perception of social connections within and outside the facility. Resident scores tended to be above the scale midpoint on measures of morale (60%) and life satisfaction (53%). The three well-being measures correlated moderately well with one another (r = .37 to .47). Six variables demonstrated significant association with well-being measures: self related health, preference to live in the facility, positive feelings about entry, having preferred visitors, receiving assistance from family and friends, and participating in facility social activities. Measures of mobility, giving assistance to others and number of visitors demonstrated significant correlation with two of three thee well-being measures. Both positive feelings about entry and desire to continue living in the facility were associated with well-being measures, supporting the notion that resident choice and perceived control are important for satisfaction and morale. Another major finding was that residents who receive ongoing attention and assistance from preferred significant others experience higher levels of well-being. Harel and Noelker’s research foreshadowed several important dimensions included in later satisfaction and quality of life scales, in particular, autonomy, choice and relationships.

Work by Harel (1981) related to the previously reviewed study (Harel & Noelker, 1982) underscored the close relationship between quality of care and quality of life related concepts such as well-being. This analysis explored the influence of congruence between resident needs and the nursing home environment on well-being. Residents from the same sample described above (Harel & Noelker, 1982) were asked to rate items describing seven dimensions (continuity of things, continuity of people, integration into the facility, personal life space, personal responsibility, need gratification-food, and social need gratification) in terms of quality importance (importance for the resident), quality of care (actual presence of the indicators of care), congruence (if the item was not present would the resident like to have it). Significant correlations and multiple regression models supported the importance of continuing ties with significant others, maintaining personal responsibility, and gratification of personal and social needs in fostering well-being. Overall quality of care and congruence (resident need and capacity of the environment to provide it) proved to be more important to well-being than the perception of the importance of a dimension. “Continuing ties with preferred members of one’s social network” emerged as a factor of primary importance in determining resident well-being. In this early study, Harel interprets this finding as reinforcing the need for improvement in the psychosocial care of nursing home residents and proposes the development of “resident services departments” to better address psychosocial needs. In general, the study supports connections among resident social needs, the ability of the nursing home to address these needs and the resident’s sense of well-being.

Drawing on previous research suggesting several discrete correlates of well-being, Pearlman and Uhlmann (1988) relied on a multidimensional orientation and associated measurement strategy to compare QOL in nursing home residents with that of community dwelling older adults. Forty-seven subjects from each setting were age and sex matched. Nursing home residents tended to be less educated, more likely widowed or divorced, and more likely to have visited a physician or been hospitalized in the six months previous to the study. Subjects were asked to complete a single six-point Likert scaled item to determine global QOL. They were also asked to rate how 33 attributes affected their QOL using a 4-point Likert scale. Attributes were chosen to reflect QOL categories derived from social science literature: “memory, mood, physical health, functional ability, interpersonal relationships, psychological well-being, life satisfaction, participation in religious activities, environmental comforts, and physical discomfort” (p. 322). Factor analysis was used to distilled attributes into seven factors: depression, health, memory, anxiety, finances, residence and interpersonal relationships. But, since factor analysis values were not presented, it is difficult to critique the fit of these factors to the QOL construct.

Participants also reported events they felt had reduced or increased quality of life over the previous year. Codes were derived from these event lists by research staff, and the two researchers in turn independently categorized the events using these codes. Agreement was achieved in approximately 85% of the cases. A third reviewer mediated differences. Participants provided data on age, marital status, physical function, chronic diseases, and health care over the previous year. This last item included two 5-point Likert scales, one requiring participants to rate health compared to similar others, the other eliciting participants’ self-reported “absolute health.”

Nursing home residents tended to rate their global quality of life positively: 36% rated it “about as good as it could possibly be,” 25.5% rated it “good enough no complaints” and 19.1% reported it to be “fair, good enough to manage.” Approximately 47% of the residents reported their health as “not good at all” yet only 21.3% indicated they believed it to be worse than most individuals of the same sex and age. In rating disability, 65.9% reported they experienced real or serious limitations in activity. Finances (42.6%) and physical health (29.8%) were most frequently reported as limiting resident quality of life.

Paired t-tests were used to analyze differences between nursing home residents and community dwellers in mean ratings of factors reported to affect QOL. Recent events that residents reported contributing to QOL centered on the beneficial aspects of housing (the nursing facility) and interpersonal relationships. Ironically, housing in the nursing home and interpersonal issues also emerged as important recent events that decreased QOL. In addition residents reported functional impairment as an important recent event that decreased QOL.

There was no statistically significant difference in Global QOL ratings between persons living in the community and nursing home residents; the mean for both groups landed between good and fair on the 6-point scale. There were few differences between the groups on most socio-demographic and health variables and factors reported to affect QOL. However nursing home residents did report significantly more disability. Analysis also indicates that resident QOL was more affected by place of residence and less influenced by relationships than those living in the community.

Turning to correlation, for nursing home residents, only problems with finances, residence and memory were associated with worse self–reported QOL. For those residing in the community difficulties with anxiety, finances and health were correlated with worse QOL. Stepwise regressions for each group probed the relationship between participant characteristics and self-reported QOL, and between reported factors affecting QOL and self-reported QOL. For nursing home residents, education, finances and residence emerged as significant independent predictors of global QOL, while for persons residing in the community, the predictors identified were anxiety, and finances.

The authors acknowledge the limitations of using a single item global QOL measure as the outcome, citing the complexity of the construct and calling for further research into the relationship between identified and emerging QOL dimensions and a global QOL measure. Though the study is limited by size and location, it suggests that prevailing beliefs about dismal QOL in nursing homes may be overstated, especially for the non-demented:

> From an observer's perspective, many facets of long-term care, such as losses of external supports, autonomy, and function, reflect a diminution of quality of life. However, nursing home residents appear to have adapted to their environment insofar as they rate their quality of life nearly comparable to that of their community peers. (Pearlman & Uhlmann, 1988, p. 327)

In the nursing home group, the disparity in responses related to residence is of particular interest. Though the majority of residents report living in a nursing home as having negative or neutral effect on QOL, nine of the residents viewed life in a nursing facility as contributing to their QOL. This finding supports the need for further investigation into the meaning of nursing home residence as a positive life event.

Overall, the studies reviewed thus far suggest that residents' perceptions and reports of QOL or well-being admit of great complexity and variability, defying simple categorization or uniformly applicable causal explanations. Thus, for any individual the experience and subsequent report of well-being may be rooted in an intricate array of personal experiences and meanings, not easily captured by quantitative research tools

Nursing Home Specific Measurement Development

As evident in the preceding review, quantification of well-being has relied heavily on morale and life satisfaction instruments (PGCMS, LSI, SWLS) developed for a general population of aging adults. In attempting to address the issue of complexity, efforts to develop ways of measuring dimensions of satisfaction and QOL in the nursing home population have begun to clarify critical issues and unique aspects of well-being of consequence for older residents. Until recently, measurement instruments related to well-being and QOL specific to nursing homes have been limited chiefly to agency or government sponsored satisfaction surveys supporting quality improvement efforts (Robinson, Lucas, Castle, Lowe, & Crystal, 2004). As Robinson and colleagues note, given that there is no widely accepted theory of resident satisfaction or associated body of empirical evidence, development of facility satisfaction tools has been haphazard. Nonetheless, research aimed at standardizing self-report instruments has begun to address the multidimensional nature of the subjective component of QOL.

Measuring satisfaction. Citing the protracted length of stay and chronic health conditions among nursing home residents, Ryden and colleagues (Ryden et al., 2000) suggest that the dimensions of satisfaction in nursing homes differ significantly from those in acute care settings. As part of a larger study, "Cost-Effective Quality: Improving

Resident Outcomes," the Satisfaction with the Nursing Home Instrument (SNHI) was developed and evaluated as one of the outcome measures to gauge the effectiveness of an intervention in which gerontological advanced practice nurses supported staff in implementing protocols to address pressure ulcers, incontinence, depression and aggression. The initial tool consisted of 49 yes/no questions each related to one of seven dimensions (respect for resident values and preferences, information, physical care, psychological care, family involvement, satisfaction with care providers, satisfaction with the environment). Instruments also included one global question ("Overall how would you rate the quality of care you receive in this nursing home?") scored on a poor-fair-good-excellent scale.

Content validity was addressed through an initial literature review and analysis to acquire relevant items. Items were confirmed and modified first by a panel of five experts and then by five resident focus groups drawn from members of nursing home resident councils.

An aim of this study was to explore construct validity using correlations with morale (predicted to be positive) and depression (predicted to be negative). Correlations between the SNHI score and age and mental status were examined to determine divergent validity. Lack of correlation would support validity since no prior theoretical or empirical work suggested an association between satisfaction and mental status or age.

Subjects (n = 110, mean age = 81.6 years, SD = 9.29) drawn from three Minnesota metropolitan proprietary nursing homes were able to complete verbally administered affect and cognitive status instruments at two months post admission. The sample was predominantly female (71.8%), widowed (57.3%) and Caucasian (98%).

Mini-Mental Status Examination (MMSE) scores ranged from 4 to 29, categorized as no impairment (score > 23, n = 52), mild impairment (scores 18-23, n = 27) or severe impairment (scores <18, n =31). A functional dependence score was assigned based on case mix level determined by staff as part of Minnesota's mandated assessments.

The SNHI was administered verbally at two and at six months post admission to these 110 residents some of whom were in test and control groups of the larger study. An item analysis was conducted on the results. The dimension "satisfaction with care providers" was dropped since most residents did not respond to questions related to providers other than nursing staff, and the response for nursing staff was 98% positive, suggesting that the question afforded little discrimination. Six more items were dropped because they were rarely answered. The final analysis resulted in a SNHI with six dimensions and 29 items. Correlations with the Philadelphia Geriatric Center Morale Scale (PGCMS) and its subscales and Geriatric Depression Scale (GDS) indicated that greater satisfaction was seen in residents who were less lonely or less depressed. In addition, higher SHNI scores were related to higher global quality of life scores ($r = .36$, $p < .001$). Researchers interpret these findings as supporting construct validity.

Results from a sub-sample of control subjects who did not experience the parent study intervention were analyzed to determine construct stability. According to the authors, stability of SNHI scores between initial and subsequent administration four months later were moderate ($r = .50$, $p = .035$) and compared favorably with stability of the GDS ($r = .47$) and PGCMS ($r = .68$), suggesting a parallel level of reliability.

Development and testing of the SNHI illustrate the challenges inherent in quantifying multidimensional constructs that rely on self report. The sample chosen to evaluate the SNHI was relatively small, and the chosen method for determining relevant factors and items weak. Evaluation using a larger, more demographically inclusive sample and employing finely tuned exploratory and confirmatory factor analysis techniques would likely provide more definitive results. Validity of specific dimension sub-scores was not strongly supported, leading investigators to suggest that a single aggregate score be used as an outcome measure. Unfortunately, requiring that sub-scores be collapsed into a single index defeats the purpose of defining a construct as multidimensional.

Two Australian studies also explored dimensions of resident satisfaction in the context of instrument evaluation. Chou, Boldy and Lee (2001) analyzed responses to the Resident Satisfaction Questionnaire (RSQ) collected from a representative sample of 1,146 older adults in residential care settings (hostels and nursing homes) in Western Australia, focusing on measured dimensions, reliability and validity. Using exploratory and confirmatory factor analysis, the number of items on the original RSQ was reduced from 50 to 24 and the number of factors (dimensions) from ten to six: room (resident's), home (facility), social interaction, meals service, staff care, and resident involvement. This short form RSQ met rigorous reliability and validity criteria. A unidimensional model in which all 24 items were loaded on a single overarching factor did not meet predetermined criteria for model fit, supporting the researchers' endorsement of a multidimensional approach to resident satisfaction and reinforcing an appreciation of the complexity of subjectively evaluated elements that contribute to the parent construct.

In a related analysis, Chou, Boldy and Lee (2002) examined relationships among RSQ dimensions of satisfaction and their difference in hostel (similar to intermediate care in the US) versus nursing home settings. Applying structural equation modeling to the RSQ results from the 394 nursing home residents produced a model supporting the following: (a) satisfaction with staff care influences all other aspects of service, (b) satisfaction with room (“hard” environment) and with staff care (“soft” environment) plays a role in satisfaction with the facility, (c) satisfaction with resident involvement (opportunities to be involved in the facility and have a say) was influenced by staff care and social interaction, (d) satisfaction with meal service was affected by staff care, the facility and resident involvement, (e) staff care and meal service directly affected the residents’ satisfaction with their rooms. (f) satisfaction with social interaction is affected by satisfaction with the facility and staff care. The key finding in this study was the centrality of satisfaction with staff care. Ironically this dimension was eliminated from the previously reviewed SHNI (Ryden et al., 2000). Investigators concluded that strategies aimed at fostering residents’ satisfaction with staff may have an effect on satisfaction in all other dimensions. By implication this supports considering the resident’s relationship to staff as an essential dimension of satisfaction, well-being and QOL constructs.

Nursing home QOL scale. In 1998 the Centers for Medicare & Medicaid Services (CMS) contracted with a research team headed by Rosalie Kane at the University Minnesota to develop a strategy for the measurement and improvement of QOL in nursing homes (R. A. Kane et al., 2004; Wunderlich & Kohler, 2001). Data collected and analyzed during this study have produced several relevant research articles and an extensive final report (R. A. Kane et al., 2004; R. A. Kane et al., 2003; R. L. Kane et al., 2004).

An initial report (R. A. Kane et al., 2003) outlines key principles that guided the QOL tool development: (a) in addition to care dimensions, a working definition of QOL must include psychosocial factors associated with life in the nursing home environment; (b) measurement should address dimensions of good quality of life that have been identified in the literature, as well as those suggested in federal nursing home regulations; and (c) since QOL is an inherently subjective phenomenon, self-report by the resident is considered the “gold standard” and preferred data collection strategy. Guided by these principles and relying on literature review, resident focus groups, expert opinion and stakeholder input, the team developed an initial measurement strategy using 88 items to capture eleven QOL domains: comfort, security, meaningful activity, relationships, functional competence, enjoyment, privacy, dignity, autonomy, individuality and spiritual well-being.

Testing the tool required an extensive and sophisticated sampling strategy that began with random selection of 40 stable and typical nursing homes of greater than 50 beds from five states. Within each facility up to 5 units were chosen. When a facility had more than five units, care was taken to include Alzheimer’s Special Care Units to ensure that cognitively impaired residents were adequately represented. Residents who were younger than 65 or non-responsive were excluded. Of the 2000 residents who were initially chosen 179 were excluded due to death, discharge, hospitalization, absence or refusal. Of those excluded, 167 were replaced yielding a total sample size of 1988. Residents were stratified into two groups based on cognitive status using the Minimum Data Set (MDS) based cognitive function score .

In addition to the 88-item QOL measure, residents completed (a) a measure of emotional well-being (adapted from the Dementia QOL scale, alpha = .80), (b) a satisfaction scale related to the nursing facility's services, programs, the resident's room and bathroom, the broader physical setting, and the likelihood of recommending the facility to friend (alpha = .75), and (c) summary ratings of QOL in relation to each of the eleven domains. Trained interview staff collected data. Data were not collected if residents (n = 325) could not be roused or did not respond coherently to the initial interview question. Most items were constructed using a Likert scale format. When residents could not respond to the Likert scale a dichotomous yes-no alternative was offered. The difference in response type was adjusted statistically and entered into the analysis. In the end approximately 60% of the interviews contained sufficient data for inclusion in analysis.

The team had assigned items to the 11 domains in advance. After discarding 12 items because of skewed distributions or inadequate response rates, the remaining 76 items were subjected to confirmatory factor analysis (CFA). As a result the individuality domain was eliminated since it proved essentially indistinguishable from the relationship domain (r = .99) and its reliability was poor (alpha = .56). Cluster analysis resulted in a reduction of the number of items to 42, and CFA validated the structure of the shorter version. Correlation of each QOL domain with overall satisfaction (range of r = .23 to .45, $p \leq .01$) and emotional well-being (range of r = .24 to .42, $p \leq .01$) were of the appropriate direction and strength to support concurrent validity. Regression analysis indicated that the summary domain score was consistently associated with the related domain scale score ($p \leq .001$) further supporting the tool's validity.

Of particular interest are findings related to cognitive status and performance on the QOL instrument. Residents with decreased cognitive function were less likely to complete the questionnaire and to respond to questions using Likert scale responses. A comparison of alpha reliability of domain sores by cognitive function (high versus low) indicated no statistical difference except for privacy and enjoyment. Nonetheless, the aforementioned analysis of concurrent validity supports the use of this tool for measuring QOL and the selected domains in a sample that includes interviewable individuals with differing levels of cognitive functioning.

The work of Kane and colleagues represents the first large scale attempt to develop a nursing home specific instrument to capture multiple dimensions of QOL: comfort, security, meaningful activity, relationships, functional competence, enjoyment, privacy, dignity, autonomy, and spiritual well-being. Though their measurement strategy shows promise researchers point to several concerns and cautions. Test-retest reliability needs to be demonstrated. Given the complex nature of the QOL construct, the domains identified are not exhaustive, and use of additional measures (e.g. perceived health, functional status, affect) may enhance QOL measurement strategies. Though the sample was large it included residents from nursing homes in only five states, limiting generalizability of the findings. Authors suggest that further study is needed to determine the advisability of eliciting a binary response when residents were unable to respond using the Likert-scale. Further research exploring the effect of resident characteristics on QOL measurement is needed as a first step in developing risk adjustment strategies to permit comparisons between facilities serving different populations.

In a subsequent report, Robert Kane and colleagues (R. L. Kane et al., 2004) used the same dataset to investigate aggregating individual QOL scores to provide facility (n = 40) QOL indicators. Facilities that scored low in one domain tended to score low in other domains leading researchers to conclude that patterns in QOL scores are distinguishable across facilities. Analysis of sources of variance in QOL scores led to the conclusion that most variation was explained by resident characteristics (ADL status, cognitive functioning, age, gender and length of stay) rather than by facility factors. Though the facility effect was small researches believed that it was still important since it "remains under the control of the facilities." (p. 632). Of concern are statistical findings that suggest interviewer effect played a more important role than facility effect on QOL scores, accentuating the importance of developing procedures to ensure inter-rater reliability.

The finding that resident characteristics predicted the largest proportion of variance in QOL scores suggests the presence of intrapersonal QOL factors that may be out of the control of the facility. Since a limited number of resident characteristics were entered into the model, further research on the effect of resident factors on self-reported QOL is warranted.

In their final report to CMS (R. A. Kane et al., 2004) the University of Minnesota team elaborated on findings summarized above and included the results of a second wave study of residents (n = 1608) and their facilities (n = 60) to confirm the QOL instrument and examine correlations with resident personality variables. In addition to findings identified in the abovementioned journal articles, the following results from both waves may be important when considering strategies for self-report of identified QOL dimensions: (a) using a standardized instrument, it was possible to collect self-report data from, on average, 60% of nursing home residents including those with cognitive deficit; (b) proxy assessments of resident QOL did not correlate strongly with resident responses; (c) though QOL varied across facilities, facility variables related to delivery of services (e.g. type of staff education, care planning, nursing structure, activities) had little relationship to resident self-reported QOL; (d) private rooms were associated with better QOL scores; (e) controlling for function, personality variables had a small independent effect on resident QOL. The authors acknowledge that due to the terms of the CMS contract, the QOL domains represented in their instrument are not comprehensive. They go on to state, "salient elements, such as functioning, health, cognition, and affect were eliminated from this study…but measures of these domains should be included in final efforts to field a QOL battery." (p. 13.5). In the context of this ambitious project Kane and colleagues have provided remarkable insight into the psychometric challenges of defining, quantifying and aggregating QOL constructs. Though quantitatively oriented, their insightful commentary displays profound respect for the complexity and difficulty inherent in the attempt to access core human experiences related to well-being, especially in the context of heath care facilities.

Rooted in self-report, resident satisfaction and QOL tools such as the SNHI, RSQ and the instrument developed by Kane and colleagues provide group summary data of selected aspects of resident well-being. They are largely limited to use for benchmarking, making management decisions, influencing policy and supporting planning efforts (R. A. Kane, 2003). They function chiefly as indicators of potential problems and would-be markers of facility-wide improvement. As such, they do not tap well-being or QOL constructs at a level of granularity sufficient to support direct intervention with individual residents or unique subsets of residents.

Challenges in Quantitative Approaches

Focused quantitative investigation of nursing home QOL is still in its early stages. As with many constructs that rely on self-report, important issues in QOL measurement are yet to be resolved, including (a) development of a widely recognized and accepted working definition of QOL for the nursing home resident; (b) refinement of the list of dimensions for inclusion in a comprehensive QOL construct and related instrument; (c) identification of a credible strategy for validating an instrument that is fundamentally dependent on self-report, (d) adequate investigation and explanation of conflicting findings related to major correlates of resident well-being, such as control; (e) identification of environmental and resident characteristics that influence or confound the QOL construct; and (f) investigation of the appraisal process residents use to choose a response and its effect on the final choice of a response and an overall QOL rating.

The first five challenges have been ongoing concerns for most investigators dealing with constructs that rely on self-report data. Hopefully, interest and support for research in nursing home QOL will persist and these issues will continue to be addressed and solutions identified. The sixth challenge, accounting for the appraisal process, has emerged as a crucial factor in developing QOL measurement strategies that rely on quantifiable self report items (Schwartz & Rapkin, 2004). Theoretical work on the cognitive process of appraisal and its influence on an individual’s response has resulted in proposed measurement models that account for the effects of the appraisal process. Schwartz and Rapkin (2004) have developed a schema that recognizes four components active during an individual's QOL appraisal process. Briefly, in arriving at response to an item an individual (a) calls on a personal frame of reference or set of experiences relevant to the aspect of quality of life being evaluated, (b) employs a strategy for sampling relevant experiences, (c) accesses personal standards for evaluating those experiences, (d) and ultimately assigns weight to each experience. This is a non-linear, flexible process that provides the framework against which an evaluation is made. Model proponents suggest that in order to arrive at more accurate quantification of QOL, researchers must account for the effects of the appraisal process. This suggests that, in answering QOL instrument items, the processes and the criteria residents use to arrive at responses may be more telling than the numerical score or final response they decide on. Thus, in addition to previously identified challenges, the potential influence of the appraisal process on individual and aggregate QOL data in the nursing home population requires serious consideration.

Qualitative Perspectives: Exploring Horizons of Well-Being

Research Directions

Though advances in quantitative research on resident QOL have occurred chiefly over the past fifteen years, first person accounts relevant to the experience of resident well-being in a nursing home have been threaded throughout ethnographic research reports since the 1960s (Diamond, 1992; Groger, 2002; Gubrium, 1975, 1993; Henry, 1963; Kayser-Jones, 1981; Powers, 1988, 1991; Savishinsky, 1991; Shield, 1988). Most of the findings in the scientific literature are consistent with autobiographical narratives of nursing home life in the lay press (Gass, 2004; Laird, 1979; Tisdale, 1987; Tulloch, 1975).

Seminal ethnographic work. Social science investigators have elicited personal accounts of residents shaped largely by specific interview guides designed to answer questions essential to specific foci of their studies. These emic data have been analyzed in concert with participant observations, field notes, document reviews and other data sources, providing a descriptive foundation to drive additional research, frame theory and influence policy. Within the pages of these accounts, the voices of individual residents disclose their varied experiences of life in a nursing home informing and refining understandings of well-being, satisfaction, and QOL.

In 1967, in a chapter entitled “Human Obsolescence,” Henry (1963) presents the first extensive published account of ethnographic research in nursing homes, a summary and commentary on findings in three settings of varying quality. Methods were limited mostly to participant observation, and the few dialogues cited were primarily with staff. Though there is no indication that researchers used formal interview to access residents’ perceptions of the quality of their lives directly, Henry’s interpretation paints a picture of the nursing home as a milieu in which the experience of well-being seems highly unlikely:

> As for the patients, they live out their last days in long stretches of *anxiety* and *silent reminiscing*, punctuated by outbursts of *petulance* at one another, by TV viewing, and by visits from their relatives. There is no inner peace, and *social life is minimal*. Meanwhile the patients *reach out* to the researcher and would engage her endlessly in conversation if she would stay. There is a *yearning for communion but no real ability to achieve it*. (p. 474)

As part of an “interpretive, value laden” critique of American culture in the mid twentieth century, Henry viewed dismal conditions in nursing homes as an expected outcome of a “lopsided preoccupation with amassing wealth and raising its [America’s] standard of living.” (p. 4-5). Despite its admittedly biased orientation, the report raised QOL and well-being issues that would be explored, and either refined or challenged in subsequent research.

Opening with an examination of the significance of private versus public space, *Living and Dying at Murray Manor* (Gubrium, 1975) represents the first book-length ethnography of life in an American non-profit nursing home. Gubrium identified three unique but intersecting worlds that operated within the facility: administrative staff, clientele (residents and patients), and direct caregivers. He suggested that each entity maintained a distinctive worldview characterized by sets of social relations, practices and rituals that were not fully appreciated by either of the other two. In the world of residents and patients "breaking up home" and "making peace with hopelessness" constituted initial challenges to doing well. Clientele strove to maintain ties with the outside world and former lives through explicit practices related to telephone use, having visitors, and "stepping out" into the community. In addition to providing relief from the institutional schedule, reporting news of the outside world to fellow residents facilitated greater social interaction and increased prestige for the narrator. Also, many residents forged and maintain social ties within the nursing home through cliques, friendships and support activities. Existing ties and hoped for ties seemed to provide an impetus for survival.

Gubrium's analysis of interviews focused on the significance of social structures, roles and relationships and their meanings in the lives of residents. Though QOL was not specifically mentioned, key issues that potentially influenced the resident's sense satisfaction and well-being included loss of "home", privacy, loss of contact with the outside world, loneliness, boredom, and the struggle to maintain autonomy and prestige.

In a comparative study of institutional care for the aged in a government-owned long term care facility (Scottsdale) in Scotland and a proprietary nursing home (Pacific Grove) in the US, Kayser-Jones (1981) used exchange theory to explain how the confluence of dependency, personal resources and power dynamics shape positive and negative interactions between staff and residents. At Pacific Grove, dysfunctional exchange often resulted in infantilization, depersonalization, dehumanization and victimization. Resident interview responses threaded throughout the text pointed to factors that threaten QOL, satisfaction and well-being. Those living at Pacific Grove reported feeling bored, lonesome, and ignored. Clientele complained of a lack of choice, of not feeling cared for or about, of being disregarded. They did not feel safe or secure, and lacked opportunities for adequate social interaction and meaningful activity. In contrast, residents of Scottsdale described being cared for, retaining a sense of dignity and self worth, being active according to their wishes and having a sense of control and choice.

Additional significant qualitative studies. Extended ethnographic works since these initial studies by Gubrium and Kayser-Jones have employed a range of theoretical lenses and standpoints to ground their conclusions. Though limited in their generalizability, studies have explored the experiences of direct caregivers and their intersection with policy and profit (Diamond, 1992), examined the applicability of "total institution" and clarified the dynamics of transition (Shield, 1988), and accessed the volunteer's viewpoint to provide a comprehensive overview and analysis of the life and work that takes place in a nursing home (Savishinsky, 1991). Conclusions have relied heavily on participant observation, using resident interviews and feedback chiefly to validate observation, suggest new matters to explore, support conceptual development or comment on policy. Nonetheless, themes that emerged from resident interviews and subsequent analyses mirrored those that had surfaced in earlier studies: autonomy, control, safety and security, the effect of physical environment, meals and social relations both within and outside the facility.

In an innovative work that shifted from the naturalistically focused paradigm used at Murray Manor (Gubrium, 1975), Gubrium applied a narrative-interpretive methodology to explore the subjective meaning of QOL and QOC for 21 older nursing home residents (Gubrium, 1993). Autonomy, choice, social relations, and the meaning of "home" emerged as dimensions of quality. Findings illustrate how a resident's life course shapes the construction and evaluation of personal notions of quality. Excerpts from interviews that encouraged residents to reflect on life in general, daily life, home, family, self and aging suggest that appraisals of present situations are rooted in "horizons of meaning" developed over the life span. As a result, positive or negative evaluations of QOL domains appear to vary as much due to evolving autobiographies as to the benefits and constraints of the physical and social environment. While acknowledging the value of standardized measures as a method to monitor and improve essentials of "'objective conditions' of residents' daily lives" (p. 186), Gubrium (1993) suggests that attending to the autobiographical nature of QOL or QOC evaluations highlights limitations inherent in nomothetic strategies aimed at quantifying subjective well-being.

Several qualitative researchers probing discrete aspects of nursing home culture have published journal reports on specific issues related to resident QOL. Schwirian (1982) used 24 structured interview questions with 84 nursing home residents (~75%

female) to explore the relationship of knowledge of finances, expressed satisfaction with health, satisfaction with financial status and satisfaction with family life to the dependent variable, life satisfaction. Descriptive data generated from coded interview responses were used to support a conceptual map. Commentary and diagrammed relationships suggest tentative and often counterintuitive conclusions. Nursing home residents who perceived their health to be poor tended to reported higher life satisfaction. For both men and women greater perceived health was associated with less satisfaction with both family relationships and with life in general. The author speculated that this might have reflected dissonance related to feeling healthy but requiring or “being placed in” nursing home care. The relationships among knowledge of finances, satisfaction with financial status, life satisfaction, and satisfaction with family relationships appeared to differ between men and women. For female residents, information on finances led to decreased life satisfaction and to decreased satisfaction with financial status but positive satisfaction with family relationships. For male residents increased knowledge of finances led to increased life satisfaction and increased satisfaction with financial status. For these men, satisfaction with financial status fostered increased overall life satisfaction. Schwirian proposed an explanation of the differences in financial knowledge and satisfaction between men and women based on changes in social role assumed in the nursing home. Dissatisfaction in men was traced to loss of control over finances, consequently knowledge of financial status without control led to dissatisfaction and a sense of dependency. Results also suggested that for women patterns of financial satisfaction represented continuing generational patterns of financial dependency and accompanying anxiety over financial matters. This raises the question that if such patterns are true, are they likely to persist given generational differences in the social construction of gender and what if any are the implications for QOL or the sense that one is doing well in a nursing home.

In asking the question “Can a nursing home be homelike?” Stafford (2003) explored the hybrid hospital-home nature of the nursing home from the perspectives of older facility residents and younger persons living in the local community. One resident-identified issue was the value of property and coming to terms with the loss of possessions. Maintaining one’s own space, the value of interpersonal ties, and transforming situations that are “given” to situations of choice also emerged as important in promoting the “homelike” aspects of facility life, again reinforcing recurring QOL themes of privacy, social relationships, autonomy and choice.

Groger (2002) analyzed interview data from 14 African American nursing home residents and 13 caregivers to gain insight into how they coped with living in a nursing home. Most residents felt life in the nursing home increased their sense of competence and well-being by offering a supportive environment that was safe and secure. For many residents, belief that family members were less worried about them in a monitored environment contributed to peace of mind. For some, moving to the nursing home provided refuge from unsatisfactory care by family members. Groger suggests that residents were able to do well through a process of adaptation that allowed them to work within the constraints of the facility without compromising essential values. Ultimately, “placement in the supportive environment of a nursing home enabled most participants to regain a modicum of autonomy and a measure of continuity of self they could not have achieved in the community.” (p. 202). Thus, findings suggest the importance of the interplay between person centered factors and immediate environment in molding the perception and subsequent report of well-being and QOL.

As part of a larger study of Health Care Promotion in Long Term Facilities, Bickerstaff, Grasser and McCabe (2003) undertook a content analysis of interviews with 180 nursing home residents that focused on loss and self-transcendence. Their findings suggest several factors that bear on the spiritual dimension as a QOL component, specifically in face of loss. These include a sense of being valued by self and others, love and the memory of love, responding to others needs, trust in God or a higher power, and continuing to be active. While recognizing the importance of residents' personal histories and resources, psychosocial support was recognized as vital to promoting self-transcendence and resident QOL.

Summary of the State of the Science

While admitting of differing epistemologies and contrasting methodologies, quantitative and qualitative researchers appear to be converging on an understanding of nursing home QOL as a complex, and inherently subjective phenomenon (Gubrium, 1993; R. A. Kane, 2003). The emphasis for quantitative researchers has been on defining and measuring QOL among nursing home residents as a potential means for supporting regulatory oversight, management decisions and quality improvements at the unit, facility, or heath care system level. Early investigations of the correlates and predictors of QOL among nursing home residents, as well as theoretical works, have identified candidate factors related to a QOL construct, providing the basis for multidimensional measurement strategies. Nevertheless, determining dimensions of QOL that are necessary and sufficient for a useful and useable QOL construct is still in process.

In addition to defining and operationalizing a QOL construct appropriate for alert and cognitively intact residents, investigators are grappling with quantifying QOL for individuals with varying types and degrees of cognitive or communication deficits (Logsdon & Albert, 1999; Mozley et al., 1999; Schnelle, 2003; Volicer, Hurley, & Camberg, 1999). One approach has been to explore the use of family or staff proxy reports. Strategies tested thus far have not demonstrated correlations between residents and proxies strong enough to support reliance on surrogate evaluation (Berlowitz, Du, Kazis, & Lewis, 1995; Gasquet, Dehe, Gaudebout, & Falissard, 2003; R. L. Kane et al., 2005; Mattimore et al., 1997). Given the burgeoning acceptance of QOL measurement as essentially reliant on self-report, there is a need for creative investigation into behaviors or behavior clusters and associated evaluation strategies that may provide insight into levels of well-being in residents with advanced dementia (Volicer et al., 1999).

Independent of cognitive and communication issues, research has been complicated further by the suggestion that a subject’s appraisal scheme itself may have a significant effect on resultant scores and may need to be captured and methodologically or statistically controlled (Schwartz & Rapkin, 2004). Such control is essential to satisfy empirical science criteria for validity, reliability and generalizability. An ancillary research challenge is to account for appraisal in a way that is both comprehensive and efficient (Rapkin & Schwartz, 2004).

Qualitative research on resident life and well-being, typically dominated by naturalistically focused observational ethnographies, increasingly includes reports and monographs more squarely committed to accessing the resident’s lived experiences and the role of narrative and biography in shaping perceptions of well-being and quality

(Gubrium, 1993). Nevertheless, the number and variety of qualitative studies with a principal purpose of accessing residents' viewpoints on or experiences of QOL remains small. Challenges that accompany a qualitative focus on resident interview as the foundation for understanding well-being are analogous to some of those facing quantitative researches, for example, addressing difficulties encountered in interviewing individuals with impaired cognition or communication, and providing credible and respectful interpretation and analysis of interview content.

Conclusion: Where We Are and Where We Need to Go

Rather than attempting to apply dimensions, domains and constructs from external populations, there is an ongoing need to refine current understandings of QOL and related well-being concepts from within the nursing home and to comprehend how they operate in residents' lives. Carefully crafted quantitative studies and structured survey approaches that result in large databases may continue to identify issues that have broad significance and serve to guide policy decisions regarding construction of environments and overall principles of care delivery. Though useful, such data fall short of providing the detail necessary to support a specific caregiver-resident relationship. Accessing individual experiences of what constitutes QOL is essential to identifying the usefulness of aggregate data to support intersection between caregivers' and individual residents' life worlds. For improvement to occur, top-down macro approaches to addressing the QOL chasm must be matched with bottom-up strategies that support increasing caregiver sophistication in recognizing and supporting residents as they deal with personal QOL issues and what it means for them to do well. Research that uncovers the variety of experiences of quality life and details the diverse ways that individual biographies and past and present environments shape a sense of well-being are key to promoting caregiver understanding of the resident as an individual with distinct strengths and needs (Bryant, Corbett & Kutner, 2001).

During nursing home licensing surveys, emphasis has been on identifying threats to QOL based on a set number of observable criteria reflecting maintenance of minimum standards such as recording instances when privacy curtains are not drawn, or staff fail to knock before entering a room, or the demeanor of staff appears discourteous, or the food is poorly prepared. This approach reflects a penchant for concern with the presence or absence of factors deemed *predictive* of QOL (Stewart & King, 1994). The driving question here is “What causes poor QOL?” Moving beyond a regulatory mindset to identification of *actual* QOL, the key question assumes a positive valence: “What constitutes good quality of life?” How do we determine good quality of life and the processes that lead to it? What are the connections that residents make among the various QOL dimensions that they deem important? And further, given the possibility that the meaning of QOL may vary greatly from one resident to the next, how can we use this information to support caregivers in promoting resident well-being? Ultimately, the answers to these questions hinge on a core understanding of the resident’s lived experience of doing and being well (Benner, 1985). Applying qualitative research approaches to elucidate what it *means for residents* to do well is a first step in answering these kinds of questions with a goal to promoting individual resident well-being.

Chapter Two

THRIVING AS A THEORETICAL STARTING POINT FOR EXPLORING THE EXPERIENCE OF “DOING WELL”

Introduction

Over the past decade, in keeping with a growing emphasis on pathways to positive health outcomes and well-being, the term “thriving” has become more prominent in both the popular press and professional health-related journals (O'Leary, 1998). This chapter reviews thriving theories in nursing and the social-behavioral sciences, evaluates the adequacy of concepts of thriving for the study of older adults experiencing various types of decline, and proposes an existentially and phenomenologically informed stance for exploring how older nursing home residents perceive and experience doing well.

Presently, two major conceptual approaches to thriving are found in the clinical and theoretical literature. The social and behavior sciences have adopted the term thriving to describe post-traumatic growth that represents a state of increased competence, a positive outcome of stress and coping (Carver, 1998; O'Leary, 1998; O'Leary & Ickovics, 1995; Park, 1998; Tedeschi & Calhoun, 1996). This conceptualization of thriving is more narrowly constructed than that of nursing which has tended to characterize thriving using holistic perspectives. Consequently, nursing concepts of thriving have been developed to support (a) a life span theory based on synthesis of existing concepts of failure to thrive (FTT) in infants and older adults, growth and development modeling, and person-environment fit constructs (Haight, Barba, Tesh, & Courts, 2002; Walker & Grobe, 1999), and (b) a focused conceptual framework developed to guide research and practice with nursing home residents

(Bergland & Kirkevold, 2001, 2005a). Critique of theory developed thus far suggests that most existing models, especially those in the social and behavioral sciences, predominantly support empirically oriented quantitative investigation (Massey, Cameron, Ouellette, & Fine, 1998).

Social Behavioral Science Approaches

Stress and Coping: Beyond Resilience

Building on the concept of resilience, O'Leary and Ickovics (1995) developed the concept of thriving as one of three potential psychological responses for individuals who do not succumb to a health challenge: "survival" representing a post-challenge level of functioning below the pre-challenge baseline, "recovery" suggesting return to the baseline, and "thriving," indicating achievement of psychosocial functioning beyond baseline (see Figure 1). Thriving occurs as a result of profound challenge, and represents

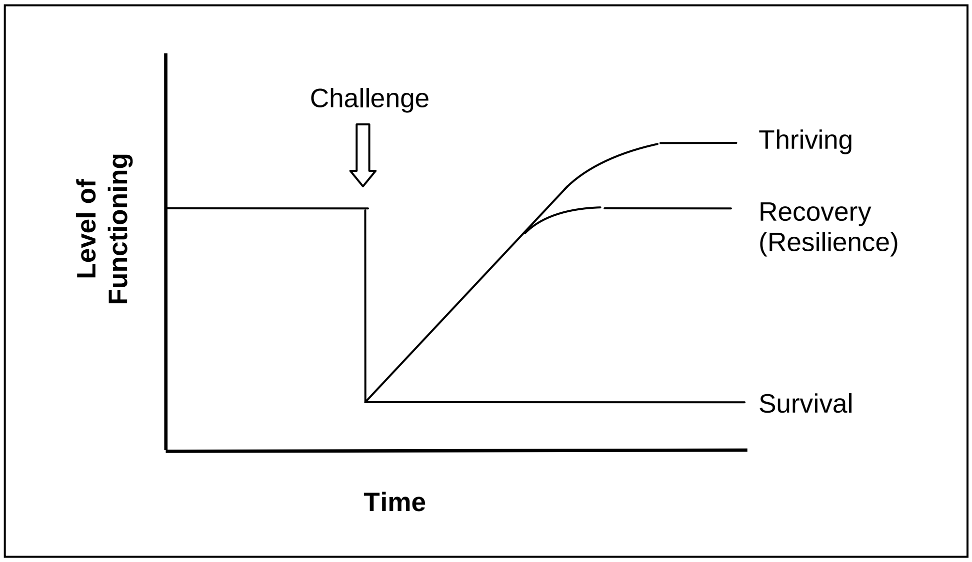

Figure 1. Responses to a health challenge. Adapted from O'Leary and Ickovics (1995)

a state in which the person is “better-off afterward.” Individuals may demonstrate growth in behavioral, cognitive and emotional domains, and this growth may take place despite physical deterioration. Of the three possible outcomes of challenge, thriving is the least common, and consequently, the least studied and least developed theoretically.

Citing research on personality, cognition and stress and coping, O’Leary (1998) posits hardiness, coping, sense of coherence, creation of meaning, threat appraisal, expectancy of good or bad outcomes, self efficacy, and creation of meaning, as individual factors that may have a role in promoting the thriving outcome. Hypothesized relevant social factors derived from research on related concepts include social support, religion, and social class. Lastly, turning to developmental process to inform the concept:

> thriving represents the outcome of an interactive developmental process. The ability to obtain and utilize resources effectively changes across the lifespan. From a developmental perspective, it is posited that the inherent features of the individual and the environment evolve and change each other over time. (O'Leary, 1998, p. 433)

Referring to the stress and coping paradigm (Lazarus & Folkman, 1984), Carver (1998) refined the concept and process of thriving described by O’Leary and Ickovics, (1995) extending it to include elements of physical as well as psychological thriving. As in the previous model, the term thriving generally represents a “better-off-afterward experience” but is expanded to include three possible adaptive endpoints (a) “desensitization”—resistance to decrement resulting from subsequent similar challenges, (b) “enhanced recovery potential”—ability to bounce back faster, (c) “taking it to a higher level”—functioning at a higher level than before the challenge. Carver clarifies that merely scaling back one’s expectations in the face of difficulty does not constitute growth indicative of thriving. Though accommodation may co-occur with thriving it does not represent an independent pathway to post-challenge growth.

Carver (1998) suggests that thriving is a response to a stressor that is perceived chiefly as a challenge (possibility of gain) rather than a threat (possibility of harm). As distinguished from instances of growth that occur under advantageous circumstances, thriving occurs under circumstances of adversity where growth is challenged and may seem unexpected. Put simply, in thriving a manageable "mismatch" between the person and the world fosters growth. Thriving represents an extreme case of growth that occurs in "circumstances that are at the outer limits of tolerability for threat…" (p. 248). Nevertheless, there may be a point at which adversity prevails and thriving ceases, leading to impairment and debilitation.

Proposed features of psychological thriving include new or increased skills and knowledge, confidence ("sense of mastery"), and strengthened personal relationships. Evaluating if thriving has occurred may involve objective criteria (e.g., measures of increased physical functioning, observed increase in social engagement) or reports of subjective change (e.g., change in personal philosophy, orientation to life, priorities, values) (Carver, 1998).

Commenting on terminological inconsistencies in prior literature on thriving, Park (1998) clarifies the difference between post stress-related growth, "any number of positive changes a person reports following successful experiences" and thriving, "a higher level of functioning in some life domain following a stressful encounter" (p. 268). This view seems to lay the groundwork for thriving as a concept distinct from growth. In applying transactional stress and coping concepts to thriving, Park focuses on the interaction between personal characteristics and stressors and attends to the influence of factors such as “personality, world view, social support, socioeconomic status, preexisting physical and psychological adjustment, and previous experience of challenge and response.” (Park 1998, p. 268). In this view, an adequate thriving model must consider the potential role of an individual’s primary appraisals of the stressfulness and controllability of an event as well as of the likelihood of a successful outcome, and secondary appraisals of one’s own resources for dealing with a stressful situation. The function of problem focused and emotion focused coping behaviors (e.g., meaning making, positive reinterpretation, acceptance, emotional support, religious coping) and their possible contribution to thriving must also be considered. Though Park does not offer a comprehensive theory of thriving she identifies the need to continue research on “the roles of personal dispositions, resources and coping …[to] pave the way for the development of more specific models of growth and thriving.” (Park, 1998, p. 276)

Extended and Alternative Social Behavioral Views

Psychological articulations of the concept of thriving have largely retained a discipline specific emphasis on personality and individual cognitive, behavioral and emotional features of antecedents, processes and outcomes (Blankenship, 1998). As such they may contribute to the development of a holistic model but by their nature and intent they do not adequately address the broad significance of physiological factors (though Epel, McEwen, & Ickovics, [1998] have introduced the concept of allostasis into the model to drive research on psychoneuroimmunological components of thriving) or the inescapable effects of social factors.

Though the need to expand the unit of analysis from the individual to groups, communities and organizations has been noted (O'Leary, 1998), Blankenship (1998), a sociologist, advocates for a more comprehensive theory of thriving that directly addresses the meanings and roles of race, class and gender. Taking this stance, a socially sensitive theory would address factors contingent on environment, social hierarchy and associated resource availability as critical determinants of the challenge, response and outcome components of thriving (Blankenship, 1998).

Advocating for an approach based on constructivist self development theory (CSDT), Saakvitne, Tennen and Affleck (1998) critique prevailing social and behavioral models, pointing to five shortcomings: (a) an over-emphasis on nomothetic approaches that tend to limit investigation to decontextualized, abstracted and generalized variables, (b) a tendency toward premature explanation that relies on taken-for-granted indicators and bypasses necessary descriptive investigation, (c) reliance on univariate indicators without consideration of the complex (at least bivariate) nature of the many hypothesized indicators, (d) lack of appreciation for the distinction between automatic and effortful processes involved in thriving, and (e) inadequate attention to the significance of pace of recovery (gradual versus abrupt) in thriving. Additional contributions of this analysis and a critique from a qualitative perspective (Massey et al., 1998) are presented in the section on limitations to present theoretical approaches below.

Nursing Perspectives on Thriving

Theories of Thriving in Nursing

Whereas the pedigree of prevailing social and behavioral models of thriving can be traced to work on resilience, post traumatic growth and stress and coping, recent nursing concepts have emerged from clinical and theoretical approaches to FTT in infants and older adults (Bergland & Kirkevold, 2001; Haight et al., 2002; Walker & Grobe, 1999). In nursing, elements of the of the FTT construct have been augmented and modified using concepts from growth and development and literature on person-environment fit resulting in models intended to support research relevant to clinical practice.

Influence of Adult FTT on Concept Development

Initially, biomedical, applied social science and nursing literature related to thriving focused exclusively on deficit models related to FTT (Kimball & Williams-Burgess, 1995; Newbern & Krowchuk, 1994; Verdery, 1997b). In this literature the positive concept of "thriving" has been at best implicitly inferred in contrast to FTT.

Roots in infant FTT. Significantly, conceptualizations of the adult FTT syndrome have been derived from FTT disorders observed in infants (Braun, Wykle, & Cowling, 1988). Rooted in reports of observations of increased death rates among institutionalized infants during the early 20th century, the infant syndrome served as a topic of intense interest for mid century psychology and pediatrics researchers such as Bakwin, Spits, Widdowson, and Bowlby (Newbern & Krowchuk, 1994). By this time the key components of the syndrome—withdrawal and undernutrition—had been described but causal mechanisms were much debated. Newbern & Krowchuck (1994) indicate that by the early 1960's investigators had firmly established the central role of maternal deprivation and subsequent despondency, nutritional decline and developmental retardation as key components of FTT in infants. The infant syndrome is characterized by a deceleration in the rate and pattern of growth and is usually classified based on etiology as organic, mixed or non-organic (Bithoney & Rathbun, 1999). Whereas organic FTT can be explained with reference to underlying pathophysiology, non-organic FTT is most frequently explained using transactional or ecological models in which the interactions of child, parent and environment are determinants of an infant's ability to thrive (Newbern & Krowchuk, 1994).

Adult FTT. Precisely how the diagnosis of FTT came to be applied to older adults in the mid nineteen-seventies is unclear. Consistent with its vague beginnings and unlike the infant FTT diagnosis which has achieved greater conceptual clarity and generally consistent clinical use, the concept of adult FTT has been plagued by imprecise definition and inconsistent application in practice. In attempting to structure adult FTT clinical knowledge using the infant paradigm, Braun, Wykle and Cowling (1988) concluded that though the presenting clinical picture of weight loss, hopelessness, and decline in physical and cognitive function mirrors the infant syndrome, differences in organic and non organic causative factors preclude wholesale application of the infant syndrome to phenomena observed in older adults.

Of those writing on FTT, Verdery (1996, 1997a, 1997b, 1998) has made the most comprehensive and significant contributions to conceptualizing and operationalizing the adult FTT phenomenon. These include the clear designation of FTT as a syndrome rather than a diagnosis, reinforcement of the existence of organic and nonorganic etiologies, and the development of a trigger model (see Figure 2). In this conceptualization, an individual with FTT is usually identified when functional ability dips below normal in relation to his age cohort. FTT is further marked by a increased rate in this functional decline. A “trigger event” initiating the downward trend can usually be observed or

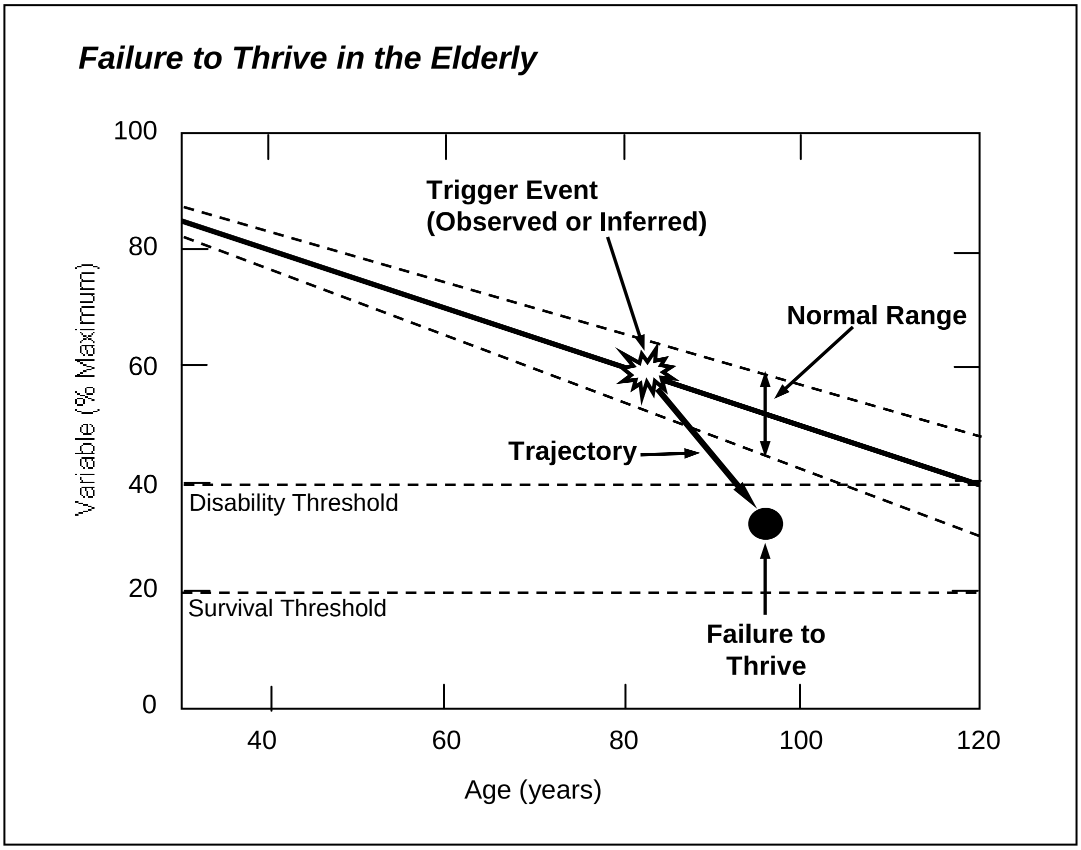

Figure 2. The trigger model of adult failure to thrive as presented by Verdery, (1997a).

inferred. Trigger events initiate a metabolic acute phase response. Verdery (1997a) hypothesizes that this acute response enters a chronic phase characterized by elevated cytokines, negative energy balance, hypocholesterolemia, anemia of chronic disease, hypoalbuminemia and, if not resolved, death. He holds that even though unexplained weight loss is the easiest measure for recognizing adult FTT, appropriate intervention requires assessment and management of coexisting biomedical, functional and psychosocial problems.

Review and research articles have dealt with specific FTT related phenomena such as depression (Hollinger-Smith & Buschmann, 1999; Katz & DiFilippo, 1997), muscle wasting (Roubenoff & Harris, 1997), and psychosocial factors (Markson, 1997). In theorizing on the biomedical basis of decline, Roubenoff and Harris (1997) advanced a model with two interrelated syndromes (sarcopenia and FTT) that influence frailty and disability. Aging is the major process in the sarcopenia syndrome, and disease is the major process in FTT syndrome. Both systems affect and are affected by physical activity. Both systems interact in the context of an individual's biologic reserves and the level metabolic demand, ultimately influencing his level of frailty or disability. Given the undeveloped state of knowledge in this area, the authors speculate on the influence of intrinsic age-related regulators (changes in hormones, cytokines, neural input, muscle physiology), non-age related regulators (insulin resistance, obesity) and extrinsic regulators (reduced physical activity, illness).

In a broad conceptual analysis of FTT, Newbern and Krowchuck (1994) attempted to move beyond the popular trend to link infant and adult FTT arriving at a comprehensive, holistic model. They proposed seven major attributes of FTT several of which are derived from Bowlby's (1982) work on attachment. These include disconnectedness, inability to give of oneself, inability to find meaning in life, inability to attach to others, consistent weight loss, depression, and decline in cognitive function. Based on an analysis of the current state of FTT science, they posited antecedents (loss, dependency, loneliness; inadequate nutritional intake, and feelings of shame, helplessness and worthlessness) and consequences (non-responsiveness to medical and non-medical interventions, giving up, and psychogenic mortality), providing a foundation for later work on thriving.

The Life Span Theory of Thriving

In developing the Theory of Thriving, Barba (personal communication, November 23, 2003) indicated that methods outlined by Walker and Avant (1995) guided nurse academicians in framing a positively oriented and comprehensive growth and development model intended to apply across all ages and support research with older adults regardless of setting (Haight et al., 2002). The authors aimed to construct a holistic Theory of Thriving that would serve to link discrete variables as well as address progression of time in relation to individual development. Identifying a gap in the theoretical literature, and building on Newbern and Krowchuk's (1994) work in adult FTT, Haight and colleagues sought to combine key concepts from biology, psychology and sociology to provide a multidisciplinary explanatory theory that would examine aging holistically over time. Though anticipated to apply broadly over the life span, the theory's immediate goal is to provide "a holistic life span perspective for studying people as they age in their environments" (Haight et al., 2002, p. 21)

The life span theory of thriving and its proposed relationships operate on two levels: one abstract and difficult to empirically operationalize, the other more concrete and conducive to the development of empirical indicators. Four major concepts operating at the more abstract level include, thriving, person, human environment, and nonhuman environment (see Figure 3). The relationships among major concepts are conceived as ongoing, fluid, and mutually influential. Causality is broadly inferred: the greater the harmony between person, human environment and non-human environment, the greater the level of thriving. Other equally abstract but underdeveloped concepts include resilience, growth feelings, values, and beliefs, continuum and life span (Haight et al., 2002).

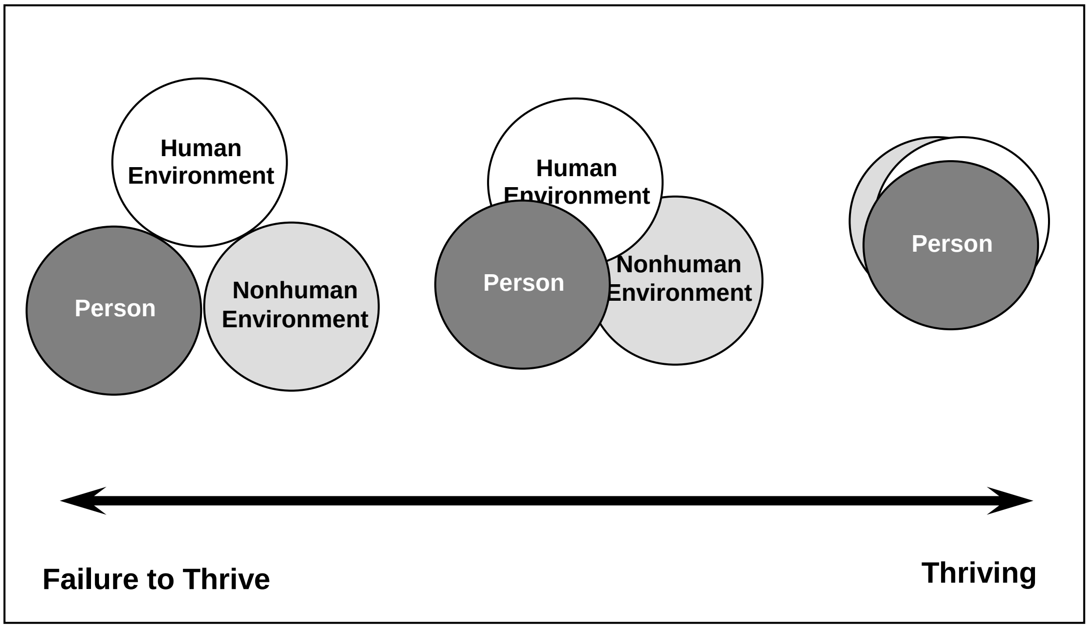

Figure 3. The Thriving Model. Adapted from Haight et al. (2002).

At the more concrete level, more substantial concepts are posited, including (a) *critical attributes of thriving/FTT*: social connectedness, giving of self, finding meaning, attachment, consistent weight, cognitive function, and affective state; (b) *antecedents of thriving*: rational ties, independency, pride and self-esteem, engagement, and self care; (c) *consequences of thriving*: medical, social and psychological resilience; (d) *antecedents of FTT*: loss, dependency, shame, loneliness, and self-neglect; and (e) *consequences of FTT*: non-responsiveness, giving up, psychogenic mortality. These concepts suggest extensively varied levels of abstraction. Thus, some might easily translate in to empirical indicators (e.g., consistent weight) while others are quite ethereal (e.g., giving of self, giving up).

A lack of clarity in the relationships between major and minor concepts and between individual minor concepts proves particularly troublesome. The final structure of the theory adequately illustrates how major concepts (person, human environment, non-human environment) influence each other and thriving across the life span, but fails to successfully link these to critical minor concepts. The theory implies that the fit among person, human environment and nonhuman environment may vary across the lifespan and the better the fit the greater the thriving. To forge a link between major and minor concepts, the authors rely on a visual model best described by combining two of the structural schemas described by Chinn and Kramer (1999): discrete overlapping circles and linear polarity (see Figure 4). However this conceptualization fails to successfully incorporate the differential structure devised for the antecedents, attributes and consequences of the thriving/FTT component of the theory. In essence what results

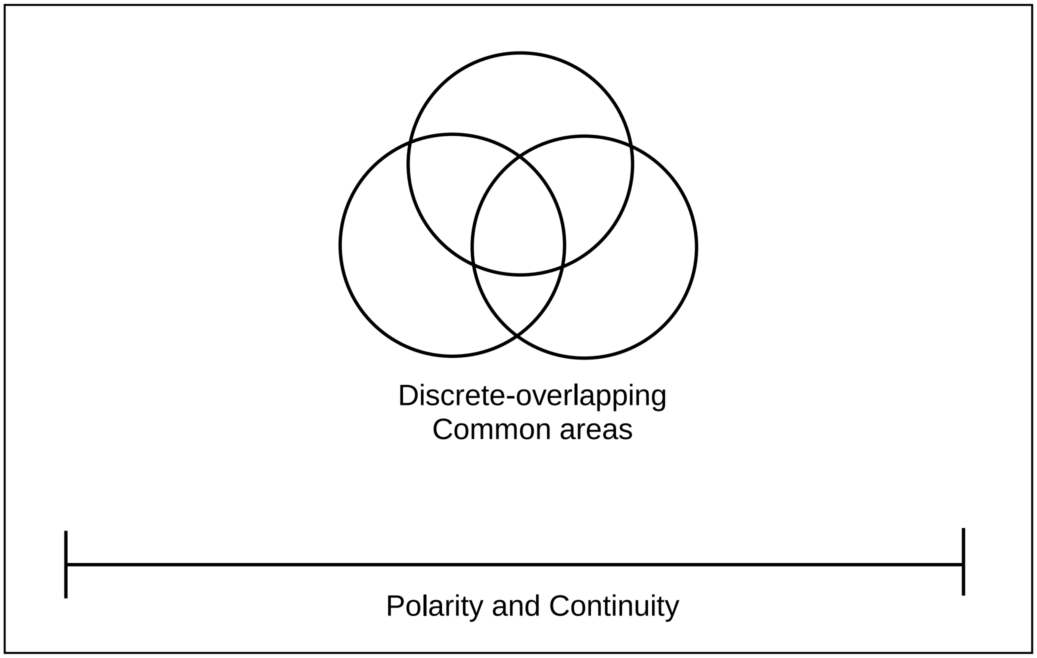

Figure 4. Structural relationships discerned in the Haight et al. (2002) theory of thriving. Diagrams adapted from Chinn and Kramer (1999, p. 93).

are two complementary theoretical models: a life span Theory of Thriving that operates at a level of abstraction approaching grand theory, and a bipolar thriving/FTT model that has the potential for developing into a midrange theory to support research and practice.

Thriving as a Concept to Guide Targeted Research

In developing thriving as a concept to support research in older adult nursing home residents, Berglund and Kirkevold (2001) expand the scope of review beyond the challenge-related growth and biomedical/nursing models reviewed above to include the social psychological interactionist model of Swedish theorist, Petersen. Social psychological interactionist models emphasize associations between the individual and the environment. Expectations are fulfilled or not fulfilled in a specific environment. Thriving is an emotional state that is the net difference between satisfaction and dissatisfaction. According to Berglund and Kirkevold, Petersen proposes a five step process leading to this state: (a) acknowledging expectations; (b) perceiving and considering opportunities for fulfillment; (c) judging expectations in terms of the environment; (d) choosing to adjust expectations or to modify the environment; (e) implementing the choice through internal or external action.

Berglund and Kirkevold conclude that present models are inadequate for the study of frail older nursing home residents, suggesting that growth related models may be unable to adequately consider late life physical and cognitive decline. In contrast, FTT based models with their emphasis on physical deterioration may not provide support for considerations of emotional and spiritual thriving. Lastly, they indicate that interactionist based views of thriving may not adequately account for the influence that environmental constriction (such as found in nursing homes) may have on the ability to effect a state of greater personal satisfaction. Thus, a concept of thriving applicable to older adults in nursing homes must address (a) multi-dimensionality, (b) disconnection from the FTT concept, (c) growth despite decline and (d) the older adult's experience of satisfaction. For Berglund and Kirkevold (2001), "Thriving is…related to an attitude of making the best of the situation, taking part in activities and social relationships according to their capacity and wishes." (p. 432).

Critique of Nursing Perspectives

From an empiricist perspective, the problem with nursing models of thriving is their lack of precision. In addition, several criticisms by Saakvitne, Tennen and Affleck (1998) leveled at social behavioral approaches above apply equally well to models developed in nursing. Of particular concern is an undue reliance on many taken-for-granted indicators that have not been satisfactorily evaluated in the context of a thriving construct. In the life span theory, though attributes, antecedents and consequences have been delineated, descriptions of potential relationships and interactions among factors are not well developed. In addition the question of how thriving differs from or relates to other key concepts in aging such as resilience, quality of life, successful aging, and well-being have not been sufficiently examined. For example, the work of Lawton (1991) on quality of life in frail elders exhibits parallels to person and environment relationships posited in the lifespan theory of thriving. Similarities between many of the thriving consequences proposed by Haight et al. and the quality of life domains for nursing home residents suggested by Kane and colleagues are evident (Kane, 2001, 2003; Kane et al., 2003). Significant overlap with concepts in emerging explorations of social process (Gould, 1992; Herzberg, 1997; McGilton et al., 2003) and spirituality (Bickerstaff, Grasser, & McCabe, 2003; Commerford & Reznikoff, 1996; Touhy, 2001) in nursing home settings are also apparent.

Although both nursing driven concepts of thriving reviewed here (Bergland & Kirkevold, 2001; Haight et al., 2002) have the purpose of addressing thriving in older adults, neither model adequately addresses the complex nature of age related decline. Bergland and Kirkevold (2001) limit discussion to physical and cognitive decline and restrict applicability of their model to “stable” and “lucid” individuals. This model has recently been used to support groundbreaking qualitative exploratory research on residents thriving in the nursing home (Bergland and Kirkevold, 2005a, 2005b, 2006). Results support the role of mental attitude in adapting to the environment. Thus far, the model has not been widely used to support investigation into specific strategies (the how) that residents use to adapt. Neither does the model address the positive or negative effects of ongoing changes in physical or functional status or the influence of personal history on “mental attitude” in the context of the setting,.

The life span theory of thriving admits that an individual’s level of thriving may vary depending on the congruence of its three major concepts, but does not speak directly to the dynamics of thriving in the face of decline. Ironically, social behavioral conceptualizations, which have concentrated on younger populations, have contended with the issue of decline by proposing that thriving may take place in various domains independent of one another (Carver, 1998; Park, 1998) a concept also evident in Lawton’s (1991) work on quality of life.

Complementing Empiricism and Quantification

Limitations of Prevailing Approaches

Despite attempts to move into individually centered holistic models, nursing theorizing on thriving has remained largely tethered to an empiricist epistemology. In the theory of thriving, emphasis on discrete indicators, attributes, antecedents, and consequences implies an essentially reductionist theoretical stance. Recent qualitative work by Bergland and Kirkevold (2005b) is likewise rooted in a preconceived framework that guides an initial discrete factor discovery project. There is a need to explore the subjective experience of thriving (or "doing well") in order to better understand the variability as well as common threads that exist. Comprehensive understanding of the phenomenon requires insight into how similar observed or reported experiences can lead to disparate subjective evaluations of one's doing well.

The burgeoning interest in thriving and parent concepts such as post-traumatic growth, resilience and stress and coping has supported development of a modest body of quantitative research in social and behavioral sciences. Nevertheless, advances in our understanding of thriving may be subject to a slow down in progress similar to that described in the broader field of stress and coping. Folkman and Moskowitz (2000) summarize impeding influences in the exploration of coping: limited assessment techniques, underutilization of qualitative methods, lack of attention to interpersonal factors. In commenting on the role of qualitative approaches in thriving research, Massey, Cameron, Ouellette and Fine (1998) voice similar concerns, suggesting that existing thriving theory runs the risk of "predetermining the conceptual boundaries of how we think thriving will be exhibited" (p. 338). Furthermore, prevailing theoretical frameworks and related research methods may not adequately account for the effect of social, cultural and political context or fluctuations in thriving across time (Massey et al., 1998).

An advantage of adopting a postmodern epistemology is acknowledgement of the validity of viewing phenomena and developing models from varying (often seemingly conflicting) perspectives (Cheek, 2000). Based on the preceding analyses and critique, it is evident that prevailing concepts of thriving have been developed largely within a positivist/post-positivist paradigm (Lincoln & Guba, 2000). Though knowledge gained from this perspective is valuable, it will always be subject to its own epistemological bias. Dislodging the conceptual logjam suggested by Folkman and Moskowitz (2000) requires more than reordering methodological priorities within the existing epistemological framework. It requires moving beyond the conceptual restrictions imposed by positivist and post-positivist epistemologies (Lincoln & Guba, 2000).

Accessing the Lived Experience of Thriving: "Doing-Well"

Assumptions

For the purpose of expanding beyond the prevailing positivist and post-positivist grounded models, thriving will be described as possessing the following attributes: (a) it entails embodiment and freedom (b) it is constituted in the life world, (c) it is rooted in a lived sense of "doing well" and (d) it may be suggested by perceptible clues.

Implications of Moving from Dualism to Holism

To state that human thriving involves the person distinguishes it from the passive flourishing often associated with biological phenomena such as plants and from collective growth characteristic of social entities such as cities or economies. An embracive view of thriving as an engaged experience requires discarding Cartesian dualism and accepting the person as unified “body-subject.” (Merleau-Ponty, 1964).

Consistent with this line of thinking, if we ask elderly individuals in a nursing home how they are doing or if they perceive themselves thriving, their response will reflect an understanding of their experienced level of dong well based not only on goals but also on self-identified standards. This evaluation will include a unique array of factors, some of which are common and expected, such as level of comfort, perceived level of health, appetite, etc., and some of which may be less evident, such as not having a preferred caregiver or having recently received a disturbing telephone call. In addition the evaluation and subsequent response will inevitably be affected by memories, preferences and habits, facets of personal history that are not immediately conscious.

Attending to Perceptions and Experience

Engaging in conversation that cultivates personal revelation places the experience of thriving and its meanings in a public space, promoting a deeper understanding of the lived experience of thriving, leading to clarification and highlighting similarities and differences in the embodied experience (Taylor, 1985). Consider the cases of two persons with terminal lung cancer, one a community dwelling older adult with a history of few health or social problems, the other a frail elderly nursing home resident who has spent a lifetime adjusting to a crippling illness. If we accept Merleau-Ponty’s (1964) view that the world and the subject are inseparable, and recognize the importance of personal, communal and cultural history as integral to life world (perspective), then though both experiences of thriving may have common elements, the embodied knowledge of thriving will differ for each of these men.

Expanding on Merleau-Ponty's line of argumentation regarding freedom and choice, it follows that each man has the potential to perceive thriving on his own terms as a consciousness unconstrained by personal limitations:

> Consciousness can never objectify itself into…cripple-consciousness, and even if the old man complains of his age or the cripple of his deformity, they can do so only by comparing themselves through the eyes of others, that is, by taking a statistical and objective view of themselves, so that such complaints are never absolutely genuine: when he is back in the heart of his own consciousness, each one of us feels his limitations and thereupon resigns himself to them. (Merleau-Ponty, 1964, p.504)

It is precisely this brand of comparison-free situatedness that fuels the frail older person's ability to thrive or do well in the face of functional decline. Thriving is no longer the tipping of nutritional or functional ability scales in one or another direction, but rather the individual's entry into a consciousness that presents him the freedom to characterize his own experience of doing or being well, wherever that may land on an objectified scale of illness-wellness.

But it is not possible to dwell comparison free continuously in the "heart of one's own consciousness," even if that consciousness does not admit of distinction or division from the world. Man by nature is a comparison making being, and cannot avoid at some point lapsing into making distinctions. (A case can be made supporting the premise that the use of language, indeed thought itself, requires the making of distinctions, but this discussion is beyond the scope of this paper.) Thriving will fluctuate across time and circumstances but it will always be embodied. Suffice it to say that taking a phenomenological-existentialist stance as outlined above allows us to conclude that thriving, when viewed in the context of embodiment and life world, can occur throughout aging and decline to the point of death. In adopting this position what we cannot quantify (nor would we consider it relevant) is where on a conceptual scale of thriving or failure to thrive an individual objectively lies or perceives he lies.

Communication and Understanding

Nevertheless, situating thriving within life worlds that admit of some degree of commensurability suggests that it is both context bound and can be appreciated in terms of the person's immediate embodied interpretation of that life world—an interpretation shaped by personal history. This is not to imply that the experience of thriving is fundamentally incommunicable, but rather that characteristics and qualities of individual instances of thriving exist that cannot be determined using an empiricist worldview. Though observable indicators of thriving may exist and may aid in appreciating specific aspects of the phenomenon of thriving, the person's thriving is inextricably bound to the incarnating self and is integral to one's life world. Postulating life worlds that admit of some degree of commensurability opens the possibility that knowledge of important aspects of thriving may emerge in disclosive spaces (Benner, 2000). For this to occur these life worlds must intersect with sufficient depth and quality. Stating this does not diminish the importance of observations or clinical attributes, but rather rights their relationship to thriving, reinforcing the supportive role of empirically derived data to a more comprehensively conceptualized description of thriving. Indeed, such data may provide clinicians with clues to enabling entry into shared disclosive space (Benner, 2000).

There are those who might object to the conceptualization of thriving outlined above on the grounds that it may not adequately describe constituents that are observable and empirically knowable, that it does not provide criteria that enable the observer to clearly determine whether a person is thriving or failing to thrive, or that the concept of embodied thriving is at best marginally relevant to what can be quantified and cured. Significantly, the view of thriving presented here is not meant to eliminate knowledge that has been derived from rationalist or empiricist methodologies but rather to complete and complement this knowledge to arrive at recontextualized understandings of the phenomenon of thriving. Knowledge of potential empirical indicators of thriving/failure to thrive (e.g., nutritional decline, decreased activity, despondency, etc) will continue to inform clinical practice, but approaches that capitalize on embodied understanding have the potential of enabling caregivers to access the lived experience of doing well at a deeper more personally defined level, arriving at interventions that address not only empirical indicators but more importantly an embodied state of thriving/failure to thrive (Wilde, 1999, 2003).

Frailty and Doing Well: Thriving Despite Decline

Does accepting the conclusion that the capacities for thriving are retained and can be enlisted despite decline necessarily indicate that thriving invariably persists until the time of death? In other words can we conclude that the capacity is consistently actualized? Customary empirical measures of thriving would indicate not. Indeed established measures and prevailing conceptions of thriving suggest the onset of failure to thrive in the older adult occurs when nutritional intake and weight decrease, social withdrawal becomes apparent and functional ability declines (Berkman, Foster, & Campion, 1989; Braun et al., 1988; Egbert, 1996; Fox, Hawkes, Magaziner, Zimmerman, & Hebel, 1996; Osato, Takano Stone, Phillips, & Winne, 1993; Verdery, 1997b). In this view, there is always a point, however nebulous, when thriving ceases.

But in moving beyond empirically driven conceptualizations of thriving, to a view that incorporates embodiment within a life world, the individual's perception of his own level of thriving emerges as an essential standard. In adopting this stance, the key question shifts to whether the person as a perceiving body-subject is able to experience an array of personal meanings constitutive of thriving, despite decline or failure of physiological systems (even to the point of death). Depending on the person's level of consciousness one might gain access to aspects of this content by entering into conversation (disclosive space) during which the individual reveals his perceived state of thriving/non-thriving—his own evaluation of how well he is doing.

Adopting an existential-phenomenological view of the person that affirms embodiment and acknowledges the intersection of life worlds supports the possibility that the frail older adult retains the capacity for thriving in spite of observable decline, even to the time of death, and that, to varying degrees, this experience can be shared and understood. Though this discussion is unable to suggest that thriving despite decline occurs in every instance, it supports the value of delving into subjective reports of what it means to "do well" with a view to advancing and developing theories of well-being relevant to the clinical interaction essential to nursing practice.

Conclusion

Over the past decade, models for studying health-related thriving (here viewed as one iteration of the larger well-being/QOL discourse) have moved from an infancy characterized by curiosity, discovery, and initial propositions of properties and potential moderators, to a period marked by the recognition of inconsistencies, and the search for methods to develop (social and behavior sciences) or substantiate (nursing) more comprehensive models. Both the social and behavior sciences and nursing have arrived at definitions of thriving that support discipline specific foci but fall short of adequately capturing the complexity and variability extant in the lived experience of thriving. Voices within both disciplinary approaches acknowledge the rudimentary nature and potential limitations of proposed models. Both have suggested the need for alternative methodological approaches to refine existing conceptual frameworks. At issue here is the need to step back from questions of methodology and to consider the epistemological assumptions that underlie the development of these models. One way to clarify and complement the content of present models—and as needed, free them from preconceptions rooted in models developed for other phenomena—is to explore the perceptual and existential nature of thriving, to adopt an epistemological posture that recognizes the standpoint of those who experience “thriving”, or, to use a term more soundly rooted in a nursing home resident’s life world, “what it means to do well.”

Chapter Three

ACCESSING EXPERIENCE, AUTOBIOGRAPHY AND ENVIRONMENT: METHODOLOGY FOR A STUDY OF DOING WELL IN A NURSING HOME

Ethnography as the Research Framework

An exploratory qualitative methodology was chosen for this research because little is known about doing well among older nursing home residents, particularly from their standpoint (Hammersley & Atkinson, 1995; Maxwell, 2005). Many qualitative researchers have used ethnographic approaches to understand how people interpret experience, pattern their behavior and construct meaning in the context of socially and culturally constituted environments (Rubinstein, 1992). The case for interpretive ethnography finds support in hermeneutic contextualism, “the view that interpretations are always context bound—that is, they always take place within some background of beliefs and practices (culture, form of life, language game, or tradition) that is never at once and completely capable of articulation” (Schwandt, 2001, p. 36). Though context can never be exhaustively articulated or frozen, ethnography provides insight into the institutional life and culture that provide the constitutive surround in which the resident “stories his life” and the researcher interprets this “storied life.” Thus, as a way of accessing, describing and analyzing human meaning-making activities in a cultural and social context, ethnography was deemed particularly appropriate for this study of doing well.

In designing a research approach to explore patterns of meaning in nursing homes, Gubrium (1993) developed a mode of ethnographic inquiry that (a) presumes and elucidates a dynamic view of nursing home life, (b) respects and accounts for point of view and different meanings that individuals may associate with a common experience and (c) recognizes and accepts subjective complexity. In addition, this method recognizes the resident as biographically active and establishes the resident's narrative as a starting point: "the life is a narrated entity, a constructed whole served up against horizons, in relation to which matters of various kinds such as the quality of care are given voice." (Gubrium, 1993, p. 178). This line of thinking supports a research framework that foregrounds autobiographical accounts of experience and the interpretation of residents' present reflections and observed behaviors in relation to their storied past. Interview and participant observation are reinforced as the mainstays of inquiry. Given results from pilot research suggesting that past experience in addition to present context informs current patterns of doing well (Walent, Chesla & Kayser-Jones, 2006, April), Gubrium's interpretive approach to ethnographic inquiry provided guidance for the development a research orientation that attends to present experience, personal history and current environment (see Figure 5).

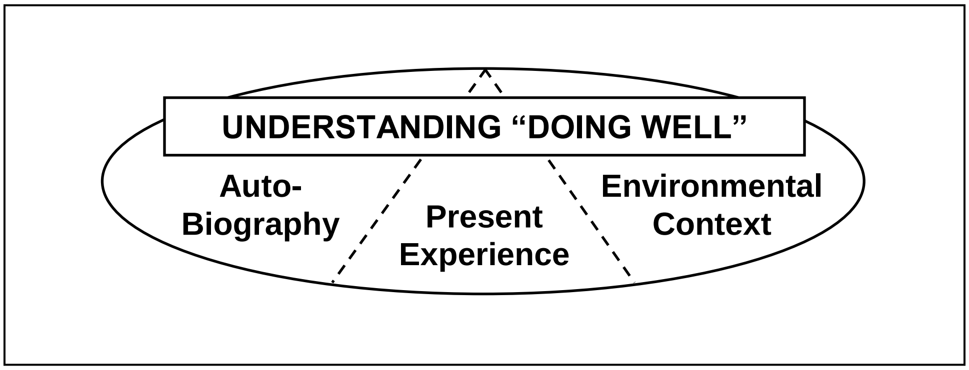

Figure 5. Conceptual components of the research approach

Study Design

Purpose and Aims

The purpose of this interpretive ethnographic research is to understand and articulate the experience and dimensions of doing well in older nursing home residents who have been identified by caregivers, fellow residents, family members and/or the investigator as doing well. The specific aims are to identify, describe and analyze:

a) Residents' perceptions of doing well in the nursing home;
b) Residents' perceptions why they believe they are or are not doing well;
c) Relationships between self reported biographical factors (e.g., significant life experiences, employment, living situations, key relationships) and the residents' perceptions of how well they are doing;
d) Resident characteristics (e.g., age, ethnicity, marital status, observed level of physical and cognitive function, length of time in the nursing home) in relation to doing well;
e) The influence of cultural and social factors (e.g., facility rituals and routines, interactions with staff, fellow residents, number and frequency of visitors) on how well residents perceive themselves doing;
f) Patterns of value and meaning in the lives of residents and their possible connections to doing well.

Research Questions

The central research question was what is the nature and meaning of doing well for older long-stay residents in large public and for-profit nursing homes. Ancillary questions included, what constitutes "doing well" for residents; what is the connection, if any, between how well a resident is doing and past experience; what physical, social or cultural features of the nursing home environment do residents perceive as influencing their doing well? Consistent with the exploratory nature of the study, additional questions emerged as research progressed and the need for clarification arose. These questions provided the basis for the content of the follow up interview.

Site Selection

While the initial recruitment strategy called for inclusion of private for-profit facilities only, difficulties in enrolling a large enough sample from a manageable number of settings required revamping this approach. In the end, the study sites selected were a for-profit chain nursing home and a large public skilled nursing facility. This change proved fortunate in that the resulting sample incorporated a proportionally greater number of male and ethnically diverse residents than would have been possible with the original site selection strategy. The diversity of the resulting sample provided for greater appreciation of the complexity and variability inherent in the doing well phenomenon.

Participants

This study was reviewed and approved by the University of California Committee on Human Research. In keeping with growing recognition of the ability of individuals with cognitive impairments to provide valuable insight into their own experience (Kane et al., 2003; Mozley et al., 1999; Whitlatch, Feinberg, &Tucke, 2005), a concerted effort was made to include cognitively impaired residents who could engage in interview.

The 17 enrolled participants who provided interview data were 65 years or older, had lived in the nursing facility for more than four months, and were able to converse in English during interviews lasting from 20 to 100 minutes regarding their “doing well” in the nursing home. It was unlikely that these residents would be leaving the nursing home to live in another setting. All participants completed the entire interview and observation protocol, with the exception of one woman, who at the beginning of the follow-up interview indicated that she just didn't feel like taking part in another interview. A more detailed profile of the participants based on collected data is included in the next chapter.

Sampling and Recruitment

Though sample sizes of less than 10 are common in qualitative studies, a sample of between 12 and 26 key informants seems to represent an agreed upon standard for a focused ethnographically framed qualitative study (Luborsky & Rubinstein, 1995). The decision to terminate enrollment at 17 participants was made when, given pre-established selection criteria, the chosen participants represented the demographic variability that existed in each of the settings (Maxwell, 2005), and when no new major themes or concerns were being identified in interviews, signaling sufficient data to address study questions (Sandelowski, 1995).

To minimize the sense of being pressured to enroll, initial contact with potential participants and/or their legally designated decision makers was made through facility staff members, using the Study Information Sheets (Appendix A). In order to reduce selection bias, the sampling plan involved combining purposive strategies (based on staff and/or researcher perceptions of who is doing well) and snowballing techniques (based on participants perceptions of other residents who are doing well) (Luborsky & Rubinstein, 1995; Morse, 1991). Ten participants were referred by facility staff based on Bergland and Kirkevold's (2001) description of thriving: residents who display an "attitude of making the best of a situation" and who show evidence of engaging in "activities and social relationships to their capacity and wishes" (p. 431). Two residents identified as "doing well" by enrolled residents, four identified by the researcher, and one resident who heard about the study and self referred brought the final sample sized to 17. Figure 6 provides further detail of the recruitment process.

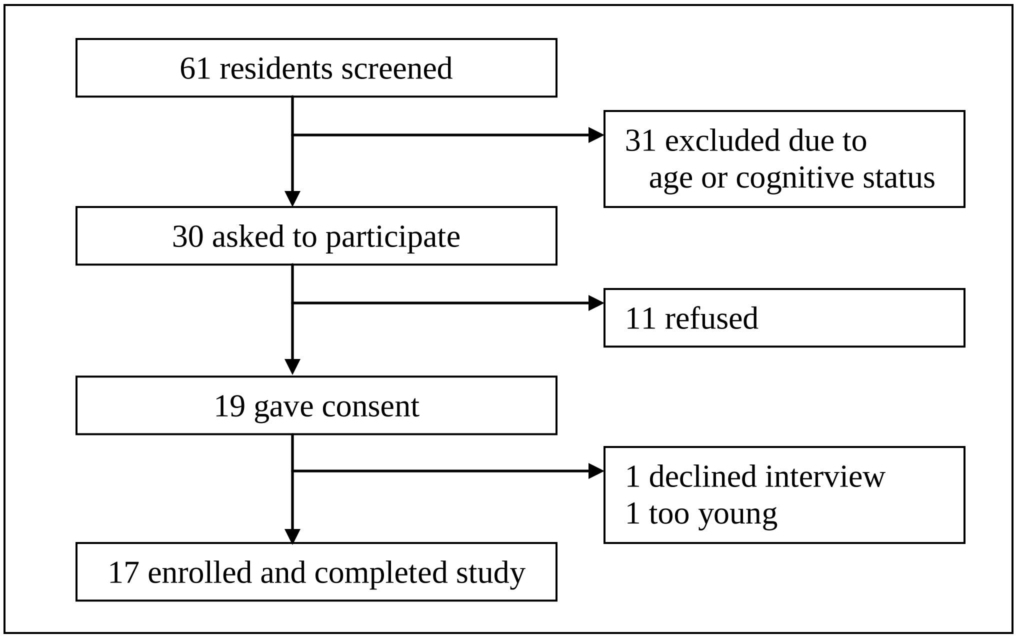

Figure 6. Recruitment, enrollment and study completion.

The decision to include participants with mild to moderate cognitive impairment required the development of additional recruitment and consent procedures. During the initial meeting, before obtaining consent, the investigator ascertained a resident's cognitive ability as a criterion for inclusion by evaluating their ability to converse and offer responses to questions (Appendix B) incorporated into the verbal introduction and description of the study (Brod, Stewart, Sands, & Walton, 1999; Mozley et al., 1999; Whitlatch et al., 2005). The introduction of the study was also used to formally assess a potential participant's capacity to consent for research (Appendix C). Residents who were assessed as having the capacity to consent for research signed a consent to participate in the study (Appendix D) and a consent for medical record review (Appendix E). In three cases where residents were deemed appropriate for inclusion but failed to demonstrate capacity for consent for research and medical record review, family members signed the forms providing surrogate consent (Appendix F), and participants signed indicating assent. Throughout the research process, in an effort to ensure ongoing consent or assent, the researcher inquired about participants' continuing interest in contributing to the study.

Data Collection

Data collection occurred in three overlapping phases: (a) initial in-depth, semi-structured interviews aimed at understanding the participants' experiences and perceptions of how well they were doing and related factors they considered relevant; (b) participant observation focusing on daily activities of residents and the nursing home environment, and (c) one or two follow-up interviews with the participants to clarify understandings of doing well that have emerged during the initial interview and observation period. Detailed field notes recorded as soon as possible after leaving the field captured observations and the content of interactions and conversations collected over the entire course of the study (Hammersley & Atkinson, 1995; Spradley, 1980).

Phase I—Interviews

Guidelines for semi-structured interviewing (Benner, 1994; Fontana & Frey, 2001; Luborsky & Rubinstein, 1995; Morse, 1991; Wenger, 2003) suggest that allowing reflections to develop conversationally with cueing only to initiate or reinitiate reflection, to clarify statements or to reorient the individual to the emerging story enhances the likelihood of capturing a participant’s viewpoint. To this end, a broadly scripted interview guide (Appendix G) was used to direct the introduction, frame the initial questions, and suggest possible follow-up questions and probes. Initial interviews, four of which were divided into two sessions, lasted from 20 minutes to 130 minutes. Demographic information (Appendix H) was collected directly from the participant toward the end of the interview and augmented during participant observation.

Phase II—Participant Observation

Participant observation totaled 212 hours in the field over period of five months in the for-for-profit facility and three months in the public facility. Since the focus of the study was on the resident standpoint, observations took place during day and evening shifts when participants were awake and most active. Observational data recorded as field notes were collected on (a) participant’s daily activities (b) informal encounters during which participants reflected on the events of their days and how they were doing; (c) interactions (e.g., with staff, other residents, visitors, or volunteers) that shed light on factors that promote or discourage doing well and (d) the nursing homes as the immediate context influencing a resident’s doing well (Hammersley & Atkinson, 1995; Spradley, 1980).

Specifically, each participant was observed over a period of twelve weeks during meals, scheduled group or individual recreational activities, interactions with licensed nurses, and daily care provided by certified nursing assistants (CNA). In addition to these routine or expected interactions, periodic events such as visits by friends and family, attendance at religious services, special celebrations (e.g., holidays, birthdays), functional therapy sessions (physical, occupational and speech therapies) and contacts with fellow residents and volunteers were also observed and noted. Observational data also included descriptions of participants' personal environments (e.g. room or bedside area and furnishings, accessories, belongings).

During this period, open medical record review provided an opportunity to collect confirmatory and additional demographic information as well as data from the Minimum Data Set associated Cognitive Performance Scale, Activities of Daily Living (ADL) score, triggered problems, diagnoses, care plan items, strengths and ongoing care issues. Toward the end of the observation period the researcher collected information to complete the Mental Status Questionnaire (Kahn, Goldfarb, Pollack & Peck, 1960) (Appendix I) directly from the resident.

Phase III—Follow-up Interviews

Toward the end of the period of participant observation each participant was interviewed one or two more times during sessions lasting from 30 to 100 minutes. These interviews were guided by questions derived from an interim analysis of initial interview and participant observation data. Initial interviews were read in full and notes taken on items that residents stated or implied were important for their doing well. Review of field notes and memos also supplied a list of items that, from the researcher's standpoint, required further clarification. This resulted in a list of possible questions to guide a follow up interview aimed at illuminating how the participant experiences and understands what it means to do well (Appendix J). Questions were reviewed with peers and with an expert in ethnographic nursing home research for relevance of content and clarity. These interviews were not intended to challenge the accuracy of previously collected data but rather to clarify further what it means for the resident to do well. This interview process enabled the investigator and participant to develop an understanding of "doing well" that underscores the participant's standpoint and articulates discrete factors and characteristics based on biography, context and experience (Fleming, Gaidys, & Robb, 2003; Gadamer, 1989; Grondin, 2002).

Memoing

Well established in traditional ethnographic inquiry (Hammersley & Atkinson, 1995) and formalized as a fundamental component of grounded theory method (Strauss, 1987), the use of memos to record theoretical insights, personal reflections and operational reminders, has become a key constituent of virtually all qualitative research (Maxwell, 2005). The memos generated during this study were of three types. First, theoretical memos recorded reflections on interviews and field notes, speculations on the meaning of the data, and insights into broader theoretical linkages that informed analysis and discussion. Second, reflexive memos and journaling provided opportunities to grapple with strong emotions and preunderstandings rooted in personal experiences in nursing homes, attitudes toward aging and, the challenges of providing support at a distance for an aging and increasingly frail parent. Lastly, procedural memos and notes facilitated management of the exigencies of the research project.

Data Management

Interviews were professionally transcribed from the audio-recordings. To ensure accuracy and preserve confidentiality, the researcher reviewed transcripts while listening to recordings, correcting errors, and removing or disguising content that might serve to identify the setting, participants or other individuals associated with the study sites. Likewise, in reporting and discussing data here, pseudonyms are used and situations disguised to ensure confidentiality for individuals and study sites. Hard copies of data were secured under lock and key and electronic data in computer files were password protected.

ATLAS.ti 5.2.0, qualitative data analysis software was used to support storage, coding, retrieving, and organizing text. This program assists with speed and comprehensiveness of searches and facilitates management of large, complex data sets (Kvale, 1996; Miles & Huberman, 1994). Quantitative data that involved simple counts were analyzed by hand, and SPSS 12.0 was used to generate more complex demographic statistics.

Data Analysis

The overarching goal of data analysis is to achieve an understanding of what it means for elderly nursing home residents to do well that attends to the influence of autobiography and context. To this end, analysis involved several complementary interpretive strategies: (a) hermeneutic analysis of initial interviews to identify themes both within and across cases; (b) Content analysis of initial interviews, field notes, and chart review information to facilitate description, interpretation and understanding of the context and to support development of questions for follow-up interviews; (c) comprehensive hermeneutic analysis of the dataset, resulting in a resident focused understanding of doing well and related constitutive dimensions.

Hermeneutic Analysis

Engagement in the hermeneutical circle provides a way of identifying themes imbedded in interview data. This is the ongoing process of working from particular sections of text and related meanings, arriving at understandings of broader themes and the narrative content as a whole, and returning back to specific accounts to test the suitability of derived themes (Benner, 1994; Cohen, Kahn, & Steeves, 2000). These interpretive methods were used for within case and across case analyses and resulted in an interpretation that elucidates the resident's individual lived experience and themes that emerged within the subgroups of the sample and the sample as a whole.

Participant Observation Data

The environmental features, events and activities observed and captured in field notes were summarized and organized using diagrams, flowcharts and matrices. Resident reflections on specific aspects of the environment were also examined and sorted out using charts and tables. This process provided an alternative view of the data and facilitated consolidation, comparison and display of complex relationships among various phenomena and pieces of data, prompting further exploration and informing subsequent interpretation (Spradley, 1980). As mentioned above examination of initial interview and observational data to identify prominent concerns and issues related to doing well directed the development of questions for follow-up interviews.

Comprehensive Analysis

The ongoing, simultaneous processes of data collection, analysis and interpretation allowed for progressive refinement of an understanding of doing well. In particular, final follow-up interviews provided opportunities for researcher and participant to meld storied biographical and observed environmental aspects of doing well into a coherent understanding of what it meant to do well in a nursing home (Fleming et al., 2003). A final analytical/interpretive step involved a review of data, memos, charts, diagrams and summaries that lead to a comprehensive articulation of findings. The resulting understanding of doing well among older nursing home residents is represented in a major theme comprised of three subthemes, and three additional themes related to discrete aspects of the phenomenon.

Attending to Rigor

Given the theoretical, methodological, representational, hermeneutic and practice-implication features of the proposed study, Whittemore, Chase and Mandle's (2001) validity criteria for qualitative research were chosen to address rigor. In their schema primary validity criteria include credibility, authenticity, criticality, and integrity. Secondary criteria consist of explicitness, vividness, creativity, thoroughness, congruence and sensitivity. Primary criteria are considered applicable to all qualitative inquiry, whereas various secondary criteria are considered more or less important based on the nature of the research.

Primary Validity Criteria.

To address *credibility* and establish confidence in the accuracy and interpretation of data, the researcher relied on careful, multiple reviews and comparison of recorded and transcribed interviews, making time to write initial field notes on site, and enlisting peers and experts in the process of reflecting on interpretation. The commitment to *authenticity* is evidenced in the judicious choice, editing and summary of quotes and observational data to maintain and communicate richness of content and emotional context. Memoing, journaling and reflecting on the research with peers and mentors were employed to minimize threats to credibility and authenticity rooted in unrecognized or covert distortion and bias. *Criticality* involved considering alternative explanations, and exploring inconsistencies, and ambiguities that arose during the process of analysis and representation of findings. *Integrity* was addressed by frequently returning to the data to ensure that interpretations were firmly supported. Integrity and criticality were fostered by an interpretive process set in the hermeneutic circle, a commitment to continually move between the whole and it parts, from close inspection to broad understanding culminating in a sincere and reflective representation (Whittemore et al., 2001).

Secondary Validity Criteria.

While Whittemore et al. (2001) stipulate that the need to address all six secondary criteria depends on the nature of the research, all the suggested norms proved relevant to the present study. In addition to data, memos and journal notes reflecting the research process, forms submitted to the Committee on Human Research, electronic and hard copy communications with potential and chosen study sites, electronic and hard copy drafts of data collection and analysis tools, provide a means for tracing study decisions in support of *explicitness*. Quotations were chosen and summaries constructed to provide the reader with a *vivid* representation that communicates thoroughly and clearly yet imaginatively. *Creativity* is most evident in a study design that attends to the complexity of the phenomenon of interest and combines qualitative approaches to address participants' experiences, environments and personal histories. *Thoroughness* was achieved during the iterative process of data collection and analysis: when no new major themes or concerns were emerging, the amount and quality data were considered sufficient to support addressing the research question.

Discussion above on the choice of method provides evidence of *congruence*, the internal consistency between question and method. Findings are consistent with the stated methodological focus on experience framed by biography and environment. In addition, the discussion situates findings in the context of existing studies and practice, and supports congruence grounded in notions of connectedness and application rather than in prevailing concepts of quantitative generalizability.

Meeting the criteria for *sensitivity* requires that research be conduced ethically in a manner that recognizes the situated lives of participants, an issue of particular concern in the case of frail institutionalized older adults. Schuster (1996) expands on the well recognized ethical principles of respect for persons, beneficence and justice (Office for Protection from Research Risks, 1993) recommending that researchers engaging vulnerable nursing home residents be guided by profound respect for autonomy, privacy and control. Strategies enlisted to ensure an ethically grounded notion of sensitivity included a rigorous capacity to consent screening, attention to participant's age and condition related discomforts during data collection, and scrupulous attention to autonomy, privacy and choice (e.g., time and place of interview, what individual activities would be observed).

Chapter Four

LIVES IN CONTEXT:

OVERVIEW OF STUDY SITES AND PARTICIPANTS

Introduction

This chapter describes the research settings and provides a summary of characteristics of the study participants. To capture what it means to do well from the resident perspective, the descriptions of the environment will focus on areas that participants frequented or mentioned during interview and interaction. These descriptions are intended to supply the reader with a sense of the environmental context that informs the resident's stories, reflections and understandings. Likewise, summarizing demographic information and participants' characteristics is not meant to diminish their individual lives and stories, nor is it intended to provide an image of the "typical resident." Instead the purpose is to orient the reader to both similarities and variability that exist in the study sample.

Study Sites

Del Rio Center

The Del Rio Center is a large (>500 beds) publicly owned and run skilled nursing facility. Originally founded as an almshouse in the mid 19th century, it is situated on a 62-acre wooded parcel of land in a residential district of a large city on the West Coast. The facility consists of an expansive main building with 30 Nightingale-style open wards, housing between 25 and 35 residents each, and a smaller 3-story structure with private and semi-private rooms housing 20 to 30 residents on each of its 6 units.

Table 1.

Characteristics of the Study Sites and Populations Served

	Lincoln Way Nursing Home	Del Rio Center
Facility type	For Profit Corporate Chain	Government Sponsored
Licensed SNF beds, *n*	>125	>500
Payment source, *%*		
Medicare	2.9	0.1
Medicaid	89.9	96.2
Medicare-Medicaid	5.8	2.9
Private Insurance	0.7	0.4
Self pay	0.7	0.9
All Other	0.0	0.1
Age, %*	65+ = 92	60+ = 68
Gender, %		
Female	70	49
Male	30	51
Ethnicity, %		
Non-Hispanic White	10	39
African American	10	25
Hispanic	9	13
Asian/Pacific Islander	57	21
Other	14	2

* Lincoln Way reports aggregate data for percent of residents aged 65 and above while Del Rio reports data for percent of residents aged 60 and above.

The Del Rio residents were younger, included more males, and displayed greater ethnic diversity (see Table 1) than national averages (Jones, 2002). In addition, the major per resident source of funding was Medicaid (96.2%). Though aggregate statistics on the socio-economic status and prior living situations of residents were not available, information in the public domain indicates that the facility cares for a large number of individuals with histories of substance abuse and homelessness and suggests that over one third of the residents have psychiatric diagnoses in addition to their medical problems.

Site Overview

All of the participants in the study lived on units in the main building. This imposing structure, constructed in stages between the mid 1920's and the 1940's, has eight floors that stagger up a wooded hillside, so that only the third and fourth floors run the entire length of the building. A wide main corridor with windows on either side forms the central spine of each floor. Long resident care units with open wards extend perpendicularly off this central spine. The front entrance provides access to the first floor, with its large auditorium, chapel, and administrative and personnel offices.

In addition to the first floor chapel (the size of a small church), and auditorium, the facility has its own library with four computer stations for residents, a large common activity space with a vaulted ceiling that serves as the facility bingo hall, several smaller common activities areas, a canteen, beauty parlor, gift shop and cafeteria. The building has numerous wings that once were used for patient care, but have now been transformed into administrative or clinical spaces and house social services, physical therapy, occupational therapy and activities departments and physician offices. Alcoves along the hallways, stairwells, unused activity spaces, and solariums provide locations where more mobile residents seek respite from the daily routines of the facility.

At the rear of the building, the fifth–floor entrance bustles with activity lasting from shift change early in the morning to five or six o’clock in the evening when most of the dayshift staff has left and residents have returned to their units. Most staff, visitors and residents use this entrance since it is adjacent to a large staff and visitors parking lot and is the usual pick-up and drop-off point for residents riding ambulances, vans, facility buses, and private vehicles. A wheelchair ramp extends from the entrance to the sidewalk and a small smoking shelter. On days with tolerable weather several residents regularly spent time in or near the shelter smoking and chatting. Occasionally one of the residents would ask passing staff, visitors and fellow residents for a cigarette or some change.

Nursing and medical operations offices are located immediately inside the fifth floor entrance, on either side of the hall. A conference room and a dental clinic also open onto this hall. Directly across from the nursing operations office, in the hallway, is a desk for a sheriff cadet who signs visitors into the facility and provides them with temporary name tags. There is much activity in this entry hall during shift change when per diem and agency staff are waiting for their assignments. The location of the admission ward has been strategically located close to the rear entrance to accommodate frequent gurney traffic to and from ambulances in the parking lot.

Easy access to the outdoors, the presence of alcoves for vending machines and tables, and the location of medical staff and nursing operations offices at the east end near the entrance means that there is much foot traffic in the fifth floor corridor. In a sense the fifth floor hallway functions as the facility's main street. Groups of from two to five residents regularly position themselves in the main corridor at the entrances to their units or near the vending machine alcoves and watch the comings and goings of staff, visitors and other residents. Periodically facility staff walking down the corridor stop to talk to one another, or briefly engage a resident in conversation. On one occasion during the flurry of activity in the hallway at the afternoon change of shift, I witnessed a staff member selling food in Styrofoam takeout containers to fellow staff and residents. This practice was discouraged by administration but persisted. In contrast to the activity on the fifth floor, I encountered very few residents or staff in the sixth and seventh floor hallways, unless one of the alcoves was being used for a group entertainment activity.

Traditionally, Del Rio's units were segregated according to sex, though now nine wards include both males and females. In addition, the facility strives to group residents according to their health care needs. This has resulted in the creation of four clusters designated chronic, complex/restorative, dementia and behavioral. Programs have been developed to address health care needs deemed important for residents fitting into each of these categories. Though each unit had a designated focus, a small number of residents did not meet the criteria for placement on their unit. Among study participants, one woman in the initial stages of dementia was housed on a chronic unit, one man with a long history of homelessness lived on a complex/restorative unit, and the remaining six participants, though not diagnosed with dementia, resided on units in the dementia care cluster. Placements such as these were usually based on the need to admit to an available bed, to address a resident's unique behavioral or physical care issues, or to honor individual or family preferences for placement on a specific unit.

Staff viewed the size of the facility as both as a plus and a minus. On the plus side, the large size enabled the facility to continue to function as a self-contained entity, providing onsite specialist, diagnostic and treatment services more characteristic of a hospital setting. On the other hand, the sheer size of the facility and its outdated architecture resulted in challenges to provision of more individualized aspects of care, such as daily menu choices, private or semi private rooms, and the ability to personalize one's immediate environment. The facility's location at the top of a steep incline and removed from the main street limited ready access to the surrounding community especially for residents. Observation and conversations indicated that administration and staff were continually seeking programmatic solutions to the challenge of balancing autonomy and safety within an archaic environment that often served to reinforce institutional thinking characteristic of a bygone era.

Care Units

Consistent with a research focus on the resident standpoint, this description will concentrate on areas of Del Rio where participants lived and engaged in activities. The units I observed conformed to a general elongated layout comprised of two contiguous sections: an entry corridor lined with several private rooms, a dining room, staff break room, blanket warmer, linen room, nursing station and medication room (see Figure 7), and an open ward with adjacent bath and shower rooms, laundry rooms and a solarium at the far end of the ward, (see Figure 8).

The entry corridor on each unit was bright clean, odor free and normally uncluttered. Closer inspection revealed cracks and flaking paint on the walls and ceilings. The combination of permanently stenciled lettering, paper signs and old bits of

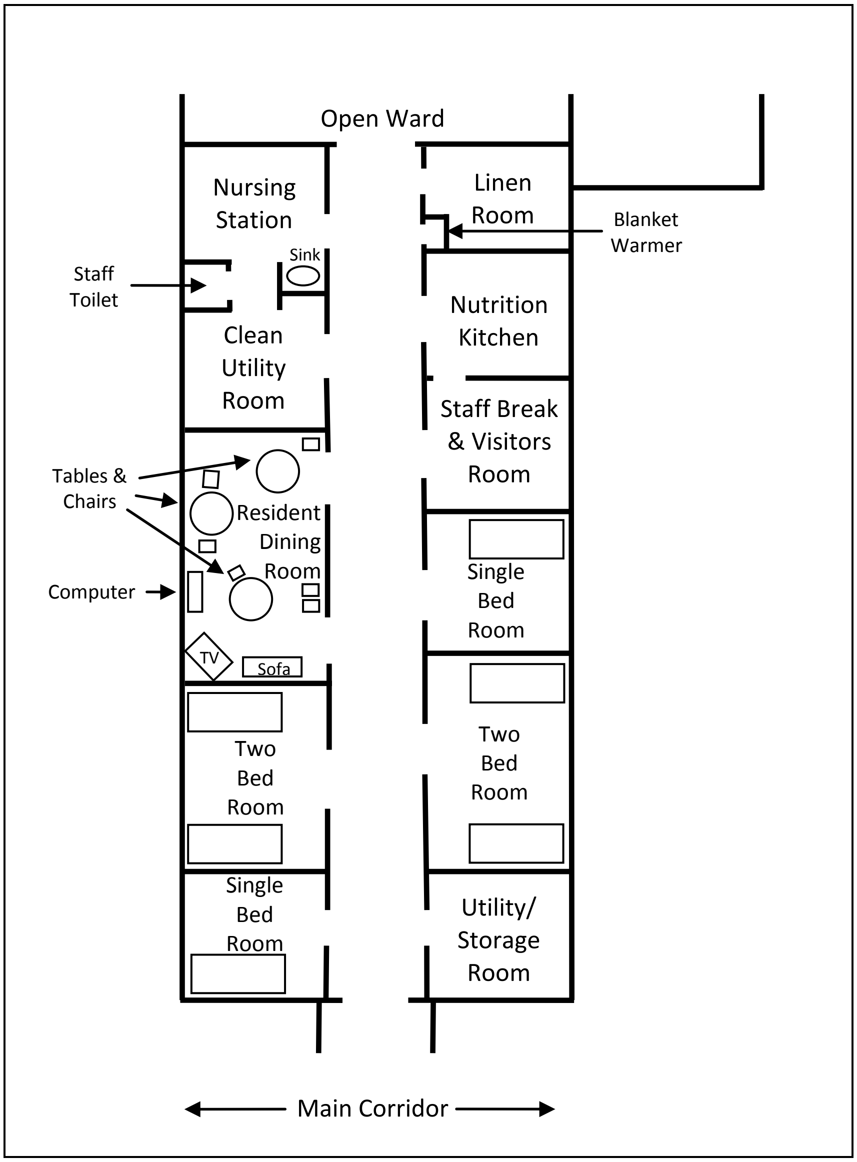

Figure 7. Del Rio Center, unit entry hall.

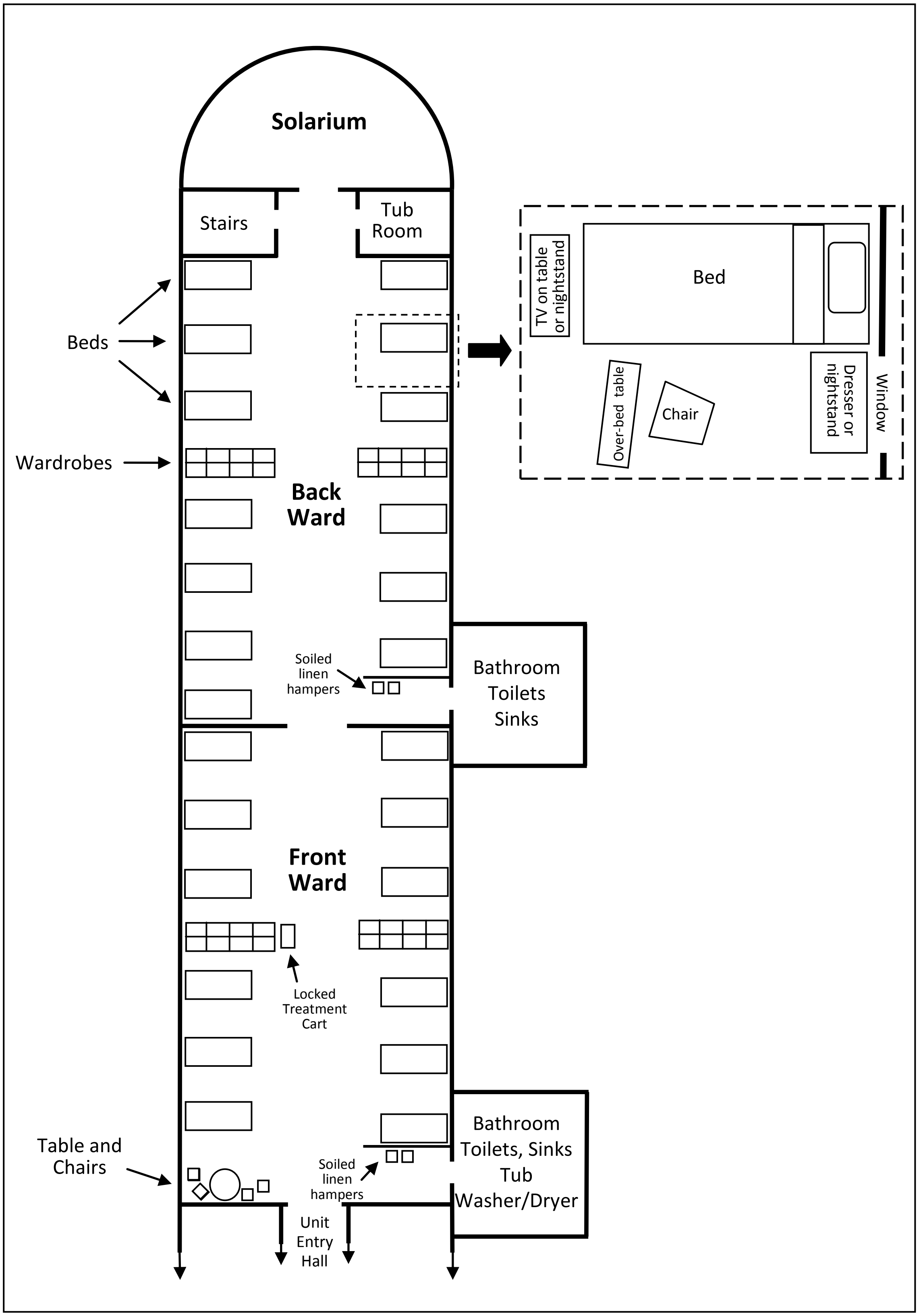

Figure 8. Del Rio Center, typical open ward.

tape on scuffed and scratched doors provided indications that the years had taken their toll on the physical plant. On several units, signs were posted making it clear that certain rooms were for staff use only, or that there were limited specific times that these rooms could be used by residents and visitors. Staff and administrators indicated that they were trying to limit spending on renovations in the main building, since over the next three to seven years, Del Rio's residents would be moving into a large modern complex of buildings, with private rooms. The new facility was being constructed immediately adjacent to the present structure.

Except during busy morning hours, residents in wheelchairs who could self-propel had little difficulty navigating the corridors. Traffic in unit entry corridors was most congested during weekday mornings as certified nursing assistants (CNA) moved about providing morning care, nurses passed medications, dietary staff transported carts with breakfast trays and residents in wheelchairs and gurneys awaited transport off the unit to clinics, group activities and therapy sessions. The area immediately outside the nursing station was often prone to "traffic jams," as residents in wheelchairs periodically approached the door to request medications, cigarettes or access to personal funds, or to inquire about an activities, appointments or some special need.

Dining Rooms

On most units, the dining room along the entry corridor had been created from larger rooms that were once four or more bed wards. The dining rooms on units that housed men tended to be clean and bright but cold and sparsely decorated. Mismatched chairs were along the walls and plastic tablecloths covered square or oblong tables. A few paintings or posters hung on walls that evidenced a few cracks and random areas of peeling paint, characteristics of an old and deteriorating physical plant. In contrast, the dining room on the unit that housed most of the female study participants, was more warmly and cozily appointed and served as an area for activities as well as dining. Round tables with floral patterned plastic coated table cloths, numerous paintings, a book shelf, a table with plants, a computer desk and a sofa against one of the walls, filled the space. In mid mornings two to four residents routinely congregated in front of a large screen television in the corner to view favorite game shows. Despite the inviting nature of the room, the women on the unit rarely used the dining room after 3 pm. By that time most were in their rooms or at their bedsides, and many had already been put to bed.

Depending on the unit and functional ability of its population, six to twelve residents regularly used the dining room during lunchtime. Reasons residents gave for eating at their bedsides included feeling as if they had little in common with other residents, a desire to avoid activity and periodic conflicts that arose in the dining room, or wanting to watch a favorite television program while eating. Very few individuals used the dining room for breakfast or dinner. Most residents ate breakfast in bed or sitting at the bedside and received morning care after breakfast. The practice of encouraging residents to retire late in the afternoon and putting them to bed before dinner persisted on the study units

Living Space

Since there are so few private and semi-private rooms along the unit entry halls, most residents live on open wards (see Figures 7 and 8). A wall with a large central doorway divides the large open ward into front and back wards. In the late 1990’s, in an effort to reduce the institutional feel of the resident living space, banks of armoires that extend perpendicularly from the side walls were installed, creating contained areas of three or four beds. While high ceilings and numerous windows create an overall light and airy feel to the open wards, limited space between beds, chairs, televisions, carts and equipment makes resident bedside spaces feel cluttered and cramped. At the far end of most units is a well lit semi-circular solarium. On some units this space has been decorated and furnished as an ancillary dining and lounge area, on others it is used for wheelchair and equipment storage.

The bathrooms, shower rooms and tub rooms open onto the front, middle and rear of the open ward space. Consequently, individuals living in the private or semi-private rooms along the entry hall must go into the open ward to access the toilets, sinks and bathing facilities. The bathrooms are large and institutional. A typical bathroom contains three or four stalls for toilets, one of which has been adapted and expanded to accommodate a lift. Along one wall is a bank of from four to six wall mounted sinks with original brass or chrome fixtures. Depending on the unit, tub and shower areas are located in the corner of the bathroom or in an entirely separate room. Only a few highly mobile residents perform their morning care in the bathroom area. CNAs typically assist residents with washing and dressing at the bedside behind cubicle curtains. One of the bathrooms on each unit contains an area equipped with washers and dryers. Residents rely on CNAs for washing, drying, sorting and folding personal laundry.

Furnishings in a resident’s immediate area typically include, a hospital bed, night stand, dresser and over-bed table (see Figure 8). Residents who are not wheelchair bound are provided with leatherette upholstered high backed chairs with cushioned metal or wooden arms. Between each bed, behind the nightstand or dresser, is a wood framed window with roller shades and draperies. Windows open from the bottom and the top by pulling in or pushing out respectively. The location of the windows and the effort required to open and close them means that only the most robust and mobile residents have the strength to manage them. Inevitably, windows and shades are open and shut by staff at the request of residents.

Over each bed is a bulletin board, hospital style combination fluorescent and reading light, and a call bell. The first name, initial of the last name and bed number is handwritten on an index card attached to the over-bed light. Bulletin boards variously hold photographs, cards, notes, mementos, pictures clipped from magazines, and, as needed a tan file folder detailing precautions for residents with swallowing difficulties and aspiration risks. Call bells do not have intercom capability, so that when a call bell is pressed the nursing staff must check with the resident directly. During my period of observation, I did not encounter a single instance when there was an adverse outcome or staff-resident conflict related to delay in answering a call bell. Typically, staff circulated on the open ward in the context of completing care. Often residents would call on nearby CNAs or licensed staff for assistance rather than use the call bell.

Each resident area on the open ward and in the semi-private rooms can be shielded for privacy using cubicle curtains. On two of the study wards, one or two residents chose to have cubicle curtains drawn permanently while on the unit. In addition to furnishings at the bedside, each resident is assigned a lockable closet in the bank of wardrobes adjacent to her area, again labeled with first name, last initial and bed number.

Most residents have a television on a table or stand at the end of the bed. Alternatively, the television is located on the dresser at the bedside so that the resident faces away from the center of the ward when watching TV. In an effort to reduce noise on the open wards, the facility provides residents with earphones for use with televisions.

Activities

Structured activities are an important part of the facility routine. Large monthly activity calendars are posted on the wall in the entry way on each of the units. Calendars measuring roughly three by four feet indicate the time date and location of activities, including facility wide religious services, poetry groups, art sessions, a lesbian-gay-bisexual-trans group, concerts, movies, Spanish club, meditation groups, weekly coffee klatch, yoga, tai chi classes, bingo and other games of chance; and unit based activities such as exercise sessions, preparing seasonal foods, board games, unit-based bingo, name that tune, current events, and birthday celebrations. Mobile residents are more likely to take advantage of activities offered in the large common activity space/bingo hall and in other smaller off unit locations. Since there is little storage for activities supplies on the units, activity leaders use large carts to transport equipment and supplies daily between the activities department and the units. Most of the activities staff spent time directing group activities in the dining room or at the center of the open ward; they rarely provided support for individual bedside activities.

In many ways, Del Rio exists in an uneasy tension between limitations imposed by an antiquated physical structure designed for efficient observation, supervision and medically focused care delivered to individuals in categories or groups, and increasing consumer and regulatory expectations that nursing homes address resident autonomy, preference, satisfaction, and integration with the community as well as provide competent physical care in a safe environment.

Lincoln Way Nursing Home

In contrast to Del Rio, Lincoln Way represents a modest sized facility (~125 beds) owned by a corporate for-profit nursing home chain. With little interior or exterior space to spare, there are no grounds and the ramp to the entrance opens directly onto a public sidewalk along a busy main thoroughfare. Lincoln Way's floor plan retains many features of the acute care hospital model prevalent in nursing home construction in the late 1960's when the facility was originally licensed (see Figure 9)

Table 1 (p. 84) provides a statistical profile of the population served at Lincoln Way . Nearly all of Lincoln Way's residents rely on Medicaid to fund their stay. With nearly 85 % of the residents over 65 and two-thirds female, the age and gender profile of the population at Lincoln Way reflects national trends (Jones, 2002). On the other hand, the census displayed greater diversity, with 57% of the residents Asian/Pacific Islander. Given the significant number of monolingual Chinese residents, two of the four staff members in the activity department were bilingual native born Chinese and provided translation during group activities and as needed to support individual care. The facility celebrated the major holidays of the Chinese calendar and scheduled presentations by Asian performers and religious groups. Urns of hot tea were available in the day rooms, and the menu usually contained an Asian entrée option. Chinese residents usually sat with one another during meals and activities.

Site Overview

The building consists of resident care units on three separate floors, and a basement that houses the kitchen, staff break room, rehabilitation and maintenance departments, and medical records, and administrative support offices. The basement also

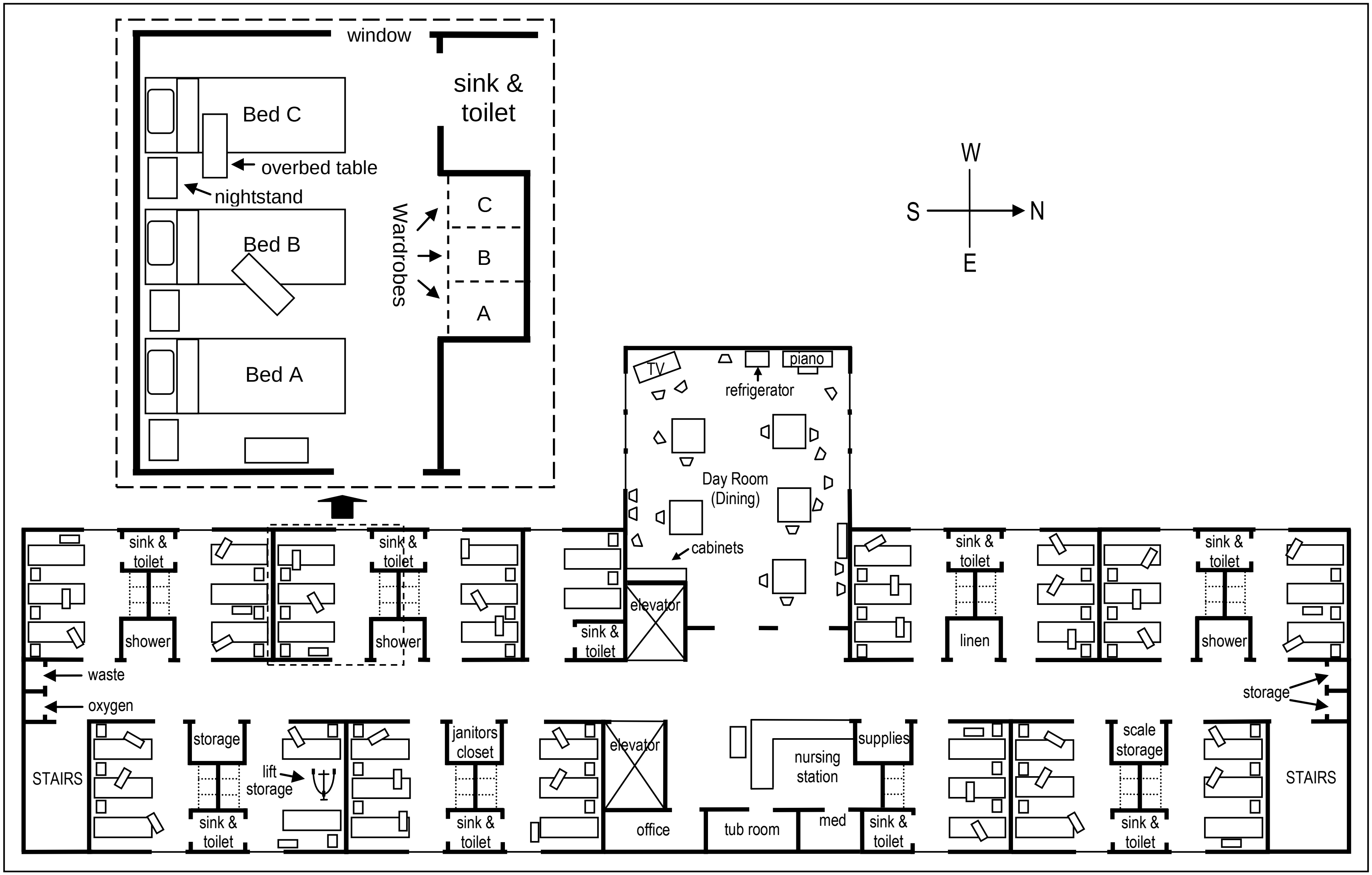

Figure 9. Lincoln Way Nursing Home, typical unit floor plan.

provides access to a parking lot and paved area where a few of the residents routinely take monitored walks as part of their exercise regimen. Located in the hall near the basement exit, vending machines with soft drinks and packaged snacks are accessed most often by staff and very infrequently by residents.

First Floor and Lobby

The first floor plan varies a bit from the plans on the upper two floors in that the nursing station is located in the lobby at the entrance to the building and functions also as the front desk. During nine-to-five weekday hours, a receptionist at the front desk, answers the phone, accepts deliveries, assists visitors in signing in and provides general information and directions. She also assists in monitoring the activity of the two or three residents who regularly station their wheelchairs in the lobby at various times during the day. The lobby is neatly wallpapered and furnished with blue satin striped easy chairs and occasional tables, some with plants. In addition to several pieces of artwork, commendations from corporate headquarters and a large quality improvement plan adorn the lobby walls. There is a bird cage with two parakeets in the corner. Residents who visit the lobby often check on the birds and spend several minutes watching their antics. Visitors frequently met with residents in the lobby. On weekends and evenings it was not uncommon to see two or three separate family groups conversing there.

The administrator's and director of nursing's (DON) offices opened into the lobby area. The DON was rarely in her office, and was more often found on one of the units doing paper work or attending to a direct care issue. Normally, the administrator was readily available to staff and residents, and participated in special events and holiday celebrations. The only restroom available to staff and visitors on the upper three floors is located off the lobby.

The lobby opens onto the main corridor directly across from the day room. The rest of the first floor shares the same configuration as the units on the two upper floors. On the two upper floors, the nursing station is located directly across from the day room, corresponding to the location of the lobby on the first floor.

Resident care units

Space was very limited at Lincoln Way. The hallways were narrow, the ceiling much lower than at Del Rio, and the standard three-bed rooms cramped. During morning care, the corridors were crowded as CNA's worked to shower residents and prepare them for the day, residents made their way to the day room for breakfast and activities, nurses passed medications, dietary staff moved carts between the elevators and the hall, and therapists transported residents to the rehabilitation department in the basement. As residents tried to navigate the busy corridors, there were occasions when they became impatient with one other and expressed irritation. The dated elevators moved very slowly and at busy times the area immediately outside the elevators was particularly prone to traffic jams.

The facility was relatively odor free, except during the hectic morning period, when the sheer quantity of soiled linen being handled resulted in a noticeable smell of feces and urine. The odor was particularly strong outside the rooms where CNAs were attending to incontinent residents, or at the end of the corridors where staff staged the soiled linen. By mid to late morning offensive odors had usually dissipated, and the traffic in the corridor began to subside. There was never a time during daylight hours when there were not at least three or four staff and residents in the corridor. Residents had no space where they could be alone, other than perhaps in the bathroom or in the minimal privacy of a drawn cubicle curtain. Though drawn curtains provided visual privacy, they did not reduce the transmission of sounds and odors.

Day Rooms

Each floor had a large central day room that served as the site for multiple activities: dining, family visits, monthly resident council meetings, watching television, religious services, performances by community groups, holiday celebrations, and routinely scheduled group activities. Wheelchair accessible square tables sat four individuals. Tables were joined together to provide a common surface for larger groups depending on the activity. Cabinets and a counter in a corner of each room held activities supplies and provided a place for microwave oven. Each day room also had a small refrigerator for storing food from families and visitors. A grand piano on the first floor and upright pianos on the upper floors were used by performers and entertainers from the community. Each day room also had one or two book cases or side tables.

In between formal activities in the days rooms, individual staff members periodically took short breaks there to read the newspaper or on rare occasions chat with residents. There were also times during change of shift when several staff would sit and converse at a table in the day room near the door, and wait for the time to record their time on an electronic time clock.

A major variation in the first floor day room was access to an outdoor patio via double doors at the west end. Staff and residents mentioned that during formal gardening activities in warmer months, monitored residents had access to raised flower boxes where they planted and tended seeds and bulbs. Though there were warm days during the study period, the patio doors were never opened nor did any staff, visitors or residents use the patio.

Though all meals were available in the day room, most residents ate in their rooms. Reasons for preferring to eat at the bedside included not wanting to see more seriously debilitated residents or not wanting to deal with the activity and noise in the day room. Only three study participants routinely took all their meals in the day room. On rare occasions when they were not dressed in time, these participants ate breakfast in their rooms. When family members exercised the option of ordering a meal and dining with a resident they invariably ate in the day room.

Activities

The day room on each floor was the hub of the formal activities program. Planned activities included current events review, morning exercise, bingo, mahjong, board games, art classes, knitting club and reminisce groups. In order to address the language and cultural needs of the large number of Chinese residents, the facility also scheduled Chinese movie nights, reminiscence groups, social hours, performances and religious services. While most activities occurred in the day room, the facility also offered outings for dining or sight seeing for from four to six residents once or twice per month. Residents who were unable or preferred not to attend group activities were regularly offered support and supplies to engage in individual activities in their rooms.

Holidays and seasons were important at Lincoln Way. Day rooms were adorned with decorations appropriate for each holiday including Chinese New Year, Martin Luther King Day and St. Patrick’s Day. On Halloween, over one hundred costumed children from a nearby pre-school, chaperoned by teachers and parents, paraded through the facility while residents gave out treats provided by the facility. Thanksgiving and Christmas were marked by multi-course meals and wine, served by administrators, department heads and other staff not normally involved in regular hands-on resident care. On these occasions, tables were covered with holiday tablecloths, and set with color coordinated napkins, centerpieces, place cards, paper hors d'oeuvre plates and wine glasses. The Thanksgiving meal occurred on Thanksgiving Day, while the Christmas “Candlelight Dinner” was held in the evening twelve days before Christmas and included entertainment and a visit by Santa. Staff mentioned that there were two seatings for these special meals: one for residents who required no or minimal assistance in eating, the second for residents with greater functional impairment who required close monitoring or spoon feeding.

Special programs, foods and entertainment marked other holidays. Even mobile residents who normally ate in their rooms, attended the holiday meals and celebrations in the day rooms. Conversant residents who had formed friendships and acquaintances usually sat together.

Personal space

The three-bed rooms are small and provide access to a wheelchair accessible half bathroom (toilet and sink) shared with the adjacent room. Though cramped, the rooms are clean and neatly painted and wallpapered. The space between beds is frequently close enough for residents lying in adjoining beds to hand objects back and forth. Rooms have one window on the far wall, so that the middle bed and bed near the door to the hallway do not receive much light from outdoors. This is true especially if the resident nearest the window keeps the window drapes and cubicle curtain drawn.

The facility furniture included a bed, nightstand and over-bed table (see Figure 9). Resident clothes and belongings were stored in a wardrobe and night stand. Wardrobes were lockable, and lucid residents had the option of controlling access with a key. A few ambulatory residents had small chairs at the bedside, but since most mobile residents used wheelchairs some or all of the time, this was the exception rather than the rule. To sit at the bedside, visitors procured folding chairs from staff or moved dining chairs from the day room.

Residents indicated that the bed next to the window was most desirable, because it was close to the bathroom, permitted control of the window, and was removed from the noise of the hallway. Residents in beds closest to the windows or to the doors to the hallway had additional wall space for small pieces of personal furniture like bookcases and dressers. One resident with a prized window bed was able set up a small area to store supplies so that he could paint water colors at his bedside. With no adjacent wall and less space for personal items, the middle bed was considered least desirable.

A resident’s bulletin board was located on the wall to the right or left of the bed, on the wall across the from the foot of the bed or at the head of the bed. Residents who were able to read usually had an activity scheduled posted there. In addition, bulletin boards variously held favorite pictures, greeting cards, religious images, artwork and small mementos. Some residents further personalized their bedside areas by taping pictures, posters and their artwork to the walls, or to their wardrobe doors or the doors to the bathroom. Though the facility provided standard maroon bedspreads, many beds were covered by afghans or comforters and held stuffed animals or special pillows to further define and individualize residents' spaces.

Most residents in the beds closest to the door or window had personal televisions mounted in ceiling-height racks on the walls across from their beds. Since there were only two spaces for wall mounted televisions, residents in the middle beds did not usually have a personal television. If one of the roommates did not have a TV, a middle residents could use the rack to mount and aim a personal television toward the middle bed. In contrast to Del Rio, residents did not have earphones and during the day, the sound in the hall from televisions was constant. In several rooms the volume of the television interfered with normal conversation. On occasion participants requested that roommates use their remote controls to turn down the volume so that interviews could proceed. Roommates' readily complied with the request.

In summary, while administration and staff strive to address the clinical needs and activity preferences of residents, a major challenge at Lincoln Way is space. Cramped three bed rooms, crowded corridors and lack of areas where residents can achieve privacy, even with family and friends, requires that residents contend with constant contact with fellow residents and staff. In some cases, residents have managed to individualize their personal bedside spaces, despite having to share small clinically structured rooms with roommates.

Participants

Demographic Data

Although there were significant environmental differences between the two study sites, participants at both locations reflected the ethnic diversity that characterized the immediate metropolitan area. (see Table 2). Participants' ages at both facilities ranged from the mid sixties to the early nineties, with females representing approximately two thirds of those completing the study at each location. One individual at each site had a living spouse. Nearly half of the participants were widowed and roughly forty percent never married or were divorced.

Eighty-two percent of the participants identified with an established western religion. Nine (52.9%) were Catholic, two (11.8%) Protestant, and one (5.9%) Orthodox. The two remaining participants (11.8%) indicated that though they believed in God, they were not affiliated with any particular religious denomination.

The educational level of participants varied greatly. Six (35.3%) were college graduates, one of whom also completed a master's degree. Five (29.4%) indicated that graduating high school was their highest academic achievement. Of the four (23.5%) whose highest credential was a grammar school diploma, three left high school before graduating in order to work. Two (11.8%) participants in their nineties had some grammar school education, but did not graduate. Interestingly, both were the oldest girls in large families and had left school to assist in cleaning and managing the household.

Participants also reported diverse occupational backgrounds. Most (52.9%) identified some type of manual labor as their major source of lifetime income. For five women this included work as a housekeeper, factory worker, cook, or tailor; for four men it included employment as a construction worker/dishwasher, mechanic, cargo handler, or machinist. Five (29.4%) of the participants had held education related positions including teacher, librarian, or coordinator of a children's art program. Two (11.8%)

Table 2.

Characteristics of the Study Sample

	Lincoln Way Nursing Home (*n* = 9)	Del Rio Center (*n* = 8)	Total Sample (*N* = 17)
Age (years), mean ± *SD* (range)	84.1±9.2 (66-94)	79.5±10.2 (66-92)	81.9±9.7 (66-94)
Length of Stay (months), mean ± *SD* (range)	38.5±33.0 (3.5-89.1)	72.6±88.1 (7.0-273.1)	38.5±33.0 (3.5-273.1)
MDS ADL Score, mean ± *SD* (range)	11.9±2.8 (6-15)	10.75±3.7 (4-14)	10.5±2.2 (4-15)
MSQ Score, *n* (%)			
No or Mild Impairment	5 (55.6)	6 (75.0)	11 (64.7)
Moderate Impairment	4 (44.4)	1 (12.5)	5 (29.4)
Severe Impairment	0 (0)	0 (0)	0 (0)
Missing	0 (0)	1 (12.5)	1 (5.9)
Gender, *n* (%)			
Female	6 (66.7)	5 (62.5)	11 (64.7)
Male	3 (33.3)	3 (37.5)	6 (35.3)
Ethnicity, *n* (%)			
White	5 (55.6)	4 (50.0)	9 (52.9)
African American	2 (22.2)	3 (37.5)	5 (29.4)
Asian/Pacific Islander	2 (22.2)	1 (12.5)	3 (17.6)
Marital Status, *n* (%)			
Married	1 (11.1)	1 (12.5)	2 (11.8)
Widowed	5 (55.6)	3 (37.5)	8 (47.1)
Never Married	2 (22.2)	3 (37.5)	5 (29.4)
Divorced/ Separated	1 (11.1)	1 (12.5)	2 (11.8)

Note. MDS = Minimum Data Set; ADL = Activities of Daily Living; MSQ = Mental Status Questionnaire women had done secretarial work. One (5.9%) participant stated he had worked as a musician and car salesman.

All participants had spent down financial resources to a level that required Medicaid funding to support their care. Whereas nursing home placement for all was considered permanent, lengths of stay varied greatly from as short as three and one half months to over twenty-two and one half years, with those with the longest lengths of stay residing at Del Rio.

Functional Status

Though the Minimum Data Set (MDS) activities of daily living (ADL) score has been used chiefly to guide reimbursement and to track changes in function, it does provide an estimate of recent functional status and the need for assistance (Morris, Fries & Morris, 1999; Snowden et al., 1999). Possible scores range from one to eighteen, with lower scores representing higher function. Four participants had scores of nine or below, suggesting early functional loss related to dressing and personal hygiene (washing, bathing, grooming) only (see Table 2). The remaining thirteen residents scored between 12 and 15, indicating impaired middle loss ADLs: toilet use, transfer and locomotion. None demonstrated deficits in late loss ADLs: bed mobility and eating. Only two (11.8%) of the participants were able to ambulate unassisted using either a walker or cane, and one of these only for short distances. Two of the remaining residents were able to ambulate using crutches or a walker under close supervision. Fifteen of the residents (88.2%) spent nearly all of their time out of bed in a wheelchair. Of these, nine required regular assistance with locomotion to the dining room.

Turning to cognitive function, participants' scores on the MDS Cognitive Performance Scale (CPS) (Gruber-Baldini, Zimmerman, Mortimore, & Magaziner, 2000; Hartmaier et al., 1995; Paquay et al., 2007; Snowden et al., 1999) ranged from zero to three on a seven point scale with zero representing the highest level of function. Ten participants scored either 0 (corresponding to Mini-Mental State Examination score [MMSE] of 24.9) or 1 (MMSE = 21.9); the remaining seven scored either 2 (MMSE = 19.2) or 3 (MMSE = 15.4). Research indicates that residents with mild to moderate cognitive impairment (MMSE 13-26) have the capacity to provide accurate demographic information and respond to questions about decision making, and daily living preferences, choices and activities (Feinberg, & Whitlatch, 2001, Whitlatch et al., 2005). Likewise, qualitative interview research reported by Phinney and Chesla (2003) suggests that participants with mild to moderate dementia have the capacity to report perceptions and experiences.

An additional evaluation of cognitive function was obtained using the Mental Status Questionnaire (MSQ), a tool that employs a three tiered classification (Kahn, Goldfarb, Pollack, & Peck, 1960a, 1960b). Eleven participants' MSQ scores fell into the "none/mild" category, five were in the "moderate" category, none were "severe" and one was missing. Interviews, observation and interaction with the participants supported the view that residents with moderate cognitive impairment are able to report information related to their satisfaction and QOL. Regardless of the level of cognitive impairment, all participants were able to comment on past events and present situations that they perceived influenced their immediate sense of well-being. The length of interviews and the detail contained in verbal reports varied across all cognitive scores.

Summary

The resulting sample reflected the ethnically diverse, working class population served by both of these facilities. Functional measures indicate that, though all required assistance with some ADLs, none of the participants were experiencing disabling impairment in late loss ADLs. All retained the ability to make choices and engage in conversation regarding how they were feeling and make themselves understood.

Participants represented three generational cohorts: those born prior to the Depression, during the Depression and during the period that led up to and included World War II. Though life events have resulted in participants living in nursing homes with certain common characteristics and admission criteria, the analysis and discussion that follow provide insight into biographical and attitudinal similarities and differences that inform what it means for each to do well.

Chapter Five

DOING WELL: BRINGING THE PAST TO THE PRESENT

Introduction

Across case analysis of interviews suggests that residents considered to be doing well both by others and themselves develop ways of being in their life-worlds that carry life-long patterns of meaning from the past into the present, despite the changes and challenges in their living situations. The means for effecting this translation of past patterns into the lived present vary from individual to individual. Within each case, the processes that an individual uses to link the past to the present are themselves significant and meaningful and relate to long held ways of being and doing in the world. Thus, the link between past and present takes many forms as indicated by the variety in stories and commentary that emerged during interaction with study participants. The data supported the development of three sub themes that elucidate this link: (a) *familiar territory*, (b) *family bonds*, and (c) *settled in.*

The Nursing Home as Familiar Territory: Seasoned by Life

Five participants referred to specific periods in their lives that had shaped expectations of institutional or group living. Prior residence in structured settings has enabled them to appreciate the challenges of congregate living and to enlist time-tested skills to adapt to life in the nursing home.

Carl

Having lived at Lincoln Way for ten months, Carl, at age 67, was the first resident identified as “doing well” by the Director of Nursing. Though he believes it was pneumonia, he is unclear on the condition that led to his hospitalization and nursing home placement, indicating that “the doctor” made the decision. The combined effects of an array of chronic ailments—including diabetes, obesity, vascular and pulmonary disease, alcohol use, hepatitis, and polio related osteopathy and paraplegia—have resulted in advancing functional impairment. He is unable to walk and can stand and transfer only with assistance; in his words, “My legs are shot.” He is quite heavy and poor arm strength prevents his moving through the facility independently in his extra-wide wheelchair. Periodically he alludes to life challenges he has faced as an African American, and, though reluctant to elaborate, suggests there are some staff who treat him differently because of race. He was married but has been separated for many years. He has no links to kin and no visitors. His entire social world is the nursing home. He summarizes his thoughts on the cooperation required to get along with others in the socially constricted environment of Lincoln Way:

> Well see, um, these people I’m gonna have to deal with.. I’m gonna have to deal with twenty-four [hours] a day, seven days a week. I can’t make them mad and they can’t make me mad... if we want to get along. So the best thing for us to do be just like a bunch of ball bearings. We rub against each other, we polish each other.

Carl often complains that care providers fail to inform him of the nature of his condition and their plans for him. He vacillates between feeling a need to be discharged and sensing that Lincoln Way is the best place for him to live. Despite identifying the need for more staff with better training, more cognitively and functionally challenging activities, and more culturally astute care providers, he characterizes this period of his life as “super,” “the golden years, ” and “the final happiness.”

Two of Carl’s reflections on his past help us to understand this glowing evaluation of his present state in life: a prolonged childhood hospitalization, and experiences living in “ the ghetto” later in life. Carl’s vivid description of a positive experience living in a hospital polio ward in the 1930’s frames present expectations for nursing home life.

> CARL: … I can remember when I was eight- nine years old, I was in a hospital cause I had paralysis. And, ah, ah- ah- the doctors thought they had corralled it, and they hadn’t. And ah, it was so nice for the nurses to come around and read, ah, stories to us. It was so nice. And asked us about wha- what we liked, and all that. And ah... It really trips [thrills] me to have somebody to come by and ask me about- about things in my life. Because, ah..., boy, when you get down to it, boy, I could write a book. A lot of people say, “Well why don’t ya.”
>
> INT: Yeah. It sounds like going to the hospital was a good experience for you when you were a kid?
>
> CARL: Yeah, well see… You can’t- in a family of nine, ah, you get to a place (i.e., the hospital) where its clean, and they feed you, and they’ve ah, ah, got Santy Claus, and all the rest of that, and you know (pause) no ah, ah, the hospital really take [took] my mind off my paralysis. I really didn’t know what paralysis was, you know. But ah, you know, goin’ to the hospital…(long pause).
>
> INT: Were you there for a while? Or, or...
>
> CARL: Seven years.
>
> INT: You were seven years in a hospital?
>
> CARL: Back when I had polio, polio would put you to bed in the morning and keep you there a week, and you’d get up feeling like a brand new penny. And as soon as they put a pair of shoes on you, plop! down you go. And the doctors couldn’t figure out why. They know all that now.
>
> INT: So how old were you when you finally got out of the hospital?
>
> CARL: Oh.. thirteen or fourteen years old.

> INT: So were you able to walk at that point?
>
> CARL: Oh. Yeah... but I walked with a limp.
>
> INT: Ah okay, I see...
>
> CARL: And ah, like I say, ah, like I say everything we tried, we tried... we had to try.   If it means playin' ball, I wasn't the best, but I'll tell you one thing, they knew I was there.
>
> INT: Sounds like you've overcome a lot in your life…
>
> CARL: Oh yeah, well I- I took things for granted and I just melted them away.

Despite the challenges of the institutional setting, living on a polio ward provided respite from the hardship of living in a large and very poor family, and shaped Carl's understanding of what can be expected of residential care. Similarly, he sees his present stay in the nursing home as a safe haven from life on the street.

> "I don't got to worry about nobody coming in here, I ain't got to worry about 'em picking a fight with me, I ain't got to worry about 'em taking nothin' from me, ah, or , ah, ah, or they say or I say or they told me... I ain't got to put up with all that.

At the same time, he deals with the interpersonal difficulties that arise now, using approaches that were essential to survival "on the street." A preferred way of dealing with the demands of living in a risky neighborhood was to "get up on a bus and ride somewhere else." Carl uses a parallel strategy to cope with difficult situations in the nursing home:

> I don't have no trouble with the residents 'cause I can come in here and get in that bed and go to sleep or turn that TV on and uh, forget there- there's anybody else here but me. Uh, that's the power- that's the power of suggestion. At least to me it is. If you uh…if you let these people- let somebody get on your nerves, it'll ruin your whole day. All you have to do is say, "Well, let's think about something else." And uh, that's the way I try to- try to handle that.

Carl usually reports that he is "doing well" or "terrific." He sees "doing well" as a matter of personal responsibility and will, stating "you know where you're at and you know what you're up against, so therefore you must make the best of it." The times he reports not doing well are the days when he feels his doctor or the staff are not supplying him with the details of his condition and the plans for his future. The director of nursing and the social worker both expressed serious doubt about the likelihood of his leaving Lincoln Way. Conversations with Carl suggest that though he appreciates the services and safety provided by the facility, he remains ambivalent about the facility as a permanent residence. This is reflected in Carl's summary of his beliefs about who does well in a nursing home:

> CARL: Well, because uh, those people came here with the idea that they were gonna get- they were gonna be improved. And uh, some people come here, "Well, this is the last stand," uh, they ain't going- going no further. And uh, the next trip is uh, the yard, and, you know. Well, you can't have that part. You got to say, "Uh, I'm gonna get well" or, "I'm gonna get back on my feet." You got to put forth an effort. If you don't put forth an effort, forget it.
>
> INT: Yeah. How about yourself? Do you feel you have that kind of attitude?
>
> CARL: I keep that type of attitude. Ain't no place on earth gonna keep me too long, 'cause uh, I'm gonna get better. I- I got an idea what was wrong, but uh, an idea and a fact is altogether two different things. Yeah. No, I don't uh, believe if you come here and you gave up hope, uh, that you can change it or these people can change it. No. 'Cause once uh, you got something firmly set in your mind…uh, forget it. Well, you gotta come here with, "Well, I'm gonna get better," or forget it. Uh-huh.

Further on he develops this theme:

> CARL: Uh…a nursing home is what you make it. Now, if you go in there with the idea that this is a concentration camp, you'll keep that idea. But if you go in there with uh, "These people are gonna help me, and they're gonna help me get along." And uh, that's uh- that's uh…that's the spirit that'll get you in and out of that place. See, mostly these places are for a person that has no place to go. You understand?
>
> INT: Right.
>
> CARL: Well, I- I'm like this here. Nuh-uh, I make my home. Yeah. It may take me- it may take me time, but I make my home. Yeah. And uh- and uh…uh, all

> you got to do is keep your head above water and eat butter. Nowadays they make these facilities for you, and uh, I can't see- I can't see where anybody would think these places are, you know, death traps and all that there. See uh, that's somebody('s) mind that they ain't gonna get well. They uh- they got their mind on self-destruction.

For Carl, a major component of doing well is the will to live and overcome the challenges life presents, a theme rooted in his early life that continues in the present.

Additional Cases of Prior Experience in Group Living

Prior positive experiences of congregate living emerged in the stories of Barbara, Shirley, Ben, and Raymond. Barbara, an 87 year old homemaker, has been living on an open ward at Del Rio for over a year and a half. A stroke left her wheelchair bound with left hemiplegia. She entered the facility for rehabilitation with the hope of returning home or moving in with her son and his family. Her condition has plateaued and there are no plans for her discharge. Though quiet, Barbara is very observant, and when asked delights in recounting the events that have taken place on the unit. A difficult home life with an alcoholic mother resulted in Barbara's being placed in an orphanage at age seven. Similar to Carl, she speaks fondly of this earlier period of institutional living as providing both respite from a chaotic family life and an opportunity for positive childhood experiences.

> BARBARA: They knew what to do. Everybody had to do the same thing. But we were all satisfied, you know? … And the food was good. They gave us clothes when we needed them, you know? They took care of all that. Donations, you know, they had a lot of donating—big cars for the sisters and the priest. We had mass every morning…
>
> INT: What was it that you liked most about living in orphanage?
>
> BARBARA: Because there was things to do.
>
> INT: There were things to do.

> BARBARA: You could play basketball, uh, baseball. Anything you wanted to do, you know.
>
> INT: Yeah. Did you miss your mom and dad when you were there?
>
> BARBARA: Yeah, but I was happy to get away from her.

Though not as thoroughly developed as the connection between past and present evidenced in Carl's story, Barbara highlights the similarity between the rules based organization of the orphanage and that of the nursing home: "It's like um…institutional, you know. We had to obey the rules there…And we do here. It reminds me a lot of it." She makes the point that doing well at Del Rio involves not being a "complainer."

Ben and Raymond report positive experiences of congregate living in the military. They attribute their easy acceptance of life in a three bed room or on an open ward to having dealt with limited privacy in the military. Ben believes that residents who "have experience in group living before, like me, in the service" are more likely to do well.

Family Bonds

Many residents point to family, and the continuation of family connections as important for their doing well. For them, conversations about the past and the present frequently focused on kin relationships outside the nursing home. For Emma and Lillian in particular, family emerged as the central reason for their willingness to go on. In the nursing home, restructuring and continuing family systems of mutual support developed over a lifetime provided the basis for their doing well.

Emma

Emma, a 90 year old resident, has been in a nursing home for nearly eight months following an acute hospital stay precipitated by a fall at home when her "knees went out." She entered Lincoln Way hopeful but uncertain about the possibility of returning home. Debilitating pain and weakness in her arthritic knees have prevented her from achieving rehabilitation goals. She states, "I look forward to being able to stand up on my legs, and be home with my kids." Extremely hard of hearing, she relies on bilateral hearing aids. Numerous chronic conditions complicate her care, chiefly, diabetes, congestive heart failure, hypertension, peripheral vascular disease, osteoarthritis, cataracts, obesity and anemia. Her major concerns are pain and limited mobility. She reports that her pain is greatest after she transfers, especially when she returns to bed. Emma uses prayer and meditation to augment pain medications that "help barely" stating "I intend to overcome the pain though."

Emma spends most of her day in bed and usually takes her meals there. Typically, facility staff use a lift to transfer her to a wheelchair shortly after lunch, and to put her back in bed before dinner. Other than Bingo once or twice a week, she rarely participates in group activities offered in the facility. She spends most afternoons sitting in her wheelchair in the hallway outside her room, reading a magazine or visiting with family. "Right now I'm not doing anything to pass the time."

Her son visits two to three times per week, usually in the mornings. On most weekends she has two or three visitors from her church. Her unmarried daughter Helen, who was her caregiver at home, visits daily in the afternoon or evening, "unless there's days she has to go to a her doctor's appointment." Helen continues to track when Emma is due for intra-articular cortisosteroid shots prescribed to alleviate the pain and stiffness in her knees, and monitors other medications and symptoms closely.

Though the care team believes discharge is unlikely, Emma retains the hope of returning home to live with her daughter. She and her family are beginning to accept the care team's evaluation that the combination of the complexity of her health care, her financial limitations and environmental barriers make retuning home a burdensome and unsafe choice. Emma's reflections provide insight into what it means to struggle with the difficulty of wanting to be home but facing health care conditions and functional barriers that prevent returning there. She recognizes the value of the "twenty-four hour care" provided by the nursing staff and counts them as friends. She distinguishes herself from other residents stating "we have different hours for doing different things," and "there's a lot of people around me in poor shape or worse than me, sometimes I think they are worse than me." Doing well in this sense involves doing better than others.

Emma is very clear on what has been most important in her life: her family and her "religious background." She lived "38 years in the same house," and her best days are the days she has spent with family. The only sad events she can recall are the deaths of her husband and son. Consistent with her focus on the importance of family she is most proud of "getting my kids through high school and part of college."

The importance of family support is evident in the number of hours that her children spend at the facility. A private phone with large numbers for Emma to call out on further facilitates daily family contact. At the times I visited when family was not present, Emma indicated they had already been there or were expected later in the day. Close connections among family members, paramount throughout her life, continue to be an essential part of Emma’s ability to “do well’ at Lincoln Way despite the challenges associated with chronic pain and limited mobility.

Lillian

Similarly, at Del Rio, Lillian’s frequent contact with her two sisters and members of her extended family is the focus of her life. Reflecting on her past Lillian describes a family committed to mutual support of its members from the time they lived in the South, through their move to the West just prior to World War II, to the present. She summarizes the family’s core value: “My mother, she always wanted us to be close to each other, which we were, *very* close.” Before her admission to the nursing home following a stroke nearly 18 months earlier, Lillian, age 93, and her two sisters Wilma, age 91, and Dottie, age72, lived together as a family of older adults in a large multi storied home—still “*very* close.”

Dottie, the “little sister,” was active in the church and local senior center, and assisted her two sisters with medications, shopping and appointments. The sisters’ vigilant support for Lillian continued at Del Rio. Though Lillian characterized her days as “lonesome,” she expressed concern that Dottie’s frequent visits to Del Rio might be interfering with Wilma’s care at home: “I told her don’t come here every day, you know. It was a bit hard for her to come here every day. And the other sister needs her too.” Dottie facilitated Lillian’s care by communicating with doctors and staff. She provided clothing, personal items and snacks, and helped Lillian stay in touch with family: “She would always bring her (cell) phone and I would call everybody.” On weekend visits, Lillian’s sisters were often joined by her niece, a grand niece and an infant great-grand niece.

Lillian reflected on the combination of environmental and financial barriers that prompted her admission to Del Rio:

> …where we live it's a stairway, you know. And by me not walking- I couldn't walk or anything, they couldn't handle me, you know. I had to be somewhere where someone could help me. Unless we could've got someone to come in every day and do that. That is very expensive, you know. So I come here.

However, since she was no longer receiving physical therapy, Lillian expressed uncertainty as to why she was still at Del Rio, and frequently voiced a desire to leave. Though she had been there for over 18 months, she and her sisters had done little to personalize her bedside space. The only personal photo displayed was a Polaroid of Lillian and Wilma taken during a unit party, taped to the wall near the foot of her bed.

Like Emma, Lillian sees herself as having little in common with other residents in the nursing home, and comments on her sense of estrangement:

> …some of them don't speak English and some of them just…I think their mind is… isn't quite well… Yeah. So no sense talkin'. I uh- sometimes we uh- like yesterday, I went uh- the little- the young lady we have working here she made a lot of little hors d'oeuvres and things for us, you know. So I went up where everybody's live (the open ward), you know. And uh, we had a nice time. But like I said, nobody says nothing... No, nothing, nothing. Nothing, no.

She relies on family visits to provide emotional support and conversation stating "I don't have anybody to talk to really, not unless somebody come visit us all the time." Lillian's stories and reflections suggest that she perceives her ability to carry on and do as well as she does as rooted more in the strength and consistency of family ties than in the support and services offered by the facility.

Midway through data collection, Lillian informed me that Dottie had been hospitalized "for tests." Several days later her sister died. She did not expect it. Her sister had been "sick" for several years, but didn't tell anyone in the family. Lillian was never able to articulate the cause of death. Interviews and interactions with Lillian took a turn after her sister's death. She was much more vocal about the aspects of Del Rio that displeased her. Her final interview revealed continuing concern for her remaining sister and focused heavily on her need to leave the facility to be with her family.

The Significance of Family Ties for Other Residents

Though not as prominent as in the stories of Emma and Lillian, maintaining family ties emerged as a significant element in personal and family lives of several other residents. Ongoing contact took two main forms: regular visits from family and frequent telephone calls. At Lincoln Way, A large part of Joseph's interview traces his journey with his now deceased wife and his two daughters from northern China to Australia and finally to the United States, where one daughter has a prestigious government career on the East Coast and the other serves as his local caretaker. He speaks with great pride of his children's accomplishments. When family members cannot visit, he maintains contact via his personal cell phone.

Rose, who spends most of her afternoons seated in her wheelchair stationed in Lincoln Way's lobby occasionally thumbing though books and magazines, often mentions with great pride the fact that her son went to Yale. She speaks frequently of him and his work as a teacher and anticipates his regular Sunday visits. She appreciates parcels from her daughter who has a family and lives nearly 350 miles away, but wishes she were able to visit more often. Despite her failing memory, she calls her son from the phone at the front desk every evening at 6 pm sharp.

At Del Rio, Dolores, Barbara and Frank receive visits from family at least weekly. Dolores's sister worked at the facility but never on the unit where Dolores lived. Several times per week, Dolores checked with staff to determine the unit where her sister was working, and would use a facility phone to contact her. When Dolores receives her fifty dollars each month, she and her niece go to a favorite Asian restaurant. Barbara’s son visited three times per week and accompanied his mother to evening bingo and entertainment offered at the facility. On alternating weekends, he drove his mother to visit her homebound sister. Barbara mentioned that she wished it were possible to live with her son’s family.

Settled In: Translating Then to Now

Though becoming a resident in a nursing home represents a major life transition, and the debate as to how much of a home or “homelike” a nursing home can be continues, several residents in this study managed to settle into the nursing home, creating personal spaces and routines rooted in pre-admission habits and activities. While they may not consider the facility as “home,” in many ways they have made it “their own.” These residents have reestablished themselves in the world of the nursing home by relying on values and techniques that have sustained them over a lifetime.

Martha

Martha, now in her nineties, had lived independently in the community and operated a small cleaning and tailoring business until the age of 89. Over a two year period she suffered several transient ischemic attacks (TIAs), had a hysterectomy, fractured her clavicle, injured her shoulder and endured a bout of “pneumonia or bronchitis.” This series of health challenges led to several acute hospitalizations, recuperation with relatives, and the decision to close her shop and enter the nursing home. Over the past four years at Lincoln Way she has managed to structure her world to continue behaviors that have sustained her over a lifetime. Martha has created daily patterns of activity that allow her to continue cherished ways of being and doing within the limitations imposed by nursing home life. She attributes how well she is doing to values and viewpoints acquired from her parents and lessons learned through life experiences, few of which she considered catastrophic. She attributes this to following her father's advice: "He'd always say, 'Use this (pointing to her head) and don't let anybody push you around. Stand on your own two feet.'"

While Martha tends to see herself as being able to deal with loss, she points to her mother's death as "the most devastating" event in her life. Though overwhelming at the time, this loss placed her in the position of having to develop skills and attitudes that would serve her through life even into the nursing home:

> MARTHA: Well I had a dog, my dad had given me a dog, and that dog followed me every place, and we were crossing the street or something and…a piece of lumber fell off, and the dog went "smack," and faintly I can remember this but it's something that I think wanted to forget… it hit the dog…and broke its back. So anyhow, I got over that. That's what I say from way back I can't remember being sad over anything too bad…
>
> INT: Right, right.
>
> MARTHA: You know what I mean. The only thing that really affected me was my mother's death… she was only 35 years old when she died… (I was) Sixteen, sixteen, and oh, those were the tough times. That's when I had to help my dad take care of my brothers and my sister, and they treated me like I was their mother. But my dad was very good. He (chuckle) he was so cute—he, he uh- , he would come home after a week's work and he'd give me his paycheck and he says, "You know what you have to do with it." So he would endorse it and I would cash it, I would put so much away for the rent, and so much for the groceries, and I made sure that he had his carfare and his tobacco money, and that's how it was.
>
> INT: So you managed pretty much the household.
>
> MARTHA: Oh yes, I took it over. So- oh it was a job believe me, and going to school (chuckle)… So, I mean actually ah- I didn't have the same—what should I

> say now—freedom that another girl who had her mother for her, you know. But I didn't mind in the long run, because I just figured it was my duty and I had to do it, that's it.
>
> INT: Right. So you managed somehow to get through that?
>
> MARTHA: Right. Oh I got through that all right and, I think that's why sometimes—I don't know—I think I'm kind of hard boiled.

Being "hard boiled" and having had to manage the household and finances prepared her for the accounting positions she held early in her career. When she was fifty, her husband taught her tailoring, and with his help she opened an additional shop as part of his cleaning and tailoring business. She counts this as the accomplishment she is most proud of. Martha continues to manage her own finances with some assistance from the social work staff.

When operating her business, Martha kept regular hours, a practice she continues in the nursing home. On being enrolled in the study, she clearly laid out the days and hours that were most appropriate for visiting her. On occasion she was noticeably taken off guard when I would stop into her room just to greet her without having arranged an appointment.

Martha has a bed next to the window. This is the location preferred by most residents at Lincoln Way because it is removed from the activity of the corridor and is closest to the bathroom. It also provides wall space for furniture and affords access to and control over the window and it's drapes. Her bedside space has a narrow dresser set against the wall next to the window, and small institutional night stand next to her bed. She has a TV that her friend and fellow resident, Doris, gave her. It sits on top of a plastic drawer unit purchased by staff at Martha's direction using her funds. She has personalized her space with knick-knacks, mementos, and pictures. Every inch of the top of her dresser was filed with treasured items. Despite the limited space available, Martha managed to reestablish some of the important elements of a “household” with its supporting environment and routines:

> And every morning I get up and do the things other people do, brush your teeth and whatever. So I can…I’m very fortunate being that I can use the walker, that I can get in and take care of myself, and I dress myself also.

Another part of her daily routine is a supervised morning walk with her walker outside in a protected area on the basement level. She sheepishly admitted there are days when she forgoes the walk. She takes personal responsibility for the periodic aches and pains she experiences associating them with inactivity and not walking enough:

> Well, um, like if I get a pain in my back, I don’t go running to them about it, ‘cause I know what it is. It’s either from sitting down, or like I went walking this morning and my back does bother me when I walk. And I say to myself, “That’s my fault because I don’t walk enough. I sit too much.” So uh, I say to myself every day, “Get up and do what you’re supposed to.” I’m inclined to be lazy [laughs].

Though she enjoys breakfast in bed (“…how lucky can I get…I think I’m being really spoiled, and that’s the nice part of it”), she continues her prior home life practice of eating her other meals alone in her room stating,

> I eat my lunch here and I eat my supper here too because, well like I said, a lot of times there’s a lot of racket in the dining room and I don’t like a lot of noise, I never did. Even when we were younger and going to- out to something where it’s a public deal or something going on and they have loud music or something, I wanted to get as far away from it. As long as I could hear it nice, fine.

Saturdays are laundry and mending days with time set aside for washing “personal items” in the bathroom sink. Displaying a sense of innovation similar to her mother’s, she dries these items on an ersatz clothes rack consisting of a series of plastic clothes hangers suspended from a back scratcher cantilevered into a slightly opened dresser drawer. She showed me several items of clothing she had mended and several more that were in the queue for repair. Often as I passed her room I noticed her mending an item or tidying her space.

On Tuesdays through Thursdays Martha’s weekday afternoons are taken up with bingo. She used to spend much of her free time reading, but macular degeneration and cataracts have caused her to forgo much of the reading in favor of television. Her greatest fear is vision loss:

> In a way it makes me- when I do things for myself, it makes me feel independent. And uh, like I said, that’s what my father taught me to be. And uh…now, I’ve been- what I’m worried about is my eyesight. I notice that uh, when I first wake up in the morning, everything looks fine. But after I ah, during the day- like right now I’m looking at you. But you’re not really clear to me. It’s like I had something on my eyes and I wanna take it away… So I was wondering if my eyesight is slipping. You know? So I won’t know for sure until um, I see the doctor next month. So…that’s the only thing that bothers me… Well, I always said if I go that way, I don’t wanna stay around. Because I don’t wanna be dependent on anybody else. I don’t like people waiting on me…well, I mean, to a certain extent. But this deal or something like that, it gets very personal. So- and I don’t really care for that.

For Martha, self reliance has enabled her to do well and to both mold situations and adapt to challenges she faced in life. Skills in confronting hardships, recognizing the possibilities in difficult situations, and engineering adaptive strategies and devices to overcome obstacles have enabled her to settle into the nursing home and make the available space and time her own.

Doris

In her mid sixties, Doris is the youngest study participant and the resident who most clearly states she had settled into Lincoln Way as her final and permanent residence. At 62 she suffered a stroke that left her wheelchair bound with a dense left hemiplegia. Her only family is an elderly cousin who lives roughly six hundred miles away. A bright, active and outgoing resident, she deals with nursing home life by accepting her present and being flexible, a mind-set she developed working as a secretary:

> I'm here forever until I die. So, um, it's not a morbid way of putting it, but I don't, um, I don't see any future in my future. If you follow me. And so I-I live day-by-day, and I think that's the best because if you live too far in advance then you get sort of slapped in the face if it doesn't work out, so I do it day-by-day. There's no problem.
>
> … most of my life there (in the community) was just my mother and myself. And um…um, for here- I mean, I'm always surrounded… more or less you're surrounded by people. And um, there's all different kinds of…things going on with the people. And uh, some people are not as nice as other people. And um, as far as I'm concerned, um, I try not to let that annoy me. Because some kinds of things here occasionally will annoy me badly, and I- I figure it this way, let's not get yourself upset because, you know, your blood pressure's gonna go up through the roof. Then they get very mad at me because that happened. And, you know, you gotta watch what you're- you know, how you react to things… I've been in business. And there, trust me, there are all kinds of people in business. And um, I managed quite well with all of them. You know? And uh, it's- it's like here. You um, you learn to bend, 'cause if you don't bend, you break.

An aficionado of fine food, Doris misses not being able to get around on her own and wander through the mall or the supermarket. She would like to have private room or more importantly, a private bathroom. Nevertheless she has managed to make the world of the nursing home her own and fills her days with an assortment of activities: work on the facility newsletter, monthly outings, bingo regularly and mahjongg periodically, duties associated with her position as Resident Council president, accessing the internet twice per week via facility computer, and weekly art classes.

Doris' position as Resident Council president combined with her assertiveness means that she is frequently the first resident to obtain news about the facility and its occupants:

> Well, to put it bluntly, I'm a royal pain in the ass. 'Cause, you know, I'll say, "Hey, you know, there's an ambiance around here that is a little bit strange. What the hell's going on?" And sometimes they say, "Well, we- we can't talk

> about it right at the moment." "Okay, fine. That's- that's good." And then um, every once in a while I'll ask (the administrator), "How's everything going here with the replacements and stuff like that?" And he'll tell me. So…he sort of cringes every time I get to the doorway.

Doris relies on CNAs for assistance mostly with bathing, grooming, toileting and transferring between the wheelchair and bed. Occasionally she requires help opening a door, opening packages, cutting food and retrieving items from her nightstand, bookcases or closet. She is independently mobile in her wheelchair and rides the elevator on her own despite facility policy that forbids it. This provides access to the basement enabling her to use vending machines at will, and to contact dietary staff to request special meals.

Signs of Doris' having settled in are most apparent in her beside area. Against the wall next to her window are four narrow bookcases filled with romance novels she has accumulated over her time at the nursing home. Most of these were ordered over the internet. She refers to the area jokingly as her "library." A large net filled with small stuffed animals—mostly bingo and activity prizes—hangs on the wall over the head of her bed. The walls are decorated with several of her colored pencil pictures of birds, works copied from calendar art during art classes. The method she uses to create these pieces—building up areas of color one stroke at a time—requires a level of patience and attention to detail similar to that needed for the needlepoint she can no longer do because of her hemiplegia. A bulletin board with pictures of family and friends and the monthly activity calendar hangs on the wall across from the foot of her bed. She uses the photographs in her room as prompts and illustrations when recounting important life events.

Doris lived her entire life in the community with her mother. At times they were coworkers and traveling companions, but each respected the other's space. In the end, she provided for and supervised her mother's care until she died in a nursing home. At Lincoln Way, Doris indicates that her most important relationships have been with older female residents, "six or seven" of whom have died. She identifies Martha, nearly 28 years her senior as her closest friend in the facility. Both were raised from birth in the local community, so sharing memories about places and events reinforces their bond: "We can reminisce to a certain degree about the places that I know, the places that she knows, good restaurants, the old- the old stuff, you know."

Raymond

In his late seventies, Raymond's twenty-three years at Del Rio, have allowed him think of the facility as a "retirement home plus a hospital for my medical problems." He recounts that he arrived at Del Rio permanently with a left below the knee leg amputation and a long history of binge drinking. Over the years he developed several medical problems, most significantly peripheral vascular disease, cardiac arrhythmias, and an intestinal volvulus requiring a permanent colostomy. He is wheelchair bound but attends to his own ADLs including ostomy care of which he states in a spirit of resignation, "It's just the business of living here with a disability."

Ray navigates the facility by propelling his wheelchair backward using his right leg. During his tours off the unit, he has a tendency to accumulate beverages, food items, napkins, cups, papers and books that eventually clutter every surface and space on the furniture at his bedside. When he is off the unit, staff routinely clean and organize his area, disposing of trash and half eaten food items, and neatly arranging books, papers and supplies—an arrangement that works well for both Raymond and the staff.

In addition to serving as home and hospital, the facility supplies a venue for Raymond to carry on and reinvent a musical career rooted early in his childhood:

> RAYMOND: At five years old I played the fiddle, violin, 'cause my mother- my mother is Irish, and she loved Irish music. And so I learned to play [chuckles] Irish music before I- before I took a lesson on the piano. I played the piano picking out the tunes. So I played the violin for eight years. I played for Yehudi Menuhin… he gave free concerts at the municipal auditorium or the high school auditorium in those days. And I played the violin of course, and we accompanied him. So that was ah- that was introduction to greatness at a young age, 12 years old, I played with Yehudi. So that's uh- and I played for eight years on the violin and then switched to piano at age 16. And that's been my instrument since… and organ for the masses
>
> INT: Oh, so you play- do you play for the masses here on the organ?
>
> RAYMOND: Oh yeah. Oh yeah. I did, but my leg is- it's very uh- it's very uncomfortable getting up in the piano bench and risky getting off, and- and on. So I took one spill and I said, "Well, we can't uh- we can't be playing an organ here too often" 'cause I might really injure myself falling. 'Cause you do get- you do get a little woozy playing music at times. And a lot of it's automatic, you know? And uh, you- you don't realize uh, how your body is uh, positioned. And uh, you make a wrong move and, boy, you topple right over. You aren't- yeah, you aren't prepared for any emergency… So I play- that's why I play guitar, now. I play guitar for the masses, which is good. It's very quiet and uh- and meaningful. You've gotta make your own chords. You know, you gotta make your own music with the guitar. It isn't set forth for you like a piano or organ. So anyway, that's uh- it's always a challenge when I- when I do a mass or any public uh, appearance. To do it right and uh- and have it enjoyable for the audience.

Here Raymond holds fast to his life as a musician and redefines his career as a performer by switching from keyboards to a guitar. He now plays guitar and sings regularly for the Wednesday morning coffee klatch in one of the hallway alcoves, on resident units and for memorial services when requested, as well as for Catholic masses. His recent purchase of a $650 electric guitar suggests his commitment to music persists undiminished.

Raymond has chosen to stay on an open ward that transitioned from serving men with complex medical and behavioral needs to supporting men with various levels and types of dementia. He treats his beside area at the far rear of the ward as home base, the location he returns to for meals, rest, reading and to manage his colostomy. The cubicle curtains are usually closed when he is there, separating him from the activity of the open ward. He forgoes participation in unit-based activities designed for cognitively impaired residents, preferring to head off the unit to pursue his own commitments and interests: to the chapel or an activity area to perform, to a quiet space in one of the stairwells to peruse the newspaper paper and listen to his radio, or to the facility library to read a book or magazine and to check out reading material or video tapes to use on the unit.

Raymond speaks of turning eighty as a milestone, detailing how all his finances and funeral arrangements are in order. Raymond sees himself as involved and contributing in the present, yet resigned to the limitations for the future.

> I'm grateful to be here. This has saved my life here, 'cause those binges I used to go on are dangerous. So I'm uh, here and uh, away from that uh- that uh, risky life, you might say [chuckles]. And uh, I have my church here and my music and uh…I'm very happy.
>
> Oh heck, I know I don't have any real uh- uh, future, that is any accomplishments to be- to be gained. Uh, no, no, I'm just happy to be alive and as healthy as I am and uh, enjoying things about me and reading and my radio.

Raymond suggests that settling into Del Rio has provided an environment conducive to managing earlier injurious behaviors while maintaining and advancing self affirming interests in music and reading established early in life.

Summary

Though experiences and values differ across the lives and stories of these residents, the common thread linking them is the ability and opportunity to translate important elements of prior life worlds into the context of the nursing home. Overall, these individuals remain biographically active and do not perceive themselves as being totally determined or defined by the parameters of institutionalization (Gubrium, 1993). For those who are doing well, admission to the nursing home does not seem to constitute a rupture in the life course drastic enough to result in feelings of abandonment and despair. Thus, doing well is rooted in maintaining and capitalizing on patterns of being and doing that residents have relied on to do well across the life span. In some cases, “making the past present” in the service of doing well involves rediscovering perspectives and reformulating strategies that proved successful in past group living situations. In other instances, it may involve devising new ways of continuing enduring family connections to sustain well-being and temper the challenges posed by failing health and loss of home. For those who “settle in” doing well involves making the most of abilities and opportunities available to translate valued ways of being in the world developed across the life span into life at the nursing home.

Chapter Six

DIMENSIONS OF DOING WELL

Introduction

While “making the past present” emerged as the predominant theme, analysis revealed three additional facets of residents’ lives that influenced how well they were doing: (a) *having a voice and being heard* (b) *immediate discomforts* and (c) *breaking the routine.* Consistent with the overarching theme, participants often mentioned the connections between these aspects of their present lives and the past. In addition to clarifying how comfort level affects perceptions of doing well, analysis of data related to “immediate discomforts” provides insight into variations in how residents understand the concept of “ present.”

Having a Voice and Being Heard: Advocacy

Cohen (2004) defines personal advocacy for older adults as “advancing, protecting and vindicating the rights, interests and preferences of the elderly individual.” (p. 10). The organizational and regulatory complexity of the nursing home coupled with decreases in physical and cognitive function means that residents must often rely on others to voice and advance their needs and wants. In this study, typically, residents who did well had a mechanism for making their wishes known to facility staff and having them addressed to their satisfaction. The individual who served as advocate or helper in any specific instance varied based on the resident’s ability to identify and communicate needs and desires, and the nature his/her social network . Four categories of individuals who served as advocates emerged: (a) family members and friends, (b) facility staff, (c) residents as self-advocates, and (d) residents who advocated for other residents.

Families as Advocates.

Nine (52.9%) of the participants had family who visited at least once a week. Family members ensured that a resident's needs and wants were addressed by the facility in two ways: they supported and reinforced the requests of residents who were able to exercise self-advocacy, or they served as the primary advocates for residents who could not identify, keep track of, or clearly articulate needs and wants.

Joseph, a Lincoln Way resident in his eighties, regularly looked to his daughter to reinforce requests he made of staff. Dissatisfied with the lack of privacy and wall space associated with having the middle bed, Joseph asked for a transfer to a bed next to the window. During her visits his daughter advanced his request, keeping his need for a window bed before the eyes of facility staff until the transfer became a reality. Shortly after the move, at Joseph's request, his daughter arranged for clergy to visit him on his name day to bless his space.

Conversations with Lillian at Del Rio indicated she considered her youngest sister to be her primary advocate, especially in health care matters. Her account of her sister's attempts to contact the unit physician and her appraisal of the availability and effectiveness of the social worker illustrate her frustration with not having a voice in her care, a voice that was further diminished by her sister's passing.

> LILLIAN: She (Lillian's youngest sister) wanted to see the doctor (about Lillian's status), he never did see her. She made a special trip. She came here one day and she told the nurse she wanted to see the doctor. He's supposed to be here the next day. She made a special trip here to see him. He was busy. He

> never could see her. She waited and waited and waited and he left and never did see her… He never did see her. Nope.
>
> INT: How about a social worker? Is there a social worker here?
>
> LILLIAN: Well yeah, she's here, but she's gone most of the time. She's not here. But she seems to be pretty nice, you know. But I don't think she can do nothing with that. Because there's a man here, he had wanted glasses and it's taking him forever to get them. He talked about it, you know. He told her… he said "She can't do nothing about getting them." T hey don't pay you no mind. And so they do what they wanna do, you know? I think this whole place is uh…I don't know why- I don't know what to think about it. I'm stuck, I think [giggles]. I guess- rrr, rrr, rrr (makes growling sound) I can't…
>
> INT: Well, do you feel more stuck now that your sister isn't- doesn't come every day?
>
> LILLIAN: Yeah, yeah. I do… Because she was such a big part of every day.
>
> INT: So do you feel you have enough to say about what happens to you here?
>
> LILLIAN: Well, uh, yeah. If I had anybody to tell. I got nobody to tell 'cause now my little sister's gone and she and I used to talk about it, you know. And she was always trying to help, but, like I say, he never did see her. The doctor never did see her! Never did see her. She, she (tried) several times to see him and he never did see her. So that's why I think he's not worth fifteen cents.

At Lincoln Way, Emma's daughter and son visited regularly and were instrumental in securing transfer to a window bed, ensuring replacement of a lost hearing aid, monitoring her medications, and facilitating smooth transitions to and from day surgery for cataracts. Rose's son made sure that his mother's complaints were relayed to staff, usually via the supervising nurse in charge during his regular Sunday afternoon visits. In addition to providing advocacy within the nursing home, all these families looked after the resident's belongings, replacing worn or lost clothing and replenishing personal toiletries, special supplies and favorite food items.

Staff as Advocates.

Though the number of participants who felt they had enough say in what happened to them in the nursing facility equaled those who felt they did not have enough say, all were able to identify staff they would contact if they had a problem (see Table 3).

Table 3.

Voicing Needs and Preferences

	Lincoln Way *n*	Del Rio *n*	Both Facilities *n*
Do residents feel they "have enough say" in their care and what happens to them?			
Yes	4	3	7
No	4	3	7
Ambivalent	1	2	3
Individuals whom residents indicate they enlist to voice problems or issues.			
Family member(s)	5	2	7
Social worker	4	4	8
Nursing staff	5	5	10
Physician	0	3	3
Activities staff	1	0	1
Administrator	2	0	2
Medical records staff	1	0	1
Dietary staff	1	0	1

Individuals who have difficulty articulating and facilitating needs and wants, or who have no family or friends to take on the role of advocate depend almost exclusively on staff to communicate their wishes to the appropriate individuals or departments in the facility.

Observation indicated that pathways for advocacy that involved staff varied between the two facilities and affected whom residents perceived as advocates.

Lincoln Way participates in a program required by the parent corporation "designed to address special needs that arise from time to time in order to meet the expectations of ... residents." Administration and department heads select staff from all levels and departments to act as advocates and match them to from six to ten residents based on the individual residents' needs and issues. When at work, selected staff are required to check their residents daily and to contact at least three families per week. Identified issues are to be documented, and communicated to the administrator and department head(s) for follow up. Policy stipulates that the staff advocate check on the status of the issue with the resident and family until it is resolved.

In addition to nurses and social workers, Lincoln Way participants identified staff from the dietary, activity and medical records departments as individuals they counted on to voice their concerns. Five of the nine Lincoln Way study participants (55.6%) were not aware of any type of special advocacy program. Of these five, four had regular family visitors, and frequently counted on family to intercede with staff. Whether or not they were aware of the advocacy program, six of the Lincoln Way participants identified by name one or more staff members they could rely on for assistance in resolving an issue. The person most frequently named was Susan, the first floor social worker. Though not aware of the advocacy program, Rita depended on Susan to communicate her needs. Rita was reluctant to speak out at Resident Council meetings but trusted Susan to look out for her welfare: "Susan, Susan is very good friend of me. She helps me with everything." "Everything" included intervening in a disagreement with another resident, managing and keeping her informed of her finances, and going out to buy Rita an new pair of slippers.

Del Rio had no formal advocacy program involving staff from all departments. Residents there mentioned they relied on individuals in three staff positions to address and communicate issues or problems: the nurse manager, the social worker, and the physician. Del Rio participants suggested that they usually spoke to the nurse manager, the charge nurse or the CNA first about direct care issues, even if they involved another department. As at Lincoln Way, social workers were most often identified as providing assistance with financial issues. Three participants said they would look to their physicians to help resolve difficulties. Fashioned largely on an acute care hospital model, Del Rio relies on a large permanent physician staff to provide medical care with the result that doctors are often more readily available to hear resident health and living concerns directly.

The ability to make one's wants and needs known and have them addressed by staff was enhanced when resident and staff shared a common language and ethnic background. Joseph, whose primary language is Russian, communicates needs readily when the few Russian speaking licensed nursing staff are on duty. Though he speaks English, he often relies on his daughter to relay information and clarify his needs to non-Russian speaking staff .

One participant at each site shared a common ethnic heritage with the predominantly Filipino nursing staff. In both cases, shared primary language between residents and staff greatly facilitated communication. For the participant at Del Rio, this connection meant that staff were aware of her favorite foods and were able to work with her family to provide Filipino fare. For the Lincoln Way participant, staff members' knowledge of the region of the Philippines she came from enabled them to interpret where she perceived herself to be and what she was referring to during her periods of confusion. Thus, cultural connection facilitated determining and addressing her needs and wants.

Self-Advocacy.

Residents who were able to articulate their needs, whose life stories revealed a great deal of independence, and who had developed skill in navigating the formal and informal social relationships of the nursing home were best able to communicate their needs and advocate effectively for themselves. Self advocacy emerged as the ability to voice one's own needs and concerns and to persist until they were heard and met. At Lincoln Way, Martha's sense of independence coupled with her skill in accessing resources available to resolve difficulties enabled her to deal with "problems" such as a recurrently disruptive, cognitively impaired roommate.

> …the best thing is come face to face with it, like this one (pointing to roommate in the next bed). Now, I don't know if they've given her some kind of medicine or something now to calm- but when the last time, it went on all night, and when she yells, she really yells. You know? Then she not only disturbs me, but the whole floor, this section anyway. So they had told me- I had complained about it before. So they were trying to- well- where the heck they were gonna move her? You know. So there was no place they could move her. So what happened, she started in- and they had told me before "Martha, we'll see where we could put her," and that was about it. So at the (resident council) meeting… I got up and I spoke about her. And they said "Well we're doing..." I said, "Listen. Talk is cheap," I said, "Do something about it!" And I- I said, "This is going- this is terrible." I says, "Anyone of you wanna change your room for mine? I'll go for that." So they uh- I haven't heard anything. She's been pretty quiet.

Within the month, the resident was moved to another room.

At Lincoln Way, Doris was an assertive self-advocate who had the ear of the administrator, but admitted that she funneled most of her concerns through Susan, the social worker. Doris' role as a resident council representative provided her with knowledge of the inner workings and limitations of the facility not readily available to most other residents. Likewise, this position increased her ability to intersect with top staff and voice issues. Her sense of independence and ingenuity enabled her to spurn the facility ban on independent use of the elevator by wheelchair bound residents, making access to the basement vending machines possible and facilitating direct contact with kitchen staff to request special food items.

Also at Lincoln Way, Rose, who exhibited clear signs of cognitive decline, attributed getting the things she wants to complaining. Ben clearly stated what he liked and didn't, and what he expected to happen next during his day. He was usually insistent, so that even if initial requests went unheeded, he continued to make his desires known until his needs were met (e. g., most often to return to bed after lunch), or his preferences honored (e. g., to modify the type of speech therapy he was receiving). Carl made his immediate needs known and got them addressed, but felt he was less successful in obtaining more substantive information related to his physical condition and prognosis.

In contrast, Del Rio participants were less likely to exhibit attitudes or behaviors associated with self-advocacy. Barbara believed that "If you complain too much, you don't get the care. They- they throw you aside, and you wait for everything, you know?" And Mary's usual response to inquiries about how she was doing or how her day was going captured the sense of helplessness and lack of control she often experienced "I can't complain, besides what good would it do?" Remarks by two other residents indicated they frequently felt that their requests were not being heard, or that they were not adequately informed of the direction of their care. Four additional Del Rio residents indicated they had settled into comfortable daily routines and believed they had enough say in what happened to them. To a large degree, the participants at Del Rio had scaled back expectations and adjusted schedules to comply with the needs of staff, frequently accepting the evaluations of those in authority without question or discussion.

With twenty-three years in residence, Raymond presented as the most active, outspoken, self motivated Del Rio participant. His reflections on what it takes to do well there provide insight into his perceptions of the qualities in a resident that the facility values:

> The attitude is that, ah, I'll do anything to keep myself in uh- to see my- keep myself presentable, and that my activities or my- my actions and my speech and uh- uh, be gentlemanly and uh- and be sociable. And uh- and uncritical, uncritical. Uncritical of other people, not criticizing or not finding fault uh, and not complaining 'cause most complaints are- the complaint itself you know, uh, disappears or fades away.

Overall, observations and resident comments suggest that advocating for oneself to obtain items and services to support doing well depends on the ability and willingness to voice needs and preferences. To be effective, resident communication and insistence must be matched by staff willingness to listen, communicate and act. Whether or not residents choose to voice concerns is affected by expectations communicated to them by facility staff, expectations which may or may not be supported by facility policy. Lincoln Way's program of staff advocacy communicated that making one's needs and preferences known was valued. At Del Rio, data indicated that the staff valued compliance and "not complaining," with at least half of the participants there suggesting that "not complaining" or doing "as your told" was important to doing well.

Residents as Advocates or Helpers

A few participants also took on the role of advocate, protector or helper for other residents. Doris, who looked after her mother in a nursing home and now shoulders the responsibilities of resident council president, points out the importance of monitoring fellow residents and the environment.

> … but you know if-if I see something's wrong or if somebody's crying and stuff like that, and I'll call them and say, "Hey, she's been crying for half-an-hour, would you do me a favor and find out what's wrong with her," and so she can't talk you know. …in the nursing home you know, being the eyes and ears for some- being the eyes and ears for some other people. Well because there's people around here that do the busy work for all of us, they take care of all of us. And in a lot of cases they're zipping around trying to do everything that they can and they don't notice the small stuff. Like if something's been spilled on the floor they don't know it and, you know, things like that. The other day some-some um, uh, somebody had come in and they were going to give one of the patients a drink of tea or something like that, and I said, "No, no, don't-don't do that, I think she's on a, um, thick liquid diet. So please check with the nurse before you give her anything," and sure enough. And-and sometimes, um, I have an unfortunate thing about hearing, I hear-hear very well and, um, you get little pieces and bits of-of things others are talking about. And ah...I mean it's-it's probably not too drastic for her [referring to roommate] but you never can tell. If it goes down the wrong way it hits the lung, you know; and if somebody's falling out of their wheelchair I yell, you know.

Doris' account also suggests that oversight provided by the facility needed to be supplemented, since the work required of staff was just too demanding to expect them to adequately monitor for safety. At times she felt overwhelmed by this sense of responsibility and the personal cost of this activity:

> I-I used to, uh, I used to be in the dining room a lot and stuff like that and, um, it got so that I was constantly looking and doing something like that and I said, "No, I- I- I'm not going to keep doing this because it's getting annoying for me to have to be my brother's keeper." You know I'll do that every once in awhile but, um, no I don't work here (chuckles), they don't pay me. I don't do windows either, that's another story (chuckles). Thinking of that I'm going to have to talk to (the administrator) and see if maybe he can get the windows cleaned.

When spending time in the day room at Lincoln Way, Carl watches out for a frail fellow African American resident whom he calls “Momma,” often relaying her needs to the staff. He describes the motivation for this care and vigilance:

> …well the- like I told her- like I told them, she looks just like my mother when my mother died. See. Uh, but uh…uh…I use that as a crutch. Uh, they may be friends, but I use her as a crutch uh, to really, to ask, ah, I asked God to forgive me the way I- I treated my mother. ‘Cause I wasn’t always there on Mother’s Day. I wasn’t always giving her a gift or something. Well, a lot of times I couldn’t afford to.

At Del Rio, acting more as helper than advocate, Dolores often fills water pitchers for Shirley, Barbara and other residents in her area of the ward, continuing a simple activity important in her former career as a CNA.

Several participants were the beneficiaries of advocacy and caring attention provided by other residents. Felicia’s roommate regularly communicated Felicia’s needs to staff. Barbara often took advantage of a fellow resident’s offer to wheel her the length of the open ward back to her bedside after lunch activities. A male resident in his fifties regularly provided Lillian with fresh water and snacks from the vending machines. Mary also had a friend who supplied her with her favorite vending machine fare: diet Coke and small bags of baked potato chips.

Among participants, activities that involve advocating for and assisting fellow resident were often rooted in personal history. For Dolores assisting other residents continued patterns of caring learned as a CNA. For Doris advocacy involved watching out for vulnerable others, much like had done for her mother in the nursing home. Carl spoke of his attentiveness to “Momma” as a way of settling karmic debt, making up for the times he had not been available for his own mother.

Immediate Discomforts and the Perception of Doing Well

Interestingly, during participant observation, it became apparent that residents' reports of how well they were doing often varied from day to day and even within the same day. To explore this further, I recorded responses to the question "How are you doing?" daily over two weeks (see Table 4). Most of our interactions occurred during the afternoon or early evening, at times when residents were not engaged in activities and most likely to be awake. In addition to their immediate responses to the question, I recorded observations and their reflections on what they meant by their evaluations.

Table 4.

Two-Week Survey of Residents on How They Are Doing

	Lincoln Way	Del Rio	Both Facilities
Number of days data were collected, *n*	14	13	27
Residents, *n*	9	8	17
Response, *n* (%)			
Doing Well[a]	84 (66.7)	74 (71.2)	158 (68.7)
Not Well[b]	27 (21.4)	8 (7.7)	35 (15.2)
Ambivalent[c]	13 (10.3)	15 (14.4)	28 (12.2)
Missing[d]	2 (1.6)	7 (6.7)	9 (3.9)
Total	126 (100.0)	104 (100.0)	230 (100.0)

Note. Data were collected from the same residents on consecutive days in each facility.

Meaning of response was clarified with resident before assigning it to a final category.

[a] Doing Well = responses such as *pretty good, very good, terrific, quite well.*

[b] Not Well = responses such as *not good, miserable, terrible, not so good.*

[c] Ambivalent = responses such as *so-so, five out of ten, can't complain, fair.*

[d] Missing = resident sleeping, off the unit or otherwise unavailable.

Two (11.8%) of the 17 participants provided 18 (51.4%) of the evaluations in which residents considered themselves as not doing well ("Not Well"). Rita, a participant in her nineties with the shortest tenure in the nursing home (four months), reported not doing well on eleven of fourteen days. Though staff perceived her as doing well based mainly on her ability to walk with a walker, use the bathroom independently and interact positively and compliantly with staff, she voiced an array of issues that interfered with her ability to do well, including, pain, difficulty sleeping, impaired vision, limited meal choices, facility control over medications and recurring doubts about the appropriateness of her placement in the nursing home. On one occasion she expressed global doubt about her present living situation: " I don't know, perhaps I make (sic) a mistake in coming here."

The second resident, Emma, a resident for nearly eight months, reported not doing well on seven days over the two week period. Her evaluations centered on uncontrolled arthritic pain, combined with the distress of upper respiratory congestion. Her reports of how she perceived herself doing varied based largely on the severity of physical symptoms. She and her family were still in the process of accepting the need for continuous nursing home care. Thus, in addition to identifiable symptoms, both Rita and Emma are dealing with adjusting to the idea of the nursing home as a permanent residence and the ensuing losses.

Eight additional participants (47.1%) reported not doing well (not good, miserable, terrible, not so good) on from one to three days over the two-week evaluation period. These residents readily linked their appraisals to a pressing physical symptom, emotional challenge or environmental irritant. Dolores indicated she was doing "not good" and connected this evaluation to pain in her left arm, stating there are times when the pain is worse and medications don't help. On one occasion Lillian reported she was not feeling at all well due to discomfort related to a bladder infection. The next day as symptoms resolved she reported feeling "one hundred percent—much better." Between visits, the focus of her conversation changed from immediate internal symptoms to the social aspects of her entire day, including recounting visits from her sisters and another resident. The one occasion when Barbara reported doing "not so good, " she stated that her roommate's yelling kept her up all night and she didn't get enough sleep.

Residents who reported "doing well" based their appraisals on the relief or control of symptoms, on a sense that the day was progressing as expected or on the occurrence of a positive event. For residents living with variations in chronic symptoms, doing well or doing better was framed as the absence or relief of those debilitating symptoms. Thus Lillian framed "pretty good" days in terms of the quality of pain control, most often relative to some other time, for example "better than yesterday." Shirley related her evaluation, "doing better than usual," to a typical day that started with a favorite breakfast that included a "cheese omelet and raisin toast" and continued with a visit from her closest friend, Bill. Special days or events residents associated with doing exceptionally well ("really good days") frequently involved special recognition and ranged from something as simple as winning at Bingo, to being chosen facility Mardi Gras queen, to attending a reception to receive a regional award from an inter-facility art program.

In summary, unresolved physical symptoms, emotional difficulties, or situational irritants commonly resulted in residents' negatively valenced perceptions and evaluations of how they were doing and feeling. When residents reported they were doing terrible, or miserable, they readily articulated the grounds for this evaluation. On the other hand, unless their day was characterized by an extraordinary event, residents who indicated they were doing well were unlikely to elaborate spontaneously on the reasons for this evaluation, requiring encouragement to articulate basis for their appraisal.

Correspondingly, observations suggest that at least two meanings of “present” operate in the day to day lives of nursing home residents influencing the appraisal process: (1) the immediate present focused on symptoms and pressing issues and (2) the taken-for-granted situational present that refers to the totality of one’s current environment or life-world. Responses to queries about how a resident is doing often fluctuate between these two senses of the present. Thus a resident is able to both complain about chronic pain yet speak of doing well globally, i.e., “all things considered.” The focused response represents the evaluation of a single pressing symptom, while the global response indicates an appraisal based on a resident’s sense of his fit and satisfaction with the environment. In addition there seems to be a threshold when a symptom or vexing condition reaches a level of intensity that precludes appreciating matters outside the problem at hand, a state of affairs where it becomes difficult for the resident to recognize any degree of harmony or quality in life.

Breaking the Routine

Even with extensive onsite activity programs at each facility, residents express a desire to periodically “break the routine,” to remove themselves from the world of the nursing home. Ways of achieving respite include actual “getting-out” by physically leaving the facility, and virtual “getting away” through self initiated activities such as television and reading. In addition, participants reflected on making a complete break from facility routine and "leaving for good."

Actual Getting Out

Participants mention three occasions when they leave the facility (a) on facility sponsored excursions, (b) for outings with family or friends, and (c) to attend medical or other appointments. This report addresses the first two of these, since residents did not elaborate on activities involved in leaving the facility for medical or other appointments; thus, it did not emerge as directly contributing to a sense of doing well (see Table 5). In addition to these opportunities for getting out evident in both settings, Del Rio's large and open campus provided a third option that involved staying on the facility grounds but regularly "getting off the unit"

Table 5.

Trips Out of the Facility

	Lincoln Way *n (%)*	Del Rio *n (%)*	Both Facilities *n (%)*
Where residents go			
On facility outings and out with family	1 (11.1)	2 (25.0)	3 (17.6)
On facility outings only	4 (44.4)	2 (25.0)	6 (35.3)
Out with family only	1 (11.1)	0 (0.0)	1 (5.9)
Does not usually get out	3 (33.3)	4 (50.0)	7 (41.2)

Facility Sponsored Excursions:

Both facilities had programs that included bus or van tours and excursions. Participants indicated that outings occurred once or twice per month. Activity calendars and participant reports revealed that the types of outings included scenic tours, trips to restaurants, visits to zoos and museums, outings to football or baseball games and seasonal activities such as excursions to view Christmas lights and visit a pumpkin patch.

Del Rio had a large school bus and several vans that had been fitted to accommodate wheelchairs for resident excursions. Lincoln Way shared a wheelchair accessible van, which accommodated four to six individuals, with a sister facility in the same corporate chain. Though residents who took advantage of outings enjoyed them, they commented that riding in a bus or van was often rough and uncomfortable.

Reasons for refusal or reluctance to participate in outings included, physical discomfort, functional challenges, and uncertainty about one’s ability to manage while away from the security of the facility. Rose states she does not go on outings because she got car sick during her first scenic tour. George, who is quite heavy and has an extra-wide wheelchair, does not express much interest in outings citing the difficulty involved in maneuvering and securing his wheelchair. Raymond feels limited by the need to manage his ostomy and though Frank has gone on outings he is cautious about going out because of the possible need to use the bathroom and the difficultly that might entail. Rita who has the shortest nursing home tenure is under the impression that she must not leave the nursing home and is unsure of her ability to manage an outing.

Though each resident’s preferences for the types of outing varied according to life long interests, the most popular activities involved having a meal outside the confines of the facility. At a Lincoln Way resident council meeting attended by more than thirty residents, the activity leader announced two outings for the coming month, a meal at a local restaurant and a scenic tour. There were six places available for each excursion. Nine individuals indicated interest in the restaurant meal while only two wanted to go on the scenic tour. Doris, Martha, Shirley, and Dolores all confirmed that from their perspective outings that include dining are most popular. Doris, whose interviews indicate an appreciation of food and dining, relishes the prospect of eating out, and includes detailed descriptions of the food served at outings to restaurants, a bakery and the regional nursing home artists' reception. In contrast, Martha has been to the usual restaurant "three times and it seems three times is enough." She now believes there isn't that much difference between the three entree items they are allowed to choose at the restaurant and the meals they usually get at Lincoln Way: "What the heck. I could have chicken here, I could have steak here or whatever… so to me its a waste of time." Nonetheless, for most of those who take advantage of outings to restaurants, getting out to dine represents welcome respite from routinely scheduled meals and often repeated menu items.

The overwhelming popularity of dining excursions aside, participants' preferences for outings reflect interests cultivated over the life span. Not very excited by the prospect of a tour where "you're going along the freeway" and seeing "nothing but trees on the hillside," Martha's most memorable outings included a trip to the zoo and going to a baseball game. Raymond, Lillian and Frank also speak of an ongoing interest in sports, and outings to baseball and football games are at the tops of their lists. Martha details the roots of her abiding interest in sports. Citing her father as the source of her love of sports, she describes herself as a youngster as “a regular tomboy” and “the only girl on the baseball team and the football team.” Having “always been very sports minded,” her account of the baseball game conveys her delight and enthusiasm:

> Oh, I loved it! And uh- ‘cause I like baseball. And I had good- we had good seats. Sitting up above first base, I think third row or fourth row. And I could see the first- and then the batter. Oh boy! The view of the field was just perfect!

Martha would “love” to get out to a baseball game every month but relates the administrator’s response when she asked if they would be going again: “And he said that the tickets are so expensive, the company doesn’t go for it, which you can’t blame them. You take four or five people, it’s kind of expensive.” Though she appreciates other types of outings, Martha is not as passionate about them stating “If I feel like going OK. A lot of times at the last minute I’ll cancel ‘cause I don’t want to go.”

The interaction and camaraderie engendered during a shared excursion can last well after the event has ended. The excitement over “getting out” was palpable when I entered one of Del Rio’s open wards the day after a outing to a cheese factory. Shirley mentioned that the bus trip was a bit rough. Dolores, Barbara and she offered separate accounts of how plans to tour the factory and the adjacent shop were aborted because of inadequate wheelchair access. Shirley and Barbara expressed disappointment because they had planned to buy cheese for family, friends and staff. Barbara surmised that the reason for being denied admission was because the proprietors just didn’t like to see people in wheelchairs. They described the box lunches and cheese samples they enjoyed outside in the picnic area, each stating she appreciated getting out in the fresh air to see the farmland and experience the sunshine. Despite, and in some cases because of, the failed factory tour, “getting out” generated a secondary gain—sharing of lively stories, commentary and debated theories as to why the day unfolded as it did, stories that persisted well into the following day.

Carl, who previously enjoyed hanging out in various sections of the city and "watching people," prefers scenic tours to dining excursions "Cause uh, ain't but one restaurant I'll eat at here in Grand City, that's "Big Lil's," that's the one where I eat." A habitual observer of urban life, he recounts how bus tours provide an opportunity to survey changes to the city that have occurred over the years.

Five of the nine participants who went on facility outings stated they would like to have more frequent trips of the type they preferred. While Ben, whose lifelong interests include literature, theater, poetry, and journalism, is not interested in getting out to restaurants, he would like the facility to offer more excursions to cultural events. Similarly, Doris expresses interest in destinations of a more instructive nature, such as museums, tours of businesses, and nature related venues such as zoos, gardens and aquariums. These are the types of places that she and her mother sought out during vacations. Not surprisingly then, the value a participant places an excursion is very much a function of whether or not it corresponds to types activities that an individual has typically enjoyed in the past.

Family Outings

Of the residents whose families visit regularly, only two of seventeen indicated that they routinely went out with family. Dolores has a much anticipated twice-monthly date with her niece to go out to eat at a favorite Asian restaurant. Every other Saturday, Barbara's son takes her to visit her sister who lives in the suburbs. Her sister is homebound and lives with a nephew who is refusing even palliative treatment in the terminal phase of cancer. While Barbara reports that it is good to get out and see her sister, she inevitably comments on how difficult it is for both her sister and nephew to cope with increasing disability.

Ben indicates that trips out with his family occur infrequently, perhaps once or twice per year. His destination is usually to attend a church service. Similarly, Joseph reported going out on a family sponsored excursion to his parish church. His daughter hired a taxi to collect Joseph's electric wheelchair from her home then proceed to Lincoln Way to get Joseph and bring him to meet them at the church. There he sang with the choir he directed before his retirement. He then independently wheeled himself to second church several blocks away for a reception. In reflecting on his ability to get out and maneuver in his wheelchair on this occasion, he does not understand why his electric wheelchair cannot be kept at the nursing home, providing him a means for getting out more frequently.

While facility sponsored outings are normally designed to attract a sufficient number of residents to make them worth the effort and cost, family outings, though on the whole less frequent, enable residents to connect with individuals, settings and activities that have highly personal importance.

Getting Off the Unit

At Del Rio, a resident's activities are most regimented while they are on the unit under the direct supervision of staff. Residents who have the ability and staff approval are permitted to "get off the unit" and navigate the facility independently on foot or via wheelchair. Getting off the unit represents a degree of respite from staff scrutiny and institutionally framed unit routines, and provides opportunities to exercise greater autonomy and choice. The small size and configuration of space at Lincoln Way means that though residents may be out of their rooms they are rarely out of the staff's sight and supervision. Whereas there are many "nooks and crannies" and several outside locations at Del Rio where mobile residents can get away and be alone, there are no such spaces at Lincoln Way where residents cannot achieve privacy except by having cubicle curtains drawn around their beds. Since each floor is a unit at Lincoln Way, there are no opportunities for "getting off the unit."

At Del Rio, George, Frank and Raymond spend most of their waking hours off the unit. George, a very large ten-year resident who has a long history of homelessness and recent intermittent bouts of confusion, relies on staff to transport him from location to location while his electric wheelchair is temporarily out of commission. His comments suggest that having the freedom to get off the unit to observe and think contributes to a sense of well-being:

> GEORGE: I'm pretty well- yeah, on my own and I pretty well know the people here. And uh, it's all right. (Long pause, as George gazes out the window and changes focus) Yup, they're beautiful.
>
> INT: Hmm. What? Those-
>
> GEORGE: Those trees. I love to look at trees with the wind.
>
> INT: Do you spend much time here (in an windowed alcove off the unit) looking out at the trees and all?
>
> GEORGE: Uh-huh… Well, when I got my electric wheelchair I can ride around…and look.

Both Frank and Raymond's comments and activities suggest they consider the open ward as a departure point and home base they return to intermittently during the day's activities. Frank spends most of his day in his electric wheelchair "off the unit," touring the halls and regularly sharing the company of between five and eight fellow smokers in a designated outdoor smoking area. He has taken on the daily responsibility of transporting outgoing mail from a facility mailbox on the fifth floor to the public Unites States Postal Service box at the front of the building. In the evenings he attends facility wide activities such a Bingo, Black Jack and Horse Races. Correspondingly, when asked where he would like to go on a facility sponsored trip, his immediate response was a gambling casino. Raymond's activities off the unit including musical commitments, time alone and time in the library have been described previously. Both Raymond and Frank see the unit chiefly as place to eat, rest, bathe and use the toilet, and for Frank also a spot to watch some television. Neither is involved in planned activities on the unit, preferring to expand their worlds by choosing their associations, commitments and diversions off the unit. For George, Raymond and Frank, though limited, "getting out" includes "getting off the unit" daily.

Virtual Getting Away.

While "actual getting out" provides opportunities for residents to break away from the nursing home routine by physically leaving a location, "virtual getting away" allows for diversion while remaining in the facility, on the unit, in one's room or even in bed. Residents turn to reading and electronic media, such as television, radio and music recordings, to pass time and get away from the facility mentally, spiritually and emotionally. In addition to reading and media, interaction with residents suggests that day dreaming or getting "lost in thought" may represent another mechanism for breaking away from one's immediate surroundings.

Reading

Over eighty percent of the participants implied that reading was an important part of their life in the facility, and seven (41.2%) indicated that they read daily. Of the three residents who did not normally engage in reading, two, Rita and Mary attributed this to deteriorating vision. For Mary, who had worked as a grammar school reading specialist, this was especially distressing. The third resident, George, stated that he never read books, papers or magazines and implied that he rarely read previous to entering the facility. Of the participants who read, Martha and Lillian express frustration that

Table 6.

Participant Use of Reading and Electronic Media[a]

	Lincoln Way *n* (%)	Del Rio *n* (%)	Both Facilities *n* (%)
Read for news or information	8 (88.9)	3 (37.5)	11 (64.7))
Read for pleasure or diversion	5 (55.6)	2 (25.0)	7 (41.2)
Read spiritual or inspirational material	1 (11.1)	2 (25.0)	3 (17.6)
Use of Electronic media			
Has and uses a personal television (TV)	4 (44.4)	5 (62.5)	9 (52.9)
Views TV for news	5 (55.6)	5 (62.5)	10 (58.8)
Views TV for sports	2 (22.2)	1 (12.5)	3 (17.6)
Views TV for entertainment/arts programs	5 (55.6)	6 (75.0)	11 (64.7)
Listens to radio for news	1 (11.1)	1 (12.5)	2 (11.8)
Listens to radio for music	1 (11.1)	0 (0.0)	1 (5.9)
Computer	1 (11.1)	0 (0.0)	1 (5.9)

[a] Data based on consistency among interviews, observations and direct questions to participants

impaired vision prevented them from reading as much as they would like.

Interview and observational data indicate that residents read for four major reasons, (a) to review paperwork and deal with the exigencies of daily living, (b) to keep up with local and world news, (c) for entertainment and escape (diversion) and (d) for spiritual support and inspiration (see Table 6). The first reason for reading is pragmatic and, rather than serving to provide respite from facility routine, tends to underscore the reasons for and realities of living in a nursing home. Reading newspapers and magazines provides connection with what is happening outside the facility and often furnishes topics for discussion. While reading for spiritual support and inspiration enables residents to deal with issues of personal value and meaning, it may also serve to maintain ties with religious and spiritual traditions and communities. Reading for pleasure was most often associated with accessing virtual worlds beyond the walls of the nursing home. This was the type of reading that participants most often associated with "getting away."

As mentioned above Doris' "settling in" included the acquisition of a sizeable bedside library of romance, adventure and mystery novels, most of them ordered from amazon.com. She maintains "I'm not bored because I'm a voracious reader," and explains how reading enables her to get away.

> DORIS: For me reading is um-, I mean, I grew up reading. And I mean, I was in…school and I'd be reading a book and somebody'd be stumbling along in the first paragraph, and I'd be three- three uh- three chapters ahead. But my mother taught me at an early age. When I went to school I knew the alphabet. And um, I enjoyed reading…
>
> INT: How do you think that works?...
>
> DORIS: …Um, when I'm reading I can be in another place, I can be there and with any of the descriptions or anything. I can see these places. …I've always had that, for some odd reason. I can immerse myself in ah-. That's one of the major problems in school because I'd close out everything…Just [makes a

> whistling sound and glances upward to indicate going away] and that's it. And I'm- I'm there. And don't bother me. Don't bo- I'm- I'm here. No! I'm having fun here. You know? And that's uh- you know, that's uh, one of the things that I've always been able to do is uh…compartmentalize myself or something. Is that the word- correct word?

Similarly, Shirley, who continues membership in a Book-of-the-Month Club, comments on what reading does for her: "I use my imagination, put myself in the characters." Ben, who usually has several books next to him in bed, reflects that "If I'm reading a good book, I—I'm not sad, I'm not lonely." An activity leader provides Joseph with Russian language books, mostly classics, many of which he read when he was younger. He admits retreating to the pages of his book when things aren't going well or don't go his way. And Raymond, who spends a few hours each day in Del Rio's library states "…to feel good, I just do a good job in my music and get home (back to the ward) and get a good book to read. …reading and music keeps (sic) me going."

Like most of the participants who are avid readers, Rose indicates that reading to occupy herself and to pass the time is rooted in her childhood. Now, aware that her memory is failing, she suggests an additional therapeutic advantage to reading: "What was I reading?... Oh yeah (picking up a book). I read in order to keep my mind active, you know. And my son-, this is *Renoir, My Father*." She is never without a book or magazine tucked next to her in her wheelchair. Rose's son is aware of her literary preferences and provides her will new books during his weekly visits.

Longstanding interests and preferences dictated the literary genre and subject matter that participants chose. Thus Raymond preferred books on ships, the military and aviation, Shirley favored mysteries, Ben liked adventures and historical novels, while Doris usually chose romance novels and occasionally a mystery or adventure.

Accordingly, reading as a mode of “virtual getting away” represents a special case of breaking the routine, since, unlike excursions or tours, it is largely under the control of the resident. Having power over the process, allows for greater spontaneity, discovery, and insight. Passages, and in many cases, even favorite books, can be reread and pondered at will. Simply put, in reading, residents have greater control over the worlds they choose to engage.

Electronic Media

Data suggest that participants also use electronic media, such as television, radio, music and video recordings, and, in one case, the internet, as vehicles for “getting away” or “passing time” (see Table 6). The more media related activities are under the direct control of the resident, the more they function as diversions similar to reading where a resident has the choice to enter or exit a virtual place.

Ten participants had their own televisions. Rose, one of the ten, rarely watched her television stating that “TV makes me nervous,” but she did not expand on what she meant. Of the remaining seven participants who did not own televisions, Dolores watched favorite quiz programs with other residents every morning in the dining room on the unit at Del Rio, while Raymond would periodically watch the news on a fellow resident’s television. At Lincoln Way, Joseph periodically viewed the news and performing arts programs on a television set in the corner of the day room, and Felicia and her roommate viewed Catholic mass early every morning on the roommate’s television. Of the thirteen residents (76.5%) who indicated they watched television, most stated they used it to keep up with the news. They variously enjoyed viewing regularly scheduled game shows, sports events, cultural programs and movies. Understandably, participants who had experienced significant declines in vision that interfered with reading, like Martha and Lillian, commonly turned to television as a significant source of entertainment and means for passing the time. Ben and Raymond who continue to be avid readers assigned little value to watching television.

Consistent with Carl's life long pattern of avoiding conflict, television provided escape from difficult situations: "I don't have no (sic) trouble with the residents 'cause I can come in here and get in that bed and go to sleep or turn that TV on and uh, forget there- there's anybody else here but me." In contrast, Martha's used television less as an escape and more as a way of sustaining her lifelong interest in sports: "I look at a lot of television. I love the sports, especially the football games and I'm waiting for the World Series." She made a point of arranging appointments for interviews so they did not conflict with scheduled sports programming.

Only two participants, Raymond and Joseph, stated they regularly listen to the radio or music recordings for news or entertainment. Interestingly, both were the residents who expressed the greatest life-long interest in music. While Raymond listened to the radio chiefly to stay abreast of local, national and international news and commentary, Joseph turned to radio and recorded media to continue a life permeated with music. Though Joseph worked as a machinist, his interview revealed an enduring commitment to music, from his early years in a student orchestra, to touring internationally as a member of a prominent religious chorus, and culminating in his long term directorship of a local church choir. The desire to have a place for his radio and "records" figured significantly in his request for a bed near the window. He recounted with great pleasure listening to ethnic music programs with a fellow Russian speaking resident who has his own radio. Joseph spent much of his time in the dayroom enjoying classical music and reading or reflecting. Music stimulated and reinforced his sense of connection with his former life in the community.

> Every time in the morning and the night then, when I wake up and go to sleep, Sometimes I, in the bed, start singing very quiet, not bugging my neighbor, what I sing in church before, you know?

Joseph suggests that listening to music kindles the recall of meaningful activities, stimulating mental and emotional reconnections with a world outside the facility. Having recorded media such as tapes or discs provides a measure of control over his ability to access preferred music.

Though regular internet access was available to Del Rio residents in the library, none of participants, even Raymond who visited the library daily, indicated they were interested in using a computer. At Lincoln Way, computer access was available to residents on each floor two afternoons per week when a cart with a computer would be rolled from the social worker’s office into the day room. Only Doris regularly took advantage of internet access. She affirmed that former experience with computers afforded her the knowledge and confidence to use one. However, she admitted her hemiplegia seriously slowed her use of the keyboard and indicated that restricted access to the computer limited browsing the web to about four hours per week. In addition to email access and the ability to order books and other items, “surfing the web” to visit news, literary, nature, and other favorite websites, provides Doris a modicum of diversion from the nursing home routine.

Lost in thought.

While not pursued in interviews, observations suggest that some residents who are staring into space and appear to be doing nothing may actually be actively involved in reminiscing, reflecting or “cogitating” (Nystrom, 1995). On afternoons that I collected data, I often found Carl seated at the same table in the day room staring into space. He frequently began his conversations with the phrase “I was just sitting here thinking about…” and would then launch into a detailed and lengthy account of what he had been thinking about while sitting there. I noticed similar encounters with other residents, and though not adequately explored in this study, the phenomenon deserves mention as another possible way in which residents virtually leave their immediate surroundings.

Leaving for Good.

While actual getting out and virtual getting away provide a temporary break from the usual facility routine, most residents still occasionally consider the possibility of leaving for good. Ten participants who were residents for more than two years suggested they had resigned themselves to the nursing home as a permanent residence and had reconciled personal preferences with the established routine. Nevertheless, while indicating acceptance and overall satisfaction with conditions in the nursing home, eight of these residents periodically reflected on possible alternative living situations. Their comments included appraisals of the pros and cons of life within versus outside the facility

For Doris, living in a nursing home was the only alternative she saw. Limited income, her need to rely on Medicaid, and doubts about the adequacy of services available precluded her moving to assisted living. Thus, she viewed nursing home life, tempered by personal attitudes of acceptance and "letting go," as her only option. She had accepted Lincoln Way as her final residence and resigned herself to concomitant constraints that resulted because you "run into state laws, " and "you're stuck with what the company (corporate headquarters) says."

> Hmm…[pause] to a degree, I don't think that anybody does well in an institution like this. We um, are here. We adapt. And uh, I can only speak for the uh, one Caucasian person, namely me. Uh, but uh, you more or less adapt. There's a few things you would wish could happen but can't. And um, it's a give and take of thought. "Gee, I wish I could've done this. I wish could do this." But you can't, and um, you just sort of let it go. Because if you don't, you'd end up in an insane asylum [laughs]. You know, if you can't do all the things you wanna do- I mean, um…one thing I really wished I could've done but never got around to it was visiting the Monterey Bay Aquarium. But unfortunately uh, that would be an overnight trip and uh, you'd have to take five or six CNAs with you and uh- because it takes what-- four hours to drive down? Four hours at least.

Though Doris is exceptionally involved in the life of the facility and took advantage of "getting out" on facility sponsored trips and "getting away" through reading, television and online activities, she had thought seriously about alternatives to nursing home life, yet returned to Lincoln Way as her only option.

In thinking about the future, Martha's comments illustrate how a resident's perception of the interplay between the demands of living in the community and one's functional ability shapes the expectation of leaving the nursing home:

> Well, being 94-years-old, I take it from day to day. Like I say to myself, "Boy if I ever get out of here, will I have my own apartment and everything like I would like to have?" And then I begin to think "you know you can't handle it." Mentally I could handle it, but it's my hands that bother me, whether I'm going to be able to cook or whatever you know, that's... but I always dream, huh, if I ever get out of here…you know… But (pause), I don't think I'll move.

Similarly, Raymond, a twenty-two year, extremely satisfied resident of Del Rio, indicated he was aware of a new veteran's retirement community, and speculated that he might be a candidate for moving there. He felt the stability of his medical conditions, his colostomy in particular, would be the determining factor: “So that’ll always be with me, see? … I’ll never be rid of this. So I can’t live in a, let’s say, a normal apartment complex because you never know when it might be coming back to do something.”

Both Dolores and Barbara expressed preferences for living with family members, but accepted that this was not a possibility due to the need for skilled medical care and functional support. Dolores pointed to the complexity of the intersection of her medical and behavioral problems, while Barbara reluctantly acknowledged the severity of the disabling sequelae of her stroke.

In reflecting on the possibility of leaving for good, several residents also suggested that financial constraints limited their options for care. While conversing with a visiting friend and age mate, Martha joked that if they won the lottery they could move into an apartment together and hire caregivers to look after them. Doris believes that because of the way reimbursement for long term care is structured, the nursing home is her only option.

Individuals who do well occasionally experience a tension between knowing and accepting the nursing home as their best option at the present time. Even those who are most resigned and by all accounts appear to be doing well, still dream of something better or different, and how things could be improved. These individuals take advantage of opportunities and develop strategies to periodically “break the routines” of nursing home life. More importantly, they express no regrets about the past, acknowledge that things in the present could be better, and periodically revisit and renegotiate a cautiously wrought peace with the limitations of their current living situation.

Summary

Residents do well when they are able to maintain a sense of continuity with valued and enduring ways of being and doing in the world. Doing well as a resident in a nursing home involves dealing with changes in physical and functional status while negotiating the challenges of settling into life in a new environment. Data presented here suggests that having a voice and being heard, achieving an acceptable level of comfort, and having opportunities to break away from facility routines are important for a resident to do well. Resident reports of how well they are doing vary across time and are frequently related to whether or not issues of physical, psychological, or social discomfort are adequately addressed.

Chapter Seven

UNDERSTANDING DOING WELL: THE INTERSECTION OF PAST AND PRESENT, BIOGRAPHY AND ENVIRONMENT

Articulating Doing Well

In the current study, nursing home residents shared experiences, stories and reflections, providing insight into their understanding of what it means to do well. Their accounts together with researcher interaction and observation suggest that "thriving" is not a term they routinely use to describe a positive state of well-being. None of the participants spoke of "thriving" in commenting on how well or poorly they saw themselves doing. Consistent with pilot and preliminary study results (Walent, 2007; Walent, Chesla, & Kayser-Jones, 2006), participants used the term "doing well" to indicate *a positive disposition toward and within the present experience of living that is shaped by the interaction of continually evolving personal history and the environment.* (see Figure 5, p. 69).

Relationship to Prior Conceptualizations

This *in vivo* notion of "doing well" moves beyond existing concepts of thriving and the temptation to construct this phenomenon as a condition in contrast to failure to thrive (Haight, Barba, Tesh, & Courts, 2002) or solely as a possible outcome of successful coping (Carver, 1998; O'Leary, 1998; O'Leary & Ickovics, 1995). It expands on Bergland and Kirkevold's (2001, 2005b) concept of thriving by including the intersection of present experience, personal history and current environment as constitutive of "doing well." This description of "doing well" also acknowledges the biographically framed, subjective appraisal process involved in responding to questions about quality of life (Schwartz & Rapkin, 2004). Thus “doing well” transcends conceptions of subjective well-being that posit sets of discrete antecedents, attributes and consequences, and suggests a cogent framework for understanding the wide variations in how residents view QOL. While not denying observable signs of decline, the proposed articulation of “doing well” recognizes the importance of an individual’s perception, appraisal and response to his own circumstances. It assumes that individuals act, evaluate their actions, and create meaning based on their perceptions and beliefs no matter how ill or well founded (Gubrium, 1993; Merleau-Ponty, 1964).

Temporality and Understanding

Though the original research question deals mainly with doing well in the residents’ present living situation, participants gravitated toward stories about the past suggesting that life-lived has laid the groundwork for how they are doing now. This finding echoes the temporal linkages espoused in the quantitatively framed developmental adaptation model: “subjective well-being...is not only determined by recent adaptive behaviors, but also directly and indirectly by existing resources and events of the distal past” (Martin & Martin, 2002, p. 86). It also resonates with Lawton’s (1991) recognition of the “*temporal* aspect of quality of life (which) emphasizes the dynamic, ongoing nature of the person-environment system” (p. 7). In qualitative research circles, foregrounding the connection between past and present is consistent with Kaufman’s (1986) notion of the “ageless self” and Gubrium’s (1993) interpretation of life narratives as communicated lives.

Commenting on the significance of recalling the past as an essential component of meaning making, Gubrium (1993) distinguishes between life histories and life narratives. His logic supports the case for attending to residents' interpretations of their lives as the key to understanding what constitutes doing well, even though resident's perceptions of their own lives may not concur with facts as perceived and reported by others:

> The truth of a life history lies less in its formulation than in its subject matter. Ideally, life histories should factually describe the lives they are about. Life narratives in contrast, are communicated lives. The past, present and future are linked together to assemble meaning. (p. 15)

Thus, understanding a resident's orientation to his present, requires deciphering stories to determine the abiding significance of past events. A particular strength of the current research stems from an approach that values the resident as both narrator and interpreter of his history and surroundings.

Whereas attending to the unique aspects of individuals' biographies and interpretations of their surroundings underscores variability, identifying shared themes and threads provides a framework for understanding unifying features of their experiences and perceptions. Accordingly, this chapter will discuss how the identified subthemes that constitute "bringing the past into the present" and ancillary findings relate to existing thought on the nursing home as "total institution, the significance of family support, and the meaning of "settling in." Next, applying concepts from the life course capital (LCC) discourse (O'Rand, 2001, 2006) to a nursing home environment framework (J. Kayser-Jones, 1992, 1994, 2003b) will be used to develop a heuristic for understanding biographically informed resources that residents rely on to do well. Lastly, insights into what it means to do well and the proposed heuristic will direct commentary on implications for caregiver practice, policy development and future research.

Past to Present: Making Connections

Institutionalized or Doing Well?

The significant number of participants in this study who spoke positively of previous experiences with institutional or congregate living prompts comment on the nursing home as an institution from the resident perspective. In general, residents with prior experience living in institutions enlist insights, attitudes and abilities acquired there to adapt to aspects of the "total institution" that surface in the nursing home.

Briefly, Goffman (1961) defines the total institution as "a place of residence and work where a large number of like situated individuals, cut off from the larger society for an appreciable period of time, together lead an enclosed, formally administered round of life." (p. xiii). How well the nursing home as a generic type fits the profile of the total institution has been a matter of considerable discussion (Gubrium, 1975; Retsinas, 1986; Savishinsky, 1991; Shield, 1988; Stafford, 2003b; Thomas, 1996).

Based on Goffman's (1961) description, Shield (1988) identified eighteen characteristics of the total institution and found that two features, presence of a privilege-punishment system and the goal of return to society, were not present in the facility she studied. Two structural aspects, stripping/mortification and a complete break with the past, were only partially present, as were Goffman's (1961) five institutionalized inmate responses: collective teasing, feeling of personal failure, stigmatization, knowing the ropes, and inmate fraternalization. Shield (1988) concludes that the nursing home she studied was a total institution of a different sort, highlighting characteristics of the facility that inhibit autonomy and personhood:

> It is a home where comforts, companionship, continuity and individuality are inhibited…Because there is no consensus about the goals for the residents, staff

> work against one another…Because they are treated like incapable children, their individualities and pasts are denied them, they are unable to contribute, and they must be grateful for the care they receive. (p. 104)

In the present study general characteristics of total institutions were evident in both study settings, including living in the same space and under the same authority. Other defining characteristics were ambiguous or only partially apparent. Thus, though in some respects participants were treated alike—for example, identical beds, and basic furnishings, scheduled meal times—they indicated they had varying degrees of choice in areas such as personal appearance, which activities to attend, and certain menu items. Limitations on personal space, as well as organizational exigencies, dictated the type and quantity of personal items that a resident could retain, constraining choice and individual expression possible for residents. The severely cramped environment of Lincoln Way meant that residents were rarely out sight of staff or other residents, whereas the amount of direct oversight residents experienced at Del Rio depended on their ability to navigate the facility independently and identify spaces for privacy. Thus, an outdated physical environment (small three bed rooms or open wards)—which supported earlier institutional and staff controlled models of care—served to reinforce programmatic values and appeared to contribute to the persistence of institutionalizing aspects of care and resident response.

Participants in the present study who had experience with institutional living constructed their stories against the backdrop of these physical environments viewed as *faits accomplis* over which they expected to have little control. They had adjusted to limitations on space and took challenges of sharing rooms for granted. They displayed little concern over lack of privacy, often indicating that privacy could be adequately achieved, simply by pulling the cubicle curtain.

Although the need for physically getting out of the facility varied among participants, study findings on "breaking the routine" and ancillary comments on programs that involved individuals coming into the facility from the community suggest that study participants may not feel as cut off from the larger society as residents described in earlier reports (Shield, 1988; Stafford, 2003a). In addition to physically getting out, participants mentioned television, radio, telephone, and in one case, the computer as ways they stayed connected to the family and the larger community. Looking to the future, it is still difficult to predict how life-long experience and reliance on internet connectivity will affect technologically savvy older adults' expectations and preferred modes of staying connected when faced with living in a nursing facility.

Gubrium (1993) notes that "lives and care are not necessarily understood by their subjects in terms of the administratively defined or scientistically attributed conditions of immediate situations" (p.186). Data from residents variously supported or disproved the existence of features of total institutions, providing no consensus on the existence of any defining characteristics. This suggests that from the residents' perspective, whatever structural or programmatic components reflect the total institution construct, they do not emerge as uniform defining criteria for doing or not doing well.

Despite the vestiges of "total institution" that persist, for some, the nursing home exists as a safe haven, offering respite from a difficult life in the community. Consider the participant in this study who refers to his stay in the nursing home as "the final happiness." Haight et al. (2002), present the case study of a woman with a long history of emotional and behavioral problems and alternating admissions and discharges from hospitals and institutional settings. The best times in her life coincided with the times she spent in the hospital and finally in a nursing home. This is not to suggest nursing homes need no improvement, but to emphasize again that appreciating the intersection of personal history and context is essential to understating subjective constructions of doing well. Findings call into question the value of assigning the blanket term "institutionalized" to resident attitudes and behaviors, and call for closer examination of how personal ways of being and doing developed and their significance to the individual.

A concurrent challenge is for residential facilities to examine how aspects of facility geography interfere with forms of self expression and serve to impede or support a resident's efforts to reframe and restructure routines to reflect enduring patterns of meaning (Andrews, 2002; Andrews et al., 2005). Facilities must assess daily living and care delivery structures and processes that influence concrete expressions of autonomy. Appreciating that an individual's interpretation of autonomy is rooted in biography challenges care providers to cultivate individualized opportunities for resident self expression in addition to eliminating the barriers to choice and action (Agich, 1990) that have been traditionally associated with total institutions.

Settling In: Nursing Home as "Home."

In contrast to "institutional," proponents of culture change often use the generic term "homelike" to frame desired improvements in residential long term care settings (Boyd, 1994; Brazil et al., 2004; Fisher, 1995; Pioneer Network, 2007). The term is rather nebulous and, in its least effective permutations, often focuses on trappings of the physical environment. The difficulty with terms such as culture change, home, and homelike lies in the inherently subjective and variable nature of the phenomena or qualities they strive to capture. Capitalizing on Rapley's (2003) rhetorical challenge to the subjective quality of life debate, "whose quality of life is it?" we can similarly query the discourses on culture change and nursing home as "home" by asking "to what or to whose culture are we changing" and "to whose home?"

Though the particulars of what constitutes an individual's experiencing a sense of home are highly personal and elusive, the consensus among researchers is that the meaning of "home" centers on having an abiding sense of comfort in the place one resides (de Veer & Kerkstra, 2001; Gubrium, 1993; Hammer, 1999). The transition and adaptation to the nursing home has been characterized as moving from feeling homeless to feeling "at home" (Brandburg, 2007). Achieving this sense of security and ease in a new environment often involves defining one's space, and creating a place for significant possessions (Kahn, 1999; Wapner, Demick, & Redondo, 1990). In the current study, it is not surprising that individuals who most consistently reported and evidenced doing well were those who had settled in and viewed the nursing home as a place of comfort and security. The finding that even those who were most settled admitted dreaming about alternative settings for living, is consistent with prior conclusions that most residents are involved in a process of "making the best of it" in a place that can never offer all that being at home involves (Kahn, 1999; Stafford, 2003a). In the present study, long-term residents who settled in and reported doing well had negotiated schedules and environments to more closely align with personal preferences and meanings, many of which involved routines and activities that were part of prior home life. In many respects they represent an elite group of residents, able to work within and around the physical and organizational limitations posed by the environment. They were able to sort out and continue aspects of their pasts that were most important to them. They sustained an identity and constructed a life in the nursing home that retained the most important features of prior lives in the community.

Family as the Locus of Support

Residents’ ongoing relationships with family members vary based on past experience and inform their expectations of nursing home life. Resident characterizations of life in a nursing home reported in the literature cover a range, from welcome respite from abusive or neglectful kin (Groger, 2002) to a major rupture that strains an established and well functioning family network (Kane & West, 2005). The stories of family oriented participants illustrate how close family ties are forged, tested and strengthened over time by confronting major challenges such as significant relocations, financial difficulties, death and illness. Robust kin networks represent a class of social ties that enable residents to distance themselves from the life of the institution (Powers, 1988). For participants with strong family bonds, the nursing home often served as a place for “existing” between times for “living” when family members are present. Family membership was the major way these residents defined themselves in the world. Findings indicate that participants with strong family bonds looked to family not only for observable support but also to reaffirm this core identity and to secure relational bonds. Correspondingly, stories from residents with strong family networks centered on family matters and relied on significant family events to frame personal history.

Though family connections may help certain residents to do well in spite of rather than because of the nursing home environment, extremely close bonds may also entail risk. In the current study, the two residents who most relied on family stated that they perceived themselves different from other residents and rarely took part in facility activities. When the supportive sister of one resident died, the resident’s dissatisfaction with the nursing home and expressions of the need to leave increased. Existing research suggests that residents who rely heavily on family networks are less likely to integrate into the life of the facility (Powers, 1988). Powers (1988) indicates that lack of integration results in increased vulnerability to the adverse effects of loss and change and higher risk of loneliness. In turn, decreased social engagement may be related to increased risk of mortally (Kiely & Flacker, 2003). In the world of practice, staff sensitivity to resident’s actual and desired patterns of autonomy and attachment, especially within close-knit families, is essential to identifying relational losses significant enough to trigger loneliness, anxiety, withdrawal, or depression. Thus, adequate appreciation of the real or potential impact of relational loss is rooted in an understanding of the significance of social relationships and the meaning of “family” developed among the resident and kin across the life course.

A Heuristic for Understanding Doing Well

Recognizing the complex, multidimensional nature of a phenomenon such as doing well, a heuristic for doing well is presented here to provide a framework for researchers and practitioners to understand, appreciate and communicate the immense variability that the notion of doing well encompasses. In contrast to constructing a population based yardstick to measure how ill or well a resident is doing, this schema offers a means for exploring doing well that centers on an autobiographically active individual situated in a specific setting.

Doing well is a result of successful experiences of reframing, negotiation, and restructuring that take place at the interface between personal history and the current environment. The following heuristic for articulating “doing well” as a disposition shaped by the interaction of context and biography combines Kayser-Jones’ (1992, 1994, 2003b) conceptual model illustrating the environment of the nursing home with dimensions of “life course capital” (LCC) suggested by O'Rand (2001, 2006) (see Figure 10). The nursing home model describes contextual elements and situates the resident in the space of the facility, while the concept of LCC supports a discussion of accumulated and emergent preferences, attributes and individual resources and situates the resident in time as an agent with a formative personal history.

Environmental Characteristics of the Nursing Home

Briefly, Kayser-Jones (1994) delineates four interrelated features of the nursing home that influence and are influenced by the resident: (a) the physical environment—things such as space, lighting, color, furnishings, equipment; (b) the organizational environment—including staffing, leadership, policy, financing and philosophy of care; (c) the personal-supra personal environment—family, friends, staff, and fellow residents and the modal characteristics of everyone in the nursing home milieu; and (d) the cultural-social-psychological environment—norms, values, attitudes and beliefs of staff, residents and others, and activities and interactions that take place in the nursing home. These domains represent immediate characteristics of the environment that the resident must contend with from the time of admission. In addition, the nursing home exists as an organizational entity in the context of the larger society and is influenced by macro factors such as ageism, health policy, health care economics and an increasingly litigious

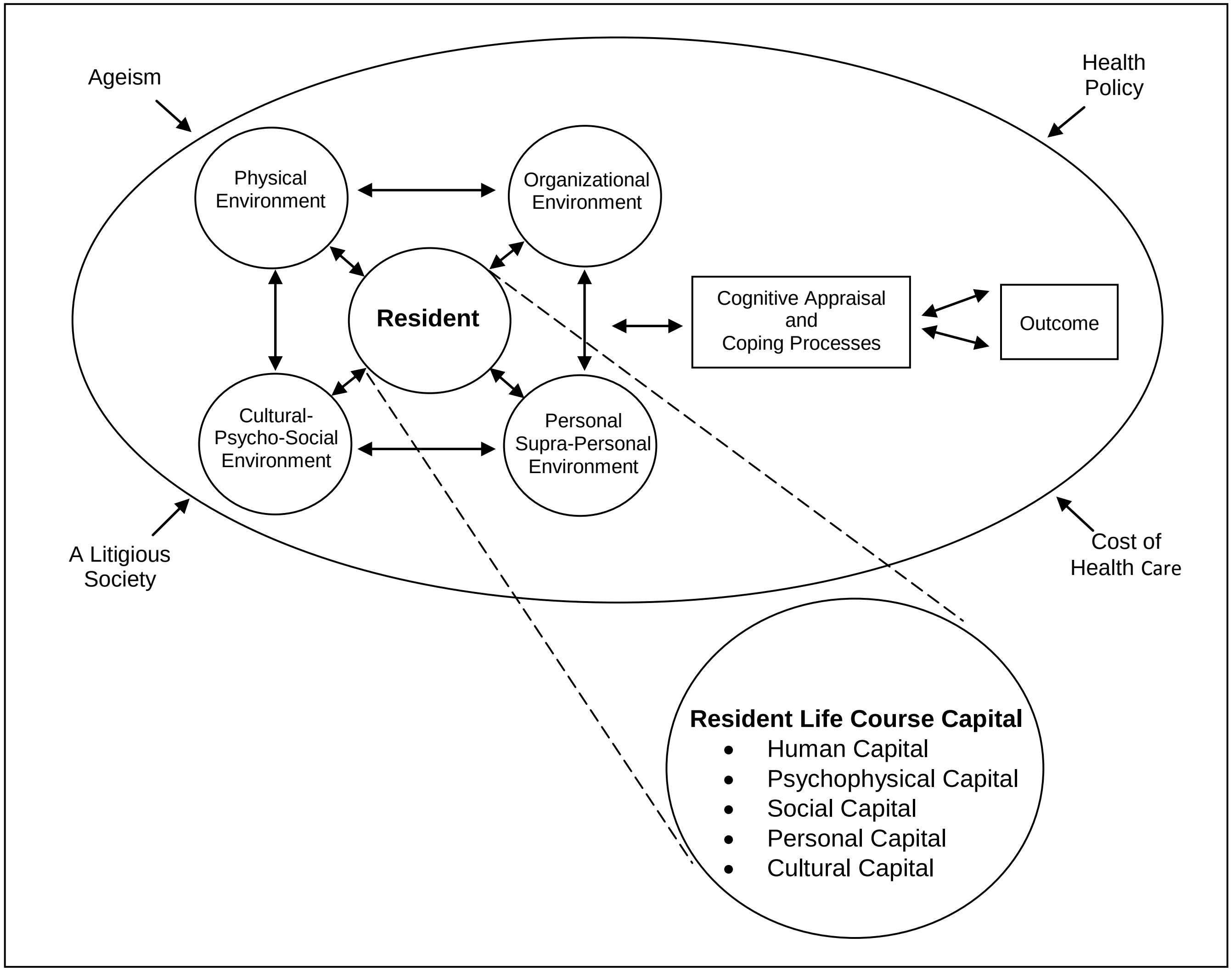

Figure 10. Fusion of Kayser-Jones' (1992, 1994, May 6, 2003) model illustrating the environment of the nursing home with life course capital (LCC) dimensions described by O'Rand (2001, 2006).

society. In attending to the intricacy of the relationships among internal components and external influences, this model of the nursing home depicts the complex web of environmental factors that may affect how well a resident does.

Life Course Capital

Understanding the notion of doing well is further complicated by variability in residents' biographies and perceptions that provide the basis for their ongoing appraisals and actions within their life worlds. Frequently enlisted as an economics based model to support research on cumulative advantage-disadvantage, the LCC perspective offers a starting point for framing a discussion of the place of biography in shaping a resident's ability to do well. O'Rand (2006) defines LCC broadly as "interdependent stocks of resources across life domains that are accumulated and/or dissipated over the life course in the satisfaction of human needs and wants" (p. 146). The major interdependent forms of capital include (a) human capital—education and work skills and experience, (b) psychophysical capital—physical and psychological health, (c) social capital—supportive social relationships, (d) personal capital—including efficacy, confidence, control, resiliency, and (e) cultural capital—the capacity to navigate prevailing socially valued practices and codes, including language.

To date, LCC perspectives have been used chiefly to support quantitative studies exploring normative and variant patterns of development and their effects on economic and social advantage and disadvantage across populations (O'Rand, 2001, 2006). Loosening LCC concepts from these highly economic and primarily nomothetic moorings provides opportunities for thinking about the individual's ability to manage current situations in light of preferences, attributes and non-material resources accrued and maintained over a lifetime.

Expected Outcomes of Life Course Capital

Outcomes of classical capital based models are frequently tied to measureable economic gain (Bourdieu, 1977; Portes, 1988; Schultz, 1961; Sweetland, 1996). Applying the concepts of LCC to resident life in a nursing home requires a broader, health oriented definition of the anticipated gains tied to taking advantage of various forms of capital (Ferlander, 2007). In the nursing home leveraging non-monetary resources to maintain and improve health and quality of life predominates over the leveraging LCC for financial advantage and related benefits that prevails among younger community based cohorts. Though prior to admission residents may have been more or less successful in enlisting LCC for economic gain, once in the nursing home it is rare for residents to call on non-monetary capital to accrue additional income. Nevertheless, while residents may exhibit less concern over economic gain once in the nursing home, the potential influence of previously accumulated monetary capital on quality of life, cannot be ignored. Individuals with sufficient income have greater latitude in choosing settings for long term care that offer enhanced furnishings and programs. Within such facilities those with adequate financial resources may often purchase additional services. In this study, reliance on Medicaid funding meant that residents had comparable secure but limited economic resources, and did not receive special services above and beyond those afforded to all residents. By and large, they did not have the means to pay for services beyond what public funding provided. Thus, from day to day, residents typically relied on unique arrays of accrued and accruable non-fiscal capital to influence quality of life. In the nursing home the gain to be had is in doing well.

Constituents of Capital in the Nursing Home

Whereas transferable goods—items from family and friends, snacks and personally crafted objects—often figure into exchanges that occur in nursing homes (Jeanie Kayser-Jones, 1981), and accumulated wealth may enable access to an array of enhanced services in private pay facilities, this study foregrounds non-material forms of capital that, though often not involved in direct exchange, influence a resident's sense of doing well. Findings suggest that residents arrive with constellations of LCC developed over unique life histories. Forms of capital that were critical in navigating the challenges of living in the community and earning a living admit of varying degrees of usefulness in a nursing home. Study findings suggest that residents who were able to leverage LLC that is valued in the nursing home environment, in the service of continuing meaningful patterns of activity, did well.

As managers of the environment, nursing home administration and staff affect factors in each of the four environmental domains that influence a resident's exercise of capital. At the overarching facility level, formal and informal standards that shape the physical environment, the services and supports that are offered, the social and cultural environment, and expectations for provider performance determine the types of capital that the facility and its staff value. For example, the ability to exercise capital will be fostered or limited by the adequacy of the physical environment to support functional independence. Turning to the social-cultural environment, how well a nursing home addresses issues of cultural and linguistic diversity will affect how easily residents with differing cultural backgrounds will be able to call on LCC. While this study does not provide a detailed analysis of each of the four environmental domains, it is important to appreciate that the effectiveness of residents' LCC is contingent on the readiness of the nursing home environment and individual staff members to recognize and support the exercise of such capital.

In order to provide an additional lens for understanding and organizing findings and support reflection on implications for practice and research, the following discussion draws on the LCC perspective to elucidate the resources residents depended on to do well in a nursing home. The five categories of capital described reflect those that frequently appear in gerontological and social science literature (O'Rand, 2006) and, though helpful in framing discussion, are not conceived of here as absolute, discrete or quantifiable.

Human Capital

Defined chiefly in terms of its relation to economic capital, human capital is the distinctive set of education, skills and abilities that sustain one's labor, trade or career as the means for financial gain (Schultz, 1961; Sweetland, 1996). Late in life, engaging in activities that were used formerly for wage earning may be largely abandoned or take on new purpose and meaning (Kaufman, 1986). Findings suggest that residents whose work was self-fulfilling as well as income generating may continue personally rewarding aspects of their careers in the nursing home. For example, the resident who had worked previously as a journalist and editor found his work editing the facility newsletter rewarding. He continued to use his career skills to provide a useful service in the facility. Then again, skills and sensibilities that were once used to generate earnings may be called on to maintain one's immediate environment and belongings. For example, the resident who had owned a tailoring and cleaning business regularly scheduled time to wash and mend her clothing providing a sense of control and autonomy. Thus for some residents, education and skill acquired to earn a living, result in secondary gain as continued self-fulfilling activities late in life. Such translation is contingent on the facility's willingness and ability to ascertain workplace activities that were particularly meaningful to the resident and provide opportunities for them to apply education and work skills, often in reinvented or reinterpreted forms.

Psychophysical Capital

The term psychophysical capital describes an individual's "stock of health" and embraces the notion of homeostatic resiliency (O'Rand, 2006). O'Rand looks to theories of biological aging to identify psychophysical capital as the outcome of both genetic predisposition and the effects of wear and tear, illness and recovery over the life course. Early discourse related to older adult FTT is framed largely in terms of declining psychophysical capital: a precipitating event overwhelms steadily decreasing age related psychophysical reserves resulting in a precipitous decline in health and well-being (Verdery, 1997). While helpful in addressing issues of disease and decline, a major shortcoming of medically framed FTT models is their intense reliance on the psychophysical perspective, undervaluing the significance of other domains and subjective factors that influence the life course.

The precipitants and paths to ill health vary among residents, but all have reached a point where living unassisted in the community is no longer an option. Linking the LCC construct to the *Model of Selective Optimization with Compensation* (Baltes & Baltes, 1990) provides an additional way of framing this care dilemma: compensatory constellations of various forms of capital that had been effective in the community have proven inadequate to support managing challenges posed by decreased health and function.

In the nursing home, decrement in a resident's stock of health can even affect his ability to enlist other forms of capital. This is most evident in the lives of residents with dementia, when impaired cognitive function affects their ability to access sources of social capital, such as family or trusted staff, or to exercise personal capital in the form of self-advocacy. Losses in vision and hearing also affect a resident's ability to communicate and engage other forms of capital. Similarly, impaired mobility can result in restricted access to those places or spaces where a resident might be able to effectively advocate for themselves.

Thus, though psychophysical well-being is not the sole determinant of doing well, it greatly influences the ease with which a resident can call on other forms of capital to promote doing well. A lucid resident with good vision and hearing and the ability to navigate the facility in a wheelchair is able to access areas such as the vending machines and administrative offices enabling her to obtain snacks at will and influence staff to have her needs met. Her ability to enlist social and personal capital are enhanced by psychophysical capital in the form of mobility, and intact cognition and senses. In contrast, a resident with extremely poor eyesight, failing memory and difficulty maneuvering her wheelchair, experiences increased dependence on staff and other residents. In addition, these same disabilities interfere with accessing those she relies on for help, resulting in a "double jeopardy" where not only is assistance needed, but also assistance in acquiring assistance. Thus, declining psychophysical capital results in decreased ability to enlist social and personal capital.

Though not explored in depth in this study, a LCC perspective may be helpful in guiding further research on the connections between psychophysical decline, social isolation, and individual, dyadic and organizationally mediated compensatory strategies. Given the increasingly complex care needs of residents and the potentially adverse effects of limited psychophysical capital on other types of LCC, nursing home settings that limit the nurse's role to disease related assessments and tasks, and regulatory compliance deserve serious scrutiny. In addition examining the nurse's role in cure and prevention, there is a need to explore how nursing activities focused on health promotion and environmental improvement influence resident psychophysical status, and in turn affect other forms of LCC that inform doing well.

Social Capital

In the work world, social capital is primarily conceived of as social networks and associated social interactions, norms and values that promote professional and personal advancement and social mobility (Newton, 1997; Woolcock & Narayan, 2007). Viewed in the marketplace as convertible resources that accrue to individuals, social capital can be leveraged for financial gain (Baum & Ziersch, 2003). Again, in the nursing home the focus on anticipated financial gain fades, with the value of social capital pegged not to its effect on income, but rather to its ability to promote a sense of doing well.

The social networks of importance to residents include external networks of family and friends (Bitzan & Kruzich, 1990; Friedemann, Montgomery, Rice, & Farrell, 1999; Kellett, 1999; Powers, 1988; Pruchno, Peters, Kleban, & Burant, 1994) and internal networks of staff and fellow residents (Bergland & Kirkevold, 2006, 2007; Powers, 1988). Residents whose doing well is sustained by close family ties look to family members as advocates and facilitators of getting needs and preferences met. Paralleling family support, visiting friends frequently acted as surrogate kin taking on the task of providing favored personal items and gifts, and periodically serving as intermediaries between the resident and staff. In addition both family and friends served as important sources of emotional support. For two resident in the study reported here, contact with representatives and friends from churches they previously attended provided a means for staying connected with biographically important communities of support.

Within the nursing home the ties residents forge with staff may result in receiving more attention and in an enhanced sense of security when trusted staff is present. Responses from residents who had consistent CNA caregivers indicated they felt more secure and that the day went better when usual staff was present. Participants also readily identified fellow residents whom they counted as friends or who were important to them.

A resident's web of relationships and social capital they represent can be quite complex. For example, the friendship between Doris and Martha in conjunction with Doris' role as resident council president meant that Martha's concerns were inevitably addressed at resident council meetings. In this case, social capital operated on two levels: Doris' position as council president facilitated access to top staff to advance issues she deemed important, while Martha's friendship with Doris provided her with a means for ensuring that her concerns were heard. Interestingly, these two network relationships were developed after admission to the nursing home, illustrating that social capital, may accrue as well as decline in the context of the facility.

Personal Capital

While social capital focuses chiefly on gains mediated through established associations with others, personal capital focuses on the function of human agency. Personal capital is evident in the capacity to effectively interact with the environment via acquired agentic skills such as self efficacy, social competence, and the successful management of life stressors (O'Rand, 2006). Of the various factors that contribute to personal capital, Bandura's (1997) concept of self-efficacy has emerged as most prominent. While detailed analysis of self efficacy is beyond the scope of this study, several aspects are particularly relevant to the discussion of LCC. Bandura offers the following definition:

> People guide their lives by their beliefs of personal efficacy. *Perceived self-efficacy refers to beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments*… Influence may entail regulating one's own motivation, thought processes, affective states, and actions, or it may involve changing environmental conditions, depending on what one seeks to manage (p. 3)

In keeping with a LCC perspective, the beliefs that shape self efficacy and influence subsequent action are developed over a lifetime and emerge in residents' stories. Likewise, the matters that a resident "seeks to manage" are rooted in what has been of value across the life course. For example, the importance that one resident attached to self reliance and associated skills of assertiveness was rooted in her upbringing and represented personal capital that enabled her to advocate for changes (e.g., relocation of a noisy roommate) to improve situations in support of her sense of "doing well." In this case personal capital in the form of self efficacy was the result of attitudes and beliefs about her ability to effect outcomes that was developed early in life, refined over a lifetime and enlisted to promote her quality of life in the nursing home.

While residents who are highly assertive provide easily recognizable examples of self-efficacy as personal capital, other residents may call on established coping strategies to maintain a sense of emotional comfort, such as personal spirituality, stress reduction/ relaxation techniques or even avoidance and retreat strategies. In an American culture that values self assertion, passive strategies that some residents rely on to maintain equanimity may be viewed by staff as less desirable or effective than speaking out. From the resident standpoint knowing when to withdraw from a difficult situation may represent a version of personal capital developed to contend successfully with prior life challenges. While not typically valued in the marketplace as an effective strategy for career advancement, retreat was key to survival in the rough neighborhoods where one participant spent most of his adult life. In the nursing home, recognizing and withdrawing from conflict represented a personal strategy (personal capital) this resident used to avoid emotional discomfort and maintain a sense of doing well. Without access to the autobiographically embedded meaning of retreat and avoidance, staff risks characterizing his response as “institutionalized,” rather than recognizing it as brand of enduring personal capital that has proven successful in managing threatening situations.

Cultural Capital

At the risk of oversimplifying Bourdieu’s seminal treatment of the notion of cultural capital (Bourdieu, 1977; Calhoun, 1993; Robbins, 2005), suffice it to say that cultural capital, which is often tied to the use of language and symbol, represents both explicit and tacit knowledge of the accepted ways things are understood and communicated in a specific culture. A person’s way of moving through the world is initially and most firmly communicated through the life world one is born into and represents “natural culture” as distinguished from “acquired culture” which refers to ways of being and doing appropriated to adjust to, navigate and succeed in cultures or aspects of culture beyond one’s natural culture (Robbins, 2005). Consideration of cultural capital is germane to this discussion of doing well on two accounts: (a) nursing homes exist as cultural entities requiring significant adaptation for those live and work there; and (b) staff and residents often come from significantly different indigenous cultures.

The concept of cultural capital provides a framework to explore the interaction between the cultural background a resident brings to the nursing home and expectations communicated by the organizational culture of the institution. Residents’ lives vary greatly in terms of the cultural influences that have shaped expectations and patterns of interaction. Participants disclosed they had met with varying degrees of success in navigating the demands of moving from one culture to another or between various cultural registers within a dominant culture. In many ways entry into a nursing home represents a clash of cultures, with the resident required to assume a new level of cultural proficiency to survive. Residents are confronted with learning a new vocabulary and becoming familiar with new customs and rules of behavior. A readily decipherable culture with familiar parameters of privacy and control, where autonomy involved choosing with whom one would live and associate, gives way to a nursing home world of common sleeping and living areas and shared bathrooms. Residents who move from situations of personal choice in association and living to congregate living settings inevitably face constituting and being constituted by a radically different life world. Even in the most enlightened residential long-term care environments, residents have little choice in whom they will rub elbows with on a day to day basis. Part of being able to do well in a nursing facility care hinges on the ability to both consciously and tacitly decode, accept and adapt to the unique cultural demands of the new setting no matter where it falls on the institution versus home continuum.

The chosen study sites represented facilities with ethnically diverse resident populations and staff, providing an additional example of the dynamics of cultural capital. In both facilities the majority of direct care staff were Filipino. For the two Filipino study participants, cultural capital rooted in a common language, shared social expectations, and ethnic and religious heritage meant that staff were sensitive to culturally mediated non-verbal as well as verbal communications. Caregivers were also able to appreciate and share stories of places, events, customs and even foods well known in the local Filipino culture. Thus, residents whose natural culture mirrors the natural culture of staff may reap benefits in the form of enhanced communication. In the case of cultures that value community identification based on ethnic heritage, a resident's ethnicity may be sufficient to ensure that cultural capital translates into special attention and advocacy and an enhanced social network.

Limitations and Strengths

To facilitate focusing on the depth of the contextualized experience, this study was conducted in two study sites with a small sample (N = 17), thus the findings cannot be generalized. In addition, the sample did not include residents with severe ADL or cognitive impairment. Whereas recruiting residents identified as "doing well" provided insight into positive and, to a lesser degree, negative perceptions of subjective well-being, the present study cannot claim that it captured the full range and density of the phenomenon. Concentrating on residents' perceptions and experiences of their environments viewed through an autobiographical lens also means that it is not possible to draw conclusions related to the congruence between residents' perspectives on their doing well and family, administration or staff perceptions of the residents' doing well, or between the resident experience and empirical quality of life variables advanced in quantitative research.

The strength of the study lies in identification of the complexity and variability that characterizes the experience of doing well, as well as surfacing themes and dimensions that suggest common threads uniting aspects of the experience. In doing so, this research provides scientists interested in well-being and QOL among nursing home residents with a broadened horizon to consider in developing future research.

The proposed schema offers a way of thinking about the significance of two closely related but highly personal features of quality of life, subjectivity and temporality (Lawton, 1991). Given the person to person variability inherent in both of these aspects, it is not surprising that these two features have eluded standardization and quantification. Regardless of the risks associated with relying on reinterpreted language from empirically framed constructions, the doing well heuristic offers a rudimentary framework for accessing and understanding doing well from the standpoint of the resident. Rather than marginalizing personal perception and preference as "idiosyncratic," the present construction considers the individual existentially, as an agent embedded in biography and environment and engaged in a continuous process of negotiating past (history and LCC) and present (context) with a goal of doing well. Thus, the heuristic inspired by this research is offered not as a natural science structured explanatory and predictive model but more as a human science framed exploratory, interpretive and action oriented tool.

Implications

Practice

The likelihood of nursing home residents “doing well” may increase considerably if care providers consciously attend to patterns of value and meaning that residents have evolved over their life spans. Such a commitment entails developing an organizational culture and care environment that support staff attention to residents as “autobiographically active” individuals (Gubrium, 1993), and not fixed objects of routine care. While nursing staff often focus on current disease, function, and bed and body work, supporting a resident’s ability to do well requires sensitivity to values and beliefs imbedded in personal history. Even as study findings reinforce the need to address physical and emotional discomfort as immediate barriers to well-being, they also indicate the importance of supporting the continuation of meaningful patterns of activity to promote an abiding sense of doing well.

In light of present findings, approaches for assessing individuals entering nursing homes as long stay residents need reevaluation. Though the mandated and regularly performed Minimum Data Set assessment provides a wealth of information regarding the clinical status of a resident, it contains very few items relevant to a comprehensive evaluation of preferences and subjective quality of life. The present study employed an initial open interview for collecting data on the meaning and experience of doing well.

Interviews rarely lasted more than one hour, yet in this relatively short time a wealth of data about the resident’s life, values, preferences and ways of being in the world was obtained. In clinical practice, short interviews focusing on life narrative and the meaning of doing well may provide useful information for developing approaches and plans of care that recognize a resident’s strengths and support long-held patterns of meaning and being in the world. Introducing such an assessment strategy will require that caregivers become adept at eliciting and interpreting residents’ stories and reflections.

Achieving and sustaining a commitment to person- and relationship-centered care requires caregivers skilled in establishing relationships that provide “comfortable spaces” for residents to share stories, values, attitudes and beliefs. Earlier personal experience as a CNA, and participant observation during this study suggest that a trusting relationship between direct caregiver and resident frequently provides the disclosive space for the resident to recount events of the past and reflect on preferences, values and beliefs. Translating stories and reflections that residents share with CNAs into opportunities, activities, and interventions to support doing well requires that these caregivers have opportunities to convey this information to interdisciplinary team (IDT) members. Thus, it is crucial that CNAs be included as active, contributing members of IDTs.

At present, formal systems of communication in the nursing home do not provide a ready means for chronicling and exchanging the rich personal information and subjective reflections that residents relate. Medical records focus largely on communicating diagnostic, functional and therapeutic data necessary for quality care; they rarely document the resident’s perspectives on values, beliefs, sources of meaning, personal history and QOL. Thus, efforts to support staff in engaging residents as autobiographically active, must be accompanied by the development of effective systems for recording and communicating residents' storied lives, personal challenges, strengths and sources of meaning.

Finally, findings related to subthemes and dimensions prompt several discrete recommendations. First, since behaviors which may at first appear maladaptive or institutionalized (e.g., retreat) may actually represent long held ways of successfully dealing with challenge and doing well, it is important to access the resident's life story and standpoint to clarify the meaning of behaviors and subsequently support appropriate care planning. Second, care teams must attend to the resident's past and current relationships to family and friends, and appreciate that changes in family structure may prove particularly devastating to the resident whose doing well is contingent on family support. Third, adequately supporting the resident in reframing, reinterpreting and restructuring the nursing home environment facilitates transition and "settling in". Individualizing interventions to promote a sense of feeling at home requires that caregivers actively seek to understand the long held patterns of being and doing in the world that are imbedded in the resident's stories of the past and reflections on the present. Fourth, patterns of advocacy (having a voice and being heard) vary greatly depending on a resident's resources including the presence of family, sense of personal efficacy, ability to communicate, and relationships with staff and fellow residents. Facility administrators and mangers need to devise systems to ensure that all residents have a voice and are heard. The previously described advocacy model at Lincoln Way, which relies on regular meetings between the resident and an assigned staff advocate, appears to hold great promise. Lastly, if residents are to achieve the sense of doing well, then the deleterious effects of physical and emotional discomfort must not be ignored or minimized. Study findings reinforce the need for vigilance in identifying, assessing and addressing distressing symptoms, emotional discomfort and vexing situations that override a resident's sense of doing well.

Education

Consequently, it is important that nurses who practice in nursing homes arrive with rudimentary skills in accessing and interpreting resident stories and reflections. Such skills need to be actively supported and enhanced through continuing education. Accordingly, a tool such as the doing well heuristic proposed in this paper may be used to illustrate the significance of the intersection of personal history and environment for doing well. Life course capital dimensions provide a practical schema for thinking about the strengths that residents draw on to adapt. Thus, the proposed heuristic may serve as a reflective resource for recognizing and thinking about the often hidden and untapped individual strengths that residents bring to and continue to develop in the nursing home.

Recent education in nursing schools, at professional conferences and in practice settings has focused heavily on evidenced based practice (EBP). Nursing approaches to EBP have largely paralleled medical models (Bliss-Holtz, 2007). Typically such models are rooted in a statistical analysis approach that relies heavily on consistent empirical data and privileges decisions based on probability based norms. As mentioned earlier in this paper, this approach is extremely valuable, especially in cases where minimal variability is expected. Nevertheless, recognizing and addressing variability is essential to individualizing care, especially those elements of care that attend to subjective experience and perception. The method, analysis and findings of this study recognize the importance of variability and illustrate ways that a provider and a resident may come to a shared understanding of what it means for the resident to do well. Such complex and nuanced understanding eludes quantification and represents evidence that can only be captured through story and reflection. In addition to EBP norms, nursing education must attend to the clinical importance of variability inherent in person-focused "practice based evidence"—evidence essential to individualizing care and supporting quality of life.

Policy

Presently, a single set of national nursing home regulations (Kumar, Norton, & Encinosa, 2006) augmented by state regulations addresses at least four identifiable resident populations with distinctive goals and needs: (a) individuals in programs of active rehabilitation or convalescence expecting discharge to the community; (b) permanent residents with progressive dementing illness requiring close supervision and increasing functional support; (c) individuals with complex end-of-life needs receiving palliative or hospice care; (d) permanent residents with complex functional impairments that, often in combination with economic and social barriers, preclude their living in the community. It is not uncommon that nursing homes serve residents from each of these populations in the same facility and frequently on the same unit.

To justify such grouping, nursing home owners point to the need for business plans that augment income from poorly funded Medicaid residents with monies from more generously reimbursed short stay Medicare residents. In addition, many nursing homes are older facilities, like Del Rio and Lincoln Way, and configured similar to acute hospital units, with long hallways, central units and shared resident rooms. Though such settings may be acceptable to short-stay residents looking to reenter the community, they constitute physical and organizational environments that challenge privacy, autonomy and the ability of long stay residents to define and create the type of personal space that provides a level of comfort and security associated with being at home and doing well

Tackling this problem requires clear regulatory recognition of the differing populations served in nursing homes. In addition, development of appropriate policy guidelines and mechanisms to establish settings that support each population and their overarching goals is called for. For the long stay residents represented in this study, ideal policy would support the establishment and adequate funding of nursing home environments *designed as permanent residences*, settings that balance safety, autonomy, quality of care and quality of life.

Research

If the value of a study is to be judged by the number and quality of questions generated as well as answers provided, then there should be little doubt about the significance of this research. Based on this study, further research is needed to explore similarities and difference between resident perceptions and direct caregiver perceptions of how well they are doing, and how these perceptions affect interaction and care delivery. In addition, findings related to the importance of family suggests the need for a closer examination of how changes in family relationships affect a resident's perception of how well they are doing and their psychophysical health and survivorship. The relationship between various states of discomfort and a resident's sense of doing well also deserves additional study.

Qualitative research that explores the experience of being cared for in facilities that combine long and short stay residents, or that serve lucid residents and those with cognitive impairment in the same setting is needed to inform policies on caring for individuals with disparate care needs on the same unit. A targeted ethnography that explores how the various types of life course capital operate in the nursing home is also warranted, as is a qualitative study of long term survivors (>5 yrs) in nursing homes and how they characterize the setting in which they live. The overarching goal and purpose of all such research is to be able to promote a level of health, function and interaction that enables residents to report that *ceteris paribus* they perceive themselves as doing well.

Summary and Conclusion

In focusing on the resident standpoint, this research illustrates how appreciating the intersection of personal history and present environment is essential to understanding an individual's sense of doing well. Frequently encoded in a resident's stories and reflections, the details of this linkage may not be readily apparent in the course of routine care provider-resident interactions. Attending to the resident as autobiographically active provides insight into the complexity and variability of life events and derived meanings that inform perceptions and cue responses in the often challenging environment of the nursing home. Sub-themes related to prior congregate living experience, tight family bonds, and settling in represent three significant aspects of continuing the past into the present that support doing well. In addition, interaction with residents suggests that having a voice and being heard, satisfactory management of discomfort, and opportunities to break from routine are central to achieving and maintaining subjective well-being. Lastly, reflections on findings in the context of the life course capital discourse has led to the development of a heuristic to promote a fuller understating of the connections between personal history and the ability to do well in the nursing home.

This research highlights the need to develop provider-resident relationships that foster ongoing identification of a resident's autobiographically rooted attitudes, values and beliefs. Promoting a sense of doing well requires that formal caregivers become familiar with a resident's strengths and beliefs about a quality life (Bryant, Corbett & Kutner, 2001) as well as problems. The proposed heuristic represents a potential tool for sensitizing caregivers to broad domains of life course resources, while bypassing prescriptive detail that risks unwarranted categorization. Such an approach foregrounds resident autonomy framed as "freedom *to*" in addition to "freedom *from*" and reinforces transition from models of rote task centered care to person and relationship centered care that provides opportunities for individual expression in addition to interventions designed to increase function and compensate for decline.

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APPENDIX A: STUDY INFORMATION SHEETS

Perceptions and Dimensions of "Doing Well" in Elderly Nursing Home Residents

(Ronald Walent, Phone: 648-9080)

Study Information Sheet for Nursing Home Residents

Here at (*Name of Facility*) there is a study going on that involves interviewing residents about how well they are doing. This study is being conducted by Mr. Ron Walent, a doctoral student at UCSF, under the supervision of Dr. Jeanie Kayser-Jones. Mr. Walent is a nursing specialist in the care of older adults. By interviewing individuals here at (*Name of Facility*), Mr. Walent hopes to find out things that help them to do well. He hopes that this knowledge will help more nursing home residents do well. I'm telling you this because you seem to be someone who would be really good at telling Mr. Walent about your life here.

Here's what would happen if you decide to participate in the study.

1. You will meet privately with Mr. Walent between two and four times to discuss your experience of living in a nursing home, and how well you see yourself doing. Mr. Walent will audio-record these interviews to capture what you say accurately. Recordings will be erased at the end of the study.

2. Off and on, over a period of three months, Mr. Walent will spend time with you to get a sense of what your life is like in the nursing home.

3. Mr. Walent will also speak with staff to get information on how you are doing.

4. All information that Mr. Walent collects and is used by the research team is strictly confidential and will not affect your care here.

If you think you might be willing to be in the study you can

- Let me give Mr. Walent your name and telephone number. He'll call you to set up a time to talk.
- Or you can let me tell him to call the staff here to help arrange a good time for a first visit.

Whether you participate or not, it won't affect your care here at the *(Name of Facility)* in any way. It's completely up to you.

What do you think?

☐ Mr. Walent may call me regarding the study
My name ___________________________________

__Numbers to call me at:

____
or ________________________

__You may have him call the nursing home staff to arrange a time to visit.

☐ No thanks.

Perceptions and Dimensions of "Doing Well" in Elderly Nursing Home Residents
(Ronald Walent, Phone: 648-9080)
Study Information Sheet for Residents' Decision Makers

Here at (*Name of Facility*) there is a study going on that involves interviewing residents about how well they are doing. This study is being conducted by Mr. Ron Walent, a doctoral student at UCSF, under the supervision of Dr. Jeanie Kayser-Jones. Mr. Walent is a nursing specialist in the care of older adults. By interviewing individuals here at (*Name of Facility*), Mr. Walent hopes to find out things that help them to do well. He hopes that this knowledge will help more nursing home residents do well. I'm telling you this because the resident you make decisions for seems to be someone who would be able to tell Mr. Walent about his/her life here.

Here's what would happen if you consent to have the resident take part in the study.

1. The resident will meet privately with Mr. Walent between two and four times to discuss the experience of living in a nursing home, and how well he or she is doing.

2. Off and on, over a period of three months, Mr. Walent will spend time with the resident to get a sense of what life is like in the nursing home.

3. Mr. Walent will also speak with staff and look at the resident's medical record to get information on how he or she is doing.

4. All information that Mr. Walent collects and is used by the research team is strictly confidential and will not affect the resident's care in the nursing home.

If you think you might be willing to have the resident take part in this study you can

- Let me give Mr. Walent your name and telephone number to contact you with more information.

- You can let me tell him when it might be good to meet you here at the nursing home.

Whether the resident participates or not, it won't affect his or her care here at the nursing home in any way.

What do you think?

☐ Mr. Walent may contact me regarding the study
My name ______________________________

Resident's name ____________________________

__Numbers to call me at:

____

or ____________________

☐ No thanks.

APPENDIX B

Evaluation of Ability to Engage in Interview

At present, there is no easily administered standardized tool to evaluate the ability of individuals with mild to moderate cognitive impairment to engage in research interview. Consequently, the following protocol is based on suggestions in literature related to the use of cognitive evaluations in quality of life studies in nursing homes (Kane et al., 2003; Mozley et al., 1999; Simmons & Schnelle, 2001)

Questions are derived from easily administered cognitive screening tools and the principles that guide them (Brod, Stewart, Sands, & Walton, 1999; Folstein, Folstein, & McHugh, 1975; Hartmaier, Sloane, Guess, & Koch, 1994; Hartmaier et al., 1995; Huff, Farace, Brady, Kheir, & Shawver, 2001; Kahn, Goldfarb, Pollack, & Peck, 1960; Simmons & Schnelle, 2001; Whitlatch, Feinberg, & Tucke, 2005). In order to minimize potential participant anxiety related to the perception of being evaluated, only questions that the researcher can incorporate conversationally in the context of introducing the study are used. Only questions that translate easily into conversational expressions have been selected. The researcher, who is a clinical specialist in gerontological nursing familiar with the limitations of cognitive screening tools in institutional settings, will rely on clinical judgment to adjust questions to the specifics of the encounter. The researcher will evaluate the appropriateness of responses to determine whether the individual will be able to engage in interviews. This evaluation will not be used as study data.

QUESTIONS TO DETERMINE ABILITY TO ENGAGE IN INTERVIEW

Today’s date: ________________

Potential Participant Pseudonym/Code number: _________________

	Reasonable Response	**Inappropriate Response**
1. What is this place? State? Country?		
2. Why are you here?		
3. Who takes care of you here?		
4. What was your last meal?		
5. About what time of day is it? What month? What season?		
6. In you own words, what do you think this study is about?		
Comments:		

Based on CoPI clinical judgment, the resident seems able to engage in interviews associated with this study: YES NO

THIS INFORMATION WILL NOT BE INCLUDED IN STUDY DATA

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APPENDIX C

Record of Assessment of Capacity to Consent for Research

Study Title: *Perceptions and Dimensions of "Doing Well" in*
Elderly Nursing Home Residents

Name of Potential Subject: ____

Facility: ______________________________________ Date: ________________

Other individuals present: ____

Researcher present: Ronald Walent, RN, MS, CNS (CoPI)

A. Presentation of research protocol and discussion (checkmark indicates item completed):

____Researcher presented and explained the research protocol to the potential subject.

____Researcher provided time for potential subject to ask questions, seek clarification and discuss the research protocol.

____During the discussion of the protocol, the researcher included questions to the potential subject regarding his/her understanding of the study, including its purpose, the time commitment involved, possible risk (e.g., potential discomforts) and benefits (e.g., social interaction), and the right to refuse to take part in the study or withdraw at anytime.

B. During the presentation and discussion of the study protocol:

Did the potential subject **make a choice** to participate or to not participate in the study?
YES NO

What was the choice: ___Participate ___Not participate ___Defer decision

Briefly explain:

Was the potential subject able to **demonstrate an understanding** of the study by verbalizing the essential elements of the study in his/her own words, including time commitment, and potential risks/benefits? **YES NO**

Briefly explain:

Did the potential subject **demonstrate reasoning** or state rational reasons for participating or not participating in study? **YES NO**

Briefly explain:

Did the potential subject demonstrate an **appreciation of personal risks and benefits**, by indicating how the study might affect his/her comfort, well-being, usual activities and routine? **YES NO**

Briefly explain:

Was the potential subject competent to consent to participate or not participate in the research protocol? **YES NO**

Briefly explain:

Was informed consent obtained from the potential subject? **YES NO**

Briefly explain:

If the potential subject was unable to consent, did he/she demonstrate **assent** by stating willingness to participate in the study? **YES NO**

Briefly explain:

If the potential subject was unable to consent, did he/she grant permission for the researcher to contact a surrogate decision maker? **YES NO**

If yes, name of surrogate: ____

Briefly explain:

Completed by: ____ Date: _____________
Ronald Walent

APPENDIX D

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: *PERCEPTIONS AND DIMENSIONS OF "DOING WELL" IN ELDERLY NURSING HOME RESIDENTS*

This is a research study about how well older people are doing in nursing homes. The study researchers, Jeanie Kayser-Jones, R.N., Ph.D. and doctoral student Ronald Walent, R.N., M.S., who is a nursing specialist in the care of older adults, of the School of Nursing at the University of California San Francisco, will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you are an elderly person who lives in a nursing home.

Why is this study being done?

The purpose of this study is to understand why some elderly individuals who live in nursing homes do well.

How many people will take part in this study?

Twenty-five people will take part in this study.

What will happen if I take part in this research study?

- You will meet privately with Mr. Walent one or two times to discuss your experience of living in a nursing home, and how well you see yourself doing. Interviews will be done at a time and a place that is convenient for you. Interviews are planned to last no longer than one hour. You may decide that you would like to continue beyond one hour if you feel you have more to say.

- If you agree, these conversations will be tape-recorded. After the interviews, someone will type into a computer a transcription of what's on the tape and will remove any mention of names. After Mr. Walent checks the accuracy of the transcription, the sound recordings will be destroyed.

- At the end of the first interview, Mr. Walent will ask you to provide information about:

  - your age, ethnicity, and marital status;
  - your former work;
  - how many children you have;
  - where you have lived during your life;
  - your admission to the nursing home, and how long you have been here;
  - your visitors.

- Mr. Walent will also check with the staff and with your medical record to make sure that he has the most exact information. In study records, your name will not be directly associated with any of this information.

- Off and on, over a period of three months, Mr. Walent will observe you and other residents as you go about your usual daily activities, such as getting ready for your day, receiving medications and treatments, dining, taking part in activities, and interacting with people who live and work here or who visit the nursing home. He will take notes to help him remember what your day is like. This will help researchers understand what it is like to live the nursing home.

- During these three months, Mr. Walent will also speak with staff and look at your medical record to get information on how you are doing.

- At the end of the three months, Mr. Walent will meet with you for one or two more tape-recorded interviews at a time and place of your choice. The purpose of these interviews is to discuss things about how well you are doing that may not have come up during the first interview. Each interview is planned to last no more than one hour. You may continue the interview beyond one hour if you feel you have more to say. These interviews are opportunities to clarify information that has already been collected. It is also a time to provide additional information.

- These conversations will also be tape-recorded. Again, after the interviews, someone will type into a computer a transcription of what’s on the tape and will remove any mention of names. After Mr. Walent checks the accuracy of the transcription, the sound recordings will be destroyed.

Study location: All interviews and observations will be done at the nursing home where you are now a resident.

How long will I be in the study?

Here is a brief summary of your participation in the study:

FIRST WEEK: Two recorded interviews (no more than 1 hour each).
NEXT 12 WEEKS: Periodic observation with nothing special for you to do.
LAST WEEK: Two more recorded interviews (no more than 1 hour each).

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researcher or staff person right away if you wish to stop being in the study.

Also, the study researcher may stop you from taking part in this study at any time if he or she believes it is in your best interest, if you do not follow the study rules, if you are unable to take part in interviews, or if the study is stopped.

What risks or discomforts can I expect from being in the study?

Some of the interview questions may make you worried or upset. You are free to refuse to answer any questions. You are also free to end the interview at any time. You may find the interview long or tiring. If you become tired or uncomfortable, you may end the interview. With your permission, a second meeting to complete the interview will take place at a time and place convenient for you.
If you have other questions about risks or discomforts, ask one of the researchers.

Are there benefits to taking part in the study?

There is no direct benefit to you from participating in this study. In any case, the information that you provide may help health professionals understand factors that enable individuals to do well in nursing homes.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. You will not lose any of your regular benefits, and you will still get your care in the nursing home the way you usually do.

Will information about me be kept private?

We will do our best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

Organizations that may look at and/or copy your research records for research, quality assurance, and data analysis include:

University of California San Francisco (UCSF) Committee on Human Research

Suspected Elder Abuse Reporting: If you reveal information that indicates you or another resident have been the victim of physical, verbal, emotional, sexual or financial abuse, Mr. Walent will report this to the Long-Term Care Ombudsman for further investigation. With your permission, he will also report this to the nursing facility staff.

What are the costs of taking part in this study?

You will not be charged for any of the study treatments or procedures.

Will I be paid for taking part in this study?

You will not be paid for taking part in this study.

Who can answer my questions about the study?

You can talk to the researchers about any questions or concerns you have about this study. Contact the researchers, Mr. Ronald Walent at (415) 648-9080 or Dr. Jeanie Kayser-Jones at (415) 476-4280.

If you have any questions, comments, or concerns about taking part in this study, first talk to the researcher (above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights).

You can reach the CHR office at 415-476-1814, 8 am to 5 pm, Monday through Friday. Or you may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

CONSENT

You have been given a copy of this consent form to keep.

You will be asked to sign a separate form authorizing access, use, creation, or disclosure of health information about you.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

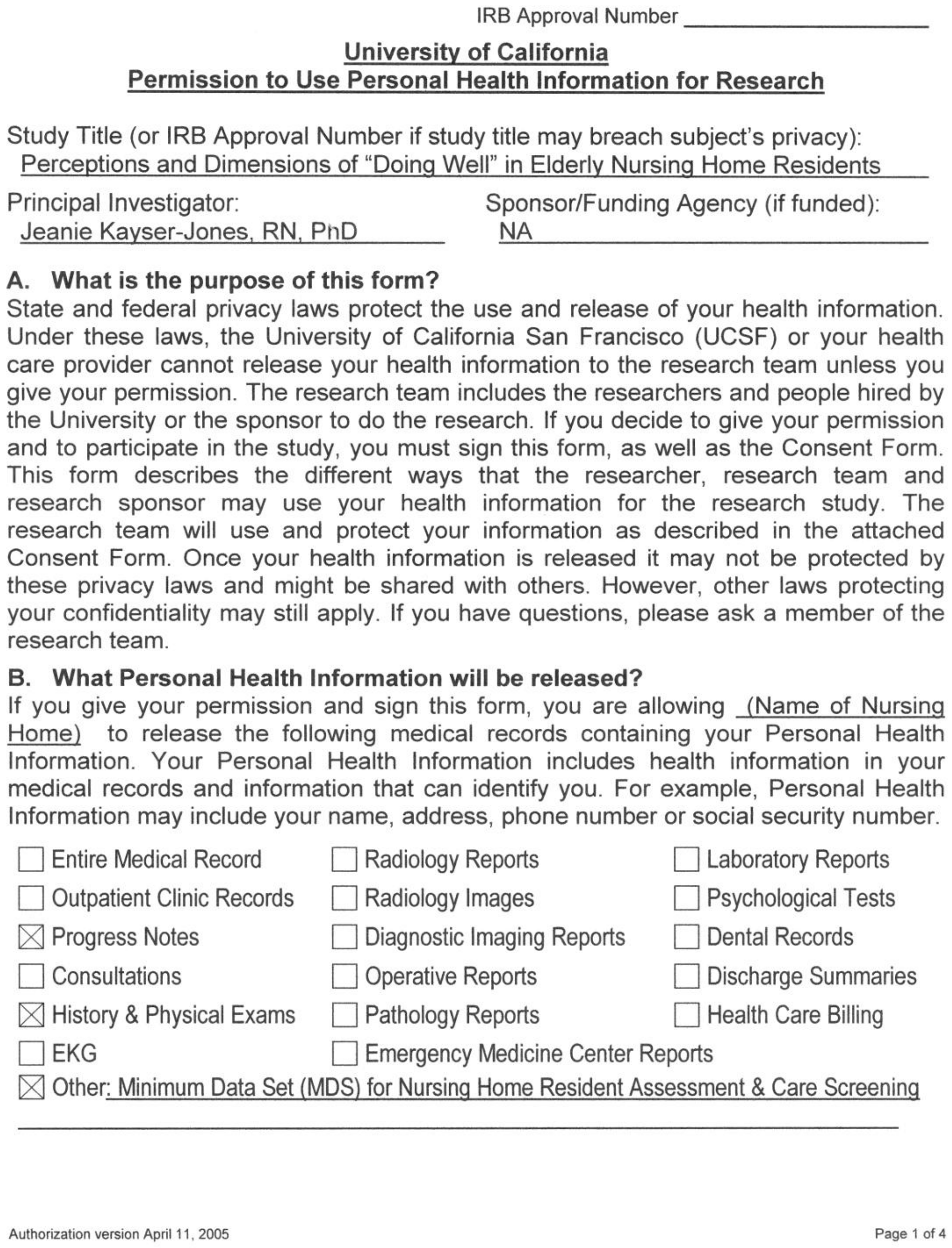
If you wish to participate in this study, you should sign below.

____________	____
Date	Participant's Signature for Consent
____________	____
Date	Person Obtaining Consent

AND/OR:

____________	____
Date	Legally Authorized Representative
____________	____
Date	Person Obtaining Consent
____________	____
Date	Participant’s Signature of Assent
____________	____
Date	Person Obtaining Participant’s Assent

APPENDIX E



IRB Approval Number ____________________

University of California
Permission to Use Personal Health Information for Research

Study Title (or IRB Approval Number if study title may breach subject's privacy):
Perceptions and Dimensions of "Doing Well" in Elderly Nursing Home Residents

Principal Investigator:
Jeanie Kayser-Jones, RN, PhD

Sponsor/Funding Agency (if funded):
NA

A. What is the purpose of this form?

State and federal privacy laws protect the use and release of your health information. Under these laws, the University of California San Francisco (UCSF) or your health care provider cannot release your health information to the research team unless you give your permission. The research team includes the researchers and people hired by the University or the sponsor to do the research. If you decide to give your permission and to participate in the study, you must sign this form, as well as the Consent Form. This form describes the different ways that the researcher, research team and research sponsor may use your health information for the research study. The research team will use and protect your information as described in the attached Consent Form. Once your health information is released it may not be protected by these privacy laws and might be shared with others. However, other laws protecting your confidentiality may still apply. If you have questions, please ask a member of the research team.

B. What Personal Health Information will be released?

If you give your permission and sign this form, you are allowing (Name of Nursing Home) to release the following medical records containing your Personal Health Information. Your Personal Health Information includes health information in your medical records and information that can identify you. For example, Personal Health Information may include your name, address, phone number or social security number.

☐ Entire Medical Record
☐ Outpatient Clinic Records
☒ Progress Notes
☐ Consultations
☒ History & Physical Exams
☐ EKG
☐ Radiology Reports
☐ Radiology Images
☐ Diagnostic Imaging Reports
☐ Operative Reports
☐ Pathology Reports
☐ Emergency Medicine Center Reports
☐ Laboratory Reports
☐ Psychological Tests
☐ Dental Records
☐ Discharge Summaries
☐ Health Care Billing
☒ Other: Minimum Data Set (MDS) for Nursing Home Resident Assessment & Care Screening

IRB Approval Number ____________________

C. Do I have to give my permission for certain specific uses?

Yes. The following information will only be released if you give your specific permission by putting your initials on the line(s).

____ I agree to the release of information pertaining to drug and alcohol abuse, diagnosis or treatment.

____ I agree to the release of HIV/AIDS testing information.

____ I agree to the release of genetic testing information.

____ I agree to the release of information pertaining to mental health diagnosis or treatment as follows:

____

D. How will my Personal Health Information be used?

Your Personal Health Information may be released to these people for the following purposes:

1. To the research team for the research described in the attached Consent Form;
2. To others at UC who are required by law to review the research;
3. To others who are required by law to review the quality and safety of the research, including: U.S. government agencies, such as the Food and Drug Administration, the research sponsor or the sponsor's representatives, or government agencies in other countries. These organizations and their representatives may see your Personal Health Information. They may not copy or take it from your medical records unless permitted or required by law.

E. How will my Personal Health Information be used in a research report?

If you agree to be in this study, the research team may fill out a research report. (This is sometimes called a "case report".) The research report will ***not*** include your name, address, or telephone or social security number. The research report may include your date of birth, initials, dates you received medical care, and a tracking code. The research report will also include information the research team collects in the study. The research team and the research sponsor may use the research report and share it with others in the following ways:

1. To perform more research;
2. Share it with researchers in the U.S. or other countries;
3. Place it into research databases;
4. Use it to improve the design of future studies;
5. Use it to publish articles or for presentations to other researchers;
6. Share it with business partners of the sponsor; or
7. File applications with U.S. or foreign government agencies to get approval for new drugs or health care products.

IRB Approval Number ____________________

F. Does my permission expire?

This permission to release your Personal Health Information expires when the research ends and all required study monitoring is over. Research reports can be used forever.

G. Can I cancel my permission?

You can cancel your permission at any time. You can do this in two ways. You can write to the researcher or you can ask someone on the research team to give you a form to fill out to cancel your permission. If you cancel your permission, you may no longer be in the research study. You may want to ask someone on the research team if canceling will affect your medical treatment. If you cancel, information that was already collected and disclosed about you may continue to be used. Also, if the law requires it, the sponsor and government agencies may look at your medical records to review the quality or safety of the study.

H. Signature

If you agree to the release and use of your Personal Health Information, please sign below. You will be given a signed copy of this form.

____
Name of Subject (print)

______________________________________ ____________________
Signature of Subject Date

Note: if the subject is a minor, an individual signing with an "X", an adult incapable of giving consent, or is unable to read the authorization, fill out and attach the "special signatures" page (sections "I" and "J").

IRB Approval Number ____________________

University of California
Permission to Use Personal Health Information for Research

SPECIAL SIGNATURES PAGE

I. If the subject is a minor, or an individual signing with an "X", or an adult incapable of giving consent (where IRB approved), the legally authorized representative or witness signs here:

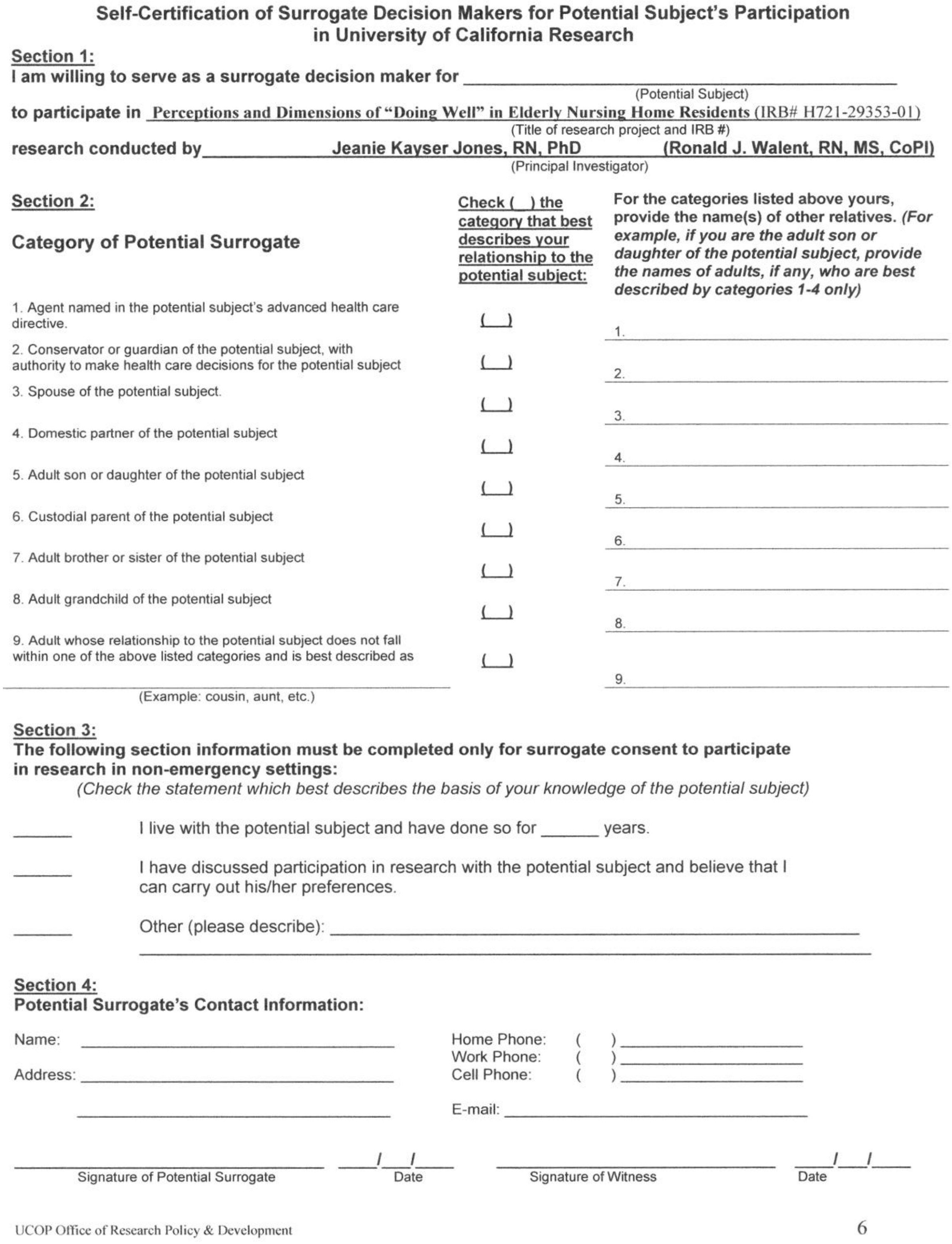
Name of Legally Authorized Representative or Witness to the "X" (print)	Relationship to the Subject
Signature of Representative or Witness	Date

J. If the subject is unable to read the authorization, the translator or reader and a witness sign here:

I have accurately and completely read this Authorization to ____________________ (subject's name) in _______________(language), the subject's primary language. **The subject has verbally affirmed his/her Authorization to me and to the witness.**

Name of Translator or Reader (print)	
Signature of Translator or Reader	Date
Name of Witness (print)	
Signature of Witness	Date

APPENDIX F



Self-Certification of Surrogate Decision Makers for Potential Subject's Participation in University of California Research

Section 1:
I am willing to serve as a surrogate decision maker for ____________________
(Potential Subject)

to participate in Perceptions and Dimensions of "Doing Well" in Elderly Nursing Home Residents (IRB# H721-29353-01)
(Title of research project and IRB #)

research conducted by **Jeanie Kayser Jones, RN, PhD (Ronald J. Walent, RN, MS, CoPI)**
(Principal Investigator)

Section 2:

Category of Potential Surrogate	**Check ( ) the category that best describes your relationship to the potential subject:**	**For the categories listed above yours, provide the name(s) of other relatives.** ***(For example, if you are the adult son or daughter of the potential subject, provide the names of adults, if any, who are best described by categories 1-4 only)***
1. Agent named in the potential subject's advanced health care directive.	☐	1. ____________
2. Conservator or guardian of the potential subject, with authority to make health care decisions for the potential subject	☐	2. ____________
3. Spouse of the potential subject.	☐	3. ____________
4. Domestic partner of the potential subject	☐	4. ____________
5. Adult son or daughter of the potential subject	☐	5. ____________
6. Custodial parent of the potential subject	☐	6. ____________
7. Adult brother or sister of the potential subject	☐	7. ____________
8. Adult grandchild of the potential subject	☐	8. ____________
9. Adult whose relationship to the potential subject does not fall within one of the above listed categories and is best described as ____________ (Example: cousin, aunt, etc.)	☐	9. ____________

Section 3:
The following section information must be completed only for surrogate consent to participate in research in non-emergency settings:
(Check the statement which best describes the basis of your knowledge of the potential subject)

______ I live with the potential subject and have done so for ______ years.

______ I have discussed participation in research with the potential subject and believe that I can carry out his/her preferences.

______ Other (please describe): ____________________

Section 4:
Potential Surrogate's Contact Information:

Name: ____________________
Address: ____________________
____

Home Phone: ( ) ____________
Work Phone: ( ) ____________
Cell Phone: ( ) ____________
E-mail: ____________________

____________________ ____/____/____ ____________________ ____/____/____
Signature of Potential Surrogate Date Signature of Witness Date

UCOP Office of Research Policy & Development 6

APPENDIX G

Initial Interview Guide (Phase I)

Introduction and key interview questions

Hello Mr./Ms.______________, thank-you for agreeing to take part in this interview. I am interested in having individuals who are living in nursing homes tell me about how they are doing, about what it is that keeps them going.

1. To begin with, can you tell me about yourself and what brought you here to this nursing home?

2. Can you tell me about how you are doing here?

Follow-up questions (to be used as needed to stimulate conversation)

1. What keeps you going here?

2. Tell me about a particular day here that you consider was a very good day.

    a. What do you think it was that made that day particularly good?
    b. How did you feel on that day?

3. Overall, what do you think helps you to do well or to have good days?

4. Are there things that interfere with your ability to do well here?

5. Tell me about a day that didn’t go so well for you here.

6. How do you think others think you are doing?

7. When you think about the future, what is it that you think about?

8. Is there anything else you’d like to tell me about today?

Clarifying questions

I want to be sure I understand what you are telling me; can you talk more about that?

Do you have a particular example of that in mind?

What do you mean when you say_______________?

APPENDIX H

Demographic Information

Today's date: _______________

Pseudonym/Code number: ________________

Gender: M   F

Age: _________

Ethnicity: ____________________

Marital status: Single   Married   Divorced   Widow/er

What was/were your major occupation(s)? _____________________________________

Number of Children: M _____   Living _____

F ______   Living _____

About how many different cities have you lived in during your life? _____

About how many different houses or apartments have you lived in during your life? ____

Did you own your own home?   Y   N

How long have you been living in this nursing home? ____________________________

What situation or condition brought you to this nursing home? _____________________

Who visits you?

1. ____________________________________   Frequency______________
2. ____________________________________   Frequency______________
3. ____________________________________   Frequency______________
4. ____________________________________   Frequency______________
5. ____________________________________   Frequency______________

How was the decision for you to enter the nursing home made? ____________________

Appendix I

The Mental Status Questionnaire (MSQ) (short version)
(Kahn, Goldfarb, Pollack & Peck, 1960)

	Score 1 for each error
What is the name of this place?	
Where is it located? (address)	
What is today's date?	
What is the month now?	
What is the year?	
How old are you?	
When were you born? (Month)	
When were you born? (Year)	
Who is President of the United States?	
Who was the president before him?	
TOTAL	

Number of errors	Severity of cognitive impairment
0-2	none or minimal
3-8	moderate
9-10	severe

Kahn, R. L., Goldfarb, A. I., Pollack, M., & Peck, A. (1960). Brief objective measures for the determination of mental status in the aged. *American Journal of Psychiatry, 117*, 326-328.

Kahn, R. L., Goldfarb, A. I., Pollack, M., & Gerber, I. E. (1960). The relationship of mental and physical status in institutionalized aged persons. *American Journal of Psychiatry, 117*, 120-124.

APPENDIX J

Examples of Follow-up Interview Questions (Phase III)

Thank you again for taking time to meet with me. I am interested in following up on some of the items that came up during initial interviews and ongoing observations.

How are you doing today?

> What in particular makes you feel you are doing well (or not doing well) today?

How would you say you are doing in comparison to most other days you've been here in the nursing home? (If needed, ask better, worse or the same as usual?)

> What makes today (better than, worse than, same as) usual?

Would you say you have more good days than bad days here or more bad days than good days?

> Can you tell me a bit more about that?

Looking over your entire life, if you had to pick a best day, what would that be?

> Can you tell me about that day?

Again, looking over your entire life, if you had to pick a worst day, what would that be?

> Can you tell me about that?

Of all the things you've done in life what are you most proud of?

Before coming to the nursing home, what was it that gave you the most happiness?

Looking over your life, do you have any regrets?

How do you feel about living in a nursing home?

What are the advantages to living in a nursing home?
What are the challenges associated with living in a nursing home?

Do you feel that there is any connection between your past accomplishments, interests and activities (the way you used to live your life), and the way you go about your daily activities in the nursing home (the way you live your life now)?

Would you say that in the time before you entered the nursing home you found it challenging to make new friends?

Do you have fellow residents whom you consider friends?

> How did (he, she, they) they come to be your friend(s)
> How often do you see them or spend time with them?
> What activities do you do with them?

Are there other people that make it difficult to live here?

> Can you tell me a bit more about why they are difficult?
> Are there other residents or types of residents that make life here challenging for you?

Are there staff members whom you feel particularly close to?

> Can you tell me about that relationship?

If things are not going well for you in the nursing home what do you do?

Who do you turn to help resolve issues or problems?

Do you feel you have enough say in what happens to you here?

> Can you give me some examples?

Are you usually comfortable here?
Are there things that cause discomfort?

> Probes: Ask about specific ADLs, transferring, getting out of bed, therapies.

Does pain ever ruin your sense of doing well?

> Can you tell me more about this?
> Is it managed well?
> Does it interfere with activities you would like to do?
> Does it interfere with sleep and rest?

Does fatigue (feeling tired) ever ruin your sense of doing well?

> Can you tell me more about this?
> Is it managed well?
> Does it interfere with activities you would like to do?

Does not getting a good night sleep ever ruin your sense of doing well?
> What is the cause of not being able to sleep at night?

Are there other symptoms that make it difficult to do well?

- What are they?
- How do they affect you?
- How are they managed?

Are there times when feel blue or down?
Are there times when you feel lonely?
Are there times when you feel bored?
What do you do you to pass the time here?

- (Ask participant to expand on responses.)

Is there anything about your physical surroundings that makes it difficult to live here?

- What about your bathroom?
- What about the shower room?
- What about the hallways or elevators?
- What about the day room?
- What about any of the other areas?

Do you feel as if you have been able to make the area around your bed your own space?

- How have you done that?
- What do you like about the space you have?
- What do you dislike about the space you have?

Where do you usually eat your meals?

Why do you prefer to take you meals there?

Do you feel that you have enough privacy here?

How do you keep in touch with what is going on outside of the nursing home?

- With family and friends?
- With cultural and world events?
- Which of the following do you use to stay informed:
  - Letters
  - Newspapers/Magazines
  - Facility phone
  - Personal phone
  - Facility Computer
  - Personal Television
  - Personal Radio
  - Regular visits

How often do you take trips out of the nursing home?

Were do you go?
Are trips frequent enough?

Is money a concern for you? What are the things you need to buy?
Who manages your finances? Who pays your bills?
How do you feel about this arrangement?

In your opinion, what kind of people will do well in a nursing home?

In your opinion, are there changes needed in this nursing home to help people do well?
Can you tell me about the changes that you think are needed?

Is there anything else you would like to talk about related to life in the nursing home?

Publishing Agreement

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I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis or dissertation to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Ronald J Walent 02-27-2008

Author Signature Date