Aging researchers frequently study “frail” elders, though the meaning of frailty remains largely ambiguous. To explore what “frailty” means, I qualitatively interviewed three nursing home residents about their thoughts on frailty and examined published literary narratives on experiences with aging, illness and disability. “Frailty” is a “catch-all” term used in the literature to refer to a web of physical, mental or emotional instability, age and presence of disability. However, it is an empty term in that it fails to capture personal experiences. The individuals we call “frail” do not identify themselves as “frail” because their experiences with asserting independence in the face of dependency and burden lend substance and story to their lives. Being “frail” involves striking a balance between resisting and accepting dependency, although this balance is disrupted by physicians’ duty to treat the "disease" rather than the person, further perpetuating the notion that “frail” individuals are inherently dependent.
FRAILTY: MEANINGFUL CONCEPT OR CONCEPTUAL MUDDLE?

A Thesis

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Chapter I

Introduction

From our life experiences, we possess seemingly limitless values and assumptions that are continuously shaped and influenced by our location within a multitude of complexly juxtaposed past, present and perceived future social and psychological spheres. Beyond such rather recognizable biases, however, we have large stores of tacit knowledge, or “unarticulated knowledge” (Maykut & Morehouse, 1994, p. 31), that by definition are difficult—if not impossible—to sift through and identify. This tacit knowledge is so deeply embedded in our unique perspectives of the world that its manifestation, while obscure on the surface, is often evident in the subtleties of the language we use to make sense of others and of life’s uncertainty. Certain words and phrases become, in a sense, reified to such an extent that their meanings—whether uniform or multifaceted—become assumed.

Two such words, frail and frailty, are used extensively and, as evidenced in aging literature, rather casually in contexts involving older adults, especially those who are in a state of dependency. The purpose of this study is to gain a more comprehensive understanding of the meaning of frailty and being frail as it is perceived by individuals residing in a nursing home and the nursing home staff that provide care for the residents—if the notion of frailty does in fact play a salient role in their everyday lives and discourse in the first place. My research question, therefore, is twofold: do elders define themselves as frail and, if so, how do they perceive it and what does it mean to them? Do nursing home staff members define residents as frail and, if so, how do they see it and what does being frail mean to them? Additionally, how do the nursing home residents and the nurses’ aides who provide their care see frailty differently, if at all? Do they perceive frailty as a permanent state, or rather as a temporary, situationally variable manifestation of health decline? Unfortunately I was unable to recruit nurses’ aides to participate in my study; nonetheless, I want to make certain that my original rationale for interviewing nurses’ aides—to gain insight from perspectives within a dyad—remains on the table as having been forefront in my research despite such an unforeseen obstacle.

Disparate ideas found in gerontological and health-related literature on aging demonstrate the importance of further inquiry into the meaning of frailty in general and my
research in particular. As such, I critically analyze the concept of frailty—starting with its literal dictionary definition and the way in which it has come to be operationalized (or not) by researchers—in terms of its function within a problem-focused, medical paradigm and the way in which frailty is simultaneously social and situationally variable.

Setting the Stage

A strong focus on the losses and health declines that older people presumably experience as they age (Kaufman, 1986) pervades the social science and medical literature on aging. The life changes that are often associated with aging—changes ranging from physical decline, onset of chronic illness, and death of friends and other loved ones—have been and continue to be presented in numerous empirical studies that document the intricate relationships between said changes and various aspects of well-being. In following the problem-focused trend in understanding the processes and transformations that occur with age, aging researchers have long studied various issues concerning frail elders, including fall prevention, risk of hospitalization, increased mortality, cognitive deficits, nutrition and a range of physical and psychological symptoms (Moran & Pouya, 2004; Mossey & Shapiro, 1982; Payette, 2005; Toye et al., 2005; Wilson, 2004). However, despite the frequent references to frailty in discussions of age and aging, the degree to which a common understanding of the term has failed to be established is striking (Chater, 2002; Markle-Reid & Browne, 2003; Rockwood et al., 2005; Rockwood, 2005).

The words “frail” and “frailty” pervade the language and literature of academic, medical and long-term care settings and typically, though not always, describe individuals who are older, physically weak, unhealthy, and—most importantly—unable to provide their own daily care. According to Webster’s dictionary the word frail has a range of meanings that all center on a theme of weakness, from “morally weak” to “easily broken; not firm or durable; likely to fail or die quickly; and unusually susceptible to disease or other infirmity” (Grove, 1981, p. 901). Likewise, the word frailty refers to “the quality or state of being frail; insubstantiality; infirmity; and susceptibility” (Grove, 1981, p. 901). Nonetheless, the literal dictionary definition of the term “frail” seems to shrink in importance in light of the broadly reaching effects of actually being frail. Important in the perception of frailty is not only the frail person but also the significant network of...
individuals with vested interests in helping the frail person (and potentially disparate ideas of what such helping should entail).

I therefore situate the importance of my research exploring the multiple meanings of frailty along three points: 1) by describing the inconsistency in existing conceptualizations of frailty and the implications of such inconsistency on people who are considered frail; 2) by describing the relationship between medicalization, autonomy and frailty; and 3) by discussing the ways in which frailty is socially constructed and may be negotiated in terms of power and dependency.

Lack of Consensus in Defining Frail: A Conceptual Muddle

A general lack of consensus on the definition of frailty is glaringly evident despite its widespread use and may hold consequences for those who are referred to as frail. At the heart of the strong focus on frailty as a variable that can be isolated and manipulated are older individuals who are being labeled and treated as frail on the basis of an implicit, assumed understanding of the descriptive term, a term that is heavily and diversely value-laden. Two significant problems exist in the use of frailty as a research variable. First, the term is all too often not defined at all. Second, when frailty is operationalized, its definition assumes a different shape depending upon the researchers’ paradigmatic perspective. For example, Moran and Pouya (2004) stress the importance of decision-making capacity as a criterion by which an elder may be considered frail and assess such capacity by way of a series of problem-focused questions: is the patient able to rationally make decisions based upon his or her values (presumably those that have been held throughout life)? Is the patient able to distinguish between various consequences of his or her decisions? Is the patient able to communicate his or her decisions to the medical staff? On the other hand, frailty has also been conceptualized as an actual syndrome in and of itself, consisting of a constellation of losses—loss of health, energy, mental acuity, and function (Rockwood et al., 2005). Also in line with this view is the idea that frailty is determinable by the number of frailty “indicators” an individual meets, ranging from urinary incontinence and impaired mobility to sleep changes and mood problems (Rockwood et al., 2005). Unfortunately, much research conducted with frailty as a core characteristic of the sample (Murphy et al., 2005; Toye et al., 2005; Young et al., 2005) fails to offer an explanation of the way in
which frailty is conceived by the researcher and often implies that living in a nursing home
is ample enough evidence of frailty—without any explanation of the logic behind such a
conclusion.

Medicalization and Autonomy

There are numerous factors that may account for the conceptual muddle in research
and lack of agreement pertaining to frailty—factors that include disagreement over the
level of analysis by which the topic should be studied and issues concerning the stability of
frailty. However, one thread of agreement that runs through the literature is the assumption
that frailty is an experience and is tied to one’s environment and the network of individuals
within it (Kaufman, 1994). The experience of frailty first and foremost involves the person
considered frail, though because symptoms of frailty are, to a certain extent, regarded as
“treatable,” the elder’s family may seek outside assistance to keep the elder safe from harm
as he or she becomes weaker and, from the family’s perspective, increasingly accident-
prone. The help that the family seeks is often that of medical and other health
professionals, and here a critical matter arises concerning multiple perceptions of and
reactions to frailty.

Medicalization is a term that refers to the “process in which personal and social
problems and behaviors come to be viewed as diseases or medical problems that the
medical and allied health professions have a mandate to ‘treat’” (Kaufman, 1994). Kaufman
asserts that there exists a paradigmatic competition concerning the nature of
frailty—the medicalization paradigm and the autonomy paradigm—and such competition
propagates discord between the elder’s desire to remain in control of his or her life and
decisions, on the one hand, and the medical professionals’ goal to “protect and treat” the
frail elder on the other hand. Since protecting and treating a frail elder from the disease-
oriented standpoint of the medicalization paradigm necessarily involves varying degrees of
lifestyle changes—including but not limited to foregoing driving, walking with an assistive
device, or allowing a health aide to supervise and support activities in the home for any
given period of time—the elder’s autonomy is inherently infringed upon as he or she is
encouraged, if not forced, to relinquish activities that previously expressed independence.
According to Becker (1994), autonomy is highly valued in America but is at risk of being
compromised in the presence of frailty. Likewise, the label of frailty ultimately imposes
dependence because people use it to reduce the autonomy of individuals and potentially
prevents them from reframing their way of life and from asserting their personal choice in
lifestyle matters. This is in line with the view that American society accepts a simplistic
view of aging—one that does not acknowledge the diversity of physiological,
psychological, emotional and behavioral processes inherent across the life span (Kaufman,
1994). Striking the balance in caring for frail elders in such a way that their autonomy is
respected and preserved is neither easy nor, unfortunately, typically conceived of by most
individuals in American society, given its strong support and reliance on the medical field.

Frailty is an experience that is fostered and fed by numerous social actors. Asking the
people who are presumably living the experience to share their perceptions of the meaning
of frailty from within a nursing home context is a logical exploration in any attempt to
further understand the concept and its various implications. The nursing home is an
environment that conventionally and by design limits individual autonomy even without
the presence of personal limitations resulting from being labeled frail. I wanted to include
in my exploration the ways in which the nursing home staff who care for frail individuals
view frailty, in the hope of an emergent illustration of frailty as it is painted by the
language and actions between key actors of a dependency-based dyad. Those attempting to
understand frailty in old age—as it is a construction of the individual and society—have
rarely asked individuals who are old and experiencing the well-studied losses and limits to
autonomy to describe the experience.

The Social Construction of Frailty

According to the many ways frailty is defined in the literature, one who is frail often
has various mental and functional limitations, needs varying degrees of assistance with
daily activities, or has a chronic or acute illness. While the use of the words frail and
frailty—however the words are defined—in healthcare environments may or may not
accurately reflect an individual’s status, when an older individual is labeled as frail a set of
assumptions invariably arises concerning the ability of the frail person; such assumptions
then guide the care of the frail person. The result is a social construction (Berger &
Luckmann, 1966) of frailty—an idea of what frailty is that is initially shaped by the
healthcare staff’s perception of frailty as a state of weakness and dependency and is then accordingly manifested in their interactions with the frail person, who ultimately experiences and applies meaning to being considered frail. The main premise of social construction, according to Berger & Luckmann (1966) is that individuals create mental representations of others, representations that then become the creator’s perception of reality. The perceived realities of all individuals in a social setting—such as in a nursing home—together “create” a joint reality, though ironically each individual has his or her own perceived reality that is simultaneously influenced by others’ perceived realities. The complex ways in which the characteristics and perspectives of socially intertwined individuals collaborate to create social reality is more clearly articulated in terms of dependency, situational variability and poststructuralist notions of language, subjectivity, social organization and power (Richardson, 1994, p.518). I will now describe each of these areas in greater detail and frame them in terms of their relevance to the social construction of frailty.

**Dependency.** Rubinstein, Kilbride and Nagy (1992) have described the perception of choice among frail elders as being a critical, yet malleable, prerequisite for attaining the American cultural ideal of independence. Frailty, as they assert, “is a term that links objective health status with both objective and subjective personal efficacy and viability” (p. 15). Frailty is portrayed almost symbolically in American culture as physical weakness and, as such, is most often measured by researchers in terms of ability to perform various activities of daily living. Since being frail is assumed to entail needing the assistance of another individual, frailty invariably implies a dependent relationship. According to Rubinstein and his colleagues, choice and control—“operationalizations of independence” (1992)—are at the root of this dependent relationship and, consequently, are the most at stake for the dependent person.

Other research also supports the relationship between choice and independence: Myerhoff (1985) interviewed Orthodox Jewish women who follow strict religious doctrine in the types of clothing they wear, the activities in which they participate, frequency and timing of sexual intercourse, and the decisions they are able to make in their Jewish community and in their families. However, Myerhoff points out that these women chose
this way of life—it was not forced upon them by others. The supposed limitations associated with their religious affiliation counter-intuitively denote great freedom for these Orthodox Jewish women by virtue of the fact that their affiliation and its limitations were *self-chosen*. In this instance, the religious affiliation and attached lifestyle these women chose are, for the most part, not particularly inclusive of more traditional notions of independence. However, because the women actively chose it, they reframe the experience of conforming to rigid parameters of behavior and way of life and subsequently do not view them as limiting. In contrast, an element of ambiguity exists concerning whether or not frail individuals see themselves as being frail—as having chosen that identity for themselves regardless of being labeled as such by researchers and healthcare professionals.

*Situational variability.* The definition—or more importantly, the meaning—of frailty may change depending on the characteristics of the individuals who comprise the social environment in which frailty might be identified as a common attribute. Through ethnographic research, Degnen (2007) investigated the ways in which old age and oldness are constructed, finding that individuals’ identification with being old was strongly dependent upon the health statuses and opinions of *other* individuals in the community: “… while old is a powerfully stigmatizing label, it is also a contextually dependent one that can at times ebb and flow with the attribution of oldness shifting in relation to others” (p. 75). In other words, oldness—like frailty—is not an attribute that develops in a social vacuum but is rather created by and among social actors themselves. Like Degnen’s conclusions regarding individuals’ self-ascription of the term “old,” the extent to which individuals see themselves as frail perhaps depends upon the extent to which *others* see them as frail, illustrating the social construction of frailty and setting the stage for negotiations of power.

*Poststructuralism.* One way the notion of power and its role within social relationships is illuminated is through poststructuralism. An element of postmodernist thinking, poststructuralist ideas center on the interaction between the self and society, linking together language, subjective experiences, social relationships, and *power* and convey that every conceivable truth is embedded within cultural webs of meaning and is
therefore just as likely to be “disproved” in one context and as it is to be “affirmed” in another. At the core of poststructuralism is social construction, and one means by which such construction occurs is through language: “Language does not ‘reflect’ social reality, but produces meaning, creates social reality” (Richardson, 1994, p. 518).

Through the language and interactions between dependent frail people and their caregivers emerges an underlying set of assumptions by and about the frail person, assumptions that may either enhance the frail individual’s choice-making opportunity or further limit it. It is in this sense that the present study proceeds: to explore the experiences of older nursing home residents, their perceptions of their own health and of frailty in general. I also wanted to understand the perspectives and health views—as they pertain to the residents—of the nurses’ aides who provide their care. I was, as previously mentioned, unable to recruit nurses’ aides and I therefore am not able to analyze frailty in terms of a dyad but rather in terms of the rich perspectives offered by my informants. Drawing from a variety of autobiographical and ethnographic sources, I weave together the voices of individuals experiencing old age, illness or disability with my interview data.

Focus of Inquiry

In light of the previously discussed lack of consensus concerning the meaning of frailty—despite its common usage in various settings involving older adults who are often considered frail—a need exists for understanding what frailty means to and how it is perceived by a group of older adults who are themselves largely considered frail. As such, it was the focus of this study to explore what frailty means by asking older nursing home residents to explain how they perceive frailty within the context of their lives in a nursing home. Nursing home residents, by virtue of the fact that they are living in a nursing home, require varying degrees of assistance with basic everyday activities. In light of the dependent relationship fundamentally involved in frailty (Rubinstein et al., 1992), I am assuming that nursing home residents are individuals who are, or have at one time been, considered frail.
Chapter II

Research Design

As described above, the purpose of this qualitative study is to better understand frailty by 1) exploring the perspectives of some of the individuals residing in nursing homes and 2) by examining autobiographical and ethnographic narratives of individuals who have reflected on aging, illness and disability. For the first strategy, I set out to interview three nursing home residents and three of the nurses’ aides who provide their care about their life (and work) in the nursing home, their health views and what they think about frailty.

The outcomes of this study are both specific and general. In a specific sense, I obtained in-depth information through a series of topics posed in my interview guide:

a. What life is like living in a nursing home
b. What characteristics make a person feel frail
c. What it might feel like to be frail
d. What factors distinguish a frail person from one who is not frail
e. What life is perceived to be like as a frail person

Furthermore, a more general outcome of my study is a broader understanding of the concept of frailty and what it means at its most basic and arguably most fundamental level—as those who are often portrayed as frail in aging literature see it. This study is a step toward focusing attention on the meaning behind the language used to describe and categorize older adults, ultimately raising the awareness of scholars and professionals to the effects of using such language on those to whom it pertains.

The topic of this research is conducive to my method of choice—a qualitative method of inquiry—primarily because it is a little-researched area. It reflects the fourth postulate of the phenomenological paradigm outlined by Maykut & Morehouse (1994), which states that events mutually shape one another and that, as a result, relationships between events and individuals are multidirectional. Frailty is perceived differently from individual to individual and, as such, use of the word frail in everyday nursing home dialogue may mutually create and define relationships between the people living and working in this setting. In addition, my selection of qualitative research methods is driven
by the nature of the research question: *how is frailty perceived by nursing home residents and staff and what does frailty mean to them?* First and foremost, the purpose of this inquiry is to unveil the individual meanings nursing home residents and staff members place on frailty. Furthermore, there are few studies (Becker, 1994; Kaufman, 1994; Rubinstein, Kilbride & Nagy, 1992) that asked both individuals who are considered frail and their care networks about their perceptions of frailty. It was my intent to illuminate the complex way in which the various perceptions within a dependency-centered dyad jointly create frailty in the social context of a nursing home, though I was not able to recruit nurses’ aides to enable such an inquiry. Therefore, in an emerging design, I methodologically focused on the literary narratives in addition to the data supplied by my interviews.

**Methods**

**Site**

The nursing home I selected for this study is a 120-bed facility located in a small town in the Midwest, which I will call Park View; it is Medicare and Medicaid certified. Skilled nursing, intermediate nursing, and a special care unit for individuals with Alzheimer’s disease and dementia are available, each offering varying degrees of assistance and care by trained professionals such as registered nurses, licensed practical nurses, certified nurse aides, a licensed social worker and activity coordinators. Park View’s administration promotes a sense of teamwork in providing individualized care to its residents, teamwork that draws upon the abilities and effort of all levels of its staff.

**Recruitment**

I recruited my informants by mailing a descriptive letter to the administrator of Park View and requesting permission to conduct my research at the site described above. After briefly meeting with the administrator, I was introduced to the on-site social worker, to whom I explained in greater detail the format, time frame, and expectations for my research.

Since each interview was to be a lengthy one-on-one discussion about health perceptions and thoughts concerning the abstract concept of frailty, I explicitly expressed
to Park View’s social worker my wish to recruit only nursing home residents who are not cognitively impaired—a measure I gauged by whether or not the resident could read and understand the informed consent form (see Appendix A). The social worker then led me through the home and introduced me to residents until I had distributed all ten of my envelopes containing a letter describing my study (see Appendix B), an interest in participation letter, and a self-addressed, stamped envelope. The social worker arranged to distribute ten envelopes with information about my study to ten certified nursing assistants (CNAs) he believed might be interested in participating.

With the hope to recruit three residents and three CNAs, each of whom works a different shift, I included ten nursing home residents and ten CNAs in my recruitment effort. I recruited more residents and CNAs than I intended to interview for two reasons: first to comply with privacy laws aimed at preserving the anonymity of the participants so that their participation in the study might remain unknown to the nursing home administration, and second to increase the likelihood that at least three residents and three CNAs would indicate interest in participating.

I received responses from three residents who agreed to participate. Unfortunately, I received no interest from any of the CNAs. As such, my data consists solely of the words and perspectives of nursing home residents along with detailed notes from my field visits.

Informants

Qualitative research does not have generalizability as one of its objectives; the small number of participants interviewed in this study is sufficient given that the complexity of the topic emerged through in-depth, inductive inquiry and not by way of a large sample size. According to Maykut & Morehouse (1994, p. 57), “It is not our goal to build a random sample, but rather to select persons or settings that we think represent the range of experience on the phenomenon in which we are interested.” With this said, my informants—all Caucasian women—range in age from middle-aged, 79 and 83. The various catalysts that prompted their respective admittance to the nursing home range from serious and progressively declining health concerns (including arthritis, fibromyalgia and related side effects), increased falls and subsequent worry from family and physician, and the death of a spousal primary caregiver to a woman with a neurological disorder that
makes daily activities difficult. These women, collectively, have been living at Park View between four and eight years, although short hospital stays preceded nursing home entrance for two of them. Two women use a wheelchair, one uses a walker, and one woman requires a mechanical lift to assist her in activities that require her to raise or lower herself from sitting or reclined positions.

Data Collection

My methods of data collection in this study are twofold: that of the in-depth interview, or “a conversation with a purpose” (Maykut & Morehouse, 1994), and examination of literary narratives of individuals reflecting on aging, illness and disability. First, I asked informants to share with me their experiences in how they perceive their health, how they came to live at Park View nursing home, and what “frailty” means to them. To do this, an interview schedule of specific questions and probes that I designed to elicit my informants’ thoughts on “frailty” is perceived and constructed is the framework for all the informant interviews (see Appendix C). During each interview I asked the resident to provide me with basic demographic information that did not spontaneously surface during the interview, such as age and race. Second, because I sought more data—a different kind of data—and different voices that might lend themselves toward a better understanding of frailty, I chose to examine autobiographical and ethnographic narratives.

Interview Content

As previously explained, I utilized an emergent design in collecting data. As such, the information I gathered from each individual interview informed each later interview. In this way, I captured a much more comprehensive picture of frailty as the subject was freely explored and built upon by the individuals whose perspectives I was seeking. The various limitations that may have potentially stemmed from my lack of understanding of what it is like to be considered frail were therefore not imposed upon the direction of the interviews; each informant determined the direction. In other words, as Maykut and Morehouse (1994) assert, I learned by asking others to inform me of their experience.

Content differed marginally on the interview schedules I devised but generally encompassed the following topics and concepts: what life is like in a nursing home, how
and why the resident came to live there, what they think about health, and their perspectives on frailty. My interviews were semi-structured and flexible enough to allow me to elaborate upon topics directed by each informant. As such, I asked various additional questions and probes so that I might better understand the informants’ stories and the rich context from which they stem. Important to note, however, is that I did not mention frailty in the beginning of the interview but instead waited to discover whether or not the term surfaced in the language of the informants themselves. My rationale for such abstention stems from Maykut and Morehouse’s (1994) assertion that

… the qualitative researcher’s perspective is perhaps a paradoxical one: it is to be tuned-in to the experiences and meaning systems of others—to indwell—and at the same time to be aware of how one’s own biases and preconceptions may be influencing what one is trying to understand. (p. 123)

In other words, my initial, assumption that the concept of frailty was in fact commonplace to my informants might have obscured their true perspectives. In light of the frequency with which nursing home residents are described as frail in the academic literature, I was curious to discover whether or not frailty was salient to residents themselves. Regardless of whether or not the informants directed me to the topic of frailty I eventually asked specific questions concerning what frailty means to them, what they think makes a person frail, and what they think it is like to be frail.

To summarize, I collected data by way of 1) one-time, in-depth, semi-structured interviews directed by—but not strictly bound to—an interview schedule, which left room for restructuring and redirection depending upon the nature of the information that the informants supplied, and 2) examination of autobiographical and ethnographic narratives.

Confidentiality

I audio tape-recorded all three interviews with the informants’ permission and subsequently transcribed them verbatim. I made copies of each transcript prior to the ensuing analysis. I kept the responses of the informants completely confidential; in other words, while I am sharing the words of my informants with readers, utterances cannot be linked to the individual who said them. This means that each informant’s identity is not
known by anyone but me (and possibly my faculty advisor). I assigned the informants pseudonyms so that their actual names were never disclosed in any written or spoken report of the study. I likewise disguised anything that the informants said that might reveal their identity and participation in the study so that their confidentiality would be preserved.

Process of Analysis

The process of data analysis in my study closely resembled the data analysis strategy outlined by Maykut and Morehouse (1994)—the constant comparative method (Glaser and Strauss, 1967). To begin, I analyzed my interview transcripts following an approach set forth by Strauss and Corbin (1990) that involves selecting aspects of the interview texts to create a descriptive narrative, an understanding of the concept of frailty as it is perceived by these three nursing home residents. This first involved generating codes that captured the essence and meaning embedded in my informants’ words. However, I quickly found that the extent to which I was able to discuss patterns in perceptions of frailty with my three interviews’ worth of data was somewhat limited. As Coffey and Atkinson (1996) point out,

Although one cannot legislate for all aspects of creative work, one can encourage success by having ideas early in the research process and being willing to explore them, modify them, and even abandon them in the light of further analysis. (p. 192)

Therefore, in a strategic move guided by my research question and fueled by my quest to make better sense of my data, I turned to published narrative literature in an effort to capture an array of diverse perspectives that center on a similarly alluded to, yet rarely identified, feeling—that of frailty. Kaufman (2002, p. 71) discusses the emergence of experimentation with the “authorial voice” in qualitative writing, explaining how “narrative has been viewed as a useful expansive tool by scholars wishing to articulate, from details of the native’s point of view, how individuals construct meaning and negotiate their worlds.” In this way, I examined several authors’ personal accounts of growing old, enduring illness, coping with disability—and any and all of the above.

From these published narratives I extracted meaningful excerpts in which the authors describe reactions to, thoughts about, and insights into their experiences with growing accustomed to a decline in their ability to do what they used to take for granted, as
well as the new lifestyle of dependency that often ensued. I copied each excerpt onto individual 3x5 index cards, which I then sorted into categories, including but not limited to “othering,” “the frail role,” “dependency,” “and “medical ‘separation’ of person from body.” I then combined these excerpts with the data from my three interviews, thereby enlarging my database and broadening the scope of my analysis of frailty while maintaining an inductive, qualitative approach and its accompanying philosophy.

To then follow the constant comparative method I simultaneously compared each new unit of meaning with those that were already identified, placing the new unit into an existing or new category and making alterations in the category structure on an as-needed basis. I then rearranged each category so that, together, they are conceptually integrated and tell a story of frailty experiences. By way of the above processes of data analysis I constructed a descriptive narrative—supplemented and enriched by the words of my informants—that serves as the basis for a better understanding of frailty both inside and out of a nursing home setting.

My informants’ stories contain several ideas that, together, reveal the multifaceted role frailty plays in nursing home life and the way it is perceived and experienced by individuals living there. To add to and enrich these stories I have I turned to literary narratives of other individuals’ experiences with aging, illness and disability. I therefore offer both increased depth and tap a broader range of experience of frailty by analyzing it in terms of an integration of residents’ voices and some voices within the published narrative literature.
Chapter III

Findings

Before I incorporate the perspectives of various people who have authored their accounts of frailty in published books—and thus, in my mind, risk overshadowing the significance of the residents’ stories—I feel compelled to devote attention to providing a description of each informant, as I saw her, as she presented herself to me. As Golden-Biddle and Locke (2007) explain,

To the extent that we choose to develop and write about particular meanings disclosed in our fieldwork, we obviously regard what we write about as constructed. Few among us today would accept the proposition that researchers go into the field to gather up the pieces of reality lying around waiting to be gleaned. We appreciate instead that researchers, as well as organization members, shape the experienced reality. (p. 14)

Having said this, the descriptions I provide and my later theorized storyline stem from my perspective—my view of these women through my own unique lens. My goal here is to illustrate a small fraction of the essence of who Betty, Susan and Mable are—as they shared themselves and their stories with me for one short moment in their lives—so that you, in turn, may better understand the context from which my later interpretation of frailty emerges.

Betty

Others in the nursing home perceive Betty, a kind and sociable woman in her late 70s, as a “people person.” During my visits to Park View I regularly saw her everywhere but in her room, whether she was in the front lobby while assembling a jigsaw puzzle with one or two other women or wheeling herself around in the dining room, chatting with whoever stopped long enough to oblige. Her motivation to remain out of her room whenever possible seems to be due in part to her roommate’s presence, as Betty mentioned on more than one occasion that we could talk in her room if we wanted to … “but she’s in there.” However, more interesting than her habitual roaming and socializing is the role of the “deliverer of cheer” that she takes quite seriously, although it is unclear whether Betty
has ascribed herself this role or whether it has been given to her by fellow residents and staff—or, most likely, some combination of the two. Betty is outgoing, friendly, congenial and always smiling and she knows that she is perceived as one who is always in good spirits. She tries to keep a smile on her face even when she is not feeling happy, and if she catches herself faltering she verbally calls her own behavior into check, similar to the way that others in the nursing home have also done:

But uh—sometimes if I’m not smilin’ I’m havin’ to ask me, “Betty, what’s wrong? You’ve not got a smile on your face.” And I said, “Do I have to smile all the time?” And they said “Yeah!” So. I just smile.

Betty puts forth considerable effort in visiting other residents of Park View and, in doing so, forges what she perceives to be bonds with them. Her positive, happy-go-lucky demeanor is her way of forming and maintaining relationships and connections with others. When a person to whom she has been devoting much of her time and energy through almost ritualistic visitation passes away, Betty feels guilty and—to a certain extent—blames herself for the death. Betty’s role in the nursing home is to make sure others are happy and feel cared about by being cheerful regardless of how she is feeling inside. However, in contrast to the joyful exterior Betty carefully exudes she also expresses an air of sadness and resignation. Sometimes her attempts at appearing happy are overshadowed by a sense of sadness. While she grows from and defines herself through her relationships with others, she seems to spend her time trying to ensure that everyone else around her is happy, often at the expense of her own desires:

They say, some of the people tells me, “oh it’s easy to talk to you.” And … I don’t know that it’s easy to talk to me, and [they] said “Ya always got a smile on your face, that is if you’re feelin’ alright.” But when I’m not feelin’ good they was um, wantin’ a smile.

Betty smiles to cheer up other residents but also because she is expected to smile regardless of her mood.

Susan

Susan is a woman who, despite a list of health problems that constantly present obstacles in her daily activities and long-term recovery, maintains a day-to-day frame of
reference that facilitates her continually renewed hopefulness and positivity, an outlook best conveyed in her personal motto: “If God gives me another day, each—each time He gives me another day I’ll do my part.” Middle aged, Susan is considerably younger than most of the other individuals with whom she lives in the nursing home, and as such she has come to understand the lack of salience of chronological age in human relationships—instead seeing the interconnectedness of the ageless human spirit. Susan pushes herself to make the most of her ability each day—she knows what she needs to do to make herself feel better and to relieve herself from physical pain, boredom and loneliness. She considers the other residents with whom she lives to be her family of sorts:

We’re all just like a big family. You know. You don’t always get along, not everybody does you know. But—we’re like a family. You have your ups and downs but you’re still a family. And we look out for each other.

In terms of her blood-related family, however, she explains how her relationship with her mother has improved in recent years as they have relied on each other in times of alternating poor health. According to Susan, her siblings are largely absent from her and her mother’s lives—a situation about which she expresses resentment, hurt and anger. In her future she sees herself as eventually no longer living here in Park View, a distant but achievable goal for Susan as long as she continues to focus on each day, one at a time.

_Mable_

Mable, a woman in her early eighties, has a large and close-knit family living nearby and visiting often. Despite being frequently visited by family, Mable sometimes feels excluded from family events that occur elsewhere without her—a feeling that she quickly discredits and, in a sense, apologizes for by acknowledging that she knows her family members have very busy lives. She seems to have had a close relationship with her late husband, recalling that he took care of her in their home and that when he retired she made an effort to be near him wherever he was in the house. Mable’s physical health limitations include vision impairment and motor skill difficulty, though she has devised ways of coping with her inability to perform ordinary tasks she once executed without so much as a second thought. Her husband’s death a few years ago marked the beginning of a seemingly streamlined and anticipated process of selling her home, distributing her un-
needed belongings to family and friends, and addressing financial matters through arranging a power of attorney. Mable appears to have mentally and physically prepared for this time, as she says she knew she would eventually move into Park View due to its close proximity to her home in the community. Mable says she is where she is supposed to be in the nursing home “because there is no other place to be.”

_Toward a Better Understanding of “Frailty”: What is Most Salient?_

While interviewing, my intention from the outset was to refrain from influencing the direction of the interviews toward talk of frailty. This was to avoid unnecessarily imposing my own set of assumptions on others to whom frailty may or may not be a salient concept. I wanted to avoid inadvertently reinforcing the use of the word frail in the aging literature that has fueled my interest in uncovering and critically analyzing what frailty means. Until I raised the subject of frailty in each interview, my informants made no mention of the term at all. Therefore, to return to my research question, “Do elders define themselves as frail and, if so, how do they perceive it and what does it mean to them?” the answer is clear. No, the elder nursing home residents I interviewed did not define themselves as frail. Instead, they perceive frailty as being applicable to others. However, more important to the individuals I interviewed are their own experiences—experiences of feeling like a burden, experiences with dependency, with asserting independence, and experiences with day-to-day interactions with physicians. My informants and the narrative authors, who are doing everything in their power to be independent, reject the notion of frailty because their everyday experiences and singular assertions of personal agency—and not frailty—are what they feel define them.

“Frailty,” it seems, is rather amorphous. It has become a “catch-all” term used in the literature (and by academics, researchers, professionals and others) to refer to a web of physical, mental and/or emotional instability, age and presence of disability, but it is an empty term in that it fails to capture—or even acknowledge, for that matter—personal experience. This might explain why, when researchers use “frailty” as a research variable, they also a definition to “frailty.” Such explanation is necessary because the concept of “frailty” by itself is really an empty box. In fact, its shape and consistency come from the varied _experiences of the individuals_ we call “frail.” Likewise, I too am taking a stab at
defining “frailty” in a sense, though in my definition, rather my description, of “frailty” I seek to focus on the experiences of individuals we call “frail” but who do not accept such identity for themselves. I am therefore, from this point forward, enclosing “frailty” in quotation marks as a continuous reminder that the meaning of “frailty” is more than age, illness or disability. My intent is to analyze what “frailty” means and criticize our use of the word by describing what “frailty” means to my informants. “Frailty” in quotation marks, therefore, refers to “frailty” as it is defined in the literature, the “frailty” that has become a catch-all term that neglects to acknowledge individual experience, and—in doing so—is really an empty box, ultimately filled by individual definitions, assumptions and ideas concerning what “frailty” is or is not.

“Frailty,” in a sense, implies a global experience that mutes individual differences. It is in this way that “frailty” is freely applied to others, for the details of others’ lives—their own daily struggles and experiences with dependency, feeling like a burden and the like—are unknown. The apparent “indicators” of “frailty” are all one has to go on in making assumptions about others’ status, so not knowing anything of others’ daily acts of personal agency we do just as researchers and health professionals do and apply “frailty” as a blanket term based on appearance. With this understanding of the salience of personal experience rather than the global experience denoted by “frailty” in mind, I frame the ensuing discussion of my findings around the experiences that my informants and the narrative authors present as being important to them.

From my three interviews with nursing home residents about “frailty” and from the personal narratives of aging, illness and disability by several authors, I choose to elaborate upon several core ideas that I believe lend themselves as essential in understanding the facets of experience that are important: othering, the balancing act between asserting independence and accepting dependence, and the role of medical professionals, particularly physicians. First, my informants describe what they perceive to be the nature of “frailty” in others—a temporal attribute that can ebb and flow depending on a multitude of interacting individual characteristics and circumstances. Next, the process of othering—or the human inclination to psychologically divorce ourselves from individuals with whom we do not identify nor wish to one day become like—invites the development of strategies for making sense of such individuals whose experiences we do not understand. One such strategy is
devising, assigning and filling various categories, as a category contains a set of implicit or explicit rights, expectations, obligations and rules regarding how one should act and, subsequently, cues for how others should react to the person. In the case of “frailty,” the potentially confining parameters involved in experiencing “frailty” may predispose that person to being dependent. Enter doctors and other medical staff: doctors, nurses and nurses’ aides have the job of treating illness, which often necessitates—at the expense of the “frail” person—an abstract separation of the person from his or her body. This focus on the illness without regard to the person embodying the illness is then manifested in the medical professionals’ actions toward the person. Here I utilize the words of my informants and the words of selected authors’ narratives of their experiences to expand upon the aforementioned ideas.

*The Nature of “Frailty”: An Attribute Shifting with Time and Space*

According to my informants, “frailty” is an attribute, a label—even a state—that can change or be negated by the presence of other factors that shift in relation to time, an individual’s situation, and personal agency. That is, a person who is “frail” can become “un-frail” by demonstrating physical activity, social engagement and “the right attitude.”

*Activity as a mediator.* “Frailty” is conceptualized remarkably similarly by the residents I interviewed at Park View, who perceive a “frail” person to be thin, physically and emotionally vulnerable, potentially cognitively impaired, dependent and devoid of energy. Mable—in referencing the wing of Park View designed specifically for individuals with cognitive impairment—describes the residents who live in the so-called “cool down room” of the building as needing increased assistance and support. When I asked her if she thinks these residents are “frail,” Mable says

Ah—I don’t think so. Huh uh. I just talked to one today. They walked her down so she could play Bingo. And uh—she was dressed nice in her own clothes. And uh—ah—I reached over and touched her and she knew who I was and—we went to school together and that’s what they—and ah—no I don’t think it’s anybody that’s frail.
Contrary to the idea that memory loss is a characteristic of “frailty,” Mable asserts that because this woman walked down—albeit with assistance—to an activity and was socially engaged enough so as to recognize a familiar face she is not “frail.” Susan, too, mentions the importance of activity and the inevitable social contact linked with activity as a determinant of avoiding “fraility”:

> Well one thing that helps with not being too frail physically is they try to, they keep activities for us. Stuff like that. And if you encourage people even if just the exercise video, or if when we do balloon volleyball, and stuff like that, and uh they bring in movies and we watch movies and stuff like that. So there’s a lot of uh—but there can be a lot of boredom. That—I think, that’s a BIG thing. Boredom, you know.

On the one hand Susan points out that “frailty” can be eclipsed by taking part in activities, often a combination of both physical activity and socialization, but on a deeper level she introduces a new degree of complexity to understanding “fraility”—that of boredom, even suggesting that the place itself induces “frailty” and further pointing toward one of the many overlapping factors that play a role in experiences of “frailty.”

Social engagement and the “right” attitude. While Mable asserts that she feels a person’s age is a major characteristic of “frailty,” she goes on to explain that age alone is not the only determinant of “frailty.” She describes a woman who, at 102 years old, goes down to the dining room to eat her supper each night. Essentially, even when a person outwardly displays “frailty”—whether it is a thin frame, excessive sleeping, dependency, and/or illness—according to the women I interviewed, “frailty” can be resisted or overcome by the presence of physical and social engagement and displays of autonomy to the best of one’s ability. Susan says it best when, in response to being asked whether or not someone who is frail can become un-frail, she says “All depends on their attitude.” She goes on to describe a negative influence of attitude by explaining an instance of learned helplessness she has observed in a fellow resident:

> Sometimes, sometimes if you (...) Instead of challenging them even just a little bit, you know, maybe if—we have a person who, you know with different people she’ll feed herself. But when this other—some people come around they don’t give her a
chance to do that, then I think that—I think that she can. But I don’t know I’m not that age.

Essentially, Susan is describing how “acting frail” is within an individual’s control, namely that one may choose to have a proactive attitude or an attitude of helplessness.

Frailty as a label for others. An overarching theme of transference of the descriptive term “frail” is evident in the dialogues of all three of my informants. Regardless of personal opinion, perception, situation, circumstance or value, my informants’ thoughts on “frailty” extend outward to apply to other residents living in Park View. Such is the nature of the use of the word “frailty”—a term applied to others.

Frailty: A Label by and for Others

Central to “frailty” are the ways in which we as humans identify and perceive “the other” in relation to ourselves. As an individual moves through life he or she perceives the self in relation to “the other,” a dichotomous relationship that is constantly changing. A state of “frailty,” which is likened to decline in or loss of physical ability to do for oneself, tends to be associated with individuals who are old, ill or disabled—in short, people who are at higher risk of needing some degree of assistance with activities in their daily lives. People who are not old, ill or disabled therefore tend to perceive those who do possess the aforementioned qualities to be “the other.” “Frailty” as a descriptor is a product of othering, is a way of organizing and making sense of unknown experiences and perspectives.

According to the nursing home residents I interviewed as well as the narratives I examined, characteristics associated directly or indirectly with “frailty” emerge as descriptors of others. Furthermore, othering appears to be a fundamental process to understanding “frailty” and its function within human relationships involving dependency. Even in the event that an individual him- or herself might belong to a group of people who are conventionally considered to be “frail,” such as nursing home residents, it seems that an element of othering still takes place—it is others in the nursing home, not I, who are “frail.” In the words of my informants and as seen in the literary narratives, adjustment of one’s perception of the other seems to occur with aging or onset of acute or chronic illness.
At this time a unique juncture is formed in which two contrasting worlds of past and present self collide, offering new insight and understanding of “frailty” from a vantage point at the crossroads of being “frail” and not being “frail.” Finally, in addition to attributing “frailty” to other individuals living in the nursing home, the residents I interviewed tend to other the “unfrail” staff members who care for them by referencing “they who tell me to do this, they who will not let me do that”—a kind of resistance in the tug of power relations, resisting the label of “frail” for the self.

*Othering fellow residents.* As Shield (1988) points out in reference to the nursing home in which she conducted ethnographic research, “… admission means that the old person is unable to care for himself given whatever outside resources he does (and does not) have” (p. 98). Assuming that “frailty,” as it is often conceptualized in the literature, entails a certain degree of inability to care for oneself, then all nursing home residents can be considered “frail.” However, in the face of such a seemingly logical conclusion, the residents I interviewed tended to conceptualize “frailty” in terms of a quality embodied by other residents in Park View. When I asked Mable what she thinks about “frailty” and being “frail,” her response indicates her close association of “frailty” with other residents living at Park View, not herself:

Some of ‘em are! Uh—most of ‘em are not, but uh—yeah that, frail, when a person gets frail and the family cannot take care of them, that’s where they come, they come into any nursing home is where they go.

Mable continues to explain her thoughts about “frailty” by referring to “they” and “them,” describing those who are “frail” as being a certain age or reliant on assistance to go different places in the nursing home: “We have one here that is um—102, I think. And she’s frail. But she goes down, somebody pushes her in a wheelchair. She goes down to the dining room and eats her supper.” Similarly, Betty frames “frailty” as a status belonging to others when she comments on the external, physical attributes perceptible to her: “Frailty (...) I call it like—elderly people, they sorta thin-like and they can’t do too much for theirself.” In response to being asked to describe what things make a person “frail,” Betty says, “Uh, being in the bed, and couldn’t get out. We’ve had a little woman next door here (...).” She shows her attribution of “frailty” to others—that being unable to get out of bed.
is a sign of being “frail,” and there is a woman next door who cannot get out of bed who is an example of someone who is “frail.” Likewise, Susan describes the woman living across the hall who recently experienced a significant decline in health to exemplify her ideas concerning who is “frail” and who is not. When asked about who is frail and what makes a person “frail,” the responses of my informants are, by and large, constructed on the basis of other people they know who are “frail.” “Frailty” is an attribute used to describe the known or visibly perceivable physical, mental and emotional conditions of others.

The way in which individuals deemed to be “frail”—deemed by those of us who are younger and healthy, that is—instead cast that label away from themselves and onto others is testament to the complexity of othering. “Frailty” is a way for people to make sense of others who are not like them or, in some instances, distancing themselves from others they hope not to be like someday.

Juncture of past and present self. To take this concept a little deeper, othering also implies, to a certain extent, a hope that one will never “get there”—a sort of denial and warding off a state that might be in one’s future, a denial of what Markus & Nurius (1986) call the “feared self” in their concept of possible selves. Whether or not those who are not old, ill or disabled can truly know what it is like to have a debilitating illness or a chronic health condition may be questioned; however, as Hillman (1999) points out concerning aging, one cannot know what it is like to be old until we ourselves are old, until we ourselves have “gotten there.” The self becomes what previously was the other, and vice-versa:

Aging opens the door to “old,” and old age opens it yet wider. That could be its point. Can we know the world’s oldness or enter into the character of anything until we are ourselves old? That the old are burdened with wisdom means that they know the ways of the world because they are old, as it is. They share the same state of being. (p. 45)

Hillman, whether intentionally or not, is describing the intricate dynamics involved in othering—that one cannot know until one is. Betty shows how she views “frailty” in relation to herself, as a state that she knows she will soon be in but is not there yet: “So I know I’m about to be getting that way because they won’t let me get up without one of
them things that lifts ya up.” Betty’s words demonstrate her current separation of the self and the other, while at the same time she is aware that her self will soon become the other; she knows this because the number of activities she can do on her own is increasingly limited.

Even when one *is*, though, a cognitive adjustment of reframing who is and who is not one’s other takes place. Sarton (1991) demonstrates her adjustment in reflecting on her age:

What is it like to be 70? If someone else had lived so long and could remember things sixty years ago with great clarity, she would seem very old to me. But I do not feel old at all, not as much a survivor as a person still on her way. (in Fowler & McCutcheon, p. 5)

Sarton is touching on a process of aging, indicating that age is only marker of “frailty” but merely one factor among many. Such is the complicated and—at times—seemingly contradictory nature of othering: individuals’ perception of the other is constantly changing with shifts in time, space, social context and own condition. Sarton demonstrates the shift in her identification with age—and implicitly her changing views of who is old—when she says that at one time she believed that 70 was quite old. Now that she herself is 70, her prior perception of 70 as being old no longer holds true for her.

Having been met with disability after a minor stroke, Sarton later describes the understanding she now acknowledges, her newfound ability to empathize with others’ experiences she previously did not know. She now identifies with individuals who previously constituted “the other,” individuals afflicted with illness: “Having a disability has a good effect. I am far more aware of and sympathetic about the illnesses some of my friends are struggling to surmount than when I was well” (1988, p. 31). Othering is a fundamental aspect of humans’ need to make sense of their worlds and, in times of gradual or sudden change, some individuals—like Sarton—find themselves at a juncture between two abstractly separate worlds of the self and the other.

Similarly, Murphy, in his auto-ethnography that details his journey into disability resulting from a spinal cord tumor, describes his experience at the eye of two contrasting cultures that simultaneously take the shape of both his self and the other as he copes with his new life as a quadriplegic:
The [disabled] individual has also been alienated from his old, carefully nurtured, and closely guarded sense of self by a new, foreign, and unwelcome identity. And he becomes alienated by others by a double-barreled mechanism: Due to his depreciated self-image, he has a tendency to withdraw from his old associations into social isolation. And, as if in covert cooperation with this retreat, society—or at least American society—helps to wall him off. (p.108)

Murphy touches on feelings of alienation exuded by those in society who are not disabled; thus, he further exemplifies the confusion individuals may perceive when they do not know or understand the experiences and ways of another, seemingly very different person. Someone who embodies the “other” is difficult to understand and, as Scott-Maxwell (1968) explains, concerning herself as an older person with health ailments often evokes a fear response in those who are not old and unwell:

With one friend of my own age we cheerfully exchange the worst symptoms, and our black dreads as well. We frequently talk of death, for we are very alert to the experience of the unknown that may be so near and it is only to those of one’s own age that one can speak frankly. Talking of one’s health, which one wants to do, is generally full of risks. Ill health is unpleasant to most healthy people as it makes them feel helpless, threatened, and it can feel like an unjustified demand for sympathy. (p. 31)

Scott-Maxwell is alluding to a sense of uneasiness felt by those to whom old and ill individuals are “the other” because they themselves have not yet “arrived” to such a status, if and when they ever should at all. The notion of individuals in old age constituting one’s other is perhaps unique in that most people can expect to eventually be old, to be the other. On the contrary, “frailty” seems to be rejected as a possible future self.

Nonetheless, Scott-Maxwell recognizes this uneasiness when she describes the experience of older people with disabilities as an experience that tends, at times, to be intentionally concealed so as to avoid the awkward and misunderstood situation in which young, well people feel threatened by their lack of understanding. She says

Few believe in the pains of another, and if the person in pain has nothing to show, can forget the pain when interested, then where is the reality of it? In one’s self,
where it ought to be kept I suppose. Disabilities crowd in on the old; real pain is there and if we have to be falsely cheerful, it is part of our isolation. (p. 32)

Scott-Maxwell is speaking of how she perceives the relationship between those who are old and disabled and those who are not—a relationship similar to that in which the misunderstood condition of the “frail” person necessitates adoption of a façade more comfortable and familiar to the individuals who are not “frail” and do not know what it is like to be “frail.” Betty, at times, exemplifies such false cheerfulness when she says, “I just smile.” In other words, as a way of mediating the gap in our knowledge about those who constitute our “others” we implicitly or explicitly devise categories into which we neatly fit others we have decided display characteristics that match such categories—categories that lend some semblance of understanding to that which is unknown to us and in turn guide our own actions toward and with people we perceive to be unlike us. The category of “frailty” seems to apply to people who are either old, have any number of health issues, or are physically or mentally disabled—or any combination of the above.

**Othering of staff.** In a nursing home like Park View, residents are either old, ill or disabled and likewise may “other” the staff members with whom they are engaged in social interactions as a way of psychologically separating themselves from the physical state of their bodies for which they are being treated, assisted and cared. Common within all three of my informants’ discussions of their lives at Park View and their perspectives on “frailty” is an apparent depersonalization, or othering, of medical staff—including doctors, nurses, and nurses’ aides. Such othering is illustrated in the women’s consistent references to “they” when describing their circumstances and happenings of everyday life and the individuals that play some sort of role in them. “They,” whether intentionally or not, construct “frailty” through rules, regulations and practices. Interestingly, my informants also hold “them”—the doctors and nurses—in high regard, trusting their decisions concerning their own health and well-being.

Aside from discussing how “they” ration her medication and how she “might as well say she likes it,” Betty describes how others express concern over her ability to walk, mentioning that “they” said certain things that reinforce for her what she can and cannot do and that “they” will no longer let her do particular activities:
(...) And, and then I got to where I fell quite a bit. And—and they say “We’re afraid you’re gonna fall and break a hip. ‘Fraid you’re gonna fall and break a hip.” I said I haven’t broke a hip yet on that cement. And—but they won’t let me go without a walker.

Whether or not Betty’s use of the pronoun “they” to refer to medical staff is indicative of anything more profound than mere simplification of everyday speech (i.e. potentially pointing toward a way of othering people who hold a degree of implicit and explicit institutional power over her) is debatable. Nonetheless, the way in which Betty perceives herself in relation to the medical nursing home staff in her environment is evident in the way she discusses their place in her daily life and larger circumstance. The medical staff imposes limitations on Betty’s range of activities, and though she does not seem to like it, she also undermines herself and her competence in favor of the expertise of her doctors and others who presumably know what is in her best interest.

Mable, in sharing the coping strategies that help her keep her independence and autonomy intact, exemplifies another way of othering the staff when she says

I do have the shakes they call them. But that comes from [motor skill impairment disease]. And it’s this way. And … uh … I have trouble with my fork and spoon, eating, but uh … nothin’ bothers me. No, nothin’ bothers them. And if I want something to drink I use two hands on it, instead of one hand, and I have to lift it up like that. Cause if I have one hand then I slop it, because I don’t have the control of it.

Mable references others’ crude evaluation of her physical health and immediately follows it with an explanation of how she has adapted, thereby defending herself from others’ uninformed assumptions about her ability. In a sense, Mabel is referencing “they” who have decided what to call her health condition and resisting the notion that “the shakes” will prevent her from eating.

“Frailty” is a category intended for others—a category based on the outward appearance and the demonstrated ability of people separate and different from ourselves to function independently—that substitutes bits and pieces of information and assumptions to make sense of such others. Othering is many-layered and involves constant adjustment depending on the individual, time and social circumstance. More importantly, though,
othering is personal, such that in the case of “frailty” even people who seem to fit into the category of “frail,” as per the widely variable literature sense of the word, do not necessarily incorporate “frailty” into their own self-identity—instead projecting it to other people they feel are more “frail,” possibly, than themselves.

The Experience of Being “Frail”: Balancing Resistance and Acceptance

Being “frail” is extraordinarily complex and involves a cautious balancing act between assertions of independence and acceptance of dependence. Underlying the balancing act inherent in “frailty” is worry over becoming a burden to care providers, perhaps because being a burden signals total dependency, to such an extent that the “frail” person becomes viewed as a problem. In essence, the experience of being “frail” is very much affected and shaped by a strong societal focus on maintaining and displaying independence. Both my informants and the voices within the literary narratives report as significant in their lives a sense of being a burden and the ever-present need to balance independence and dependence.

Being a burden. With increasing dependence, people who are old, ill or disabled report not wanting to be a burden to others. When I asked Mable during our interview how she was feeling, she launched into a story of her family’s activities—activities of which she frequently feels left out. In her narrative Mable shifts back and forth between admitting her desire to be included while simultaneously discrediting those feelings, noting that her inclusion is likely to become an unnecessary burden on her family, who has numerous other obligations. Her concern with not being a burden is evident in the following passage from her interview:

The only thing that makes me feel left out is I have a daughter that, um, has a van that will hold seven. And they had made a, a ramp that will go to the front door. And that is fine. But I don’t get to go very often. Maybe, once a month. And sometimes not that. But I know she works. She works at a school. And—and she’s got laundry to do. She has mine and hers. And uh. I said, I know things are there that have to be done. But still I, I just feel—left out.
Mable is aware that she may be perceived as a burden by her family and, despite her strong need for continued inclusion in family events, she downplays her feelings of being left out by acknowledging the obligations and busy-ness of everyone else. Florida Scott-Maxwell (1968) expresses a similar concern; she says

> Another day to be filled, to be lived silently, watching the sky and the lights on the wall. No one will come probably. I have no duties except to myself. This is not true. I have a duty to all who care for me—not to be a problem, not to be a burden. (p. 31)

Important in Scott-Maxwell’s worry over being a burden is the way she likens dependency to a problem—and not just a problem in and of itself but *internalizing* her sense of being a burden so that *she* herself is the problem, not the dependency. Later, in reflecting on her nursing home stay following surgery, Scott-Maxwell again discusses her fear of becoming a burden. She worries “what if I became an invalid? What if I became a burden, ceased to be a person and became a problem, a patient, someone who could not die?” (1968, p. 91). To cope with “walking the tightrope” and avoiding being a burden, she describes the “somber nursing home dance” in which she followed the steps she knew, in effect acting a sort of frail person role: “I must conform. I must be correct. I must be meek, obedient, grateful, on no account must I be surprising” (p. 91). It is evidently by these means that being perceived as a burden may be avoided—or, arguably, *feeling* like a burden may be avoided.

*Negotiating loss of independence.* Herein lies a critical aspect of the role of being frail: even within a group of people who are all considered “frail” by academic and professional standards, such as those residing in a nursing home, American society’s value of independence prompts individuals to whom independence is limited to seek it in whatever unique capacity is possible. Being frail is a condition that does not fit neatly within the strong, culturally American focus on maintaining independence—Independence that is achieved often, though not always, by way of activity. As Simmons (2000) mentions, “we equate doing nothing with idleness, and we all know idle hands do the devil’s work” (p. 118). Indeed, asserting independence in whatever way one is able to do seems to be of utmost importance to individuals who are increasingly dependent.
In the following passage Shield (1988) illustrates “The Good Resident” role that “Franklin” nursing home resident “Ida Kanter” holds as a means of maintaining her independence:

She wears a staff card that reads “Sunshine Committee” and is always cheerful and energetic. She needs to stay busy, she says, and furthermore, it makes her feel good if she can visit some of the sick residents “on the other side” and cheer them up a little. So every day, if she feels well, she walks over to the new building, and makes her rounds, welcoming new residents and cheering up the sick ones. She considers herself a social worker; “better than some of them,” she maintains. (p. 164)

Ida shows her independence by being active and by establishing her ability to help other residents, residents she believes are in worse condition that she. In Park View, Betty holds a “good resident” role similar to that of Ida in that she has designated a duty for herself to regularly visit the sick residents, many of whom are receiving hospice care:

And, the lady down here and she passed away. And I got friendly with this other lady that was 107—and she has just now passed away and I said I must do something that causes them to die, but it isn’t I know that. And—but uh—she was on the other floor, up that a way, and uh went three times a day to see her…. And I said well I’m going every day, I don’t care what goes. And, so, I went.

In line with the previously discussed theme of an ever-present balancing act, Betty is in a sense proclaiming her independence by proving how important her role is in Park View, particularly the extent to which she is needed by others who want to see a smiling face. Gubrium (1975, p. 119) similarly describes what he calls the “supporters” in Murray Manor: “(…) a person who is socially tied to another by the offer of voluntary assistance.” The supporters routinely reach out toward and intervene on behalf of fellow nursing home residents who they feel need help.

In their efforts to maintain autonomy under circumstances that by nature limit it, individuals find other strategies for exerting personal agency and resisting being called “frail.” Such strategies may include reaching out to others who are perceived to be in a worse condition, as demonstrated by Betty in the above passage, or amending one’s attitude and outlook. Susan, who is not old, speaks of her personal credo that helps her get through each day, doing what she can to help herself. Her physical effort and mental
commitment to warding off dependency mutually translate into her personal code of independence, which she inevitably portrays to others in the nursing home:

I think, I think a lot of it has to do with how young the spirit is. You know? And if you’re, if you’re uh—if you’re uh—I—I came up with a motto for myself recently. If God gives me another day, each, each time he gives me another day I’ll do my part. So I figure that- that’s pretty good.

Although she may be perceived as “frail” in the amorphous, devoid-of-personal experience sense of the construct present in aging literature, Susan alludes to her acceptance of what she can do rather than focusing on what she cannot do. Her internal resonance communicates to those at Park View who are ready to assume she is unable to do for herself that she is independent because she has chosen to live that way. Susan does what she can and, more importantly, she has made up her mind not to accept help for whatever she is able to do herself.

Striking a balance. The American core value of independence is at odds with encroaching dependence associated with “frailty,” a situation that creates a constant give-and-take between asserting oneself and accepting help. Navigating her changing physical ability with an eye toward others’ perceptions of her, Scott-Maxwell (1968) describes her experience of growing older. Her words are wrought with a keen awareness of how her status is perceived by others as she evaluates her personal agency and maintains a role of appearing as able as possible:

The crucial task of age is balance, a veritable tight-rope of balance; keeping just well enough, just brave enough, just gay and interested and starkly honest enough to remain a sentient human being. On the day when we can boast none of this, we must be able to wait until the balance is restored. When we sink to nothingness we must remember that only yesterday our love was warm. (p. 36)

Here Scott-Maxwell starkly illustrates, though somewhat facetiously, her perceived association of frailty-related dependence with loss of humanity, loss of ability to experience and exude warmth and love. She also tells of the almost surprising onset of the effects of frailty despite careful attention to maintaining a balance between her formerly independent self and her dependent self that is rapidly coming into focus. According to
Scott-Maxwell, old age is equated with nothingness when it reaches a point when dependency is unavoidable.

Continuing to assert independence is particularly difficult in a nursing home where, by the very fact of living there, residents need some degree of assistance and are largely considered “frail.” My informant Betty demonstrates the way in which she struggles to assert her independence when it is increasingly limited by Park View staff. She says

So—I know I’m about to be getting that way because they won’t let me get up without one of them things that lifts ya up. Oh I hate them with a passion—those um—stand-up things that lifts ya up. They lift me up outta bed and they take me to the bathroom and they lift me up and put me on the commode. And lift me off of it and put me back on the chair. That bothers me a whole lot. Cause I wanna, I don’t wanna do that. I wanna get up and down by myself and I can’t.

To counterbalance this potential threat to her personal agency, Betty has assumed a routine within the nursing home in which she pays visits to other residents and presents a happy face to staff and to others. Potentially in this way Betty exhibits her “independence” in the face of dependence, striking the very balance referenced by Scott-Maxwell. It is in this way that old, ill or disabled individuals seem to resist frailty and dependency, off-setting their potentially apparent “frail” presence by demonstrating personal agency and competency.

Sarton (1996, p. 27) also speaks of the independence-dependency balancing act, as she illuminates here in the following passage from her book At Eighty-Two: “Later, while I lay down after lunch, I thought that one difficulty is the balance of accepting dependence and at the same time not giving in, doing everything possible for oneself.” Avoidance of dependency—or at the very least keeping it at bay—is at the root of efforts to maintain independence. Such avoidance may invoke a startling realization that previously taken-for-granted activities now mandate careful weighing of one’s ability and various forms of adaptation. Betty explains her encounter with this reality and her frustration when she says, “I can’t go to the bathroom without being on a lift. It aggravates me to no end. That someone has to wait on me.” An activity as ordinarily private as going to the bathroom is no longer a private activity for Betty due to her physical inability to safely manage the routine on her own; her annoyance with such a circumstance is paramount.
Day-to-day frustrations resulting from relying on others or simple exhaustion from determination to do for oneself regardless of the condition of one’s body play a vital role in the balance between asserting independence and resisting dependency. Such frustrations make it difficult to continue to be independent, testing individual determination and confidence. My informant Susan remarks on the active life she has always led and the difficulty she has experienced in trying to remain active in the face of illness while living at Park View. She says, “I was a very active person, still am—*trying* to be.” Susan proceeds to explain the contradictory nature of trying to nurture her health back to normal by way of staying active—and thereby independent—while simultaneously contending with her doctor’s orders to remain off her feet to prevent swelling:

Well, it’s a catch-22. The doctor, cause I was getting frustrated, ya know, and the doctor said “Well, keep your, you gotta keep your feet and legs up.” But at the same time, you gotta—haha—be active in order to, keep the keep things moving keep the blood flowing!

By taking her doctor’s directions in stride and remaining committed to her need for activity, Susan is able to maintain a sense of independence despite currently living with a medical condition that to a certain extent limits her mobility. Important in Susan’s words, however, is an underlying recognition of her doctor’s perspective of her health as being different from her *own* perspective of her health. Sarton (1988) expresses a similar sentiment indicating her recognition of a discrepancy between her opinion and the opinion of her doctor when she says,

(…) Dr. Petrovich came in. Yes, I have to take the pill or have another stroke. The hardest thing psychologically to take is that he does *not* believe this drug makes me sick. He insisted it was the fibrillation that did. (p. 73)

Sarton’s experience contending with her doctor’s orders that diverge from what she feels she knows and understands about her own body wear down her morale and her ability to cope with her stroke recovery.

In Havemann’s (2002) experience with Parkinson’s disease, the effects of increasing disability permeate all areas of one’s life and contribute to dependency. He alludes to divergent perspectives between himself and healthy others, noting that
As symptoms accumulate, adjusting to them becomes progressively more difficult. We become dependent on others to help us do things that healthy adults take for granted—buttoning a shirt, changing a lightbulb, even getting out of bed and feeding ourselves. Our energy deserts us; the smallest chores tire us out. The disease colors the most routine of decisions. (p. 118)

According to Havemann, the experiences at the heart of “frailty” affect an individual not only physically but also mentally as one finds that stores of energy seem depleted and all decisions—big or small—must be evaluated with consideration to a new set of circumstances. Ironically, as energy plummets and daily chores become more difficult the apparent dependency of the “frail” person becomes ever more evident. Activities one used to mindlessly execute now require careful thought (what am I able to do, not only in terms of effort but also in terms of safety?) and often assistance. In line with Havemann, Sarton (1988) reflects on her return from the hospital following her stroke, also describing her physical and mental exhaustion from contending with household chores as “insuperable” (p. 29). She says “I am aware for the first time perhaps what courage it takes to grow old, how exasperating it is to no longer be able to do what seemed nothing at all only a year ago” (p. 31). In addition to mounting frustration, worry that one will become a burden plagues the thoughts of “frail” individuals.

As Scott-Maxwell says, being “frail”—or being perceived as such by others—is like walking a veritable tightrope. One wants to continue living as independently as possible, whether this is by making choices or having the energy to engage in daily activities, but the worsening physical state of one’s body works against this objective. A certain degree of dependency is often unavoidable but it is unwanted by someone who is “frail.” Such dependency is deeply complex and is both fostered and continued by the medical directive to treat what is perceived as a problem that is distinct from the person.

The Role of Physicians

Being “frail” seems to entail varying degrees of reliance on others, although grappling with a lifestyle that apparently runs counter to that which is looked upon approvingly in American society proves to be a rather startling and undesirable endeavor, albeit only during recovery from an illness or over the course of growing older. Since
“frailty,” as it is conceptualized in aging research and literature, implies the presence of any number of health-related impairments and difficulties, medical professionals are often involved in the management or treatment of such ailments—thereby setting the stage for trust in and extended reliance on physicians and perpetuation of dependency. The Park View residents I interviewed express varying attitudes toward doctors and medical staff, ranging from disgruntledness at the relative infrequency of and lack of advance notice for their visits to attribution of authority for “calling the shots” in terms of their own well-being. Furthermore, within the literary narratives is a tide of agreement on the extent to which physicians and other healthcare professionals—in their line of work—seem to lose sight of the person embodying the illness being treated. Attitudes toward physicians as well as a critical dichotomization of person and body on the part medical staff contribute toward a state of dependency among “frail” individuals—those who are old, ill or disabled.

**Attitudes toward physicians.** The ways my three informants feel about and toward the medical staff at Park View first include surface-level complaints concerning doctors’ visits. Susan expresses concern over the infrequency with which community physicians visit their patients in Park View, particularly when a resident’s well-being might be in danger due to depression that is detectable only by his or her family or doctor:

- Well—I think some people can get depressed. You know? I think, I think that there’s a lot more vulnerability to depression that maybe gets misdiagnosed as something else. You know. And and, sometimes when they’re older um—some are very talkative and some don’t talk hardly at all. You know. But uh, I think depression can be really subtle in an older person, you know? And uh, but that’s up to like family—and the doctors to know and—it helps if the doctors come in more than once a month. You know so they, especially if they’ve known the patient for a long time so they can see, you know, a person, if any changes, stuff like that.

Susan further explains how she feels all the doctors should visit more than once each month and should give their patients who reside at Park View advance notice of their visit. Underlying Susan’s remarks, however, is the idea that “frailty” and its various health and wellness implications are ultimately detectable and determined by doctors, not anyone else. She shows concern for a situation in which she perceives a gap to exist.
Betty more directly addresses the authority and trust she places in the hands of her doctors in her response to being asked if she thinks Park View is where she’s supposed to be right now: “Well, I’m here! And Dr. Johnson’s the one that sent me here. So I guess this is where I’m supposed to be.” When further prompted to explain what she thinks must happen for someone to be frail, Betty issues a disclaimer after her assertion that frail people sleep a lot and lose their memories—that, though that is her opinion, she is not a doctor and that “that’s just the way I feel. And what it would be like.” Betty, like Susan, seems to acknowledge that frailty is a term, a descriptor, a state of being that is best understood and rightly utilized by physicians—as such, they also imply that “frailty” is to a certain extent measurable by those with expertise. Betty additionally frames her feelings about living in a nursing home around the advice of and the decision made by her doctor—she is there, and the doctor put her there, so this must be the place she is supposed to be because the doctor would not put her somewhere she should not be.

Separation and dependency. While individuals seem to place authority in the hands of their physicians, their trust is often not quite as assured. Many times a discrepancy exists between the physician’s opinions of the person’s health and the person’s view of his or her own health, thereby generating feelings of being treated as a disease instead of a person with a disease. For example, Sarton (1988) questions her trust in Dr. Petrovich in light of what she perceives to be his separation of herself from her body:

Why do I trust Dr. Petrovich? He has been talking about electric shock for months. Is he just an experimenter with drugs? I do not feel I am being treated as a whole person or that he has the slightest idea what it is for me not to be able to work. (p. 64)

In effect, someone who is “frail” shifts, whether intentionally or not, into a state of dependency that is exacerbated by the duty of medical professionals to treat the illness, often at the expense of neglecting the self-hood of the individual to whom the illness is a daily facet of existence. Shield (1988) also talks about the gap between care provision and consideration of the person living in a nursing home:

(…) the work that nursing assistants and orderlies do on the bodies of Franklin residents goes on separately from considerations of the persons who inhabit those
bodies. Because the persons are effectively separated from their bodies, these procedures are promulgated as ends in themselves. (p. 101)

Embedded within the nature of medical care provision in nursing homes is a division of the person from the body being treated. Understaffing issues contribute to a busy work load for nurses’ aides who do not have extra time to spend relating to each resident as a person in addition to attending to their basic needs. Beyond an already present division of body and person in the care they receive, the dependent status of “frail” nursing home residents is intensified by the fact that opportunities for reciprocity with their caregivers is limited if not altogether absent (Shield, 1988). Shield speaks of the “layers of dependency,” noting “the basic fact of life in the nursing home is that residents receive care, and staff members dispense care. The lack of resources with which residents can repay staff members reduces their control and increases their dependency” (p.154). As such, nursing home residents are perpetually in a position of receiving—services, time, care, assistance, etc.—from others, of being dependent on and indebted to others.
Chapter IV

Conclusions

While much ambiguity surrounds conceptualizations of “frailty” in gerontological literature—including what it means, to whom it pertains, and the various implications of being “frail” (or labeled as such)—the voices of my informants and the literary voices I examined lend clarity to the conceptual muddle concerning what “frailty” is, demonstrating how it develops within a social and interpersonal context and what it is like from the perspectives of individuals who are themselves categorized as “frail” in the literature.

“Frailty,” in and of itself, is relatively meaningless in terms of my informants’ self-perceptions and to the individuals whose personal narratives I examined. The frequent reference to “frailty” in aging research as a way to describe older adults—their appearance, competency, status, health, etc.—is indeed so problematic because it implies a global experience. Being “frail” is not really about “frailty” at all, but the day-to-day personal experiences of individuals coping with various life circumstances that put them in a position of being dependent, feeling like a burden, and making sense of their changing self-views. More salient and rich to my informants than the global experience implicit in “frailty”—the assumption that all “frail” people can be lumped together and uniformly categorized to have the same needs, perspectives and abilities—is the constant push and pull of not only finding but also maintaining a balance between asserting independence and accepting dependence.

In my data and the literary narratives from which I draw, “frailty” appears to be an attribute created by and for others—not owned by individuals themselves—and despite the fact that I ultimately introduced the term in my interviews, my informants did not describe themselves as “frail.” Attributing “frailty” to others may help those of us not “frail” to make sense of unknown experiences and create organizational categories of the environment around us. In other words, “frailty” is a socially constructed concept—we use it to describe others, to organize and predict human behavior and competency—but most importantly, the meaning of “frailty” changes shape depending on the individuals involved (and their respective experiences). Interestingly, our application of “frailty” to others also may help us ward off or reject a status of dependency that we—as scholars,
professionals, nursing home residents, as people—hope will not one day characterize ourselves. When a person’s independence is in any way limited, whether in terms of physical health, mobility or decision-making, avoiding dependence becomes a priority in daily life. Signs of dependency to the outside observer may be eclipsed by specific efforts to assert independence—such as Betty’s routine of paying visits to sickly fellow residents—or conscious decisions, such as Susan’s commitment to herself to have the right attitude. These acts of independence frame individuals’ self-perceptions and, in turn, they reject the idea that they are themselves “frail.”

A major aspect of the experiences of my informants and the narrative authors appears to be the loss of physical ability to independently engage in daily activities, which is often a result of various health concerns. As such, physicians and other medical professionals are necessarily involved in their lives, although the medical paradigm’s mandate to treat illness and disease often interferes with acknowledgment of the person embodying what is perceived to be illness. Such an oversight propagates feelings of dependency. To reiterate Kaufman’s (1994) earlier conclusion, medicalization and autonomy are at consistently at odds with each other. In other words, because “frailty” is so often perceived as a medical “problem,” an individual whose physical being is to some extent under the care of physicians is assumed not to be able to make the right decisions regarding his or her care, let alone actually independently provide such care him or herself. Dependency is perpetuated in this relationship regardless of the individual’s assertions of independence. For example, Susan remarks that her doctor’s orders to keep off her feet is contradictory to both her personal inclination to be active and her doctor’s other line of advice that activity will increase the circulation in her legs, thereby aiding recovery. Susan knows what she needs to do to hasten her recovery, but at the same time she perceives her doctor to be an expert in the illness affecting her and, as such, is partially dependent on her doctor’s recommendations.

“Frailty” is complex and amorphous; it assumes a different shape depending primarily on the individual(s) involved, but also on time, space, perception, social context, condition of the body, and even the presence of and characteristics of a support network. With so many interacting facets involved in experiences of “frailty,” the potential exists for
much further research investigating the role of any or all of the above factors on the meaning and nature of “frailty.”

Limitations

Researchers interested in further exploration in this area might learn from a few of the recruitment and sample-related limitations in my study, such as the small number of one-time interviews and the absence of the voices of nurses’ aides. Furthermore, the very fact that I am calling into question the use of the word “frail” inevitably subjects to scrutiny the perceived “frailty” of my informants.

Recruitment

An important limitation in my study is the content of my sample—three individuals, all women, all Caucasian. In future studies seeking to capture nursing home residents’ perspectives on “frailty” and what is salient, researchers might want to expand their recruitment efforts to include several nursing homes. In this way, the researcher may more easily select a purposive sample of informants that offers a breadth of perspectives that cut across gender, race, age and health status characteristics. Furthermore, conducting multiple interviews with each informant—as opposed to the single interviews I conducted in my research—would yield a more in-depth understanding of the experiences important to each individual whom we, as researchers, tend to call “frail.” The inclusion of either more informants or more interviews with each informant—in essence, gathering more data, having more text—would better allow one to discuss themes and patterns in the informants’ words, rendering unnecessary a strategic turn, such as mine, to literary narratives. With repeated interviews and attention to other integral individuals involved in the experience of “frailty,” perhaps a deeper understanding of the experiences that are meaningful to those we call “frail” might emerge, offering a more comprehensive understanding of the way “frailty” is socially created, utilized and maintained by and amongst individuals.
Nurses’ Aides

As my intent in my research was to capture perspectives on “frailty” from within a caregiver-care receiver dyad in a nursing home, I remain committed to the idea that exploring “frailty” from such an angle might uncover another layer of the dependent relationship embedded in notions of “frailty.” Many feasible explanations likely exist regarding my difficulty in recruiting certified nurses’ aides (CNAs) for my study. The nature of nurses’ aides’ work and the amount of free time available to them, their respect and appreciation within an organizational hierarchy in a nursing home, job security and commitment, and non work-related familial obligations and stressors are only a few possible explanations for why the CNAs I attempted to recruit did not indicate interest in participating in my research. Additionally, despite my continual reinforcement of the emptiness of “frailty” as a descriptor, the word does have a negative connotation and, as such, “frailty” may be viewed as a sensitive subject to discuss—particularly to CNAs who perceive that their actions with and toward nursing home residents might be under scrutiny by an outside researcher whose motivations and allegiances are largely unknown. Fear of losing one’s job by participating in a study that might a) expose one’s own manner of care toward residents or potentially falsely portray it in a negative light or b) lead the nursing home administration to believe that one is painting a negative image of its facility are quite possibly enough to have discouraged CNAs from participating in my research. The multitude of structural factors that might have created a barrier to CNA involvement in my study are a case for further investigation in and of themselves.

The “Frailty” of my Informants

Finally, an overarching sampling-related limitation in my study is the possibility that the individuals I interviewed—because they were able to be interviewed at all—are to some extent “less frail” than others living in Park View. Supposing that Betty, Susan and Mable are, in fact, “less frail” (although even here I question what “less frail” means), then perhaps that is why they so consistently engage in othering fellow residents who they deem to be “frail.” While I do not know how “frail” my informants are—and really, is there any way to know this anyway, given that “frailty” is about individuals’ experiences and any
empirical measure of “frailty” largely ignores such experiences?—I can only acknowledge
that this is a limitation that might be cause for me to turn a new lens on my data or to
prompt further consideration in future research.

Discussion

As othering is a significant foundation involved in better understanding “frailty,”
the extent to which one may ever truly know the experience of another individual
inevitably comes into question. Researchers in the phenomenological paradigm speak of
the researcher as instrument and the process of indwelling, or “living within” (Maykut &
Morehouse, 1994, p. 25), as a way of attempting to acquire the insiders’ perspective.
Inherent in indwelling, however, are inescapable biases and assumptions that color the lens
of the researcher as instrument and are simultaneously an asset and a detriment to the
qualitative research process. Similarly, while my informants speak of their experiences
with and perspectives of life in a nursing home and their thoughts on “frailty,” the vast and
unique histories that have shaped each of their perspectives must be considered with regard
to the information they have shared with me and that I, in turn, share with you.

Through the process of my qualitative research on the meaning of “frailty” I
encountered several personal assumptions, of which the effects on my research may be
elusive but that nonetheless call for acknowledgement. When I initially began
brainstorming ideas for my research I was struck by the way the words “frail” and “frailty”
have come to permeate the language and images surrounding older adults. While I noticed
both lay people and professionals in the field of aging use these words perhaps
unthinkingly, their dominant presence in the aging literature as key characteristics of older
people being studied piqued my interest and concern. However, much to my surprise and
dismay, when I began formulating my research questions I found that I, too, had fallen in
to the trap of conceptualizing “frailty” as an inherent quality of old age. I assumed that I
could ask nursing home residents to talk with me about their thoughts of “frailty,” in effect
assuming that “frailty” was a concept on their minds in the first place because they are old
and living in a nursing home. How might my research have been different had I not
identified this assumption, instead waiting to see if “frailty” was at all important to my
informants before I imposed it on their dialogue? I invariably would have acquired rich
data on “frailty,” yes, but my data would have been devoid of the insightfulness of considering who I was speaking to, why I was speaking to nursing home residents, and what I was presuming to know about their realities based upon my own perspective as a young, able-bodied individual whose (then) only view of “frailty” was a reflection of the message portrayed in gerontological literature—the message I am calling into question.

“Frailty” is about individual experiences, not a global experience that seemingly “captures” the daily perspectives, struggles and triumphs of those we as researchers tend to call “frail.” Perhaps this is why “frailty” is infrequently—if at all—an identity that is chosen by individuals.

Two significant sample-related issues are present in my data and beg further discussion. First, what exactly is the relationship between age and “frailty,” as it is so casually applied in gerontological literature and by aging researchers and health professionals? My sample includes Susan, a middle-aged woman living in a nursing home. I chose to include Susan as one of my informants because of her age, first because I did not want to impose my assumption—an assumption that is additionally reflected in literature—that only older people are “frail,” and second, because I recognized a discrepancy between the academic conceptualization of “frailty” being applicable to individuals living in nursing homes and the simultaneous academic assumption that frailty is a characteristic of old age. In this way, Susan is a sort of anomaly and the perspective she provides on “frailty” is one I intentionally sought to include for that reason. How do we—researchers, physicians, anyone—make sense of someone like Susan, someone who seemingly contradicts the schemas we have created for the prototypical nursing home resident, the prototypical “frail” person? Even Susan gives the impression that she believes there are age-related differences affecting what it is like to be dependent when—in telling how a fellow resident allows staff to do things for her that at other times she is able to do for herself—she concludes that she ultimately does not know what it is like because she is not that age. Clearly age matters in perspectives on “frailty;” its significance is further magnified by my other informants.

Age frequently surfaces in the words of both my informants and the literary narrative authors. Both Mable (age 83) and Betty (age 79) mention age—specifically old age—to be one of many indications of “frailty,” although exactly what, to them, constitutes
old age is unclear (and technically whether or not Betty and Mable themselves are old). Is old age a quality that is typically seen in others, much like “frailty” is typically seen in others and not in the self? In other words, “no matter what age I am, there are other people who are older than me so therefore I am not old; I am not ‘frail.’” Betty says she calls “frail” “like elderly people,” though when I asked her if a younger person can be frail she remarks that it depends on how sick the young person is. Sarton (1988) frequently equates her recovery from stroke to being thrown suddenly into old age, in a sense implying that old age is a place for “frailty.” Age and its relationship to “frailty” is complicated, as evidenced by the scattered opinions and perspectives of my informants. This complexity is likely due to its socially constructed nature—“frailty” means something different to different individuals, each with their own sets of experiences and their observations of others.

Furthermore, what is the relationship between gender and “frailty”? Since dependency seems to be a core aspect of “frailty,” then perhaps a different set of standards valuing independence exists for men, standards that are obscured in my discussion of the “frailty” because I only spoke with women. My informants do not allude to gender differences in their interviews and consistently describe other female residents as examples of individuals who are “frail,” though this might be explained by the fact that the number of women residing in nursing homes is considerably larger than that of men—there are simply more women to present to describe. Nonetheless, I must wonder what I did not learn from those with whom I did not speak and contemplate the impact such knowledge might have on my understanding of “frailty.”

From where I now stand, I cannot make up my mind as to whether or not the word “frail” has strictly negative connotations. If “frail” is a label that is never actually owned by anyone but instead attributed to others, does it even matter whether its application implies a negative condition or inferior ability? My research reinforces an important question, to which I am not sure an answer exists: Who really has ownership over the words “frail” and “frailty”? Clearly, the label serves functions for multiple parties, both “frail and not frail,” as we see that it functions as an organizational category for making sense of others, our environment, and understanding how and to what extent to help someone who needs assistance. While an answer may never be agreed upon concerning
“ownership” of frailty—as there are so many actors with their own webs of meanings and perceptions of reality involved in its creation, application and identification—I stress the importance of simply stopping and considering what we mean and to whom we are referring when we describe someone as “frail.” I urge a keener awareness of the context of and the assumptions implicit within our use of the words “frail” and “frailty,” acknowledging that these words are so often mistaken as accurate descriptors of individuals whose vivid experiences are immeasurably more important and telling of their being than any operationalization of frailty can ever hope to be.
References


Appendix A

Consent to Participate

I understand that I am participating in a study on the health views of nursing home residents and nursing home staff and how they think about frailty. Jennifer Brunk from Miami University has explained the study to me. I understand that Jennifer will be interviewing me once in my current residence and will be audio tape-recording my interview. I understand that my participation is entirely voluntary and that I am free to stop participating at any time during the interview or the study. If I have any further questions or would like to talk more about this study, I can call Jennifer Brunk at (609) 335-0093. I also understand that if I have questions about my rights as a research participant that I can call the Office of Advancement of Research and Scholarship at Miami University at (513) 529-3734.

______________________________  ______________________
Signature               Date
Appendix B

Informational Letter

February 8, 2007

Dear ________________________:

My name is Jennifer Brunk and I am a graduate student in gerontology at Miami University. With the supervision of Dr. Lisa Groger, a professor in the Department of Sociology and Gerontology, I am working on a research project for my Master’s thesis.

You are invited to participate in my research study. The purpose of this project is to learn about how nursing home residents think about their own health and the health of others. What makes this study unique is that it is seeking to learn how nursing home staff and residents think about health and frailty. In this study I want to find out first-hand how different people in the nursing home environment think about frailty and what it means to them.

If you agree to participate in this study I will interview you in your current residence. I’d like to ask you what you think about your health, the health of others, and what frailty means to you. With your permission, I will tape-record your interview and it will take no more than one hour to complete. It will be scheduled for a time that is convenient for you.

Everything you say in the interview will be kept completely confidential. This means that what you tell me will only be shared with me and my faculty advisor Dr. Lisa Groger. Your real name will never be used in any written or spoken report of the study. Anything that you say that might reveal your identity and participation in the study will be disguised to preserve your anonymity. For example, if you happen to mention a personal name or location, I will change that name when I write my report. All of the data collected from this study will be kept in a secure, locked location in my office.

I hope that you will choose to share with me your opinions and insights. You are free to choose whether or not you wish to participate. Even if you agree to participate you can choose to stop participating at any time during the study. You can also stop the interview at any time.

I think you might find it enjoyable to share your experiences with me. Your willingness to share your knowledge and experience will help me to learn and understand more about the health views of nursing home residents and what frailty means to them.
Whatever you decide, I ask that you please return the enclosed addressed and stamped postcard indicating your decision. If you have any questions about this study please feel free to call Jennifer Brunk at (609) 335-0093 or Lisa Groger at (513) 529-2914.

Sincerely,

Jennifer Brunk
Appendix C

Interview Schedule

• How do you feel today?
  - Is that why you’re here?
  - Does this keep you from living in your house?

• Do you think this place is where you are supposed to be?

• What do you think about your health?

• Some people talk about frailty as something that is related to being old. What do you think about this?

• From your perspective, what does becoming frail mean? Can you give me an example? What makes that person frail, in your perspective?

• Do you know a frail person? Please describe that person for me.

• What is it like to become frail, from your perspective?

• What do you think makes someone frail?

• What has to happen for a person to be frail?

• Can a frail person become unfrail?

• What are some characteristics of someone who is frail?

• What does a frail person look like?

• In your opinion, what do you think it is like to be frail?

• Is a frail person able to make decisions?