VOICING CARE: DISCOURSE, IDENTITY, AND THE MAKING OF FAMILY CAREGIVERS

by

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Abstract

Voicing Care: Discourse, identity and the making of family caregivers

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Caring for a loved one was once considered a family matter – invisible work nested within the private sphere of home. Current advances in medical technology, altered illness patterns, extended life spans, and changes in traditional family structure have rendered family caregiving increasingly visible. Psychological/ medical literatures on family caregivers have traditionally focused on caregiver stress, strain, and burden; however, people actually experience caring for loved ones as part of a lived life. Research tools and perspectives that reflect the embeddedness of caregiving in social life are urgently needed.

This qualitative study is based on the construct of caregiver voice. Voice is the manifestation of a given orientation toward caregiving and is used to explore the ways in which family caregivers create/negotiate/ understand the caregiver role through their interactions with others. Three caregiver voices are discussed: Caregiver as Patient, Caregiver as Kin, and Caregiver as Advocate. Each voice represents a different conceptualization of the family caregiver as it emerges from the intersection of historical influences, social organization, cultural meaning and personal experience.

Utilizing multiple read method (Brown, Debold, Tappan, and Gilligan, 1989) informed by positioning theory (Davies and Harré, 1990), the study explores the patterns and positionings of these three voices as they emerge through the exchanges of a virtual support group for family caregivers. Posts made by group participants over a 6-month period (N=138) are analyzed for levels of caregiver labeling and identity, and for the presence and prevalence of the three caregiver voices. Simple summary statistics are used to describe patterns of interaction between and across the voices. Finally, a conversational thread (an original post and eight responses to the post) is analyzed how the Patient, Kin and Advocate voices appear, disappear, overlap and counterbalance each other over the course of an exchange. Key findings are used to support voice as a useful construct in the study of family caregiving, and the utility of positioning theory combined with multiple read method in the examination of caregiver narratives. Implications for future research are discussed.

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There are only four kinds of people in the world:
Those who have been caregivers,
Those who are currently caregivers,
Those who will be caregivers,
Those who will need caregivers.

Rosalyn Carter (1996)

Caring for a loved one was once considered a family matter – invisible work nested within the private sphere of home. Over the past couple of decades, however, advances in medical technology, altered illness patterns, extended life spans, and changes in traditional family structure and dynamics have rendered informal or family caregiving and caregivers visible. There is an increased attention to what family caregivers actually do and how they do it. There is a growing awareness of the important roles they play within the confines of family and as part of an overtaxed public health care system. And there is a growing acknowledgment that those who care for critically ill loved ones need to be supported and sustained in their public and private caregiver roles over time.

Family caregiving is simultaneously an intimate relationship and a public issue, spanning psychological, social, cultural, economic, and political domains. The separate but related discourses that emerge from those who study caregiving and those who live it reflects this complexity, and further, reveals contradictory and overlapping conceptualization of what family caregiving is. Psychological and medical literatures on family caregivers have traditionally focused on caregiver stress, strain, and burden; from this perspective, caregiving tends to be treated as a variable to be isolated (Brummett, et al., 2008; Cacioppo, Poehlmann, Kiecolt-Glaser, Malarkey & Burleson, 1998; Kung, 2003; Ratnakar, et al., 2008; Tran, 2008; Vitaliano, Zhang & Scanlan, 2003). The nursing, gerontological and AIDS research literature have suggested that there are other aspects of caregiving that are equally important: resiliency, mastery, spirituality, etc. (Bunting, 2001; Davis, 1992; Hall, 2002; Wuest, 2000).

Within the past decade, a new literature has emerged, generated by family caregivers themselves. Derived from the sharing of real life caregiver experiences, this caregiver literature is created and disseminated through caregiver advocacy groups (e.g. National Family Caregivers Association, National Alliance for Caregiving, etc.), memoirs and self help books written by and for caregivers (e.g. The Emotional Survival Guide for Caregivers**,** The Fearless Caregiver, The Caregiver's Tale, etc**.**), online and face-to-face support groups (e.g., Empowering Caregivers™, Family Caregivers' Alliance) and the day-to-day conversations of caregivers talking caregiving. The hands-on research literature generated by caregivers for caregivers, in tandem with the professional literatures from medical, psychological and anthropological research reflect the need for more contextualized approaches to the understanding of caregiving – approaches that can inform the checklist approach commonly used in assessments and interventions (Reinhard, 2004; Toth-Cohen, et al., 2001).

In the research presented here, I seek to bring these assorted literatures together through the study of *caregiver voices* – what they sound like, how they're used, when and where they can be heard. *Voice*, as used here, is the manifestation of a given orientation toward caregiving. I offer three different caregiver voices that illustrate particular ways of speaking, thinking and knowing about caregiving: Caregiver as Patient, Caregiver as Kin and Caregiver as Advocate. Each voice represents a different conceptualization of the family caregiver as it emerges from the intersection of historical influences, social organization, cultural meaning and personal experience. Tracing these voices can reveal the processes by which caregiving is created and enacted from a variety of perspectives. This in turn can leads to a better understanding of the needs of informal caregivers, to the creation of targeted, meaningful interventions, and to the promotion of social changes that support family caregivers in what they do.

To support my discussion, I turn to a variety of different literatures and venues. The sources for my theoretical grounding include but are not limited to research literatures in psychology, anthropology, nursing and history, feminist philosophy, reports provided by assorted caregiver advocate groups, exchanges from Internet-based caregiver support groups and countless conversations with anyone wiling to share a story about caring for a loved one (see Appendix A for a breakdown of citations by literature base). The narrative data used for analysis is drawn from an online support group for caregivers that I have followed from its earliest stages for almost a decade.

The voices I describe were not created by a single individual, but they are used by individuals who add their own personal variations in tone and pitch. My ongoing research on virtual support groups augmented by real-life conversations with all sorts of caregivers (many of whom don't think of themselves as such) have taught me to listen for these variations, and for how different voices move in and out of hearing – even within the same utterance. They've kept each voice firmly in my ear, grounding my understanding of all the other literatures referenced.

In the next section, I present an overview of caregiving, and of the informal or family caregiver. I then move to the discussion of *voice,* describing the theoretical and methodological processes used to develop the construct. Three caregiver voices are introduced: the Caregiver as Patient voice, the Caregiver as Kin voice and the Caregiver as Advocate voice. In the analytical sections that follow, I present a subsection of an online virtual support group for caregivers, using the exchanges between members to trace the presence and prevalence of the Patient, Kin and Advocate voices. I then present an in-depth analysis of one of those conversational exchanges to illustrate how the voices work in context. My discussion ends with some final thoughts about what the voices have to offer family caregivers and those who study them.

I) CAREGIVING, AN OVERVIEW

Caring for others represents a special kind of human interaction that is both purely private and deeply embedded in the social life. It spans all levels of social organization from the micro to the macro. Caregiving as a phenomenon reflects the big shifts we experience over time, shifts that are historical, institutional, cultural and individual.

Caregiving puts us face-to-face with the big psychological question: *Where do I end and you begin?* It illustrates many of the core conflicts inherent in Westernized cultures like our own, e.g. individualism vs. collectivism, self interest vs. altruism, self vs. others. American culture prizes self-actualization; Americans are constantly being told that to “just go for it,” to “be all that we can be.” Psychologist Dale Miller (1999) refers to this as the *norm of self interest,* and sees it as a kind of self-fulfilling prophecy. We believe that it is human nature to put ourselves first, and that belief is reflected in the social institutions we create. Those institutions in turn feed into the social norms that shape our beliefs – and so, our belief in the primacy of self is reconfirmed (Miller, 1999).

If self-interest is truly the norm, what room can there be for caregiving? Psychologist/ethicist Alan Radley (1999) claims that in highly individualistic societies, the concept of compassion becomes extremely problematic:

> Even for those who have to care for sick members of their own family, there can be no assumption that giving up opportunities of furthering one’s own career will be met with accolades or even understanding from peers. And the health policy messages that blame individuals for behavior that leads to illness run the risk of backfiring in terms of garnering support from the healthy. [p. 177]

And yet we do care. Radley offers a crumb of hope: although Western individualism predominates in the discourses of health and illness, it’s not the only cultural viewpoint available to us; “the debate about moral and ethical features of health and illness takes place within the space created by these competing viewpoints (p. 181).”

Social psychologist Shelly Taylor (2002) takes one step further, claiming that caring for others – the tending instinct, as she calls it – comes as naturally to people as self-interest or aggression:

> Nurturance and caring are wired in to our nature…. Our nurturance and caring lives right alongside our selfish indifference and aggression. Sometimes the selfish side overwhelms the nurturing side, but often our caring gains control, and even if it does not eliminate the more base or violent tendencies, it can at least subdue them. [p.198]

Caregiving then is simultaneously the most “natural” and the most “unnatural” of human interactions – most certainly a ripe premise for psychological study.

There are other, more practical reasons to study caregiving, and to study it now. We stand at the intersection of technological, demographic and policy changes that are both reflective of and precursors to the way informal care is provided. Here are just a few:

- ***People live longer.*** Advances in medical technologies and in the understanding of disease processes have extended our lifespan. The U.S Census Bureau estimates that the population of people over 65 will increase from 38.7 million in 2008 to 88.5 million in 2050; the 85 and older population will increase from 5.4 million to 19 million (U.S. Census Bureau, 2008).

- **Illnesses tend be chronic rather than acute**; people now survive health crises that would have killed their ancestors. Caregiving therefore has been transformed from an immediate and time-limited response to acute illness into a process that can last years, decades, or even the course of a lifetime.

- ***Care is more complicated.*** Under managed care, hospital stays have become shorter, and more medical procedures are done on an outpatient basis. Aftercare becomes a real priority, as patients are expected to recover at home rather than in the medical institution. At the same time, medical innovation has led to new and complex technologies – technologies that now must be mastered by the caregiver. Today's caregivers therefore have a bigger, more complicated job to do than before.

- ***The care recipient is now the care consumer***. In the past, there was a common understanding in place: the doctor's role was to treat, and the patient's role was to passively comply with that treatment (Parson, T., 1951). Now, people are expected to research their medical providers and treatment options as if shopping for a car. As consumers of health goods and services, patients and their caregivers now have a different responsibility, a different kind of learning to master. The influx of health-oriented internet-based web sites means that health consumers potentially have greater access to medical information than they've ever had before. However, a corresponding framework is needed to help people evaluate and interpret the information they find. The flow of information has far outpaced the creation of these evaluative and interpretational tools, leavings us all with both more and less than we really need to become savvy health consumers.

The aging U.S. population, medical advances and technological innovations, the struggle to update medical policy to meet emergent and ongoing needs – all have implications for caregiving and for caregivers.

The Informal Caregiver

Who are informal caregivers? And what is family based care? From a statistical perspective, these questions are surprisingly difficult to answer. The estimated number of people in the U.S., who currently provide care for an aged, ill or disabled family member, significant other, or friend, ranges from 22.4 million to over 50 million[1]. This wide variation in estimated population is due to different approaches to data collection and reporting, but most importantly, to variations in criteria. For example, a recent policy brief issued by the American Association of Retired Persons Public Policy Institute reports that in 2007, there were 34 million family caregivers providing care at any given time, and that approximately 52 million provided care at some point during the year (Houser & Gibson, 2008). However, these numbers include only those adults who provide care to adults with limitations to daily activities, and they do not include caregivers less than 18 years of age. The difficulty in pinning down exactly how many people are family caregivers in the U.S. speaks to the wide range of caregiving scenarios, and to the multiplicity of the phenomenon itself. Who are family caregivers, and what is family-based care? It depends on who you ask, and how you ask.

From a conceptual point of view, these questions are easier to address. Pearlin, Mullan, Skemple & Skaff (1990) describe family caregivers as “providing help and assistance to relatives or friends who are unable to provide for themselves.” Gerontologists Walker, Pratt and Eddy (1995) use a similar working definition, but specify such care as outside the norm of family relationships, “occurring when one or more family members give aid or assistance to other family members *beyond that required as part of normal everyday life*” (emphasis added, p.402). Nurse/researcher Lynne Davis (1992) takes a more functional approach; the informal caregiver is simply defined as “the relative, friend, or significant other of a care recipient” (p.2.). She adds however the following criteria: a) care is given in the home/community, and b) the caregiving work is unpaid. Those who study geriatric settings (e.g. nursing homes) claim that family caregiving extends outside home and into the institution. They further suggest that while family care is unpaid labor, family caregivers are responsible managing the paid labor of others (Foner, 1994; Levine, 2002a; Walker Pratt & Eddy, 1995). To sum up, the informal caregiver may or may not be defined in relation to the care recipient, may or may not be working from home, is almost always defined in terms of the tasks they perform and are almost never paid for what they do.

Vocabulary

When Shakespeare famously asked “What’s in a name?” he was not thinking of family caregiving. Names count. The labels that emerge over time to describe informal care reflect who caregivers are perceived to be. As I read through all my source materials for this dissertation, I found myself compiling a glossary of caregiving terms. Review of these terms reveals the evolution of the family caregiver.

- ***Carer*** is the term most commonly used in the U.K. It implies a kind of intimacy between care recipient and care provider.

- ***Caretaker*** was the term used in the U.S. until the 1970’s. However, it was mostly used to describe hired help as opposed to family and friends caring for loved ones. It refers to the care of persons, places and/or things. Unlike the more generous term carer, caretaker implies a definite separation between the one who cares and the object of care.

- ***Caregiver*** came into usage in the 1970's as caregivers became the object of interest and study. It's a kinder, gentler version of caretaker; it similarly implies a firm boundary between caregiver and care recipient. However, there is an emotional relationship implied in ***caregiving*** that is lacking in *caretaking***.** To give care sounds less like a job and more like a relational exchange.

- ***Informal caregiver*** is the term most commonly found in research literatures. Not only do we have the separation of caregiver from care recipient, but we also have an implied distinction between formal (i.e. professional) and the informal (amateur) care provider.

- ***Primary care provider*** is the term is currently used by corporations, government organizations and some medical professionals. It's reminiscent of *caretaker*, in that it positions care as a job with specific responsibilities. It has a quasi-professional sound to it, and suggests a connection to other members of the health care team – and this connection again, implies specific responsibilities. The positioning of the care provider as *primary* suggests the expectation that one family member – and only one – will take the lead in providing care.

- ***Family caregiver*** is the term embraced by caregiver advocates. It explicitly ties together the work aspect of care (caregiver) with the relational aspect of care (family). In doing so, it avoids the whole formal/informal caregiver dichotomy, giving family caregivers an identity that is solely their own. The caregivers I've interacted with much prefer this term to any other, if they use a term to describe their caregiving selves at all. The nursing research literatures have been using ***family caregivers*** for some time; it's now gradually making its way into other research literatures and into medical and corporate vocabularies as well.

- And then there are people who don't use specific terms to identify themselves as caregivers; they refer to themselves in terms of their relationship to the care recipient, e.g. "I care for my mother"). Many people are reluctant to label their caregiving experience; either they aren't happy with the terms available to them (see caretaker above), or they feel that such labeling diminishes the relational aspect of the care they give.

The variety of terms, and the different messages they send about caregiving illuminate what we think we know about family caregivers. They reflect history, as the caregiver is named, unnamed and renamed in response to the times.. They are prescriptive: a caretaker is not a caregiver; one can be a carer but not necessarily the primary care provider. They reflect critical shifts in positioning between all parties concerned. For example, the term *caregiver* reflects a one-to-one relationship between caregiver and care recipient. When we layer terms like informal, or *family* onto *caregiver*, that dyadic relationship is expanded to include others. These terms not only describe the caregiver, but the people being cared for, and implicitly all others who come into contact with them. And they raise profound questions about caregiver identity: Are family caregivers an adjunct of the health care system, or a separate entity? Is caring for loved ones a job or a relational exchange or both? In listening to caregiver voices, it's important to pay attention to vocabulary as well as to tone, pitch and inflection.

In keeping with the goals of this dissertation, I will use the terms informal caregiver (the research term) and family caregiver (the "real world" term) interchangeably.

Informal vs. Formal

Who gets paid for their labor, and who doesn't? Whose work is valued and visible, and whose is not? These questions help to articulate the divide between the formal and the informal caregiver. In American culture, it is common to identify the professional based on two criteria: their level of expertise and the money they command. These two factors add up to the total value placed on the work performed and this in turn becomes a marker for the level of professionalism involved. From this perspective, the informal caregiver is defined oppositionally, through direct comparison with the formal caregiver. Informal caregivers are not considered experts (at least not in comparison to health care professionals); they are not paid for what they do. They are *not professional.*

The need to set boundaries between formal and informal realms of care comes from the boundaries placed between the workplace and the home. In his seminal work, American culture in American kinship: a cultural account[2], anthropologist David Schneider (1980) describes the symbolic positioning of work and home. Work, according to Schneider, is inherently productive in that the outcome of work is always some kind of product: "Work has an objective or goal which is clear, explicit, and unitary." On the other hand:

> Home has no specific, explicit, unitary objective or goal… Home is not kept for money and, of those things related to home and family, it is said that there are some things that money can't buy! The formula in regard to word is exactly reversed at home: What is done is done for love, not for money! And it is love, of course, that money can't buy. (p. 46)

In real life, people sometimes work from home, and informal caregiving often extends outside the home. But in traditional American cultural consciousness family care is perceived as located within the private sphere of the home, as a labor of love and not money. Social activist Bertha Pappenheim (1927, cited by MG. Guttmann, 2001) takes this to an even higher realm.

> "The difference between the professional social worker and the voluntary caregiver is like that between a craftsman and an artist…. The artist works (and starves if necessary) for the sake of art, the voluntary social worker, for the sake of love – both driven by an irresistible urge to perfection that liberates the soul." [p.237]

It would seem that the rewards of informal caregiving must be in accordance with the work of caregiving: intangible, unseen and unheard. It's not surprising then, that the caregiver advocacy movement draws attention to family caregivers as a presence by tying informal caregiving to dollars. Consider the following estimates, as presented in a recent AARP Public Policy Institute brief:[3]

- Conservatively figured, the value of services provided in 2007 by an estimated 34 million caregivers (defined as people 18 years or older that provide an average of 21 hours of care per week at any given time) was roughly $375 billion dollars.
- In 2004, U.S. businesses may have lost as much as $33 billion dollars in productivity for full time employees who are also caregivers. These costs include the replacement of employees, absenteeism, workday interruptions, unpaid leave and reduction of full time to part time hours.

There are also considerable out of pocket costs for caregivers, as they often contribute financially to their loved ones' care. A recent study by Evercare™ in conjunction with the National Alliance for Caregiving (2007) explored the financial implications of providing family care. One thousand caregivers who provided care to a friend or relative age 50 or older for a minimum of 5 hours per week over a 30-day period participated in a telephone survey that addressed the financial implications of care.

Respondents indicated that they helped the care recipient with household goods, food, travel and transportation costs and medical co-pays. More than a third of the participants used their own savings, cut back on home maintenance and cut back on their own health care to do this. And 37% reported that they had quit their job or reduced their work hours in order to provide care.

The bottom line is clear; invisible work costs money. By necessity, the boundaries between the formal and the informal caregiver are being renegotiated. Carol Levine (2002b, November 12) writes:

> "Thinking of family caregiving as a job may seem inappropriate. After all, this is what families are supposed to do and, in most cases, want to do. But family caregivers should not be forced into poverty, martyrdom or serious illness." (¶ 4)

Invisible Women

> I realized that there was nowhere on the "survey instrument" to record that Harry was alive because of his mother. …I began to see that Harry did not see his mother as helping him but as doing what she had always done. But how long, I thought, could he remain living "in the community" without his mother to shop, cook, clean, plan meals and do the daily work that keeps a household running? [Schiller, 1993]

In the passage above, anthropologist Nina Schiller describes an interview with an AIDS patient. As the interview unfolds, she's aware of Harry's mother moving silently through the room, pouring water, throwing a sweater over Harry's shoulders. Mom's presence is unacknowledged, but nevertheless vital to Harry's well being. She is, Schiller says, the invisible woman.

Historically, caring for the family has been women's work – and that includes the extra caregiving imposed by chronic illness or disability. Caregiving is an extension of housework: necessary but not necessarily valued, nonproductive because repetitive, home-based and therefore invisible (Strang, 2001). Women have traditionally been held responsible for those outside the labor market, e.g. children, the elderly, the disabled or the chronically ill (Schiller, 1993). As women, they've been socialized to care and to give care from girlhood. As noted psychologist Carol Gilligan (1995) points out, this is a double edged sword:

> Girls' initiation into womanhood has often meant an initiation into a kind of selflessness, which is associated with care and connection but also with a loss of psychological vitality and courage. To become selfless means to lose one's voice in relationships. [p. 123]

Invisible women in an invisible space doing invisible work. That's been the history of the family caregiver.

How then did these women and the phenomenon of informal caregiving become visible? In a nutshell, the women who had traditionally been family caregivers became conspicuous through their absence. As more and more women entered the formal workplace, there were fewer women at home to provide care. It became clear that the care these women provided was more than a domestic arrangement. Informal care began to be recognized for what it was: critical support to an overburdened and inadequate health care system. On the heels of this recognition came the realization that something must be done to sustain these women in their crucial caregiver roles. This led to a new interest in what these caregivers did, how they did it, and what it might take in order to keep doing it. The informal caregiver as the object of study was born.

Today, women are most strongly identified with informal caregiving – and understandably so, since women still comprise the majority of family caregivers in the U.S. However, the changing demographics of the U.S. have brought other caregivers into the mix. For example, the percentage of identified male caregivers has risen over the past decade from 25% to 45%. Much of the existing caregiving discourse reflects the voice of women, but may render men silent. What voices and vocabularies are there that would allow everyone to speak their caregiving?

Similarly, there has been a lack of caregiving literature on minority families. Some of the preliminary literature I found suggests a kind of silencing that parallels the historical muting of women caregivers. Studies on African American, Latino, and most recently Asian families suggest that certain cultural factors – e.g. extended family network patterns – lead to a kind of "ethnic compensation" (Cool, 1987 as cited by Fox, Hinton & Levkoff, 1999) that makes caregiving less burdensome than for their European American counterparts. Another theory spans racial, ethnic and socioeconomic considerations, proposing that those who've worked extensively in service industries (maids, janitors, nannies, etc.) find the tasks of caregiving less obtrusive; if you've worked all your life as a cleaner, then toileting Mom isn't all that taxing (Steinberg, 1995, as cited by Fox, et al., 1999). And there is the pervasive suggestion that for those who live under conditions of oppression and economic disadvantage, family caregiving is small potatoes indeed. As both a researcher and a caregiver, this troubles me greatly. Cultural considerations are by necessity a critical part of interpreting the family caregiving phenomenon, and research is urgently needed to explore these considerations. However, this particular approach comes perilously close to "the women as natural caregivers" perspective.

The dissertation project presented here reflects my orientation towards caregiver research in general. The task of such research is to add to the context of caregiving, to move past outdated monolithic constructions of gender and racial/ethnic differences. We need to look and to listen with closer attention to how all kinds of caregivers live their lives (Fox, Hinton, & Levkoff, 1999; Mendez-Luck, Kennedy, D. & Wallace, 2008; Ortiz, Simmons, & Hinton, 1999). And we need to develop vocabularies and voices that allow them to speak and to be heard.

II) VOICE

> To have a voice is to be human. To have something to say is to be a person. But speaking depends on listening and being heard; it is an intensely relational act. By voice I mean something like what people mean when they speak of the core of the self. Voice is natural and also cultural. It is composed of breath and sound, words, rhythm, and language. And voice is a powerful psychological instrument and channel, connecting inner and outer worlds. [Gilligan, 1982]

The term *voice* is used throughout this dissertation to describe particular ways of talking and thinking about caregiving. Voice reflects the ways in which information is internalized, how caregiving experiences are integrated and interpreted. As it articulates not only what is said about caregiving, but how it is said and to whom, voice serves as process and product, medium and message.

In the early days of this study, I found voice to be such a natural, intuitive metaphor for describing the array of potential orientations toward family caregiving, that it was hard to operationalize the term. Psychologist Carol Gilligan (1982) spells it out for us: to voice your experiences is to be a human, a person. What more do you need to know? But as *voice* is used for a very particular purpose – to illuminate various orientations towards caregiving and caregivers – I must be precise in my definition. In the context of my research, voice is:

- an extension of Foucault’s concept of ***gaze***
- the expression of Bakhtin’s concept of ***ideological becoming***
- the embodiment of Davies and Harré’s concept of ***positioning***

The Hearing/Speaking Gaze [Foucault]

The Foucauldian concept of ***gaze*** is roughly described as “as a way of looking at or, indeed, hearing, smelling and otherwise sensing or comprehending the world”

(Heaton, 1999). We look at the world, the world looks back at us, and a kind of perceived reality is created.

But gaze is also about power, the power to identify, to categorize, to define. In The Birth of the Clinic, Foucault (1973) speaks specifically about the medical gaze, of how the clinical observation of medical authority has historically created and informed the reality of the patient. Foucault describes the myth of the “speaking eye” that looms over the work of defining medical methods and scientific norms – an eye that looks and looks and then speaks of what it sees in order to create knowledge. The clinical experience becomes “a moment of balance between speech and spectacle.” But this mythical balance is based on the premise that “all that is *visible* is *expressible* and that it is *wholly visible* because it is *wholly expressible”* (p.115, emphasis added) – and this, Foucault says, cannot be.

Foucault is right, I think; as human beings, we cannot say all that we see or see all that we say. But the term *voice* allows us to come closer to the “speaking eye,” to “the hearing gaze and the speaking gaze” (p.115). It allows informal caregivers to be fixed to important historical and social reference points, just as gaze would do. Voice admits the possibility of multiple gazes: those who gaze, those who return the gaze and those who avert their gaze. Most importantly, voice allows for agency in a way that gaze intentionally does not. We quite literally speak the world we live in and; as we speak, we create ourselves in the world.

Ideological Becoming [Bakhtin]

The concept of internally persuasive discourse arises from Bakhtin’s discussion of ideological becoming: “the growth of the individual’s belief system” (Dentith, 1995). In this discussion, Bakhtin draws a firm line between authoritative discourse and internally persuasive discourse. Authoritative discourse (e.g. political or religious dogma) is monologic, rather than dialogic: this is how things are, no discussion needed. Internally persuasive discourse does something quite different:

> The internally persuasive word starts out as the word of another, in competition with other words that have similarly been internalized; the process of ideological becoming is one in which these different words are more and more thoroughly assimilated, brought into contact each with the other, made more thoroughly one's own though never becoming wholly so and thus always remaining in some sense double-voiced. [Dentith, 1995]

Voice then serves as the expression of ideological becoming. As caregivers negotiate all the words available to them, they are engaged in the creation of their own individual caregiving voice. Assimilation of “the word of another” is never total, and this is what makes each caregiver’s voice unique and personal – but each voice contains the echoes of the larger discourses that surround it.

Positioning [Davies and Harré]

Davies and Harré (1990) define positionality as, “a discursive practice whereby selves are located in conversations as observably and intersubjectively coherent participants in jointly produced storylines.” Positioning is quite literally where we stand within a given discourse, a given social context, a given relationship. It can be interactive, as one person positions another; it can be reflexive, as one positions oneself within the discourse. In taking a given position, we take on a kind of “conceptual repertoire”:

> Once having taken up a particular position as one’s own, a person inevitably sees the world from the vantage point of that position and in terms of the particular images, metaphors, story lines and concepts which are made relevant within the particular discursive practice in which they are positioned. At least a possibility of notional choice is inevitably involved because there are many and contradictory discursive practices that each person could engage in. Among the products of discursive practices are the very persons who engage in them. [p. 46]

Positioning is a way to tie together the exterior layering of Foucault’s gaze and the inner movement implied by Bakhtin’s ideological becoming. It allows for personhood – for the “singular self” – but also for the multiplicity of selves that emerges through an individual’s interactions with others and with the world. There is “a possibility of notional choice,” and this provides a sense of agency. But there is also the understanding that the ability to choose one’s position is circumscribed by social, political and historical contexts, e.g. gender, ethnicity, race, socio-economic status, etc.

Voice, as I use it, is the embodiment of position. The voices described in this dissertation reflect different but related conceptual repertoires available to caregivers. Sometimes caregivers choose their positions, sometimes they are placed there by others. Sometimes they make deliberate shifts between positions, and sometimes take more than one position at a time. The way caregivers voice their positions tells much about what those positions mean and how they’re used. In a later section of the dissertation, I’ll return to positioning as an analytical tool for getting inside these caregiver voices.

Thus far, and for the purposes of definition, I’ve used voice as a singular term. However, the real story behind this research project is not the singular, prototypical voice, but rather the negotiation of multiple voices generated through caregiving. People don’t just pick a voice and stick with it. They live through a kind of polyphony, or *multivoicedness* (Bakhtin, as cited by Dentith, 1995). There may be a solo voice that predominates at a given time; there may be multiple voices in greater or lesser harmony. But all voices are present; all are part of the chorus of experience. As Bamberg & Budwig (1992) ruefully note, “Taken as prototypes, these voices strive after purification and perfection, and they mutually exclude each other. In most real-life interactions, however, they are not absolutes.” (p 166).

There are multiple voices that surround the phenomenon of informal caregiving – possibly as many voices as there are caregivers. This dissertation focuses on just three of them as an exploration of how family members who care for chronically ill loved ones become caregivers.

A Kind of Methodology

The methodology used to develop these three voices mirrors the trajectory of my own initiation into my academic and caregiving lives. The Caregiver as Patient voice was revealed through my immersion in the stress and coping literatures required by my health psychology classes. The Caregiver as Kin voice was at first so much my own voice as a daughter/granddaughter/sibling that I didn’t really hear it. It later became audible as a kind of counter-discourse to the Patient voice; in fact, these voices mutually constituted each other as a kind of “yes, but” dialogue. Much later in the process, I became aware of the Caregiver as Advocate voice, first as a kind of bridge between the Patient and Kin voice, and then as a separate but related caregiving voice in its own right. These voices came to represent different caregiving positions:

- **The Patient voice** positions the caregiver as a patient and caregiving as a kind of pathology.
- **The Kin voice** positions the caregiver as family, first and foremost. Caregiving is conceptualized as the embodiment of love and duty.
- **The Advocate voice** positions the caregiver as an advocate for the person cared for, and for themselves. Caregiving becomes a calling or profession.

I first associated each voice with specific literatures, in keeping my initial conception of a research/real-life dichotomy. The Patient voice was located in the research-based literatures generated by medicine, psychology, nursing, gerontology, and AIDS. The Kin voice came from conversations with real-life caregivers, the people I met and talked with on-line, my own family and friends. The Advocate voice became clear to me, as I pursued my dual roles of psychologist/researcher a psychologist, and concerned caregiver, through my exploration of grass root organizations, popular news media and online caregiver resources.

Over the course of my explorations, I found it harder to locate firm boundaries between literatures. Nursing research on family care often taps into both Patient and Kin voices. The recent flood of how-to guides for caregivers reflects a blend of Caregiver as Kin and the Caregiver as Advocate voices. And through it all swirls the narratives of the caregivers I speak with online and/or in person – narratives that encompass all three of the voices described here. Clearly, my approach to capturing these voices had to become simultaneously more generous and more precise. Here's what happened next:

- I revisited all the materials I had initially collected. The Brown, Tappan, Gilligan, Miller & Argyrols (1989) multiple read method[4] was used to look for these three different voices, wherever they might appear.
- I looked for additional materials to round out what I already had from a historical and cultural perspective. This took me into the fields of anthropology, history, medical ethics and feminist philosophy.
- I looked for the best exemplars for each caregiver voice as a way of highlighting different aspects of the voice.

Presenting the voices: Exemplars

In the sections that follow, each discussion opens with an excerpt or passage that serves as an exemplar of the voice in question. I discuss the historical positioning of the voice: how it came to be, what influences have shaped it. I then identify one or two themes that are particularly salient to the voice, and end with a discussion of what the voice does and doesn't have to offer those who speak and hear it. After treating each voice individually, I look across the three voices for ways in which they compliment and contradict each other.

The Patient: Caregiving As Pathology

> These were the seeds of the BAOBAB. The soil of the planet was infested with them. A baobab is something you will never ever be able to get rid of if you attend to it too late. It spreads over the entire planet. It bores clear through it with its roots. And if the planet is too small, and the baobabs are too many, they split it in pieces. [A. de Saint Exupéry, 1943]

The above passage comes from St. Exupéry's novella The Little Prince; the title character is describing the greatest threat he faces in caring for his prize possession, a rose. The baobab serves as a metaphor for caregiving, with stress, strain and burden as its roots; the imperiled planet is normal life under inexorable pressure as experienced by the caregiver. If unchecked, the cumulative stressors associated with caring for a chronically ill loved one will destroy the caregiver's world, as surely as the roots of the baobab will inevitably destroy the planet. Caregiving has a life of its own, exclusive of caregiver or care recipient.

> After the doctor said she would be home bound if she did not get PT, I just sat there and broke down. I guess the stress of having four kids to take care of and my mom too. I was telling the nurse how I have 8 brothers and sisters and I am the one who care for her full time. Then I can't do as much as I should because of my own family to take care of. I guess at that moment, I realized how much was on me. [excerpt of message posted to online caregiver support group]

The Caregiver as Patient voice is the voice of the overwhelmed caregiver: unprepared, unready, and undone by the burden of caregiving. But it is also the voice of Science with a capital S — the reframing of complex human experience as question/answer, as cause/effect problem/solution, as dichotomy rather than continuum.

Caregiving as Pathology

The phenomenon of informal caregiving has traditionally been studied through a biomedical orientation. In health psychology research, caregiving is often positioned as a chronic stressor: an ongoing stressful life event that is associated with mental and physical health deficits. Studies have shown that people who care for chronically ill or disabled loved ones tend to be more anxious, more depressed, report more physical symptomology, and are more at risk for assorted illnesses themselves in comparison to non-caregiving counterparts (Brummett et al., 2008; Cannuscio et al., 2002; Di Mattei et al., 2008; Folkman & Moskowitz , 2000; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Hall, 2002; Ratnakar, et al., 2008).

Much of this research focuses on mental/emotional components (depression, anxiety. etc.) as part of caregiver psychological well being, and also in terms of indirect health effects. There is also an interest in indirect health effects. Some researchers hypothesize that the depressed/anxious caregiver is less able to practice good health behaviors and so their physical health declines accordingly; a recent study suggests that older caregivers may be more prone to accidents (Hartke, King, Heinemann & Semik, 2006). It’s been arguably more difficult to identify direct physiological links between caregivers and health status (Pinquart & Sörensen, 2007; Tran, 2008) and there are a variety of theories as to why this might be so. Measurement problems, selection bias due to the healthy caregiver effect[5], and the length of time it takes for stress effects to manifest themselves physically make it difficult to trace direct pathways between caregiver lives and caregiver bodies **(**Hartke, King, Heinemann, & Semik, 2006; Tran, 2008).

However, there is growing evidence that caregiving as a major stressor affects body systems in the way any major chronic stressor is supposed to do: through elevated cortisol levels, excited HPA systems, suppressed immune function, etc. (Brummett et al., 2008; Cacioppo et al., 1998; Ratnakar et al., 2008; Vitaliano, Zhang, & Scanlan, 2003). And there does seem to be a relationship between levels of psychological distress and physiological well being. In a meta-analysis of 176 caregiver studies that examined the correlates of caregiver physical health, Pinquart & Sörensen (2007) report that psychological distress –especially depressive symptomology – had stronger associations with physical health status than did objective stressors.

A simple but powerful equation underlies the research discourse on caregivers, and it forms the basis of the Caregiver as Patient/Caregiving as Pathology voice:

- Providing care for someone you love [on a long term basis] is stressful
- Chronic stress is bad for you, both physically and mentally
- Therefore *caregiving is bad for you (caregiving as pathology)*

This equation has informed traditional psychological and medical literatures, and has guided the research on caregiving, right down to the vocabulary that describes what caregiving is and does. The research terms used – *caregiver stress, caregiver strain, caregiver burden, caregiver burnout* – underscore the emphasis on pathology. This research is disseminated into the real world, through magazine articles and news briefs, through web links and sound bites, providing family caregivers with a formalized framework and vocabulary to interpret and describe their caregiving experiences. Both the caregiver equation and the Patient voice gain power from the intersection of scientific discourse and real life experience. Research-based and real world understandings of caregiving form a kind of hermeneutic circle: the research frames caregiving as illness and caregivers as patients in the making; informal caregivers use these frameworks to shape their own experiences, to reproduce and add to the vocabularies created in the research.

To better understand the construction of caregiving as pathology, it's helpful to look at how the experience of caregiving has been studied. As suggested by the caregiver equation outlined above, research on caregivers has been traditionally framed in terms of *stress* and *burden.*

Caregiving, the stressor

A most helpful and widely used theoretical model for describing how caregiver stress works is provided by sociologists Pearlin, Mullan, Semple & Skaff (1990). The model describes multi-level potential stressors both directly and indirectly related to caregiving, discusses ways in which these stressors interact to affect the well being of the caregiver, and illustrates how coping and social support may modify these effects [see Appendix B]. Most importantly to this discussion, the potential pathology of caregiving is seen as emerging from the complex interactions between accumulating stressors – not from caregiving in and of itself. Caregiving is the behavioral extension of caring and as such is an integral part of intimate relationships. It isn't caregiving per se that's bad for you; it's the ways in which your life is disrupted by the stressors arising from caregiving that become problematic:

> Considering how quotidian caregiving is, it hardly seems the stuff out of which severe stress springs. *Under some circumstances*, however, caregiving is transformed from the ordinary exchange of assistance among people standing in close relationship to one another to an extraordinary and unequally distributed burden….Caregiving which previously might have been but one fleeting component of an encompassing relationship, can come to be the dominant, overriding component. Under conditions of chronic and progressive impairment, therefore, caregiving may imperialistically expand to the point where it occupies virtually the entirety of the relationship. [p 583, emphasis added]

Pearlin et al. (1990) are careful not to position caregiving as pathology but ironically, much of the research that makes use of their model does – and this is where the Caregiver as Patient voice can be heard loud and clear.

Studies on caregiving have often been based on the comparison of caregivers to non-caregivers(Brummett et al., 2008; Cannuscio et al., 2002; Di Mattei et al., 2008; Folkman & Moskowitz, 2000; Haley et al., 2001; Hall, 2002; Ratnakar et al., 2008). Gerontologists Beach, Schulz, Yee, and Jackson (2000) note that the usual research strategy is **“**to compare a group of caregivers with a comparison group of noncaregivers in terms of health outcomes, or to compare caregiver samples to population-based norms on morbidity indicators” (p.259).

However, there are drawbacks to this approach to the study of caregiving. First, the framing of caregivers in opposition to noncaregivers imposes a dichotomy between the “sick” caregiver and the “well” non caregiver. Direct comparisons between informal caregivers to non-caregiver controls may be helpful to the researcher in the initial operationalization of caregiver stress, but this approach doesn’t really take us much farther than that. If Pearlin et al. are right – if caregiving is inherently part of every intimate relationship – then no-one is truly well.

Second, the traditional caregiver/non caregiver comparison approach flattens out the subtle differences between caregivers: a caregiver is a caregiver is a caregiver. Such studies are limited in what they can tell us about how caregiving really works over a variety of experiences and conditions. Is all caregiving the same, in terms of health effects? Do the health effects of caregiving change over time, as the nature of caregiving changes? Are all caregivers at risk, just by virtue of being caregivers? Or are there specific vulnerabilities that, in conjunction with caregiving, create a greater risk for negative health effects?

These kinds of questions are changing the ways in which caregivers have traditionally been studied; researchers are moving away from caregiver/non-caregiver comparison and are concentrating on the caregivers themselves. Age, gender, race/ethnicity, socioeconomic status, and the duration and intensity of the caregiving experience are not just variables to be controlled, but potential mediating factors in determining which caregivers are at risk (Fox, Hinton, & Levkoff, 1999; Mendez-Luck, Kennedy, & Wallace, 2008; Navaie-Waliser et al., 2002; Ortiz, Simmons, & Hinton, 1999; Pinquart & Sörensen, 2005). The search is on to identify the *vulnerable caregiver*; to identify the factors that make some caregivers especially prone to depression, anxiety, and all the other negative effects associated with caregiving. This shift in research direction is promising, because it offers a more detailed and contextualized understanding of caregiving. But it’s one that’s still deeply rooted in the Caregiver as Patient voice: *Caregiving is bad for you.*

Caregiver Burden

A critical part of the caregiving literature concentrates on *burden*: “the practical difficulties and mental pain that are the lot of the caregiver” (Kung, 2003, p. 548).

Research literature based in psychology tends to categorize burden as either objective or subjective in nature. *Objective burden* includes the practical difficulties suggested by Kung: “[the disruption of] domestic routine, social and leisure activities, social isolation, and financial and employment difficulties” (p. 548). *Subjective burden* reflects the emotional strains of caregiving: feelings of shame, stigma, guilt, resentment, grief, worry, anxiety, sadness, fear, loss, anger, and rejection (p.548). It’s interesting to note that many researchers classify care recipient characteristics (disruptive behaviors, negative symptoms) as objective rather than subjective burden for their caregivers, because such characteristics are readily observable by others. This makes it clear where the boundary between types of burden truly lies: objective burden is that which the outsider (the researcher, the non-caregiver) can readily identify; subjective burden is the private experience of the caregiver that can only be measured through self report (Verhey et al., 2007). Objective burden is what others see; subjective burden is what the caregiver knows.

What We Do With What We Know

To date, there have been no clear cut findings regarding the relationship between objective and subjective burden. Some researchers report that high levels of objective burden are correlated with high levels of subjective burdens while others find no such relationship (Kung, 2003; Wight, LeBlanc, & Aneshensel, 1998). And yet the actual assessment of caregiver stress is usually focused on objective burden. Caregiver assessment typically involves the use of task sheets and check lists – measures that are meant to capture the caregiver’s ability to perform given caregiving tasks. These tasks are divided into Activities of Daily Living (ADLs) e.g. bathing, dressing, feeding etc. and instrumental activities of daily living (IADLs) e.g. shopping, housework, managing finances, etc. The caregiver is given a list of tasks and is asked to check off which tasks they perform. They are then asked to indicate how difficult they find it to perform these tasks. Originally developed to measure patient functioning, these ADL and IADL assessment tools were lifted wholesale into the study of caregiver burden. This is more than a historical footnote, I think; here the positioning of <u>caregiver as patient</u> is reflected in the very methodology used to study the population of interest. Interventions for stressed out caregivers are mainly focused on helping them manage their objective burdens. This is certainly an important component in addressing some of the stresses and strains of caregiving, and has the potential for being a relatively quick fix – but is it enough? At a conference given by the United Hospital Fund, nurse/researcher Susan Reinhart (2004) reported that a caregiver's ADL/IADL functioning only explains about 20% of the burden experienced.

There is now a complementary interest in the measurement of subjective burden through tools like the Caregiver Burden Index (S. Zarit, ©1983). The Zarit Caregiver Burden Index is commonly used in psychological research on caregiver stress along in combination with anxiety and depression-specific measures, and is sometimes offered as a self-help diagnostic tool on caregiver support websites, e.g. ThirdAge.com. Items are phrased as "Do you feel" questions: "Do you feel you should be doing more for your relative?" "Do you feel your health has suffered because of your involvement with your relative?" etc. Clinicians are sometimes reluctant to use the ZCBI or other similar caregiver subjective burden measures for screening the caregivers of their patients. In 2007, the Indiana Center for Evidence Based Nursing Practice began the first systematic review of caregiver burden measures for psychometric properties and feasibility of use:

"Clinicians are more likely to use screening tools that are psychometrically sound and are easy to use in their place of work." (Whalen, 2007).

The item list approach to studying subjective and objective burden, while efficient, is limited (Barer & Johnson, 1990; Wuest, 2000). Wrubel & Folkman (1997) note that traditional checklists, no matter how detailed, can't possibly capture the wide spectrum of care informal caregivers provide for their loved ones. Further, these lists don't take into account important contextual factors in caregiving, e.g. the relationship between caregiver and care recipient, the intensity and/or duration of the patient's illness, etc[6]. As Wrubel and Folkman (1997) found in their study on informal caregivers for people with AIDS:

> The narratives themselves were often very explicit about the physically exhausting and emotionally draining aspects of informal caregiving… This is the kind of stress caregiver burden studies try to assess, but it is not what the caregivers in this study usually said was stressful for them… The central stress for these caregivers was the meaning of their partner's illness…*The stress of the situation was not due directly to caregiving, but rather to what prompted the caregiving* [pp 704-705, emphasis added]

In the literatures most commonly used to shape clinical assessment and intervention for caregivers, the caregiver is positioned as patient, and caregiving as pathology. The experience of caring for an ill loved one is framed as a kind of illness trajectory: the person providing care may start off as relatively healthy, but as the threat/stress/burden increases over time, their resistance weakens and they become sicker. Finally, a crisis or turning point is reached where the caregiver as patient either "lives" (regains the ability to give care) or "dies" (gives up the role completely). Since the study of family caregiving emerged from the very real need to maintain family caregivers in their role, this caregiver/illness trajectory is an important part of the professional dialogue surrounding caregiving.

It's now time to address the other part of the hermeneutic circle: the informal caregiver. A heuristic is drawn from real life and reified by research: caregiving is bad for you. There is a corresponding voice to express this conception of caregiving, with all the vocabulary that goes along with it. What does this voice offer the caregiver? What does it mean to speak and live in this voice?

The Caregiver as Patient Voice: What does it do?

N cares for her 20-year-old son who suffers from traumatic brain injury. She posted the following message to an online caregiver support group[7]:

> HEY ITS ME T AGAIN TODAY I AM SO TIRED AND OVERWHELMED WITH WHAT SEEMS LIKE EVERY THING AND EVERYONE I JUST WANT TO ((SCREAM)) LEAVE ME ALONE FOE JUST A FEW MINUTES PLEASE IS THAT TO MUCH TO ASK? MY HEAD HURTS MY LEGS HURT I FEEL LIKE I'M GOING TO FALL ALL TO PIECES......... AND MAYBE KNOW ONE WILL BE ABLE TO FIND ALL THE PIECES TO PUT T BACK TOGETHER AGAIN. I KNOW I SOUND FOOLISH I'M JUST SO DOWN LATLEY JUST WANTED TO WRITE IT DOWN TO SEE IF I MIGHT FEEL BETTER ..... NO..... I DO NOT....BUT I AM HOPEFUL THANKS FOR LETTING ME VENT IF MY SON READ THIS AND KNEW I WAS TALKING ABOUT HIM I WOULD FEEL SO AWFUL BUT THANKS FOR LISTENING HOPE YOU ALL ARE DOING FINE AND ARE FEELING AT BEST (GOOD) TAKE CARE WRITE YOU LATER ...PEACE.... N

In the netiquette of online communications, messages typed in capital letters are the equivalent to shouting – and N is yelling at the top of her lungs. She has a lot on her plate. Although her son recently graduated from wheelchair to walker, he is still very dependent on his mother's care and may never recover the full use of his faculties. N's husband has distanced himself from the day-to-day care for their son. N is still mourning the recent death of her eldest son. And while everyone in her life has an opinion about the way she cares for her remaining son, no one seems willing to pitch in and help her do it. N is tired, overwhelmed, physically falling apart, emotionally depleted and (adding insult to injury) feeling guilty about the way she feels. She’s come to the online group in order to put words to her pain – and while she can’t feel the benefit right now, she’s hopeful that she will. And apparently she does; she writes the next day to say she’s feeling better about things.

The responses to N’s cry of pain were generous and gentle. A few people offered practical advice, but most simply responded with expressions of identification, love and support. Caregivers with very different experiences related strongly to each other through the common experience of pain. There was an implicit understanding that before N could pick up her burden and go on, that burden had to be acknowledged.

The Caregiver as Patient voice gives validity, visibility and vocabulary to the very real suffering of caregivers. It suggests that the person being cared for is not the only person of interest. By identifying as a kind of patient, caregivers become visible. As journalist/caregiver Hugh Marriot (2003) notes:

> Caregivers don’t get much publicity. Or attention. When someone pushes a wheelchair through a crowd, it’s the wheelchair that attracts the sideways glances. Or which causes passers-by to look politely away. In either case, the person who’s doing the pushing is invisible. Those people in the crowd don’t spare the caregiver a thought. Be fair, did you ever, before you became a caregiver? [¶ 9]

However, there is a cost to defining yourself as a patient in Western culture. To be the patient is to be the loser, the victim – and this is an identity most Americans do not prize. The only way to redeem oneself from the caregiver/patient/loser trap is to become a survivor, and once that’s done, the Caregiver as Patient voice loses momentum. This voice is the voice of immediate need; survival takes some time.

The voice of caregiving as pathology frames the whole phenomenon of caregiving as an illness to be cured. The research community positions caregiving as problem/solution: if caregiving is a problem, then there must be a solution. This could be immensely reassuring to the family caregiver. The caregiver doesn’t know what they’ll be called upon to do, how long they’ll have to do it, or what it will cost them and others to see it through. Reducing the ambiguity of caregiving to a problem/solution format makes it all seem more manageable. But here again, there is a cost involved in taking this stance. Speaking from the Patient voice forces the caregiver into the sickness paradigm that all invalids deal with: If you follow the steps correctly, and do your part, you should get better (Parsons, T., 1951). By extension, if the caregiver gets a grip on their stress and their burden, they can be a good caregiver, and do right by their loved one. But in order to get better, they must first label themselves as sick. This forces the caregiver to focus on what they’re not doing well, and to identify themselves in those terms. This is may be a necessary stance, but it is not an empowering one.

There is an emerging awareness that labeling a given population as at-risk or vulnerable may hurt as much as it helps. People may genuinely need help in dealing with the burden of caring for their loved ones, but are unwilling or unable to access the Caregiver as Patient voice. Such caregivers can be the tree falling in the forest with no one to hear it. Earlier in this dissertation, I referenced studies that suggest certain populations are better suited to caregiving, because they don’t feel (i.e. report feeling) stress the way others do. Do these caregivers really feel less stress, or is the vocabulary of caregiver stress and burden simply unable to capture their caregiving experiences? Kim, Sherman and Taylor (2008) reviewed a series of studies on social support use that compared Asians, Asian-Americans and European Americans in terms social support seeking behaviors. The researchers found that Asians and Asian Americans are less likely to solicit support from others, and are more concerned about the negative implications of asking for help than European Americans. The Patient voice may simply not be a culturally appropriate or accessible voice for this population.

Caregiver stress and caregiver burden are not just theoretical constructions created by researchers but are part and parcel of the real life experience of caregiving. A voice that allows these stresses and burdens to be acknowledged is critically important; it's the validation for individual experience and the wake up call for institutional change. But caregiving is much more than stress, strain and burden. There must also be voices that express creativity, gratification and purpose – and research methods, assessments and interventions are needed to support them.

Caregiver As Kin: Caregiving as Love & Duty

> A few lines of acknowledgment your letter shall have, whether well or ill. At present I am confined to my bed with illness, and have been so for 3 weeks. Up to this period, since my marriage, I have had excellent health - my husband and I live at home with my Father - of course I could not leave <u>him.</u> He is pretty well - better than last summer. No kinder, better husband than mine, it seem, to me, can there be in the world. I do not want now for kind companionship in health and the tenderest nursing in sickness. [C. Brontë, 1855]

This letter was written by Charlotte Brontë shortly before her death from pregnancy- related complications at the age of 39. Over the course of her life, Bronte had seen her mother and all five of her siblings through their final illnesses. She'd cared for her father who suffered a series of minor strokes, bronchial attacks, and periods of blindness. Charlotte herself was not physically strong; not surprisingly, she was almost morbidly aware of the state of her own health. What makes this letter so poignant – and so relevant to the discussion that follows – is the way in which caregiving flows through her discussion: from herself to her father, from her husband to herself. Charlotte writes simultaneously as a daughter, a wife, and an expectant mother, as both caregiver and patient.

There is much history hidden within this brief note. Charlotte doesn't speak directly of the early death of her siblings. She doesn't mention that she'd made living with her father a condition of her marriage. And she has no way of knowing that after her death, her husband will continue to care for her father until his passing. This is a family story; there are waves of love and duty flowing through it, both heard and unheard. Charlotte's note, the shifts it makes between the silent and the spoken, create the perfect metaphor for the next part of my discussion: the voice of love and duty, of the caregiver as kin.

The American Family

As introduction to the Caregiver as Kin voice, I begin with a brief discussion on family – what it is and what it means. I draw upon anthropologist David Schneider's (1980) seminal book American kinship: a cultural account. Schneider's goal is to outline the symbolic role of the American family. The preface of the book contains an important caveat regarding what his work is and isn't meant to do:

> This book is *not* to be understood as an account of what Americans *say* when they talk about kinship and family, although it is based on what Americans say. It is *not* about what Americans *think*, as a rational, conscious, cognitive process, about kinship and family, although it is based in no small part on what Americans say they think about kinship and family. This book should *not* be construed as a *description* of roles and relationships which Americans can be observed actually to undertake in their day-to-day behaviors in situations of family life, although it is based on what Americans say they do and what they have been observed to do. This book is about symbols, the symbols which are American kinship. [p.18]

This point is critical to understanding both Schneider's work and my inclusion of the work in this discussion. Schneider is talking about cultural meaning, not literal fact;

without this understanding, much of what he says seems prescriptive and out of date. Originally written in 1969, and updated in 1980, it could be argued that Schneider's American culture reflects an America that no longer exists: predominantly white, predominantly male. But Schneider was the first anthropologist to discuss kinship as a system of symbols, as opposed to a series of interconnected familial roles. He speaks of the symbolic family – and our symbols change much more slowly than the world around us. Schneider therefore provides an important historical context for the Caregiver as Kin voice, and in doing so inspires us to find other contexts potentially more relevant for where we are and who we are now.

Schneider (1980) describes a very traditional conceptualization of family, one that is based on reproduction. A family, or more specifically "the family" or "my family," is one's family of origin: a husband, a wife and their children. The extended family includes all those related to the family unit by blood and/or by law. Blood relatives are linked materially, objectively, through the essence of their bodies. Spouses are linked subjectively, through emotional connections, through custom and through law. And then there is adoptive or fictive kin: the people who are not related to you by blood or law but who are nonetheless family (p.100). As Schneider points out, "The family, as a construct of American culture, thus resolves the radical opposition between nature and human reason, bringing these two together into a workable, livable, human arrangement."

In this rendering of family, there is an inherent tension between natural and constructed ties: you can't choose your relatives … or can you? The traditional family unit of mother/father/children is no longer a given. Advanced reproductive technologies make it hard to define what the family of origin would be. Families break apart and reconfigure in new and sometimes surprising ways. The boundaries between blood and law are blurry, and are both more and less important as they used to be. On first glance, Schneider’s (1980) cultural sketch of family seems somewhat dated in light of the way we live now. However, this cultural dream of family is where many American families come from. It informs the existing social and legal systems and influences social and personal interpretations of current experiences. In terms of caregiving, the symbolic meaning of family is a key component in creating the voice of the family caregiver.

So much for what family is; now we turn to what family means. Schneider (1980) provides three major precepts that are particularly evocative of the symbolic family as it relates to caregiving.

1. *The Family as Dictionary*

> Whatever other meanings husband, wife, mother, father, son, daughter, brother, and sister may have, they share that set of meanings defined for the family because they are made of them. The family, therefore, stands for how kinship should be conducted and, because they are members of the family, it stands at the same time for how the husband and wife and their children should conduct themselves. [p.44]

The family is the living embodiment of kinship; the shared meanings they create as a family constitute the family. In terms of caregiving, this means that the definitions of good and bad care, as well as the designation of who cares and in what ways they care are already nested into the family vocabulary.

2. The Family as Operating Manual

> The family” stands for each member and for all members of the family, for how each member of the family should behave, and for how family relations should be conducted by whoever is conducting them. If “the family” were right, then the child would not be delinquent, the marriage would be stable, and so on. This means that if everyone in the family behaved according to the proper standards for family life, all would be well. [p.45]

This is a powerful message about the power of the family. The successful family, the family that properly conducts the business of family, thrives. In such a family, everyone does their part to care for each other – and if they do it right, everyone stays well, and those who aren't well, recover.

3. Love is…

> The family, then, as a paradigm for how kinship relations are to be conducted and to what end, specifies that relations between members of the family are those of love. One can speak of the family as "the loved ones." Love can be translated freely as *enduring diffuse solidarity*. The end to which family relations are conducted is the well-being of the family as a whole and of each of its members. [author's emphasis, p. 50]

Love is care, care is love; all for one, and one for all. Love is the basis of all actions taken by the family, individually and collectively, and therefore caregiving is part of each and every family interaction.

The family then, is an important cultural marker for all kinds of important social relationships, for the definition of health and illness, for the meaning of meaning both within and without the family unit itself. It can be said that family, however defined, ***is*** health. Psychologist Virginia O'Leary (1998) sets this out clearly:

> The family, as the most basic unit of culture, is *the* primary source of validation. Research has drawn attention to the synergy between family relationship and adaptive functioning. In addition to the give and take of emotional support and material aid families provide, mutual interchanges among family members may serve as reality checks – a way to validate one's personal sense of meaning and social identity against the pressures of racism and acculturation. Therefore, it is possible to think about families surviving, recovering, and even thriving. [p.436]

And Shelley Taylor (2002) puts it even more simply:

> Beginning in the womb and extending into adulthood, who we are – our character, even our physical health – depends upon the people who tend to us and how well we get along with them – our mothers, fathers, friends, and lovers. [p. 12]

Kin & Care – Turning Points

Anthropological terms can be very helpful in tracing the connection between kin and care. C.D.F. Parsons (1984) speaks of the *doing of sickness* and the *doing of kin.* She begins by positioning sickness as a family affair: “Sickness is necessarily a collective phenomenon which can best be understood not simply as a clinical event, but as an experience that is part of the experience of ‘family’.” *Doing kinship* refers to “the range of social knowledge, and the actions that follow, consistent with public notions about being a dutiful family member (p.73). And *doing sickness* is “the range of activities involving kinfolk when the phenomenon of sickness arises” (p. 74) – in other words, caregiving.

There are many different ways to “do” caregiving, and a corresponding number of ways to look at how it’s done. If Caregiver as Kin voice is positioned as reflective of how kinship is done, it can be used to trace the twists and turns of the caregiver experience over time. The careful listener can trace the ways in which the trajectory of a given illness changes the dynamics between caregiver, loved one and all others surrounding them. We can track the historical changes to the family unit itself, e.g., how the roles of mother, father, children, and spouse have been defined and redefined. We can examine the ways which families are constructed; people may be born into their families, but they also choose them. Taylor (2002) notes, for example, that due to geographic dispersal and high rates of divorce and separation our friends often replace our relations as our closest bonds (p.195).

These are just a few of the factors that help to shape the voice of Caregiving as Love and Duty. Reluctantly, I’ll limit myself to the discussion of one: the rise and fall of the institution. In the following section I trace the historical path by which care begins in the home, shifts to the formal institution as representative of medical authority, and then is returned – at least in part – to the family.

The Rise and Fall of The Institution

As counterpart to the cultural assumptions held about family, there is also a kind of shared nostalgia for the way things used to be. People long for a time when “Traditional communities governed by ties of need and connection rather than autonomous individualism and commodities … integrated their members and cared for them in the way modern society does not.” (Gottlieb, 2002). Of course, Gottlieb also notes that families nested within such traditional communities, “were also rooted in hierarchy and tradition. Everyone felt at home, but as in most homes, authority and privilege were neither equally shared nor democratically allocated.” Still, there was a synergy between community and family when it came to caring for the ill. Sharon Rothman (2004) takes a given timeframe (1844), a given location (New England) and a given illness (tuberculosis) to describe how familial caregiving was supported as a community project. She points out that due to the debilitating nature of tuberculosis, wives and mothers stricken with the disease were simply not able to keep up with their domestic duties – often for years:

> Each would have required, and received, the sustained assistance of family and friends. If the invalid women could not afford domestic help, the sewing circle would repair their clothing, and friends and neighbors would supply meals and provide nursing. When the invalids became incapacitated, an unmarried sister or cousin or perhaps a widowed mother or aunt would move into the household. As death neared and the invalid became still further debilitated, the obligations of family and community to provide care for the sick and those they cared for would have become still greater. Indeed, the "intensive care" given in a New England family was not provided by a machine monitored by strangers but, rather, was bestowed in the home of the chronically ill by a network of female family members, friends, and neighbors. The level of care intensified as the illness progressed, often reaching a crescendo as death neared. (p.60)

The passage above specifically describes the work of women, but men also had their place as caregivers. Male tubercular patients sent to the island of St Croix, for example, “visited one another, nursed one another, watched over and prayed for one another, and, as a last duty, wrote to the family of the courage and serenity with which husband or son had faced his final trial.”

Rothman’s (2004) discussion places caregiving as nested in familial, communal and religious practice; caregiving was the overt manifestation of one’s relationship to others. Based on this understanding, institutionalization was the very last resort, reserved for those without family or for those too disturbed – or disturbing – to be kept at home. “It took an extreme manifestation of disease to justify having strangers – that is, those who were not family or friends – provide caregiving for chronically ill kin.” (Tomes 1994, as cited by Rothman, 2004, p.62.).

However, a shift in caregiving patterns emerged by the turn of the 20th century. Families were becoming smaller, and were no longer concentrated in the same geographic area. Ideas surrounding community and society were moving from the religious to the secular. Technical innovation was rewriting medical knowledge; diseases once considered to be hereditary were now understood as infectious. The proper setting for care relocated from the home to the formal medical realm – a realm where specialized care could be administered by trained professionals. It was the time for medical authority as reified by formal institutions: the asylum, the sanatorium, the hospital.

Giddens (1991) describes the hospital “a setting where medical technology can be concentrated and medical expertise fostered” (p161). Foucault (1973) demonstrates how the hospital setting linked the emergence of medical authority to the displacement of the family caregiver

> As soon as medical knowledge is defined in terms of frequency, one no longer needs a *natural* environment. What one now needs is a *neutral* domain, one that is homogeneous in all its parts and in which comparison is possible and open to any form of pathological event, with no principle of selection or exclusion. In such a domain everything must be possible, and possible in the same way. [p. 109, emphasis added]

The "natural" values inherent in family based care had no place in the neutral, standardized and homogenous environments of hospital and sanatorium. Rules, regulations and protocols bolstered medical authority; "Knowledge replaced familiarity; authority replaced compassion." (Rothman, 2004)

Shifting care from the family to the institution did something more than legitimize medical authority; it created a division between patient and family. Giddens (1991) speaks of *institutional sequestration*, the processes by which basic life events are hidden beneath institutional routines:

> Like prisons and asylums, the hospital is also a place where those who are disqualified from participating in orthodox social activities are sequestered, and it has similar consequences in terms of the concealment from general view of certain crucial life experiences – sickness and death. (p.161)

If patients were locked into the hospital, away from their loved ones and their normal lives, their loved ones were similarly locked out and away from their caring familial roles. From this perspective, the family caregiver can be seen as yet another victim of early 20th century modernity. But there was also an implicit contract in place between medical authority and displaced family caregiver: "Give your loved one over to us – we will fix them and return them to you."

In time, the pendulum swung back again. By the mid -1960's, American institutions of all kinds were being questioned and medical authority challenged. The rise of class action and medical malpractice suits became the practical demonstration of a loss of faith in the medical system. Pharmacological advances (e.g. psychotropic drugs, antibiotics) allowed more people to be treated at home. There was a new impetus to release patients back to their communities and their homes. The 1970's saw a growth spurt of halfway houses and rehabilitation centers to ease people back into their communities. As those facilities closed down in the 1980's and 90's, people were sent back home to their families. Community care often became a euphemism for family care.

The pendulum swing continues today. While people hypothetically have access to the most aggressive treatments for cure available, options for care are limited. Carol Levine (2002a) notes that in past, people stayed in hospital until they were well enough to leave; now they are released as soon as possible, often requiring extensive and complicated aftercare. Family caregivers now find themselves responsible for aspects of care earlier caregivers could never have imagined. And in the words of a hospice nurse:

> We nurses learn how to do IV's over a period of weeks. Now in 24 hours we expect the family to do this IV in the home. Sometimes I think we expect a lot. It's really crash learning, but they need to do it because by and large, they want to be the ones to give care. [Wilson, 1992, p. 79]

Mixed Messages!

And so we left to wrestle with contradictory assumptions and mixed messages about caregiving that are embedded within the Caregiver as Kin voice. On the one hand, there is the cultural tradition of "family is best" – a tradition that takes on renewed significance when backed by current trends in health care policy.

> Health care reform has increased demands on families to take on caregiving responsibilities previously managed by professional caregivers. McKeever (1996) suggested that such changes stem from fundamental beliefs that such care is a family responsibility, women are the primary caregivers, family care is good, family resources should be exhausted

> before public resources are offered, and family care is free. [Wuest, 2000, ¶ 1]

On the other hand, there is the intellectual tradition of Science, of medical authority and the medical gaze. The result is a voice that includes multiple, mixed and contradictory messages about what family care should be. Consider the following excerpted message board exchange between two participants in an online caregiver support group for caregivers. The initial poster, L and her husband have been living in her father's house as his full-time caregivers. Reluctantly, L is considering nursing home options for her father, but:

> The only problem is that my husband and I live in my father's home and we would need to sell the house in order to place him somewhere. If we sell the house then we won't be able to afford to live in this area.

The rest of the post concerns L's efforts to get her sister's help in coming up with a solution. Most of the group responds to that aspect of her problem, but one poster focuses on the house issue. After taking L to task for ingratitude, D pointedly remarks:

> In plenty of cultures, it is considered standard practice to have multiple generations living together, and it would be unthinkable to sell a parent's hard-earned home and put them in a nursing home.

L shoots back a spirited response:

> I am well aware that in many cultures it is standard practice to all live together forever. It is also standard practice in many cultures to sacrifice chickens because you've had a bad dream! You are also not mentioning the fact that there are still other cultures that don't expect the children to take care of the elders at all! My friend in Sweden can't believe what I do because in their country it is all taken care of by the government. Don't you dare lecture to me about cultures. I can find just as many to contradict you.

Here we have two different interpretations of what family is supposed to do and be. D invokes the kind of traditional family described by Schneider: all living together, with dad as the nuclear head of the family, in a state of “enduring, diffuse solidarity” (Schneider, 1980). L's take is not all that different, really. She'd like to sell Dad's house and move the whole family to be near her sister, where housing options are cheaper. L sees this as being for the greater good of the family as a whole – Dad, L and her husband, L's sister and her family. But L questions the cultural imperative suggested by D, and most certainly the rigid application of that imperative to her own situation.

This exchange between L and D reveals something more about the ways in which different caregivers bring out different tonalities in the love and duty voice. D frames her accusations of ingratitude by invoking a sense of obligation and sacrifice:

> Well, it IS your father's home, isn't it? He is doing you and your husband a BIG favor by providing you a home to live in, right?

L on the other hand claims reciprocity in her dealings with her father. She reframes the scenario in terms of exchange rather than as obligation or debt:

> Duh! I am well aware that it is my father's home. Unbeknownst to you, though, he is not doing my husband and myself a "BIG" favor by providing us a place to live. This is not where we want to be and we could make it just fine elsewhere. We may not pay rent, but we pay for everything else. Plus, just think of the money my father saves by not having to employ anyone 24 hours to take care of him. Somehow I think that more then makes up for rent.

This is more than a quibble about who does what for whom. This exchange illustrates two distinct but related orientations towards caregiving: obligation and reciprocity. In the section that follows, I discuss obligation and reciprocity in terms of how they color the Caregiver as Kin voice.

Obligation & Reciprocity

The Caregiver as Kin voice embodies a fundamental question for caregivers: What do we owe to those we love? Do we owe care to our loved ones because they're ours? Because we love them? If they're not really family, or we don't actually love them …what then? Is the care we give to our loved ones based on their need, on our obligation, as part of a familial relational exchange, or on some amalgam of these motivations?

These are questions that might be asked in any of the caregiving voices – but they are at the very heart of the voice of caregiving as love and duty.

The American Heritage Dictionary (1998) provides the following primary definition for obligation:

> 1. The act of *binding oneself* by a social, legal, or moral tie.
> 2. A requirement, such as a contract or promise that *compels* one to a particular course of action.
> 3. The *constraining* power of a promise, contract, law, or sense of duty.
> 4. The fact or condition of being *indebted* to another for a favor received.
> (p. 574, emphasis added)

Obligation then, is unilateral – it's a promise given from one person to another, one that binds, compels, constrains. In an editorial on minority caregivers in the UK, Yasmin Alibhai-Brown (2002) muses on caring for her own mother: "Until today I thought of myself as a daughter with some *absolute obligations* – as non-negotiable as those I owe the children I brought into the world. (p. 20, emphasis added) " Schneider (1980) puts it with characteristic bluntness:

> The contrast with one's own children [and say, the family dog] is clearest. One expects diffuse solidarity and loyalty from one's own children. But if they turn mean, they cannot be taken to the local humane society to be "put away." They are yours and you stay with them as they stay with you. [p.54]

The care of elderly relatives is fertile ground for the discussion of who owes what and to whom. Feminist philosopher Jane English (1979) poses the question, "What do grown children owe their parents? I will contend that the answer is 'nothing'." English argues that there is no debt between child and parent; after all children do not choose to be born. Any service rendered by child to parent should be based on "mutual beneficence" – in other words, through love. If there is no love, no sense of "diffuse enduring solidarity" (Schneider, 1980), there can be no obligation.

Christina Hoff Sommers (1986, as cited by Post, 1990) finds this position a little too extreme. It’s true, she says, “exceptional parents can forfeit their moral claims on their children”; bad parents don’t deserve their grown children’s care. But most parents are not exceptionally bad, and most people do feel some sense of obligation towards their parents. Sommers suggests that English’s no debt philosophy flies in the face of our common moral sensibilities; it’s simply not the way most people think about their parents. She proposes *gratitude***,** rather than simple obligation as the foundation of care for one’s parents. The gratitude we feel towards our parents for giving us life and for their ongoing care through childhood counterbalances their parental failings.

In their different ways, English (1979) and Sommers (1986) are talking about *reciprocity*: the give and take between people in relationships. Reciprocity is based on equity theory which states in part that relationships based on an unequal exchange will ultimately die out (Neufeld & Harrison, 1998). Obligation is a one way street, directed towards someone else; reciprocity is a two way street, where two or more people must participate in some way. English calls for reciprocity from a kind of “what have you done for me lately” stance. Sommers, takes the long view:

> Embedded within tradition is the recognition that reciprocity remains valid as the norm of intergenerational morality despite the expected failures of both children and parents to manifest a consistent generosity. [p. 87]

However both English (1979) and Sommers (1986) position the ties between the grown child and the parent in need of care as relational in both fact and deed. Care given and received in the present has roots in the past relationships between caregiver and care recipient. This relational history is an important dynamic in understanding what kinds of interventions would truly work to support <u>this</u> caregiving situation in <u>this</u> family. In my explorations of online caregiver support groups (Dobbins 2002, 2004, 2007), I've rarely found a caregiver that did not offer some kind of family history as part of their story. It's all the more surprising to find that the formal health literatures seldom address family dynamics when discussing the implications of family based care. The Caregiver as Kin voice can bring these dynamics to light..

Let me end my discussion of obligation and reciprocity with a brief report on a research project that suggests some intriguing implications for family caregivers. In this study, researchers Neufeld and Harrison (1998) conducted a series of unstructured interviews with 22 male caregivers for cognitively impaired adults. The goal of the study was the exploration of reciprocity as used by these caregivers in their dealings with the care recipient, family and friends. Neufeld and Harrison identified four variants on reciprocity:

- ***Generalized reciprocity* –** the "pay it forward scenario"; you will get something back but not necessarily from your loved one.
- ***Waived reciprocity* –** the "you can pay me back later" scenario; the loved one will be able to reciprocate when he/she is better.
- ***Constructed reciprocity* –** the definition of giving back is reconstructed in terms of what the loved one can actually offer ("When I brushed her hair, she smiled.")
- ***No reciprocity or obligation* –** you care because you "ought to"

The majority of the group (12 out of the 22 men) reported that they dealt with their loved ones from a sense of obligation. The next largest group was the constructed reciprocity group. Those men who worked through obligation reported more anger, more depression and more negative feelings than those who used any other kind of reciprocity.

Those who used constructed reciprocity reported more positive feelings about their loved ones and about themselves than any other group. It seems that constructed reciprocity gave these caregivers more to work with, a stronger foundation for their caregiving.

However, the most intriguing part of the story is the identification of the factors that encourage constructed reciprocity. The first factor is the pre-existing relationship between the caregiver and care recipient. The second is the exposure to nurses who showed these men how to look for tiny nonverbal cues by the care recipient that could be constructed into a different kind of reciprocity. In other words, care and caregiving relationships can be modeled for others. It strikes me that women are exposed to such models all their lives, while men are not. If there were more models for male caregivers, would there be more male caregivers?

The Caregiver as Kin Patient Voice: What does it do?

This voice allows the caregiver to normalize the caregiving experience, to reframe it terms of ordinary familial exchange. Nurse/researcher Lioness Ayres (2000) suggests "It may be that for many, caregiving is an ordinary circumstance like marriage or parenting, in which individuals assume substantial responsibilities whose meanings are more complex than, although related to, the responsibilities themselves." It may be too painful to think in terms of turning points and crisis, to give up a cherished relational role (e.g. as husband, as mother) in order to take on the new and unfamiliar role of caregiver. However, illness and disability are not normal; maintaining the normal family status quo of normal care exchanges during a health crisis may prove impossible. And conversely, if the voice of the family works too well, caregiving – and by extension, caregivers – disappear into "normal" family interactions.

The Kin voice expands our vocabulary**.** If the voice of love and duty has been used to silence women in the past, the need to break that silence has led to the formal acknowledgement of informal caregiving. Now, the voice can be used to hear from other caregivers: men, minorities – and due to the AIDS crisis, children. Studies have found that many women with HIV rely heavily upon their children for emotional and instrumental support (Bunting, 2001). The Caregiver as Kin voice may be a way to tap into this most vulnerable caregiver population.

The Kin voice provides context by reminding us that care never happens in a vacuum. It suggests the need to look outside the caregiver/care recipient dyad and broaden our perception of care. It provides a sense of connection by positioning caregiving as an extension of family interaction. But it can also isolate the caregiver by locking the caregiver experience within the privacy of the home.

I began my discussion with Charlotte Brontë's letter as an exemplar of the Caregiver as Kin voice. Here is a communication made by a participant in an online caregiver support message board that is almost the mirror image of Brontë's note. The poster, J introduces herself as the caregiver for her father. She explains that her husband cares for her father as much – perhaps more – than she herself does:

> There are days when I can't even get out of bed and he takes care of my dad. I really think that my husband does more then I do... All I do is sit here and watch.

J goes on to describe a recent disagreement between her husband and her father: craving some downtime, her husband tried to order her father to bed, and Dad refused to go. Bitter words were exchanged, and J finds herself caught in the middle:

> It kills me because I understand both sides. I wish my husband would remember that talking to my dad is kind of like talking to a four year old these days. I wish

> my dad would remember that my husband does a heck of a lot for him. I wish that I wasn't so tired!

J is wife, daughter, caregiver and care recipient. And she’s not the only caregiver involved; husband R appears as a full partner in the family project of caring for Dad. R also cares for J herself, both directly and indirectly, taking over much of her caregiving duties when she can’t perform them. Is his helpfulness surprising, given that this is not <u>his</u> father? Is it a reflection of his love for his wife? A “natural” extension of his ongoing relationship with his father in law? What is the core of his caregiving – the direct care he provides to his father in law, or the support he gives his wife in what she has to do? The questions we might ask Brontë are the same questions we want to ask J and R. Family-based care can be best understood within the context of the family.

Caregiver as Advocate: Caregiving as Calling

- I will fearlessly make my voice be heard with regard to my loved ones’ care, and be a strong ally to those professional caregivers committed to caring for my loved one and a fearless shield against those not committed to caring for my loved one.
- I will fearlessly not sign or approve anything I do not understand, and will steadfastly request the information I need until I am satisfied with the explanations.
- I will fearlessly learn all I can about my loved one’s health care needs and become an integral member of his or her medical care team.
- I will fearlessly care for my physical and emotional health as well as I care for my loved one’s, I will recognize the signs of my own exhaustion and depression, and I will allow myself to take respite breaks and to care for myself on a regular basis.
- I will fearlessly acknowledge when providing appropriated care for my loved one becomes impossible because of either his or her condition or my own and seek other solutions for my loved one’s caregiving needs.[Barg, 2001]

The above passage is drawn from The Fearless Caregiver’s Manifesto, the introduction to Gary Barg’s (2001) book <u>The Fearless Caregiver</u> (see Appendix C for complete manifesto). Barg, a noted public speaker, author and the editor-in-chief of <u>Today’s Caregiver Magazine</u> has collected a series of articles, poems and tip sheets by expert caregivers: doctors, nurses, social workers, homeopaths, medical facility administrators and just plain folks immersed in the day-to-day business of caregiving. Barg had two goals to accomplish in this book. The first is clearly spelled out in his subtitle: “How to get the best care for your loved one and still have a life of your own.” The other is the creation of the fearless caregiver:

> First, they believe they can make a difference. Second, they see their role in their loved one’s care as being just as important as any of the professional caregivers. And third, they ask questions. They research and do not easily take no for an answer. [p.xxiii]

Barg positioned caregiving as a vocation, a calling. The fearless caregiver has a proper job to do, complete with concrete rights, privileges, responsibilities– and a formal, visible identity. This is the voice of the Caregiver as Advocate.

On first hearing, the Caregiver as Advocate voice is a deceptively simple one. I initially conceptualized this voice as a kind of balancing act between the other voices described in this dissertation; a corrective to the Caregiver as Patient voice, a reaction to the Caregiver as Kin voice. One way to hear the Advocate voice is as the continuation of the institutional rise and fall story I describe in the Caregiver as Kin section. From the Caregiver as Kin perspective, the story ends with the medical institution handing the patient back to the family for ongoing care. The voice of Caregiver as Advocate says, “Yes, return our loved ones to us for care – but know that things are different now.” Now that the critical role played by informal caregivers in sustaining the current U. S. health care system has been publicly acknowledged, these caregivers can no longer be remanded to the silent sphere of the home. Family caregivers have emerged as both a public and a private presence – and they need voices that acknowledge and express this dual presence.

While the Caregiver as Kin voice may have emerged from the need to counterbalance those other caregiving voices, it has since taken on a life of its own. This is a peculiarly American voice, one that proposes a creative approach to the self-interest/altruism dilemma posed in the Caregiving Overview section of this dissertation. The Advocate voice deliberately arches across private and public domains, drawing together the singular and the collective experiences of caregiving.

The Advocate voice also has something special to offer the psychologist: a window into the processes of constructing identity. From this perspective, identity work is not a merely a byproduct of the caregiving experience, but rather an integral part of giving care to a loved one. The caregiver voice is not discovered by accident; the creation of individual caregiver identity becomes a deliberate act. And the more work each caregiver puts into developing their individual caregiver identity, the better caregiver they become. As caregiver/activist Suzanne Mintz claims on the NFCA website:

> Who am I? I am the sum of all of my labels - and then some. I am wife, mother, daughter, Jew, Sherlock Holmes fan, fair weather jogger. I am a type "A" personality. I am a writer. And yes! I am a family caregiver too.
>
> It is not the first way that I describe myself, but it is definitely part of who I am, and I believe it is a part that all of us in this role need to own - for our own sakes and for the common good.
>
> Yes, I am a family caregiver! It is becoming a mantra for me, and I think it should for you as well. [Mintz, 2002, ¶ 6-8)

The Caregiver/ Identity Connection

The voice of the calling is based on a very simple formula: *doing x being = caregiver identity.* In other words, the performance of caregiving tasks in conjunction with the meanings ascribed to those tasks and the need for their performance all contribute to the creation of self as caregiver. Of course, this broad formula could be applied to any of the caregiving voices I describe – perhaps to any voice in any context at all. But the Caregiver as Advocate voice reframes both tasks and meaning in a unique way. On the website for the National Family Caregivers Association founder/caregiver

Suzanne Mintz (n.d.) asks and answers the question: *What is the essential bond between all caregivers?* It's not the tasks performed; they vary by condition, by illness severity, by situation. It's not the timeframe; caregiving can last anywhere from a few weeks to an entire lifetime. It's not proximity; there are up-close caregivers and long distance caregivers, and caregiving doesn't end when the patient is no longer at home. What then is the common thread that ties all family caregivers together?

Based on a series of surveys the National Family Caregivers Association (NFCA) has been conducting since 1998, the answer seems to be the emotional impact of caregiving: the sadness and loss as normal life disappears, the isolation that comes from living outside the norm, the frustration at how hard it is to get the simplest things done, the stress that comes from being overburdened and underappreciated. But NFCA founder Mintz also draws attention to another shared emotional bond between caregivers:

> It is the inner strength that most of us never knew we had….It is the fortitude to go on despite the pain. It is the wellspring of hope we always dip into. It is the power to make a difference. It is the clever way we solve a difficult problem. It is the knowledge that we have been tested by fire, and we have survived. [Mintz, n.d., ¶17-18]

Notice the emphasis on we; the caregiver is no longer caregiver singular, but part of caregivers plural. The caregiver identity equation can now be revised accordingly: *doing x being = identity.*

When speaking from this voice, what you do and who you are as a caregiver become inextricably tied to others in the same position. You no longer exist solely as an extension of your family or in relation to the person you care for; your alliance is with other caregivers. A new kind of kinship emerges. Identity then becomes a public issue, as well as a private one. Here is Mintz (n.d.) again:

> By identifying myself as a family caregiver, part of a group, I am building recognition of what I do. I am saying I am not an isolated instance, an oddity of one. I am part of a group of people - in fact a very large group - with common issues, characteristics, needs and concerns. We caregivers so often fall into our roles, just taking on tasks one after the other, as a matter of course, feeling feelings we are afraid to own. By giving a name to our situation we validate our experiences, and all of our feelings. We say to the world: Here I am. Look at me. Acknowledge me. Help me. [¶ 9]

Special people

An important part of the identity work done through the Caregiver as Advocate voice is the recognition of caregivers as special people. Caregivers may not have <u>chosen</u> to become caregivers in the first place, but they have <u>been chosen</u> to do a very specialized job: to care for someone they love. In observing online support groups that prioritize this voice (Dobbins, 2002, 2004), I'm struck by the "big picture" perspective they take. Their rendering of the Caregiver as Advocate voice stakes a powerful claim: the care you give has implications far beyond those most personal to you and your loved ones. Gail Mitchell, the founder of the Empowering Caregivers™ site, speaks of this as she describes the evolution of her own caregiver identity:

> I constantly prayed for guidance and direction to be used as a vehicle for the highest good of all concerned whether it was for my parents, my family, my animals, friends or just for me. I knew deep within myself that the most important lesson I was learning and conveying to my family was listening to my heart and opening to love. I was determined to serve for the highest spiritual good of all I came in contact with. [The Evolution of Empowering Caregivers™]

There is a strong spiritual inflection and a definite moral stance here; Mitchell suggests that caregiving as a vocation cultivates special virtues in those who practice it. Gottlieb (2002), writing as a father caring for a disabled child, claims that the intense labor and out-of-norm experiences such care entails means that

> Caretakers often cannot develop many virtues that we should. At other times we are called on develop other virtues – such as looking on the

> bright side of things or putting up with endless rounds of frustration – to
> an extreme degree. (p.228)

And caregiver/activist Suzanne Mintz (2002) positions caregiving as a role that, "tests our abilities, our faith, and our character." She concludes simply, "Caregivers are very special people" (¶ 26).

As a vocation, informal caregiving rests on two basic concepts: service and advocacy. The service is rendered towards the loved one in need of care, and towards society at large. The advocacy is an extension of care from the private to the public domain. And the connection between service and advocacy is love. In this voice, the caregiver is Joan of Arc, a spiritual warrior in a noble crusade. But Joan of Arc would not have been Joan of Arc, had she not acknowledged her voices. Similarly, the power of the Caregiver as Advocate voice is based on the critical step of "coming out" as a caregiver. Through identification comes empowerment.

Empowerment, And How to Get It

On the NFCA web site, Suzanne Mintz (2002) provides a clear-cut definition of what caregiver empowerment entails: "Empowerment for me means a sense of self confidence, a belief in one's ability to have some control over situations, a sense of pride, a feeling of self respect and self worth." In this next section I present the three aspects of empowerment that are clearly heard through the voice of the Advocate: self love, mastery and advocacy.

Self Love

Mintz (2002) continually references the inner strength of the caregiver and how it is used on behalf of the loved one in need of care. However, she says, "We need to begin to use it to take better care of ourselves, to feel proud, to experience the ***beauty of self love.***" (¶ 23, emphasis added). A key message offered by the Advocate voice is that you are an advocate for yourself as well as for your loved one. “Take care,” these caregivers tell each other, “you must take care of yourself.” On first hearing, this sounds somewhat like the Patient voice as it positions the caregiver as vulnerable, at risk. But the Advocate voice is based on caregiver as survivor, not caregiver as victim. Gail Mitchell (n.d.) , founder of the Empowering Caregivers™ firmly rejects the victim in her own caregiver identity: “Many a time I came from a victim attitude, but I always stayed focused on creating choices that would take me away from this faulty belief pattern” (¶ 21). She also rejects it on behalf of other caregivers, albeit gently:

> I would like to offer Empowering Caregivers™ as an opportunity to create a safe space where you can come to work through issues on a positive level. Leave your victim at the entrance to the chat room or while you are reading the newsletter. (If your victim slips in, we will support it, but encourage you to move past it, to see the larger picture that awaits you). [¶ 21]

The “larger picture” Gail refers to is the provision of quality care for your loved ones. Self love is legitimized as the high road to good caregiving; if you care for yourself, then you will be better able to care for your loved ones. Gail’s message appears wherever the Caregiver as Advocate voice is heard:

> Do whatever is necessary to nurture yourself so that you remain focused through your challenging situations that are before you. Reach out for the support you need emotionally, physically, mentally and spiritually. Share your experiences from your own life as well with others to help yourself and serve others as well. [¶ 21]

Hugh Marriot, a journalist and spousal caregiver puts it even more bluntly:

> No, it’s not burnout. Or lack of information. Or even poverty, fatigue, back pain – or any of the many other problems and afflictions that we care-givers are heir to. It’s not even guilt. It’s that we need to be more selfish than we are. [¶ 1]

The Caregiver as Advocate voice provides an interesting approach to the self-interest vs. altruism dichotomy inherent in our Westernized, individualistic culture: self interest as the means to an altruistic end.

Mastery

Mastery is demonstrated when caregivers learn to walk the walk and talk the talk of caregiving. These days, the family caregivers are called upon to be a medical technicians, service coordinators, interpreters and counselors; they are expected become proficient in areas that are both unfamiliar and unfamilial. And the learning curve is very steep indeed.

> The doctor has at least twelve years of training. The nurse has four, and the case manager at least two. They all have training, but your job begins in an instant, the moment the doctor reports your loved one's prognosis, or the moment you realize your loved one can no longer take care of himself or herself without assistance. [Barg, 2001]

This is a daunting prospect, and becomes even more so when the caregiver lacks the essential training to do what needs to be done. A recent joint study by the United Hospital Fund and the Visiting Nurses Service of New York found a serious deficiency in the provision of training to informal caregivers in New York City. Nearly 60% of these caregivers reported that they had received no training from health care professionals on how to care for their loved ones. 38% of those surveyed claimed that they'd had no instruction on how to change bandages and dressings. Over 18 % said they hadn't been trained to operate essential medical equipment. And 16% said they were not instructed on how to manage a prescription medication protocol (United Hospital Fund, 2000).

To add insult to injury, informal caregivers are often not acknowledged for the expertise they do possess. In her ethnographic study on nursing home aides, anthropologist Nancy Foner (1994) noted the lack of appreciation expressed for the families most involved their loved one's care:

> One might expect them [the aides] to be pleased when patients' relatives visit frequently and assume some of their work burden… Yet far from being grateful to family visitors, I found that nursing aides tended to be annoyed, occasionally deeply angry, with them. The general view is that actively involved relatives are another source of pressure on the job. [p. 112]

And Carol Levine (2002a) described the common complaint among caregivers for hospitalized patients who feel that "their intimate knowledge of the patient's behavior and medical condition is frequently disregarded by hospital staff, who assume that they have all the expertise that is necessary" (p.178).

The struggle for mastery is a ferocious one, but as the work done by family caregivers becomes more visible, the traditional paradigm for health professional/ patient/ informal caregiver interactions has started to shift. Traditionally, the lines of communication ran from health professional to patient, with the family caregiver somewhere in the periphery (see Appendix D, Figure 1]. But there's a new paradigm in the making – Barg calls it the Fearless Caregiver paradigm – that positions the patient in the center of a circle of care that includes professional health care workers and informal caregivers alike [see Appendix D, Figure 2]. The family caregiver is repositioned as a paraprofessional, one with distinct responsibilities and areas of expertise. Nurse/ researchers Toth-Cohen, Gitlin, Corcoran, Eckhardt, Johns, and Lipsitt (2001) refer to family caregivers as "lay practitioners," and describe the relative contributions made by family caregivers and health care professionals:

> Caregivers bring in-depth knowledge about the role history and daily behaviors of their family member and what may or may not work in providing care. Providers, in turn, offer specialized and technical knowledge from their respective disciplines. [p.25]

The voice of caregiving as calling is a claim for recognition, a call for mastery and a demand for the proper tools to do a proper job.

Advocacy

The acknowledgment of family caregivers as valued and valuable members of the care team makes the invisible work of caregiving very visible indeed – but what then? Hard-won rights come with new responsibilities and caregiver/author Barg (2001) makes this very clear, as he describes the fearless caregiver:

> You have become the most significant human being in the life of your loved one, and that gives you power. Along with that power comes responsibility. You now have to learn all you can about caring for your loved one. You have to stand up for your loved one, when necessary. If something seems wrong, unfair, awkward, inappropriate, or it's just not what you want or expect, you do have the right to do something about it. More important, it is your responsibility to do something about it. [p 6]

The family caregiver is not only responsible for the care they themselves provide, but must also stand watch over the professionals. This adds an interesting tension to the Fearless Caregiver paradigm with its presumption of seamless interaction between professional and lay caregivers. In a recent exchange between members of an internet based caregiver support group, T writes:

> The nurses on the floor now call me "trouble maker." So be it. I was just expressing my concerns over mom's medication, and things that they should have know about her. If they feel that I am a trouble maker so be it. Someone has to take the bull by the horns every once in awhile. They were not doing their jobs, that is one reason why she ended up in the hospital. They over drugged her too, with Percocet every 3 hours and the Oxyocitin on top of it.

T's post is greeted by a chorus of "me too's". For example, M responds:

> I'm glad your Mom is doing better. As for being a trouble maker, you are not, you're looking out for your Mom. I can imagine I'm considered a trouble maker too, even though I'm 1,200 miles away, I really get on them when they make a mistake that could be critical!

Another member laughingly calls herself a “pit bull” when it comes to getting her questions answered by the doctors. Jokes and anecdotes fly, and it’s generally understood that this kind of hyper vigilance is a critical part of caregiving. This is striking in that that this group’s orientation towards the medical profession is generally quite positive. Recently, a member of the group was roundly scolded for her portrayal of nursing home employees as “morons” and “monsters.” Still, everyone acknowledges the need to monitor the professionals – to question, to prod, and sometimes, to confront.

However, the need to “do something” doesn’t end with the interaction between particular caregivers and the health care professionals they deal with. The voice of the advocate moves the discussion out of the personal and into the public domain. Anthropologist C.D.F. Parsons (1984) eloquently described this movement as “idioms of distress”:

> Where the particular problem is one which arises in the lives of many members of a particular society, and where the stressful situation persistently occurs, personal distress may come to be expressed collectively… The idiom articulates a rift between cultural knowledge and human experience, a recurrent dissonance, or social distress which motivates people to take action. [p. 89]

The Caregiver as Advocate voice provides idioms of distress that allow people to translate their personal experiences into a call for social action. The caregiver who is formally identified as a caregiver has both the right and the responsibility to call society at large to account. Advocate/caregiver Suzanne Mintz (n.d.) lays it out for us:

> By all of us identifying ourselves as family caregivers we are saying that family caregiving is not just a personal issue for those involved, to be dealt with only within the confines of our family, but rather a national issue that must be addressed. By identifying ourselves as family caregivers, we are calling attention to the inequities in our healthcare system. By identifying ourselves as family caregivers, we are saying we matter. By identifying ourselves as family caregivers, we are alerting researchers, policy makers, payers and others in a position to make a difference, to the impact of

> family caregiving on us as individuals, on our families, and on society at large. [¶ 13]

The Caregiver as Advocate Voice: What does it do?

> By identifying myself as a family caregiver, and by asking you to do the same, I no longer feel alone, angry or displaced. In fact, I feel strong and empowered. Armed with statistics and stories, I hold my head high and reach out for help with dignity. I talk to the press and members of Congress. I meet with other groups whose issues converge with those of family caregivers and chart a course for change in our healthcare system. I feel okay about my pain and understand my frustration, but best of all, I now take true pride in myself and all I have overcome in my role as a family caregiver. [Mintz, n.d. ¶ 12]

In the course of my research, I have sometimes thought: Why wouldn't someone chose to speak in this voice? As with the Caregiver as Patient voice, the Advocate voice offers the caregiver an identity that isn't solely based on the person being cared for; however this identity is based on strength and health rather than frailty and illness. The proactive stance implied by the Caregiver as Advocate voice allows the caregiver to demand help as a right, as opposed to asking for it as a need. This may engage those caregivers who would ordinarily avoid help-seeking behaviors, e.g. men. The emphasis on identifying with other caregivers seems to increase opportunities for support, as in the validation of personal experience and the exchange of helpful tips and advice. As previously suggested, this voice offers a creative solution to the tension between self interest and altruism, with a potential win-win result for all concerned. Again, who wouldn't choose to speak with the voice of the Advocate?

It's possible that some people would be silenced by this voice, rather than empowered. The tone of this voice is positive, and whining is discouraged; what happens to those who are not able to master the right tone, the right vocabulary? The affiliation between caregivers is heavily emphasized; what does this do to the affiliation between caregivers and their loved ones? Some would argue that the Caregiver as Advocate voice is divisive in that it deflects attention from the appropriate object of interest, the care recipient. In her editorial Caregiver Advocates Miss The Point, disability rights activist Laura Hershey (2003) expressed great "leeriness" regarding the caregiver advocate movement. While completely in favor of appropriate acknowledgement and compensation for caregivers, Hershey was dismayed by the shift in focus:

> These caregiver advocates focus entirely on their own needs and issues, to the exclusion of the bigger disability issues like accessible housing and transportation, in-home attendant services and independent living programs. They fail to analyze the effects of disability oppression. Thereby, they implicitly put the blame on disabled and older people.[p31]

Hershey goes on to claim that this misapplied focus is the gateway to poor caregiving and potentially, to the abuse and abandonment of care recipients. Further, the family caregiver becomes "both the caregiver and the consumer of services, rendering the disabled or older person invisible." And, she argued, if the care recipient's needs are not the priority, then both care recipients and caregivers will undoubtedly suffer. Hershey's position is extreme, but it raises an interesting question: Does the raised voice of the Caregiver as Advocate implicitly drown out that of the care recipient?

Finally, there's the sheer effort of being Joan of Arc. Speaking from this voice takes a lot of psychic and physical energy. The Advocate voice can be exhilarating and empowering, but it can also be overwhelming. At a recent conference on caregiving, I listened to speaker after speaker exhort the audience to take a stand, to speak out, to fight for their loved ones and themselves. At first I felt exhilarated, but as the message was pounded home, I felt my anxieties rise: What if I'm just not up to the task? What if I'm not strong enough to do all of this and also provide day-to-day care for my loved one? Does that make me a bad caregiver? And this led me to one last question: Is the goal to become a fearless caregiver, or to acknowledge and work through the fear that caring for a loved one inevitably brings into one's life?

As in all the other voices I've attempted to describe, the voice of the Caregiver as Advocate has much to offer – but not for everyone and not all the time. Despite its seemingly straightforward message, this voice is as complex as the tangle of influences and experiences that have brought it into being.

Across The Voices

Now that I've broken down each caregiver voice, it's time to put them back together again. In looking across these voices, the ways in which they complement each other and what gaps they fill becomes clear. We can begin to imagine how people might put them together to create a personal caregiver voice of their own.

Each voice has a different orientation to caregiving and how it fits into a lived life. In the Caregiver as Kin voice, caregiving sounds "natural", like an extension of day-to-day interaction between family members. Normalcy is the key to this voice; caregivers take a low profile as caregiving is blended into the life of the family. The Caregiver as Patient voice takes a very different stance; caregiving is unnatural, an imposition that warps and destroys normal life. To use this voice is to become highly visible albeit in a negative way. The Caregiver as Advocate voice is also a high profile voice; unlike the Patient voice, caregivers are present in a positive way.

Each voice identifies a different turning point in the caregiving experience. In the Patient voice, the critical transition is from healthy to sick, i.e. from coping to not coping. The Kin and Advocate voices seem to share the same turning point: from family member to family caregiver. However, the Kin voice positions this turning point as a traumatic event, while the Advocate voice hails this transition as the dawn of empowerment.

The focus of each voice differs as well. The Kin voice is explicitly patient-centered; the family member in need of care is always firmly the object of interest. The Patient voice is also patient centered, but offers an interesting twist: the caregiver is identified as the patient. The Advocate voice, with its message of dual advocacy for caregivers and their loved ones alike, illustrates a kind of interaction between the Kin and Patient voices: *patient-centered x self-as-patient centered = the Advocate voice.*

To look across these voices is also to look at the relationships they support. The Kin voice speaks in terms of relatedness, i.e. the caregiver in relation to the patient and to other family members. The Advocate voice heavily emphasizes affiliation; the caregiver joins with others who share the common experience of caregiving. In comparison to the others, the Patient voice is a solitary voice; the dual status of caregiver and patient seems to isolate the caregiver from others.

Looking across sociological levels, the Patient voice appears at the most personal individual and micro level of social organization. The Kin voice, with its explicit ties to home and community can be placed at the local or mezzo level. And the Advocate voice is the big picture voice that crosses micro, mezzo and macro levels. Each poses an important moral and philosophical question about the nature of human existence. The Caregiver as Kin voice asks: What do we owe to the people we love? The Caregiver as Patient voice asks: Where do your needs end and mine begin? And the voice of the Advocate asks: Who am I? Who are we?

III) COMMUNITIES: SITES OF DISCOURSE

Self-Help and Peer-Led Support Groups

The growth of the self-help support group [8] over the past 40 years forms an interesting parallel to the burgeoning awareness of informal caregiving as a phenomenon. Jacobs and Goodman (1989) attribute the self-help group boom to changes in traditional familial support structures, to advances in medical technology, to post-Watergate skepticism regarding major intuitions such as organized medicine, to the advent of managed care and the attendant obsession with cost containment, to increasing awareness within the general public about the links between social support, experience-based knowledge and health, and to media exposure and dramatization (e.g. disease of the week movies). These same factors can also be seen as contributing to the gradual shift in how informal caregiving is conceptualized: from the natural extension of familial roles to an imposition that disrupts familial life.

What do these groups do?

Self-help and peer-led support groups are based on the premise that people facing similar challenges are best equipped to help each other find productive ways of dealing with them (Davison et al., 2000; McKenna & Green, 2002) Self -help support groups are typically formed around a common problem shared by participants; identification and acknowledgement of the problem is a condition of group membership (Jacobs & Goodman, 1989; Levy, as cited by Glasser-Dass, 1997; Rosenberg, 1984). They are low- or no-cost to their members (Jacobs & Goodman, 1989; Stewart, 1990). The goals of the support group are to increase members' coping abilities, to develop effective interpersonal insights that will support effective interpersonal behavior, and to provide a safe place for reality testing (Rosenberg, 1984). However, self-help groups differ from group psychotherapy per se; in psychotherapeutic groups, the goal is usually to eradicate some negative phenomenon. In self-help/support groups the goal is not to eliminate an unavoidably stressful situation, but rather to develop healthy coping strategies for dealing with an ongoing situation as a part of life. As a bottom line, the task is not to cure, but rather to sustain and maintain group members over time. This is potentially powerful approach to family caregiving, with its indefinite timelines, uncertain trajectories and unknown outcomes.

Self-help groups are generally peer-led, and as Davison et al. (2000) remark: "The power of this approach lies in the belief that a collective wisdom is born through the shared experience of participants rather than through the professional training or style of the leader." A 1991 study found that peer-led support groups report stronger levels of group cohesion, expressiveness and self-discovery among group members (Meissen, Gleason, and Embree, as cited by Phillips, 1996).

There are two additional and unique features of self-help groups that are of particular interest to my research project. The first is the concept of ***continuity*** within these groups, as suggested in Wende Phillips' discussion of on-line versus real life support groups (Phillips, 1996). Members of a given support group may share a common problem, but they are not all in the same place in terms of experience. Some are old-timers who can share the benefit of long and multiple experiences, others are newcomers who are dealing with the situation for the first time, and still others fall in between the two extremes of experience. Jacobs and Goodman (1989) suggest a related characteristic in their discussion of ***symmetry*** within self-help groups:

> Perhaps the dynamics of complementarity and the cohesions supported by similarity of problems create group equilibrium peculiar to many SHGs. We suspect they encourage a rapidly attained “sense of symmetry” within individuals – a simultaneous sense of common bonding and dependence on differences. That experience seems central in creating a frequency of disclosure behavior, which in turn induces high frequencies of empathic communication in the typical group. [p. 539]

In other words, group members need to be similar enough to share a common vocabulary, but different enough to feel the desire to communicate. The ongoing effort to compare and contrast, to share experiences creates a sense of community and a site for discourse.

Virtual Support Groups

Virtual support groups potentially combine the benefits of traditional (i.e. live) support groups with the flexibility afforded by Internet-based communications (Davison, & Pennebaker, 1997). As with any support group, participants in virtual groups come together in order exchange experiences, advice and support with others who are going through similar situations. Internet-based group members can reach out to each other at any time, and can come and go at will; they express themselves without the usual boundaries of face to face interactions, transcending the limits of time and space (Davison & Pennebaker, 1997; McKenna, & Bargh, 2000).

The unique qualities of virtual interactions – the boundaries they reveal between online and offline worlds – have deep implications for the kind(s) of relationships that develop between members of web-based support groups (Dobbins, 2007, McKenna & Bargh, 1998). Participants in such groups may speak more openly online than they would in a face-to-face setting; they forge intimacies more quickly and feel freer to ask for what they need. Without physical or visual cues to act as gatekeepers, there may be a greater openness to feedback. Unlike actual self-help groups that meet at specified intervals, caregivers can access a virtual group 24 hours a day, and a person always gets their turn to speak (Dobbins, 2007).

In my prior research on virtual support groups (Dobbins, 2002, 2007), I found another intriguing aspect of virtual relationships: A person doesn't have to be in direct contact with others to feel connected to them. Research on the Internet refers to lurkers, those who read message-board posts but don't respond. Within these support groups, it's not uncommon for people to lurk for some time before making their presence known. People can therefore come to know each other before they ever share an interaction – and if and when interaction does take place, it is informed by this prior knowledge. The careful observer can often pinpoint the moment at which people first express their online relationships as the point at which they first respond directly to another's message, but it's not always possible to identify when that sense of relationship truly begins.

Virtual support groups, then, provide a certain freedom from time and space. Although this freedom is potentially liberating, it can also be very frightening. People who seek online support need to create safe spaces in which they can reach out to others. The creation of relationships in this context is a critical part of creating safe space – quite literally an act of good faith[9]. At the most basic level, virtual relationships arise from the same impetus as those in real life: the desire to connect with others.

Virtual support groups usually function in one of two formats: as a chat room or as a message board format. For the purposes of this study, I sought a group that used a message board format for the present study.

Message boards: what they are, what they're not

Groups that use a message board format function in a straightforward way: someone posts a topic of interest – a question, a problem, a story – others respond, and a conversational thread ensues.[10] Multiple threads occur simultaneously at any given time; some begin and end in a brief exchange, some unfold over months. Interactions may take the form of a lively debate between multiple participants or an intimate chat between just a few.

I'm drawn to the message board format for a variety of practical and conceptual reasons. Like a *chat room*, message boards function in a conversational way. However, in support forums chats are usually offered at scheduled dates and times, while message boards are active 24/7. Message boards allows the group to generate a kind of database of specialized knowledge – much in the way *wikis* are designed to do – as participants share experiences, practical tips, references and resources. Unlike wiki collaborators, message board members can't edit each other's posts, but can only add to them. And I find that message boards are infinitely richer than *blogs* as a site of discourse. In a blog, a main entry is posted, and others are free to comment – a series of exchanges may be generated, but not necessarily conversation. The message board format allows members to respond to each other as well as to the initiator of the post, to spin off into other topics, to offer their own stories as full narratives, rather than as appendices to the initial post. Message board communications are unique in that they combine the call and answer of conversation with the introspection of a journal. This format yields a wealth of rich narrative, whether in consideration of individual posts or messages, or in looking across a conversational thread.

*The right site: Selecting an appropriate virtual support group***.**

Through my earlier research on Internet based support groups (Dobbins, 2002), I'd identified the following criteria for selecting the virtual support group for this study:

- **A group with a clearly defined identity.** The site should be clearly labeled as a caregiver support group, and there should be a clear mission statement regarding the purpose of the group. The founders, moderators and/or hosts of the group should be clearly identified.
- **A group with history, longevity and stability.** As is often the case with Internet-based entities, virtual support groups may be here today but gone tomorrow. They exist under the jurisdiction of the Internet Service Provider Network (ISPN) that hosts them; support group web sites can be redesigned, reformatted, merged with other groups or simply shut down. Stable sites – sites that maintain a consistent look, feel and presence over time – tend to build a loyal and highly participatory membership. The ideal site for the present study will have been in existence for at least two years, and will have accessible archives for all posts for a minimum of one year.
- **A group that is peer led, rather than professionally moderated.**. Peer-led caregiver support groups are run by caregivers for caregivers without any kind of professional intervention or moderation. Members swap stories, exchange emotional support, practical tips and information, and together explore different models of caregiving.
- . **A group that utilizes a message board format for communication.** As per my discussion above, the message board format provides rich narratives and accessible data. It is also usually a public forum for those who wish to read posts, although some require registration in order to post a message.

The site I've selected – **Empowering Caregivers**™ – fulfills all these criteria. In the sections that follow, I describe the site as virtual caregiver community, and then describe the specific message board forum from which the texts used for analysis have been drawn.

Introducing Empowering Caregivers™

The virtual community whose communications form the basis of my research project is called Empowering Caregivers™ (www.care-givers.com). Created in 1999 by Gail R. Mitchell, Empowering Caregivers™ is a website geared towards family caregivers, past, present and future. The website provides a broad spectrum of practical and emotional support through a wide variety of media: chat rooms, message board forums, featured articles on by experts, a bi-monthly newsletter, references and links to other support services, an ongoing prayer circle. As of this writing, Empowering Caregiver™ boasts an estimated participant base of over 5 million, spanning 175 countries. Please refer to Appendix E for the Site List as it appears on the Empowering Caregivers™ home page.

Empowering Caregivers™ is supported by private contributions (mostly from Gail herself) with very minimal advertising and almost no promotion. Anecdotally, many people seem to find their way to the Empowering Caregivers™ site as I did: by typing "caregiver support group" into their favorite Internet search engines. Empowering Caregivers™ is also part of a health-related Web Ring[11] and people sometimes discover it in their travels through other Web Ring sites.

The clearest statement of Empowering Caregivers' goals and overall orientation appears on the Our Mission page (Empowering Caregivers™, Our Mission, n.d.):

- To provide a safe, nurturing site for all Caregivers with emotional and spiritual support.
- To provide a vast amount of resources both online and off-line for Caregivers.
- To provide tools which EMPOWER Caregivers to help themselves as well as their loved ones.
- To provide chat rooms and message boards where Caregivers can freely discuss various issues involving their loved ones and receive both support and information from others in same or similar situations; where they can also express their emotions without fear of repercussions.
- To guide Caregivers into choices thus creating a more meaningful and loving experience throughout the Caregiving process.
- To educate Caregivers and their loved ones about the spiritual and emotional needs in the issues surrounding "end - of life - issues."
- Help caregivers to see a debilitated and deteriorating loved one as a whole person in body, mind and spirit. We help to surround them both with love and dignity to create a sacred experience for all concerned.

The mission statement clearly the reflects the orientation and philosophy of the group; caregiver talk is integral to the Empowering Caregiver™ community and the work of this virtual community is the creation of meaning.

From a practical perspective, Empowering Caregivers™ is a good venue for this project, as it fulfills the key criteria outlined earlier in this section. However, the real “goodness of fit” is revealed through the intersection of two separate but related historical positions: the caregiver story of founder Gail Mitchell, and the physical evolution of the Empowering Caregivers™ site.

Gail’s story

By her own estimation, Gail has been a caregiver for over 15 years. She cared for her husband until his death in the early 1980s, and for their beloved cat. In the 1980s and 1990’s she helped to care for friends stricken with HIV/AIDS, In the early 1990’s Gail’s father was diagnosed with terminal cancer and Gail served as his primary caregiver until his death in 1995. As her father entered hospice, Gail was also caring for her mother: "my mother almost died, because she had burned out from her role as a caregiver to him for two solid years." (Evolution of Empowering Caregivers™, n.d.)

Gail's experiences in caregiving led to her participation in online support venues, and ultimately to the creation of Empowering Caregivers[12] in 1999. Over the next few years, Gail maintained an active presence on the website, creating new links, generating chats, gathering resources and enlisting caregiving experts of all kinds. She infused the site with the deep spirituality and self-reflective search for meaning that she believed had carried her through her own experiences. At the same time, she was lecturing and conducting workshops for professional and informal caregivers around the country. Family caregivers were now becoming a recognized phenomenon, and there was great interest in creating and maintaining informal caregivers to supplement an overburdened health care system. The year 2004 was a watershed year for Gail; she created the National Organization for Empowering Caregivers™ (NOFEC), a national non-profit organization for family caregivers. And in that same year, Gail's mother passed away.

In the years that followed, Gail's health became a prime concern; she struggled with hormones, with metabolism, with anxiety/depression and with grief. After a promising start, NOFEC could not maintain its funding, and Gail finally closed it down in 2007. She kept the original Empowering Caregivers™ site up and running – there was simply too much activity there to shut down – but she could no longer participate the way she had in the past: "I had burned out so much from caregiving and helping others, I had no desire to write newsletters, maintain the site, etc." (7/25/08 Current Status post, What's New Forum).

Gail has taken since some time away from the boards to recreate herself as something other than a caregiver voice. She's reconnected with her creative side, becoming deeply involved in ceramics and traveling extensively to other countries to study and to practice. She seems to have rediscovered her joy:

> I am 60 years old. I must say for the first time in my life, I am happy... truly happy... and not in need for anything. Yes, I am still on this physical plane. I would still like to be in a relationship again... I still enjoy nice things.. etc.. but the peace had to come from within... and no one.. nothing could do this for me... [7/25/08 Current Status post, What's New Forum].

As of this writing, Gail is actively participating on the Empowering Caregivers™ site once more. She no longer responds to every post and she doesn't moderate every chat, but she is there. And she's there with something new to share, a new phase in caregiving to be explored.

Empowering Caregivers™, the site

The story of Gail is intertwined with the physicality of the Empowering Caregivers™ site; the site reflects Gail's vision, her ties to spirituality, her dawning sense of advocacy, her struggles to move from one life stage to another, from one phase of caregiving to another. However, the site's history reflects more than Gail's personal trajectory; it also reflects a shifting cultural discourse about family care. Consider the evolutionary timeline for the Empowering Caregivers™ site:

- **1999 -2000:** The start up years, punctuated by changes in format and the search for the right webhost server. Initially, the site consisted of a welcome message/mission statement, a couple of chat rooms, and a handful of message boards. The two constant elements are the heavenly background of blue sky and clouds, and Gail's presence.
- **2001 – 2004:** More and more links to other caregiver websites, an ever-growing roster of experts. The number of message boards has almost doubled as general topics are

broken down into specialized interest areas. Gail has taken on two, and then three additional moderators to help run the message boards and chat rooms.

- **2004.** The creation of the National Organization for Empowering Caregivers (NOFEC):

> The mission of the National Organization For Empowering Caregivers is to provide assistance; education, support, referrals and respite for informal family caregivers, as well as to promote public awareness about the realities of those who care for loved ones. NOFEC is a charitable non-profit organization deeply committed to helping family caregivers from all walks of life.
> The Empowering Caregivers™ is now positioned as a subsidiary of NOFEC: "Empowering Caregivers™ is under the umbrella of the National Organization For Empowering Caregivers, (NOFEC) www.nofec.org.. a 501(c)(3) charitable non profit organization." (Empowering Caregivers™ About Us, n.d.)

- **2007-2008** NOFEC shuts down, due to lack of funding. Caregiver services offered through NOFEC are transferred to other caregiver resource facilities. Empowering Caregivers™ continues to thrive with an estimated participant base of 5 million plus over 175 countries. There are currently 6 online chat rooms, 24 message board forums, innumerable links to references and resources. However, the site is no longer financially supported by NOFEC's non-profit status and per Gail, future funding is uncertain:

> I have chosen to keep the Empowering Caregivers™ web site alive as it supports so many in their time of need in so many ways. Since we are no longer a non profit, the money to sustain it has come from my own pocket….I will be rethinking a plan of action to maintain it within the next few months and will keep you posted when some decisions are made [7/25/08 Current Status post, What's New Forum].

The evolution of the Empowering Caregivers™ site, informed by Gail's personal history traces the move from local discourse to public awareness. The rise and fall of NOFEC delineates the limits of advocacy when there are no resources to support it. And the enduring appeal of the Empowering Caregivers™ site speaks to the importance of the creation of meaning for family caregivers, and the need for space to do this work in.

The Message Board/Forum: Introduce Yourself

Empowering Caregivers™ offers 24 different message board forums that tap into different aspects of caregiving (see Appendix F, Empowering Caregivers Message Board/Forum List). There are forums that reflect specific care recipient populations (e.g. Caring for a Child, Caring for a Parent) and forums that reflect different stages of caregiving (e.g. End of Life Issues, Caregivers' Issues re Illness & Diseases). There are forums for sharing ongoing relational and emotional issues (e.g. What are You Feeling, Family Issues and Communication) and forums that address practical concerns (e.g., News Updates, Legal, Financial and Insurance Issues). Some forums are specifically dedicated to sharing jokes, poetry and other creative outlets and at least two are dedicated to spirituality. When I first discovered the Empowering Caregivers™ site in 2000, there were only 4 message board groups posted: one for sharing daily affirmations, one for web site specific updates, one for Miracles and Gratitude and one for Caregiver's General Concerns. The broad list of topics and perspectives now available to those who visit the Empowering Caregivers™ site underscores the complexity of family caregiving as an experience, and the richness of the caregiver discourse that has evolved in response to that complexity.

For the analysis presented in this dissertation I've selected the Introduce Yourself To Others Here At The Boards forum. Introduce Yourself is the third largest[13] of the 24 message boards, comprising 536 topics or conversational threads since its inception in 2001. When I began collecting data in 2007, there were two moderators for this group; a third was added in 2008. The Introduce Yourself board is open for any visitor to read; as of late 2006, participants need to register as a member of Empowering Caregivers[14] in order to create a topic/thread or post a response.

Why this Message Board Forum?

When the Message Board/Forum home page is accessed, the descriptive blurb appended to the Introduce Yourself message board link appears as follows: "Tell us about yourself, what you did prior to caregiving, about your family, your interests, your career, your dreams..." (Message Board Forum list, Appendix F). The Introduce Yourself forum is overtly positioned as a way to reach out to others and to start conversations that reflect a range of life experiences.

I chose the Introduce Yourself forum because of the overt narrative positioning described above, but also because of how participants work around and through the stated purpose of the board to create other narrative positions. As per the descriptive blurb, visitors are encouraged to talk about themselves outside the caregiving experience, knowing that they have 23 other forums to talk in caregiver terms. Some newcomers do just that: introduce themselves in general terms, provide some baseline information about themselves, and then move on to other forums that are targeted to their particular concerns. However, those who present themselves in this way are welcomed by other members with a barrage of question about their caregiver life: "What is your mother's diagnosis? Does she live with you? Who takes care of her when you're at work?" Conversely, some new members introduce themselves solely through their caregiver life, without providing any "outside" information. Those newcomers are met with questions about the missing details: "You say you're in school; what are you studying?" "Do your children still live at home?", etc. Participants in this virtual support group want to know the whole story, and are not shy about asking each other to fill in the blanks.

Veteran members who welcome newcomers often take the opportunity to reintroduce themselves to the group; they may refocus part of their own caregiver story to align with a key point in a new member's introduction, they may bring in a new aspect from their participation elsewhere on the Empowering Caregivers™ site. Most importantly to my research, they offer their stories as models of experience: "This is how I talk about caregiving, this how I talk about my caregiving, this is how I talk about me". This narrative work is at the heart of the Introduce Yourself forum; everyone is trying out their stories – and everyone is trying to find the voices that will allow them to tell those stories in a meaningful way.

The following section reflects the key demographics collected for the people who actively participated[15] in the Introduce Yourself forum during the six month period of analysis (January – June 2007). This information is drawn from the member profile that are completed at the time of registration, supplemented by the deep reading of member posts. Please refer to Appendix G, Tables 1 -6 for full demographic reports.

Who’s talking? General Member Demographics

Gender (Appendix G, Table G1)

Of the 32 participants who post during the six month period, only two members (6%) do not identify their gender. The rest of the participants are all female (30 members, 94%). No male posters were identified during this period.

The first question that arises from this report is clearly: where are the men? In looking across all forums on the Empowering Caregivers™ web site, I find that male posters seem to introduce themselves through specific situations, rather than as potential/actual members of the group. For example, a male caregiver who cares for his ailing spouse is more likely to go directly to the Caring for a Spouse forum and introduce himself there.

Age (Appendix G, Table G2)

Over half the participants (17 members, 53%) reference their age at some point. Ages reported ranged from 31 to 55+ years (mean = 48 years). The largest age group represented are the 50 -65 year olds (8, members, 47%), with the next largest group – between 35 and 49 years – not far behind (7 members, 41%).

Thus far, the reported age breakdown seems to correspond to the popular conception of today’s family caregiver as part of the sandwich generation: ranging from 35-60 years of age, and potentially caring for children and parents simultaneously.

Marital status (Appendix G, Table G3)

Of the 32 participants, 25 (78%) make reference to their marital status in their member profile or at some point of their correspondence with the group. 18 members

(72%) indicate that they are married, three (12%) are divorced, one (4%) is widowed and three (12) identify themselves simply as single women.

I was initially surprised at the number of participants who don't indicate their marital status as part of their member profile or introduction to the group. The blurb appended to the Introduce Yourself forum clearly invites posters to talk about all aspects of their lives, and marital status would seem to be part of that discussion. However, the posts made by some of the married members suggest some possible explanations for not bringing marital status into the conversation:

> "Although I'm married to the best man ever, I'm all alone."
>
> "As a result of all this stress, I have been pretty much emotionally unavailable to my husband of 9 years. He has been incredibly supportive, but I just tend to shut down where he is concerned."

Upon closer review of the individual posts, the careful listener can hear a tendency to compartmentalize relationships; e.g., the relationship with a spouse is something other, something outside the caregiving relationship.

Employment (Appendix G, Table G4)

Drawing from the member profiles and posts, I was able to identify the employment status for 26 of the 32 participants (81%). Of those 26 members, 12 members are employed to some extent, and 12 members are not. The 12 members who are employed include those who work full time, part time, and/or are self employed. Five members indicate that they are unemployed, two describe their occupation as Student, and three are retired. It's interesting to note that the remaining two members list Caregiver in the Occupation field of their member profiles.

Missing demographics

There are a couple of obvious demographics that simply can't be traced within this group: ethnicity and religious affiliation.

- **Ethnicity:** As noted in my earlier discussion on health-based virtual support forums, people don't talk much (if at all) about their ethnic backgrounds. In the present group, this is almost completely missing from the caregiver conversation: one member makes a passing reference to her Mexican grandmother's cooking; another mentions her American Indian heritage.
- **Religious affiliation**: As indicated in my overview of the Empowering Caregivers'™ web site, all of the early group interactions were strongly infused with a specifically Christian ethic of care and service. That specificity has broadened over time; the orientation of the overall website and all the forums within the site is still overtly spiritual in nature, but no longer explicitly Christian. People no longer need to make specific references to their religious affiliations (or lack thereof) as part of their introductory statements – and so they don't.

These missing demographics clearly have implications for if, when and how the caregiver voices I propose are used and heard. In the Limitations Of This Study section, I'll discuss what this silence does and doesn't allow us to say about caregiver voices.

How Do Members Use The Group?

As a way of understanding the level of engagement demonstrated by these participants, I examined the posting patterns for each member: how many posts they made to all 24 Empowering Caregiver forums since their initial registration, and how many posts they made during the six month period to the Introduce Yourself forum. For a breakdown of the posting patterns described below, please refer to Appendix G, Tables 5 and 6.

Posting Frequencies by Member, across all forums (Appendix G, Table G5)

I began by examining how many times each of the 32 members actively participated in any of the 24 Empowering Caregiver™ forums since registering. Three members (9%) are one-time posters; they made a single post during the period of analysis and were never heard from again. Three members posted over 500 communications since registering; they include the two moderators and one long time member. Other members' posting frequencies fall somewhere in between these two extremes; again, see Table G5 for details.

It makes sense that the three one-time posters were all recent registrants, and that those who made the highest number of posts were those who were most invested in the site overall, i.e. the two moderators and/or those who'd been around a while. But the real question is how these patterns play out within the Introduce Yourself forum during the 6-month period of analysis.

Posting Frequencies by Member, Introduce Yourself Forum (Appendix G, Table G6)

For these 32 participants, the posting patterns for the 6-month period of analysis are somewhat similar to the posting patterns across all forums. The majority of the members post between 2 and 9 times (20 members, 63%). A smaller group posts between 10 and 20 times (3 members, 9%). There are 9 one-time posters, reflecting 28% of the participants.

In interpreting these patterns, it's helpful to look at some member demographics based on registration status: Newcomers vs. Old Timers and Moderators vs. Members.

Newcomers and Old Timers

Of the 32 participants, 22 (69%) signed on as members in 2007. Eight members signed on during 2005-2006, one registered in 2004, none registered in 2003 or 2004, and the founder registered in 2001 (the first year that registration was a formal option). As befits a forum labeled Introduce Yourself, the majority of participants are newcomers[16] to the Empowering Caregivers™ site.

Moderators vs. members

The two moderators for the group comprise 6% of the total participants for the six months. The two moderators – or rather the moderator and moderator/founder of Empowering Caregivers™ made 25 posts between them, reflecting 18% of the total posts generated.

By keeping these demographics in view, and in reviewing the individual posts, the patterns of participation described above can be put into context. The nine one-time posters are all newcomers to the group. Did they find what they were looking for? Some continue to post on other forums. Some have just moved on. The three heavy posters (10-20 posts) are revealed to be two fairly new members (registered 2006 and 2007) and the newer of the two moderators[17]. Most members during this period made between 2 and 9 posts, and reflected a mix of newcomers and old-timers. Newcomers not only responded to the posts their introductions received, but offered their own responses to the introductory posts of others.

These general demographics provide an initial snapshot of those who participated in the group during the period of analysis. In order to listen for caregiver voices in their communications, it’s also important to know who these people are as caregivers. In the section that follows, I provide caregiver demographics for the 32 participants.

Who Are These Participants As Caregivers?

Who do these caregivers care for? (Appendix H, Table H1)

In looking at these Caregiver/participants, we are also looking at the people they care for. As I read across the individual posts made during the 6-month period of analysis, the following care recipient categories emerged: Parents, Spouses, Adult Children, Siblings, Grandparents, In-laws and Friends. During the period of analysis, 75% (24 members) indicated that they were caring for a parent. Seven members (19%) care for an ailing spouse; two members (6%) care/cared for an adult child. One member cares for her brother, one cares for her grandmother and one cares for her father in law (3%, 3%, and 3%, respectively). Two caregivers care for friends (6%). And two participants don’t seem to be caring for anyone, directly. One is a pastoral counselor seeking to create a caregiver seminar for her church, and the other simply provides a link to home health services[18].

The range of illnesses these caregivers and their loved ones deal with is as broad as the categories above would suggest. Alzheimer’s, Parkinson’s and assorted aging conditions are heavily present, as are MS, COPD and CHF. Complications from strokes and diabetes are discussed, as are surgical complications from gastric bypass. Cancer is a recurring issue, in all its forms. Mental and neurological issues arise, either as the direct result of chronic illness (e.g. senile dementia) or as a complicating factor (anxiety disorder, autism).

Where does caregiving take place? (Appendix H, Table H2)

Over half the members (17 members, 57%), reported that the care recipient(s), lived with them. Twelve participants indicated that their family members lived outside the home, either in nursing/hospital facilities, in independent housing or with other relatives. Only two members described themselves as being long distance caregivers; i.e. coordinating care from out of state.

Caregiver/Care Recipient Clusters and Constellations (Appendix H, Table H3)

In compiling these caregiver demographics, I'm struck by how many of the participants have provided care for more than one family member. While 18 of the 30 caregivers indicate that they are caring for one chronically ill family member, 12 members – 37% of the participants – report caregiving for multiple family members, either concurrently or over time. Ten caregivers (82% of multi-caregivers) provide care for two family members; two (18%) describes themselves as having cared for three to four family members over time.

This leads me to re-conceptualize my care recipient categories as **caregiver constellations** (Appendix H, Table H4): patterns of relationship between caregiver and care recipients**.** From this perspective we see that a little more than half the members (17 members, 57%) are caring solely for a parent; four are caring for both a parent and a spouse (13%), two are caring for both a parent and an adult child (7%) and one is caring for both a parent and a sibling (3%).

Caregiving, Past and Present (Appendix H, Table H5)

Those caregivers who describe themselves as providing a lifetime of care to multiple family members lead me to a key observation: people don't stop being caregivers when the care recipient dies. Of the 30 caregivers who participated in the group during the period of analysis, 19 members (63%) indicate that their care recipients are living, 6 members (20%) indicate that their care recipients are deceased at the time of posting, and 5 members (17%) reflect a mix of living and deceased care recipients. These demographics – especially those caregivers who are technically no longer caregivers – reflect the profound and transformative effect that caring for another has on individual lives. The care recipient may be gone, but perhaps for some caregivers, the meaning remains… and so does the person they've become.

What's in a name? (Appendix H, Table 6)

As the final step in presenting my caregiver population, I turn to a quick examination of caregiver labeling/identity. On first glance, it seems that all participants identify themselves overtly as caregivers; why else would they be drawn to a website that is packaged for that target audience? Why would they register as members, and why would they participate, if they did not see themselves as caregivers?

However, the posts made by these caregivers suggest multiple levels of labeling. All communications contained either general references to caregiving (e.g. caring for, taking care of, looking out for), or referenced specific caregiving tasks (took Mom to the doctor). However, across the 138 posts made during this period, only 20% (27 posts) used the terms *caregiver*, *caretaker*[19], etc. to describe the poster. Looking at this breakdown by member, half the members (15 members) used caregiver specific terms, while half did not. Of the 15 caregivers who referred to themselves as caregivers[20], nine members (60%) used the term only once, four members (27%) used the term 2-5 times, one (7%) made between 6 and 10 references and one prolific newcomer (7%) used the term over 10 times. Clearly it is not necessary to call oneself a caregiver in order to feel like one or to communicate with others who do.

Now that I’ve provided an initial overview of who the participants are in this caregiver conversation, it’s time to turn our attention to the caregiver voices.

IV) VOICES ACROSS THE BOARD

The analyses that follow are based on all posts made to the Introduce Yourself message board forum over a 6-month period (January – June 2007). A total of 138 posts or individual communications, organized as 26 conversations or threads were made during this period. All identifiers were removed, and random identification numbers were assigned to individual posts, to the conversational threads and to the 32 participants who participated in these conversations.

Data Coding by Caregiver Voice

Using a variant of the Brown et al. (1989) multiple read method, all posts were read three times: once for the Caregiver as Patient voice, once for the Caregiver as Kin voice and once for the Caregiver as Advocate voice. As each post was read for a given voice, the post was scored on a scale from 0 to 4, as a representation of the strength of that voice, from non-existent to very strong. A score of 0 indicates that the voice could not be heard within the post; a score of 4 indicates that the voice can be heard loud and clear (see Appendix I for scoring rubric Tables I1-I3).

Coding for Vocal Presence and Volume

After all posts were coded for each voice, I grouped the resulting scores to represent vocal presence vs. vocal absence by voice. A score of 0 indicates that the voice in question was absent for the post; a score of 1, 2, 3 or 4 indicates that the voice is present, at least to some degree.

Posts that reflected vocal presence for a given voice (scored as 1, 2, 3, or 4) were then subcategorized in terms of vocal volume, or strength of presence. Posts scored as 1 or 2 reflect low volume; posts scored as 3 or 4 reflect high volume.

For example, consider the coding for fictional post T88-505:

Patient voice scored as 0

Kin voice scored as 2

Advocate voice scored as 4

Using the categorization schema above, this post can be described as follows: The Caregiver as Patient voice is absent from this communication post (code = 0). The Caregiver as Kin voice is present (code = >0) , but at a low volume (code =2). The Caregiver as Advocate voice is also present (code = >0) , and at a high volume (code = 4).

Data Analysis for Vocal Presence and Volume

Based on the categorization of scores for vocal presence and volume derived for each voice, I generated some simple percentages to reflect relative vocal presence and volume across voices. I then rearranged the data by member and by thread to see what that might do to the patterns of vocal presence and volume.

It should be noted that this set of analyses is not intended to make any generalized statistical statements about correlations, interactions, etc.; I performed all coding and analysis myself, and performed no additional reliability checks in doing so. I use these analyses as simple snapshots of how these voices play out across the group, and as the basis for speculation regarding the ways in which participants use and don’t use each voice. More importantly, the patterns described here are meant to provide an environmental context for the thematic coding analysis presented in the Voices In Context section of this dissertation.

Caregiver as Patient: Vocal Presence

Please refer to Appendix I, Table I1 for Patient Voice scoring rubric.

Presence By Post (Appendix J, Table 1): During the 6-month period, 138 posts were made to the group message board; roughly two thirds of those posts (90 posts) reflected the presence of the Caregiver as Patient voice.

Presence By Member (Appendix J, Table J2): Of the 32 members who participated in the group during this time, 6 members (19% of total posts made) never use this voice at all. Ten members (31%) use the Patient voice to some degree in all their posts. Half the participants (16 members, 62%) sometimes use the voice and sometimes do not in their communications with the group.

Presence By Thread (Appendix J, Table J3): The Caregiver as Patient Voice is completely absent from only two of the 26 conversational threads initiated during the period of analysis. Eight threads (31%) reflect the Patient voice in all posts. 16 threads (62%) reflect both vocal presence and vocal absence in the posts they contain.

What does this tell us?

The Caregiver as Patient voice is definitely a presence in this group – but not all the time, and not for everyone.

Caregiver as Patient: Vocal Volume

Please refer to Appendix I, Table I1 for Patient Voice scoring rubric.

Volume By Post (Appendix J, Table J4): As indicated in the Patient Vocal Presence analysis, the Caregiver as Patient voice can be heard in 90 out of 138 posts. Sixty-six posts (73%) reflect low volume posts coded as 1 or 2, while only 24 posts (27%) reflect high volume usage (posts coded 3 or 4).

Volume by Member (Appendix J, Table J5): As indicated by the Vocal Presence analysis, 26 members use the Patient voice. Eight of these participants (31%) whispered their Caregiver as Patient voice; all posts made by these members scored 1or 2. Three of them (12%) shouted their Patient voice, consistently scoring 3 or 4 in all posts made. More than half the participants (15 members, 58%) both whispered in low volume and shouted in high volume their Patient voice over the course of the 6-month period.

Volume by Thread (Appendix J, Table J6): For roughly half of the 24 threads that reflect vocal presence threads (13 threads, 54%), all posts made within them reflect low volume (scores of 1 or 2) for the Caregiver as Patient voice. Only one thread (4%) contains exclusively high volume posts coded as 3 or 4). The remaining 10 threads (42%) include posts that reflect both low and high volumes for the Patient voice.

What do we now know?

The patterns of vocal presence and volume across the board indicate that Caregiver as Patient voice has a definite presence within the group, but that the presence is a somewhat muted one – a slow steady rumble, rather than a rising wave of sound. I suspect that part of this is due to the orientation of the group itself; the mission statement reflects the emphasis place on positive thinking: "If your victim slips in, we will support it, but encourage you to move past it, to see larger picture that awaits you." (Empowering Caregivers™ Evolution page, n.d.).

Caregiver as Kin: Vocal Presence

Please refer to Appendix I, Table I2 for Kin Voice scoring rubric.

Presence by Post (Appendix J, Table J1): The Caregiver as Kin voice is can be heard in 98 of the 138 total posts made during the period of analysis (71%). The proportion of vocal presence to absence is roughly the same here as for the Patient Voice.

Presence by Member (Appendix J, Table J2): Of the 32 participants, two members (6%) don't use the Kin voice at all – and they are not the same two members referenced in the Caregiver as Patient discussion. Thirteen members (41%) use the Kin voice to some degree in all their communications. As in the Patient voice, about half the members (17, 53%) use the Caregiver as Kin voice in some of their posts, but not in others.

Presence by Thread (Appendix J, Table J3): The Caregiver as Kin voice is absent from only one thread of the 26 threads initiated during this 6-month period. Nine threads (35%) reflect vocal presence in every post within each thread. The remaining 16 threads (62%) each contain a mix of posts of posts where the Kin voice is present or absent.

What does this tell us?

For this group, the vocal presence of the Caregiver as Kin is roughly as strong as – or a little stronger than – the Patient voice. And like the Patient voice, people pick it up and put it down as needed.

Caregiver as Kin: Vocal Volume

Please refer to Appendix I, Table I2 for Kin Voice scoring rubric.

Volume by Post (Appendix J, Table J4): Once the 40 posts marked for vocal absence have been removed, there are 98 posts that reflect the Caregiver as Kin voice. There is an even split between low volume posts (coded as 1 or 2) and high volume posts (coded as 3 or 4); 49 low volume and 49 high volume posts were made.

Volume by Member (Appendix J, Table J5): After removing the two members who don't use the Kin voice, 30 members remain. There are seven members (23%) who whisper the low volume Kin voice (all posts scored 1 or 2), and six members (20%) consistently shout the high volume Kin voice (all posts made scored 3 or 4). Seventeen members (57%) sometimes shout and sometimes whisper their Caregiver as Kin voice, adjusting their volume to the conversation at hand.

Volume by Thread (Appendix J, Table J6): Of the 25 threads where the Caregiver as Kin voice is present, six threads (24%) reflected low volume whispers where all posts were coded as 1 or 2. Eight threads (32%) reflected high volume shouts, as all posts were coded 3 or 4, and 11 threads (44%) reflected a mix of high volume and low, shouts and whispers.

What do we know now?

For the Caregiver as Kin voice, vocal volume reveals more than vocal presence. In looking across the board for this voice, and in particular, when looking at the member and thread analyses – we can hear the modulations in volume as relational in nature. People adjust their volume in relation to the responses they receive from others, to the general volume of the thread. This is in keeping with the nature of the voice itself; the Caregiver as Kin voice voices relationships.

Caregiver as Advocate: Vocal Presence

Please refer to Appendix I, Table I3 for Advocate Voice scoring rubric.

Presence by Post (Appendix J, Table J1): The Caregiver as Advocate voice is present in 112 posts. At 81% percent of all posts made, this voice is the most present voice thus far.

Presence by Member (Appendix J, Table J2): The Advocate voice is used at some point by every single participant in the group – 32 members in all – over the period of analysis. Half the group (16 members) uses this voice in every post; the other half (16 members) sometimes uses the voice and sometimes doesn't

Presence by Thread (Appendix J, Table J3): Of the 26 threads initiated over the period of analysis, only one thread (4%) contains no trace of the Advocate voice. Slightly over half the threads reflect the Advocate voice in all the posts they encompass; 11 threads contain a mix of vocal presence and vocal absence.

What does this tell us?

The Caregiver as Advocate voice is an extremely present voice – and this is not surprising, given the overt mission of the group. But does this presence always reflect caregiver orientation? Or does it represent a social endeavor – an attempt to join in, to master the vocabulary of this particular group? Or both?

Caregiver as Advocate: Vocal Volume

Please refer to Appendix I, Table I3 for Advocate Voice scoring rubric.

Volume by Post (Appendix J, Table J4): Based on the 112 posts that reflect vocal presence, the Advocate voice is heard at low volume (coded 1 or 2) in 42 posts (38%) and at high volume (coded 3 or 4) in 70 posts (62%). This breakdown reflects the highest percentage of high volume voice thus far.

Volume by Member (Appendix J, Table J5): In reviewing the breakdown by member (n=32), the ratio of high to low volume becomes a bit more balanced. Eight participants whisper the Advocate voice, scoring 1 or 2 in all their posts. Ten members consistently shout their Advocate voice, scoring 3 or 4 in all posts made. The remaining

14 members (44%) use a mix of high and low vocal volume in their interactions with the group.

Volume by Thread (Appendix J, Table J6): Based on the 25 threads that reflect Advocate vocal presence, the breakdown between high (all posts coded 3 or 4) and low (all posts coded as 3 or 4) vocal volumes falls between the analysis by post and the analysis by member. Five threads (20%) reflect a low volume voice across the posts they contain; four threads (16%) reflect a consistently high volume posting pattern. Of the 25 threads, 16 (64%) reflect a mix of high and low volume for the Caregiver as Advocate voice

What do we know now?

The Caregiver as Advocate strongly reflects the general philosophy and orientation of the board. Presence is strong as participants are encouraged to try out the voice; volume rises and falls as people pick up the tone of the ongoing conversation.

Across the Board, Across the Voices

Across Posts

In examining Vocal Presence by Post, the Caregiver as Patient had the weakest vocal presence, the Caregiver as Kin voice has a slightly stronger presence, and the Advocate voice has the strongest presence of all. As suggested earlier in my discussion, these patterns may be reflective of the general orientation of the board. The Caregiver as Patient voice is acknowledged but not necessarily encouraged; the Advocate voice seems to be the voice most participants are trying to achieve. The Kin voice performs an important social function for the group, providing easy entry and instant identification between strangers.

The Vocal Volume by Post analysis offers some modulation to the initial impressions described above. We can now hear the Caregiver as Patient voice as a low, steady rumble, only occasionally punctuated with high volume exchanges. The even split between high and low volume in the Caregiver as Kin voice underscores the flexibility of this voice; not only can the voice be picked up and put down as needed, it can be modulated to suit the caregiver's needs and the conversation at hand. The strong presence of the Caregiver as Advocate voice is augmented by the high percentage of high volume posts; taken together, they speak to the power of the caregiver voice as caregiver orientation.

Across Members

When I first set up my analytical schema, I planned to look only at dichotomies: presence vs. absence, low volume vs. high volume. Looking at the member breakdown has moved my analysis to a more layered approach. I've included the categories MIXED and BOTH to capture those members who sometimes use a given voice, and sometimes don't (MIXED), who sometimes whisper and sometimes shout (BOTH).

In looking across the three voices for Vocal Presence by Member, we see that while the overall posts by presence may vary strongly by voice, the relative percentages of presence by member in the MIXED category are pretty close (Patient 50%; Kin 53%; Advocate 50%). This reinforces the concept of voice as adopted: sometimes you speak in a given voice, sometimes you don't.

The Vocal Volume by Member analysis reveals a somewhat similar pattern; the relative percentages of members who use both high and low volume Patient and Kin voices are the same (57% for each). However, for the Advocate voice, the percentage of members who use both high and low vocal volume is much lower (44%). This voice would seem to be a polarizing voice for those who use it; people speak low or speak high but seldom both. Is this because (as per my earlier discussion) the Advocate voice most closely represents the overt mission of the group?[21]

Across Threads

The By Post analyses provided me with some useful background, and the analyses by Member suggest some interesting avenues for future exploration. I find that looking across the three voices by Thread is the most helpful approach to understanding the vocal patterns of the group.

In analyzing Vocal Presence by Thread, I'm struck by how few threads reflect the complete absence of any given voice (Patient 2 threads; Kin 1thread; Advocate 1 thread). This means that all three voices have some kind of presence in almost every conversation that unfolds over the 6-month period. The relative percentages of threads categorized as BOTH are identical for the Patient and Kin voices (62%) – but once again, the Advocate voice shows a different pattern. The percentage of uniformly present posts is high, while the relative percentage of posts containing both vocal presence and absence is comparatively low (42%). The advocate voice seems to call forth a certain level of mutual commitment; threads are dedicated to the voice…or they're not.

It's in the Volume by Thread analysis that all vocal patterns come together to form snapshots of each voice. The threads that reflect Patient voice tend to be whispered in low volume, there's a balance of high and low volume in threads that reflect the Kin voice. And we finally hear a kind of balance in the Advocate voice – a true blend of high and low volumes, depending upon the conversation in progress.

While the examination of patterns is helpful, interaction is the key to understanding how these voices work. To that end, I now turn to the close examination of a particular thread drawn from this period of analysis.

VI) VOICES IN CONTEXT: LEARNING HOW TO DO THIS

The thread upon which my multiple read analysis of voice is based is entitled Learning How To Do This. This online conversation unfolds over a two week period in 2007 and consists of nine posts between five participants. The thread in its entirety can be found in Appendix K; what follows is a brief overview of the conversation as it unfolds over time.

New member **Rose** begins the thread by introducing herself to the group: "I'm 49 and presently a caregiver to my 72yr old mom who lives with her 78 yr old husband. I am here at this site, hoping to find some information and support." Rose goes on to describe her mother's medical condition (COPD, asthma, sleep apnea, high blood pressure, obesity), which is complicated by negative attitudes and behaviors; Mom "is mobile but she refuses to do anything. She gets these 'bad feelings' and refuses to go to the hospital but then wants everyone to cater to her and sit with her." A key component in Rose's caregiver narrative is the difficult relationships that exist between family members:

> My mom controls through her illness….My mom and her husband do not get along. He leaves her here most evenings for hours on end… I have 2 brothers both of whom cannot come and help. They don't understand why I can't just make Mom go to the hospital.

And as she wistfully remarks: "The house is sad, they are sad and I am sad."

But Rose is more than sad; she is overwhelmed. Her mother's long time housekeeper is now sick herself, and Mom is unwilling to bring in outside help: "We have to help her bathe, fix all of her meals, clean, laundry, comb her hair etc. And she won't stay in a room by herself, although she can. I also take care of all her bills etc." Rose finds herself with an exhaustive to-do list and depleted emotional and physical reserves: "There is so much more I cannot begin to tell you. I feel guilty because I want to leave. It is taking a toll now on my health and well being." After less than a year of intensive caregiving, Rose has reached her limit: "All I can do is sleep and cry when I'm not taking care of her needs." She closes her introductory note by thanking the group for listening.

The first to respond to Rose's post is **Bonnie**, a long time member of the group and caregiver to her husband. Bonnie's first step is to offer reassurance: "Welcome to a safe corner of the world. First let me give you a big cyber-{{{HUG!}}}." She gently urges Rose to do something that is just for herself, because "It's important that you get some time alone and just breathe."

Bonnie then jumps into a brief description of her husband's illness (complications from heart bypass surgery and diabetes) and ongoing maintenance and recovery (the right diagnosis, the right medications). She draws a parallel between her husband and Rose's mom: "With my DH I had the opposite problem of his wanting to go to the ER whenever he doesn't feel 'right'." But Bonnie has found a solution: "So we have a routine where we check his vitals (BP, pulse, glucose - he's diabetic, temp, etc.) If any of his numbers are in the ranges his dr's [sic] gave him as emergency, then we decide whether to go." Perhaps, Bonnie suggests, this approach might work for Rose and her mother too. Bonnie closes her note to Rose with thoughts and prayers and another cyber-hug.

Gina, another long time member and moderator for the board is the next to respond. She too formally welcomes Rose to the board and offers a cyber-hug. She acknowledges Rose's situation as difficult ("this is a heavy load on you") and urges Rose to take Bonnie's advice about taking care of herself: "This will help you find time away from the sadness." Gina then makes a firm recommendation:

> I think that home health care is in order. While she [Rose's mom] may resist, it is possible that she may hit it off with one. You would be

> surprised how much influence a third party can have. It is worth a try and it would take a BIG load off of you.

Gina closes her note with a strong statement of affiliation and support: "Just know, Rose, that we are here for you." She again acknowledges the difficulties of caregiving ("It is not an easy path that you are on"), taking Rose's fears to their logical conclusion: "You must get some help caring for your mother or you will burn out..." and ending with an injunction to "take care of yourself!"

Karen next responds with empathy for Rose's distress: "This is horrible, isn't it." She describes her own intensive experiences in caring for her friend J as "sinking." She offers the story of how she simply took it upon herself to arrange home health care for J, and describes the adjustments and negotiations they went through to make it work:

> The first few times the aide was there, J was calling me constantly and finding reasons why I had to come back immediately, but now after about five visits he is beginning, just, to be reconciled to the fact that I need time off.

Karen urges Rose to "just try your luck and present your mother with a fait accompli. If you do, then stick with it." She wishes Rose luck, and closes with a kind of mission statement for caregiving: "Remember whether you are driven by duty or by love, it is still an act of grace when you care for someone in need."

At this point, **Rose** posts individual responses to Bonnie, Gina and Karen, expressing her gratitude for their welcome, support and shared experiences. She is enthusiastic about Bonnie's checking vitals idea: "That makes it into something concrete rather than the amorphous 'bad feelings'." and is already thinking about how it might work for Mom. Rose is equally appreciative of Gina's take on the home health care issue ("you are so right about it being for the caregiver too") and she asks the group as a whole for ideas on how to approach the topic with her mother. In her response to Karen, Rose is clearly moved by the conceptualization of caregiving as an act of grace. She sadly notes: “It is also tough to have to care for someone who was not fond of you as child (but that is another story).”

Nested within Rose’s response to Karen is a general update on Mom for the group. She describes Mom’s latest visit to her PCP, who has referred her to a psychiatrist for depression. Mom threw a temper tantrum at the doctor’s office: “It was something to see. Mom acted terribly sick one minute and in the next was caustic and biting.” Rose further interprets Mom’s behavior at the doctors’ office and at home: “I don't think dementia is an issue, I think Mom is having anxiety on top of depression.”

Gail, the moderator and founder of the group weighs in next with a strong message of support (“sending lots of healing energy in your direction…”). She immediately acknowledges Rose’s allusions to the problematic family relations at work: “Your mom is very needy... she probably has been all her life…. Your dad's chronic heart failure is just as difficult as your mom's copd [sic]… so I am sure he is unable to cope even more.” Gail reminds Rose of the ways in which cardio-pulmonary disease shuts down the body, and suggests that some of the relational problems Rose experiences with Mom are tied to the physical distress Mom experiences: “copd [sic] can make anyone fearful.” However, Gail aknowledges, “There is more to it than meets the eye.”

Gail then makes some practical suggestions on how to enlist the support of other family members: “I would strongly encourage you and your siblings (even if they are unable to help out) participate in a family meeting to discuss what choices are available from all vantage points.” She suggests that an impartial third party – a social worker, or religious advisor – might serve as a mediator in setting boundaries and shaping expectations. Gail makes some firm suggestions on how Rose might negotiate with her mother for outside help:

> You can point blank say to your mother, that your health is in jeopardy… if something were to happen to you, who would she have to take care of her…. You explain to her that she has to cooperate by letting a home health care aid come in to care for her and bathe her, etc with your supervision so that you can tend to other issues at hand …

And finally, Gail returns to the strained relationship between Rose and her mother:

> Please be gentle and nurturing to yourself. Your mom beats up on you enough. She cannot make you feel guilty... the guilt is from conditioned patterns you have with her… you are doing the best you can to help her and advocate on her behalf and you are in need of some cooperation...

Caregiver as Patient, Caregiving as Pathology

Rose begins her initial post by presenting her situation in a somewhat objective way; she is a caregiver who is seeking support and advice from others. However her quasi-professional tone soon evaporates as she repeatedly interrupts the narrative of her mother's medical condition with her own cries of distress:

> "I need some help and am crying as I write this."
>
> "The house is sad, they are sad and I am sad."
>
> "There is so much more I cannot begin to tell you."

Rose provides a detailed list of the multiple ways in which she's expected to care for Mom, explicitly positioning herself as the one at risk: "It is taking a toll now on my health and well being." At the end of her post, Rose expresses the tension between her mother's needs and her own: "Right now, all I can do is sleep and cry when I'm not taking care of her needs."

Bonnie responds to Rose's post with an acknowledgement of the danger inherent in caregiving: "Welcome to a safe corner of the world." She gently urges Rose to make her own needs a priority: “I hope you have something that you can do for you …It's important that you get some time alone and just breathe.” Bonnie makes it clear that she’s responding to Rose as the person in need: “I’ll keep you in my thoughts and prayers today.”

Gina recognizes both Mom and Rose as dual patients: “I am sorry to hear of your mother's health *and* how difficult things have become for you (emphasis added).” She refers to caregiving as a “heavy load”, “a BIG load”, “sadness”, and concludes that “it is not an easy path you’re on.” Rose’s fears regarding the cost of caregiving on health and well being are repositioned as an explicit threat: “You must get some help caring for your mother or you will burn out.” Throughout her response, Gina reinforces Bonnie’s message about the importance of self care as the cure for caregiver burden**: “**It is important to find time to take care of yourself. This will help you find time away from the sadness….Meanwhile, take care of yourself!”

Karen’s response to Rose is strong and empathetic: **“**This is horrible, isn't it.” She describes herself as “sinking” under the burden of caring around the clock for her friend J. Karen tackles the tension between the needs of the caregiver and care recipient head on; she takes it upon herself to arrange for a home health care aide for J, telling him, “this is not for you, it’s for me.” As Karen tells it, J gradually comes to accept “the fact that I need time off.”

In Rose’s response to Bonnie’s post, she expresses her appreciation for Bonnie’s cyber-hug (“I needed that”) as well as for the practical suggestions on checking for vitals: “That makes it into something concrete rather than the amorphous ‘bad feelings’.” Rose is ostensibly referring to her mother here; the “it” is the decision on whether or not to go to the hospital and the amorphous “bad feelings” are Mom’s. However, when read through the Caregiver as Patient voice, there is an additional interpretation we can bring to this passage. Rose may also be grateful for the suggestion on how to concretize her own “bad feelings” – the illness that caregiving has become for her. Bonnie has provided Rose with a way to turn these bad feelings into something objective, something that can be addressed concretely and put back into proper perspective.

In the same manner, Rose responds to Gina’s statement re the necessity of bringing in outside help. Rose’s initial post makes it clear that she feels isolated and overwhelmed by the practical and emotional burdens of caring for Mom; when Gina presents the home health care option as a remedy for Rose’s caregiving ills, Rose is relieved: “You are so right about it being for the caregiver too. A home health aide would be *a relief for all concerned* (emphasis added).”

Rose strongly identifies with Karen’s metaphor for caregiving: “Karen, you are right. I was sinking.” She responds to the group message regarding the importance of self care by directly embodying it: “I'm going to focus on my self-care for even as I type this, I'm aware that a cold is trying to take hold of me.” And she closes her responds with a health message of her own for the group: “Have a great day all, *be well* (emphasis added).”

Gail opens her response to Rose by acknowledging the stress and strain Rose has shared with the group:“Sending lots of *healing energy* in your direction.” Unlike the other members of the group, Gail actively seeks to[re]position Rose’s mother as the true patient in this scenario:

> copd [sic]... can make anyone fearful… afraid to be alone… to walk and exert themselves...especially since she is overweight… she has all she can do to breathe… her air passages are closing down during this process...

Mom’s husband and his difficult relationship with Mom is also repositioned terms of his patient status: “Your dad's chronic heart failure is just as difficult as your mom's copd [sic] so I am sure he is unable to cope even more.”

However, Gail’s redefinition of patient does not mean that Rose has no claim to patient status herself. Gail acknowledges that Mom’s ill health may not be the only factor in the sad home Rose has described: “My sense is that there is more to it than meets the eye.” She urges Rose to follow the advice others have provided as a way of dealing with “some of *what you are going through* (emphasis added).”

Gail further suggests, that Rose might use the Caregiver as Patient voice as a strategy for establishing boundaries with Mom: “You can point blank say to your mother, that your health is in jeopardy, if something were to happen to you, who would she have to take care of her and then move on from there.” She closes her response with a call for self love as well as self care: “Please be gentle and nurturing to yourself….take care**.”**

In Rose’s final response, she expresses again her gratitude for the support she’s received from all. She clearly feels that participating in the group is good for her: “I feel such a relief being here at this site.”

In reading the Learning How To Do This thread through the Caregiver as Patient voice, some critical thematic questions emerge: Who is the patient here? What is the illness? And what is the remedy?

Who is the Patient?

Rose initially identifies her mother, her mother’s husband and even her mother’s housekeeper as being sick and in need of care. While she makes repeated reference to her own distress throughout her introductory post, she doesn't explicitly state the impact of caregiving on her health until the latter part of her post. However, once others have acknowledged her as being in need of care and support, Rose is relieved; she's then ready to think about what can be done to alleviate her stress and burden.

Bonnie is the first to identify Rose overtly as the patient in question – but interestingly enough, she does not identify herself in this way when telling her own story. In Bonnie's caregiving story, the only patient is her husband. Gina does not bring her own caregiving story into this conversation; while she acknowledges Rose's mother as the visible patient, she sees Rose as the patient too. From this perspective, care for one means care for all. Karen identifies both herself and Rose as the patient in need of help and support; the story she offers has a happy ending where the caregiver can stake their claim and everyone's needs are potentially met. Gail resists positioning Rose as the patient at all; Rose is certainly stressed but is not "sick" per se. However, as described earlier, Gail proposes the Caregiver as Patient voice as potentially useful in negotiating boundaries.

What is the illness?

If caregivers are patients, what is the illness they labor under? Sometimes group members describe the pathology of caregiving in terms of emotion: Rose speaks of her sadness, of doing little but crying and sleeping; Karen refers to caregiving as "horrible." Others speak in purely physical terms; Gina describes caregiving as a heavy load, a difficult path. Karen embodies her experience as sinking; Rose fights off a cold. Rose, Gina and Gail make larger statements about the toll caregiving takes on body, mind and heart. There is a sense of impending doom, a point of no return inherent in these statements:

> “It is taking a toll now on my health and well being.”
>
> “You must get some help caring for your mother or you will burn out.”
>
> “Your health is in jeopardy... if something were to happen to you…”

The connection between the emotional and physical costs of caregiving would seem to be stress. For these women, stress is defined as both too much and too little. There is too much to do, too many expectations to meet, too many claims for support, attention, care. There is not enough time, not enough help, not enough understanding of what caregiving actually entails, not enough that is “just for <u>me</u>.”

Remedies

The proposed remedies for the pathology of caregiving run along the same spectrum as the symptomology described above. All the participants in the <u>Learning How To Do This</u> conversational thread express emotional support, from cyber hugs to exhortations to “take care of yourself”. Garnering support from those outside the group is seen as important too, whether it’s enlisting family members or bringing in outside help. Self care and self love are seen as critical strategies for healing. Journaling, long walks, hot baths – making time for yourself and taking care of yourself is all part of the treatment. And finally, reformulating the situation – and the caregiver’s roles within that situation – may help the caregiver keep going. Breaking down emotionally fraught decisions into performable objective tasks, making your needs known, and setting appropriate boundaries for others all can make caregiving sustainable over the long haul.

Caregiver as Kin; Caregiving as Love and Duty

In her initial post Rose introduces us to the key players in her caregiver story, sketching the family network and outlining the relationships between family members.

There is the care recipient, Rose’s 72-year old Mom; whom Rose says “controls through her illness.” Mom’s 78 year old husband is also present; recently diagnosed with heart failure, he and Rose’s Mom were recently hospitalized simultaneously. Their relationship is rocky: “My mom and her husband[22] do not get along. He leaves her here most evenings for hours on end.” Rose also has two brothers, “both of whom cannot come and help. They don't understand why I can't just make Mom go to the hospital.” And there is Rose herself who apparently moved to her mother’s house some months ago specifically to care her mother**:** “I have been here helping since Aug 06.”

Rose hints at a troubled family past**: “**There is so much more I cannot begin to tell you.” She longs for escape but is ashamed to put down her familial role: “I feel guilty because I want to leave.” Her only family support seems to be a non family member, i.e. Mom’s long term housekeeper. But now the housekeeper is sick too, and Rose is alone.

Bonnie’s only direct reference to family is to the person she cares for: her husband. She outlines the course of his illness, the steps taken to reach the right diagnosis, and the different medications they’ve tried. In other forums on this website, Bonnie shares in great detail the strain her DH’s[23] illness has put on their marriage, but here she merely hints at the cost:

> He had spells of not sleeping well, not wanting to be alone, not wanting to do anything at all…He spends almost half his waking hours out of bed now, but still doesn't want to go outside or *go with me much of anywhere* (emphasis added).

Bonnie presents her relationship with her DH as a special kind of partnership. They work together to address his needs, evaluate his immediate health status and figure out next steps:

> With my DH I had the opposite problem of his wanting to go to the ER whenever he doesn't feel ‘right.’ So we *have a routine* where *we check his*

> *vitals* (BP, pulse, glucose - he's diabetic, temp, etc.) If any of his numbers are in the ranges his dr's [sic] gave him as emergency, then *we decide* whether to go (emphasis added).

Bonnie serves as her husband’s reality check; her expert status as caregiver is greatly based on her position as the one who knows him best, and who can therefore interpret what he really needs: “Sometimes having normal readings is enough to calm him down enough so he can rest.”

Gina doesn’t speak directly of her own family caregiving in this post; however, she came to the boards in 2004 as the primary caregiver for her father. Her father died in 2006, but Gina remains a strong presence on this board, moderating forums, facilitating web chats, etc. She makes the direct connections between Rose’s mom and Rose herself, positioning both caregiver and care recipient as inextricably linked**:** “I am sorry to hear of your mother's health and how difficult things have become for you.”

Gina suggests a kind of counterbalance between insiders and outsiders in her push for bringing in a home health care aide. She acknowledges that Mom may not be comfortable with having a stranger around, but is optimistic that the outsider may become an insider: “While she [Mom] may resist, it is possible that she may hit it off with one.” And, Gina suggests, in addition to the instrumental help the home health care aide would provide, Rose might find a caregiving ally: “You would be surprised how much influence a third party can have.” Mom might be more amenable to someone who is not family.

Karen’s is an interesting story from the Caregiver as Kin perspective, because she technically is not kin to J at all. In her own 2007 introductory post, Karen describes her “real” family’s ambivalence regarding her taking on a familial role (i.e. caregiving) in relation to someone who is not truly family. This adds a special poignancy to the mission statement Karen presents now**:** “Whether you are driven by duty or by love, it is still an act of grace when you care for someone in need.”

For Karen, caregiving for someone you love is like any other high stakes relationship; it calls for active role negotiation, shifting boundaries and ongoing engagement.

> I finally said, look have arranged for a health aide to come once a week, and this is not for you, it's for me….The first few times the aide was there, J was calling me constantly and finding reasons why I had to come back immediately, but now after about five visits he is beginning, just, to be reconciled to the fact that I need time off.

Rose does not pick up on Bonnie’s story from the Caregiver as Kin perspective, but the journaling suggestion offered by Bonnie and seconded by Gina gives Rose pause: “I journal every day but for some reason have not journaled [sic] too much about what is going on here with my mom etc. That is interesting and I'm going to look at that.” In her initial post, Rose tells the group that “there is so much more I cannot begin to tell you” about her family, but now it seems that she is ready to try. In her general update to the group she provides some examples of Mom’s acting out in public: “Mom threw a fit in his office. It was something to see... This further reinforced the Dr's idea for her to see the Psychiatrist.” Rose’s relief at having an outside- the-family witness is palpable – and the validation this witness provides allows her to see some of Mom’s other relational difficulties as part of her illness:

> I think Mom is having anxiety on top of depression. She came home and sat in the chair for almost an hour, refusing to take her coat and hat off. Her husband came home and she told him that the Dr does not know what is wrong with her. She also yelled at her husband and told him to shut up etc.

In response to Karen’s caregiving as an act of grace mission statement, Rose allows herself the most explicit reference to family history thus far: “It is also tough to have to care for someone who was not fond of you as child (but that is another story).”

Gail follows through on Rose’s difficulties with her mother right away: “Your mom is very needy... she probably has been all her life.” Gail strives to reposition Mom’s neediness in terms of her illness and then applies the same approach to Mom’s relationship with her husband; however, she admits that family history can’t be ignored: “Some of these tendencies may be why your parents don't have a great relationship but my sense is that there is more to it than meets the eye.”

Gail then turns her attention to the rest of Rose’s family – her brothers – and recommends that a family meeting be held. This may be the way to get the entire family engaged in proactive planning, “even if they are unable to help out” in more practical ways. She returns to Gina’s proposal for an informed outsider to help set boundaries: “You might want to ask a social worker or priest or someone impartial to mediate.” Gail also suggests that Rose make her familial role as caring daughter clearly visible to Mom: “You just say point blank to her…if something were to happen to you, who would she have to take care of her.”

Finally, Gail returns to Rose’s troubled relationship with her mother, shifting from the past firmly into the present**:** “Please be gentle and nurturing to yourself. Your mom beats up on you enough. She cannot make you feel guilty... the guilt is from conditioned patterns you have with her.” Nested within Gail’s message to Rose is the suggestion that self care and self love are not only the cure for caregiver burden, they can help to redeem the past.

Shifting Roles, Shifting Boundaries

The Caregiver as Kin voice allows us to hear the shifts in roles and boundaries, as traditional family patterns, values and expectations are challenged. In Rose's initial post, old family patterns of powerful parent and disempowered child are superimposed upon the current caregiving situation: Mom controls through her illness, Mom refuses, I just can't make her, all I can do is, etc. Bonnie, Gina, Karen and Gail all model different ways of disrupting the power dynamic to reflect the realities of chronic illness and care. Bonnie takes the power dynamic out of the conversation by creating an objective framework. Gina suggests another kind of objectivity: bringing in the outside helper. Karen extends Gina's suggestion into reclamation of power: do what needs to be done, present it as a done deal, and give everyone time to adjust. Gail implies that Mom by virtue of being the patient is already on the wrong side of the power dynamic; Rose must take advantage of the shift to parent her parent.

There is also a shift in the perception of family loyalty and privacy, i.e. how much family business can be shared and with whom. There may be a connection between the kind of personal care Mom requires and Mom's refusal to bring in outside help; should Rose respect that completely by continuing to perform all personal services for her mother? Or does the practical need for a home health aide trump Mom's sensibilities? Rose is also clearly torn between the need to share the whole story of her family with the need to respect her family's privacy. The conversation with other family caregivers helps Rose to figure out what she can tell and to whom and what purpose such disclosure may serve.

Family history as destiny? Not!

The history of the family forms the background for the current context. Rose's history with her mother shapes her perceptions of caregiving in the present moment: "It is also tough to have to care for someone who was not fond of you as child." The other caregivers again model different approaches to repositioning history. Bonnie alludes to a history of illness that has reshaped her relationship with her husband; she seems to have figured out a new definition for life partner. Gina and Gail acknowledge family patterns, and Gail in particular frames them in terms of illness – but she does this as a way moving beyond them. She also suggests working on more recent family patterns, e.g. getting Rose's siblings involved in a family meeting to discuss ways and means. If Rose's brothers "cannot come and help" in expected ways, there may be other ways they can be involved in family care. What Gail proposes is a new formulation of Rose's family, one that is based on caring for Mom.

The Un-Kin

One of the more interesting themes the Caregiver as Kin voice reveals is the juxtaposition of family to nonfamily. As this thread unfolds, we can see those un-relations as performing critical roles that reify the family caregiver's role:

<ins>As practical outside help:</ins> The proposed home health care worker for Rose, Rose's mother's long term housekeeper.

<ins>As buffer/boundary/reality check.</ins> Gina's perception of what home health care has to offer the family caregiver; the extra help Karen arranges for J.

<ins>As witness.</ins> Bonnie describes DH's doctor as witness to his illness and recovery; Rose echoes this theme in her update on Mom's visit to her primary physician.

As mediator. Gina speaks of the home health care aide as a third party with "influence"; Gail suggests an informed outsider (social worker, priest) to help with potentially tricky boundary negotiations.

Caregiver as Advocate, Caregiving as Calling

Rose first introduces herself almost formally as "presently *a caregiver* to my 72yr old mom who lives with her 78 yr old husband. I am here at this site, *hoping to find some information and support* (emphasis added)**."** She's here to help her Mom, but is frustrated and overwhelmed by the task she's taken on: "I need some help and am crying as I write this." Rose's brothers "cannot come and help" – and they don't really understand what Rose is dealing with: "They don't understand why I can't just make Mom go to the hospital."

Much of Rose's introduction of herself as caregiver is comprised of the list of things she has to do for her mother. "We have to help her bathe, fix all of her meals, clean, laundry, comb her hair etc…I also take care of all her bills etc." Mom is also emotionally draining; she "wants everyone to cater to her and sit with her", and "won't stay in a room by herself, although she can." Mom's constant need for attention adds exponentially to Rose's to-do list; and by the end of her introduction, Rose makes it clear that this job is too much for her: "Right now, all I can do is sleep and cry when I'm not taking care of her needs."

Bonnie offers Rose a model for turning anxiety into agency for both caregiver and care recipient by creating objective assessment measures. "With my DH I had the opposite problem of his wanting to go to the ER whenever he doesn't feel 'right.' So *we have a routine where we check his vitals … If* any of his numbers are in the ranges his dr's [sic] gave him as emergency, *then* we decide whether to go (emphasis added).” Rose might try something like this with her mother: “So maybe you can get your mom to agree to go to the hospital if her vitals get too far out of whack.” This approach would eliminate the emotional power struggle Rose describes regarding who decides when and if Mom should go to the hospital.

Gina sees self care as important to the caregiver’s overall well being, but as also critical to maintaining an appropriate level of care for the ill family member. Self care includes getting outside help when needed and Gina is absolutely clear about this: “I think that home health care is in order… You would be surprised how much influence a third party can have.” Gina is also clear that you need the right tools to do a proper job: “You must get some help caring for your mother or you will burn out.” One of the tools on offer to Rose is the group itself: “Just know, Rose, that *we are here for you.* It is not an easy path that you are on (emphasis added).” Gina’s statement not only offers support but affiliation with the other caregivers; if Rose is on a difficult path, there are others on the road with her.

Karen’s model for caregiving involves taking control of the caregiving scenario and setting boundaries. Just go ahead and get the help you need, she tells Rose: “Present your mother with a fait accompli. If you do, then stick with it.” Karen’s implicit message is that if Rose is doing this caregiving job, then she should have some say in how it should be done and what it takes to do it. In Karen’s own story, there was a bit of learning curve: “J was calling me constantly and finding reasons why I had to come back immediately… but now after about five visits he is beginning, just, to be reconciled…” Karen initially describes herself as “sinking while caring 24/7 for my friend J” but has learned how to reposition her caregiving role in a way that allows her to maintain it. Karen is clearly relieved at the way things have turned out, and is very happy to share her experiences with Rose. She reminds Rose, herself and the group as a whole that whatever you do is enough, if only because you are doing it: “It is still an act of grace when you care for someone in need.”

Rose responds to Bonnie, Gina and Karen with heartfelt thanks for the support they express. Their assorted statements of affiliation (“we’re here for you”, “I’ll keep you in my thoughts and prayers”, “keep us posted”) are not lost on her, and she feels a sense of identification and belonging the group “I’m so glad I came here.” She immediately picks up on Bonnie’s checking for vitals idea (“that makes it into something concrete…it is a formula, a great idea”) and can’t wait to put it into action. She takes ownership of Gina’s home health aide scenario (“I’ve been mulling over the idea of a home health aide”), and actively solicits the group’s input as to how to make it happen: “If any of you have any ideas about how to approach this with Mom, I'd appreciate hearing them.” In her response to Karen, Rose commits to taking better care of herself: “Karen, you are right. I was sinking. I'm going to focus on my self-care.” In all these responses, Rose expresses a shift in her caregiver positioning; rather than bottomless needs that can’t be met and never-ending to-do lists, there are strategies, game plans, things to try. This shift becomes evident in the update section of her response to Karen; Rose no longer simply reacts to Mom but instead offers her observations and interpretations of Mom’s behavior and affect as caregiver data:

> Mom went to her primary physician for an appt. He referred her to a Psychiatrist to give her someone to talk to about her *obvious depression*. *It was good* that he recognized this. He had already prescribed Zoloft (*at my urging*) which has helped her tremendously…. *I don't think dementia is an*

> *issue, I think Mom is having anxiety on top of depression* [emphasis added].

Gail reinforces Rose's emerging sense of ownership by offering some additional strategies for setting boundaries and taking control. The proposed family meeting will give all parties the chance to discuss "what choices are available from all vantage points." It's also an opportunity, Gail suggests, for Rose to renegotiate her caregiving contract with her mother:

> This would be the time you could set some boundaries and take some control. You explain to her that she has to cooperate by letting a home health care aid come in to care for her and bathe her, etc with your supervision so that you can tend to other issues at hand that she has personally neglected such as the taxes.

As an extension of Gina and Bonnie's perspectives, Gail positions caregiving as a kind of social contract between caregiver and caregiver recipient, where all parties must do their part to get the job done. Rose's job is to care for her mother directly, and to supervise others in doing so; her mother's job is to cooperate. Gail's last words to Rose are a reminder to appreciate all she has been able to do and will continue to do for her mother: "you are doing the best you can to help her and advocate on her behalf and you are in need of some cooperation."

Rose's visceral response to Gail's post and to all those that she's received is literally illuminating: "Oh my goodness, reading what you wrote to me was like little xmas [sic] light bulbs going 'pop,' 'pop'." She embraces the experiences and advice the others have offered: "I am going to follow your advice and the advice of others that have replied." And she closes by reiterating what being in the group means to her and does for her: "I feel such a relief being here at this site. It feels wonderful and empowering!!" As Rose moves through the conversational exchange, she listens and responds to the

Caregiver as Advocate voice as practiced by the others – and the others collaborate with Rose as she experiments with her own emergent Advocate voice.

The Caregiver as Advocate voice highlights two separate but related conceptualizations of caregiving: caregiving as a job, and caregiving as a vocation

Caregiving, the job

As they talk through their assorted experiences, the group builds a composite job description for caregiving. Rose's to do list includes Mom's personal hygiene, household chores, handling her finances and managing her anxiety. Bonnie adds health assessment and historical/medical record keeping; both Karen and Bonnie include the making of critical medical decision as part of the caregiver's job. Gail suggests that in addition to performing caregiving tasks, the caregiver also supervises the care provided by others.

This is a high pressured job, where as Karen says, the caring is "24/7." However, there is a kind of liberation in treating caregiving as a specialized job, rather than as an emotionally laden phenomenon nested within personal relationships. People can speak of what's required to this important job properly – a potentially more empowered and empowering stance than that of someone who can't keep up with shifting family dynamics, or who sinks under the burden of unmet needs and uncertain outcomes. From this perspective the big questions become: What do we need to do this job right, and how do we get it? Negotiation with the patient, with other family members, with the outside world, setting limits and boundaries and managing expectations all become part of answering these questions.

Caregiving, the calling

Another conceptualization of caregiving is as a calling or vocation; caregivers are literally chosen people. This embedded within the history of the Empowering Caregivers™ site itself; Gail's mission statement makes it clear that caregivers are very special indeed – and this plays out in the Learning How To Do This thread. According to the group, caregivers are called upon to help and to advocate for their loved ones, they bear witness to suffering and recovery, they are present in body and in spirit, they keep the care recipient's personhood intact, they interpret and mediate between the inner world of the care recipient and the outer world.

Gail speaks of "doing your best", Karen refers to the "act of grace". Gina describes caregiving as a load to be shouldered, a difficult path to travel. Caregiving is seen as imbued with meaning, combining a practical on-the-job approach with deep emotional and spiritual resonance. The big question from this perspective becomes***:*** *How do caregivers hold on to the big picture, to the deeper meaning of what they do*? In this thread the answer seems to be the sense of connection and affiliation generated between Rose, Bonnie, Gina, Karen and Gail. They remind each other and themselves that their caregiving work – their caregiving life – is meaningful and important.

Listening Across the Voices

"Learning how to do this."

Rose uses this phrase just once, but it captures the spirit of the conversation, and so I use it as the working title for the thread. On the surface, Rose seems to be referring to mastering the message board format itself: "My apologies for replying so many times, I'm learning how to do this." After her initial post to her unknown audience (i.e. the group of potential readers), Rose replies separately to each person who addresses her. She apologizes for sending piecemeal responses, but Rose's learning curve is our gain. We can follow her shifts in narrative position as she responds to the individual voices adopted by Bonnie, Gina, Karen and Gail. Her response to Karen, for example, blends the Patient voice with the Kin voice to tie past and present together; Gail's emphatic use of the Advocate voice tempers the Patient and Kin voices, and this elicits a corresponding shift in emphasis from Rose. Therefore, the "this" in Rose's "learning how to do this" also refers to mastery of the communication conventions shared by this particular group, from how to construct a caregiver narrative (Rose's midpoint update, as compared to her initial post) to the small common touches that express support and affiliation ("hugs!").

At the deepest level Rose is reflecting the work of the group, i.e., learning how to do this caregiving thing. Rose, Bonnie, Gina , Karen and Gail are actively engaged in co-constructing the caregiver role: how to identify when you're at risk, how to negotiate for help, when it's OK to be "selfish", when to let the past go and when to let it illuminate the present/future. The Patient, Kin and Advocate voices are tools used by the group as part of this work, for excavation and exploration.

"Thank you for sharing your experience."

This phrase reflects another important shift made by Rose in the course of her correspondence with the other caregivers. Rose ends her initial post by thanking her unseen, unknown audience for listening – not for their response, but merely for their presence and attention. The others do more than listen; as they make themselves known to Rose, they often[24] do so by sharing some part of their caregiver experience, and Rose in turn thanks each of them for sharing their experience.

The sharing of experience works on a number of levels, as is illustrated in Bonnie’s post. She directly welcomes Rose to the board and reinforces the welcome by sharing an extended story about her husband. It’s the kind of story you don’t typically tell to strangers, but Bonnie acknowledges Rose as a caregiver, and therefore no stranger. Bonnie crafts her story to pick up on Rose’s introductory post, creating direct comparisons between their related yet different situation and adding a layer of Advocate voice to Rose’s blend of Patient and Kin voices. Bonnie offers her experience to Rose, to the group as a whole, and to herself as an alternate model for the caregiver role – a unique polyphony of caregiver voices that reflects Bonnie as caregiver.

Sharing experiences allows all participants in the conversation to revisit individual histories in light of the experiences of others, to identify similarities and differences and to explore alternate interpretations. Their individual experiences are positioned as reflections of alternate models for caregivers and caregiving. These different positionings are an open invitation to experimentation: you hear about it, you try it out, and then you report back with results, additional insights, etc. Rose clearly demonstrates this process; the experiences of others have suggested some new approaches to her old situation and she can’t wait to try them out. Her experimentations are revealed through the vocal shifts she makes in response to the voices used by Bonnie, Gina, Karen and Gail. We can hear this most clearly in Rose’s midpoint description of her Mom’s doctor visit; in sharing this experience, Rose offers her observations as emotional response, but also as caregiver data. She is eager to share her findings with the others, to contribute to the general body of caregiver knowledge under construction – and finding her own unique polyphony of caregiver voices is a key part of this work.

"Take care!"

This phrase runs through all formal and informal caregiver literatures, regardless of their source, and appears in every online and offline caregiver support venue I've ever encountered. In the Learning How To Do This thread, every participant enjoins Rose to take care; in listening across the thread, and across the board, each caregiver voice resonates through the phrase. In the Caregiver as Patient voice, the phrase "take care" has a sense of immediacy: fix yourself, heal yourself, protect yourself, sustain yourself, nurture yourself. "Take care" takes on a temporal cast when read through the Caregiver as Kin voice: remediate the past, prepare for the future. Finally the Caregiver as Advocate voice calls for a big picture interpretation of the phrase: take care of yourself so that you can care for others.

VI) LISTENING, LEARNING, KNOWING, DOING

What can we now say about Caregiving?

Tracing caregiver voices as they emerge through conversations between caregivers provides more nuanced understanding of what family caregiving is, and what it means.

1. Caregiving as Relational

Earlier in this dissertation, I presented positionality as part of the theoretical foundation for this research project. Davies and Harré's (1990) concept of *positioning* returns as relevant***:*** "A discursive practice whereby selves are located in conversations as observably and intersubjectively coherent participants in jointly produced storylines." People in conversation position themselves in relation to each other. As they do so, they "produce one another (and themselves) situationally as *social beings*" (Bamberg, 1997, author's emphasis). If caregiving is understood as relational, and the interplay of caregiving voices as conversations, positioning can be a very helpful concept indeed.

Talbot, Bibace, Bokhour and Bamberg (1996) describe three different levels of positioning: the there-and-then, the here-and-now and the self-to-self. The level of **there-and-then** represents the actual story that is being told. The **here-and-now** level reflects the relative positioning between the narrator and their audience. At the **self-to-self** level, the narrator positions his/herself vís a vís his/herself. When these levels of positioning are applied to the Learning How To Do This thread, the ways in which the Patient, Kin and Advocate voices are intertwined become easy to hear.

On first reading, the **there-and-then level** reveals a series of individual happenings: the story of Rose and her family, of Bonnie and her DH, of Karen and J., etc. But the unfolding of each story – and the unfolding of the relationships embedded within the experiences described – shifts as we listen through each voice. Is Rose a daughter dealing with a problematic mother? Is she a caregiver to her mother, or some one in need of care herself? **The here-and-now level** reflects a different kind of relationship in the making: the caregiver group formed by Rose, Bonnie, Gina, Karen and Gail. Through the Patient voice, we hear the creation of the safe space, where sensitive issues and painful emotions can be acknowledged and discussed. The Kin voice highlights the processes of sharing and comparison of common human experiences as a means to identity and affiliation. The Advocate voice features the shared work in progress: the co-construction of the caregiver knowledge base and the creation of voice(s) with which to speak that knowledge. Finally, the **self-to-self level** reveals the conversations between the individual and the emerging self as caregiver**:** I am sick/at risk (Patient), I am daughter/wife/sister (Kin), I am the advocate, the paraprofessional (Advocate).

The use of positioning to guide the analysis of caregiver voice is a reminder that caregiving is never just about an individual caregiver, or even about a caregiver/care recipient dyad. There are always more people involved than those who are doing the talking. Positioning can be used to track where caregivers are in the speaking of these voices: where they appear, where they disappear and (perhaps most importantly) where they reappear, and in what voice. And finally, positioning as an interpretive framework for caregiver voices keeps us firmly aware that caregiving is first, foremost and always about relationships between people – relationships that are continually in motion.

2. Caregiving as temporal

Caregiving has an uncertain trajectory; it ebbs and flows, moves from crisis to plateau and back again. As described in earlier sections of this dissertation, caregiving has traditionally been studied in crisis mode, but that's not necessarily how family caregivers experience caregiving in the day to day.

Caregiver voices allow us to hear the ebb and flow of individual caregiving experience. The Patient voice positions caregiving as pathology or illness and in doing so reveals the crisis, the right now. The Caregiver as Kin voice positions caregiving as love and/or duty, adding historical and emotional context to the current situation. The Caregiver as Advocate voice positions caregiving as a calling or profession, potentially providing an overarching framework to a sequence of experiences – not just where people are going, but how they maintain course when the destination is unclear.

Just as the temporal trajectory of caregiving is uncertain, the start and end points of caregiving can be equally hard to determine. Does caregiving begin at the time of diagnosis? At the first hospitalization? When insurance forms are filled out? And when does it end? The obvious answer would seem to be when the care recipient dies or recovers – but the caregiving identity discussion that follows suggests a more open ended conclusion. Tracing caregiver voices through caregiver narratives can help to reveal when and how people truly come to know themselves as caregivers.

3. Caregiving as identity

In the What's in a Name section of this dissertation I discussed the different ways in which posters over the 6-month period of analysis overtly label themselves – or not – as caregivers. I concluded that the caregiver label and caregiver identity are not the same thing. There are those caregivers who never refer to themselves as such; the verbs that describe caregiving (caring, helping, washing, taking Mom to the doctor) seem to resonate more powerfully than the caregiver label itself.

The disconnection between label and identity is clear within the Learning How To Do This thread. Rose starts with the label ("am presently a caregiver") but needs help in crafting an identity that does justice to her full experience; the one she has in place isn't working for her. In helping Rose explore her experiences and in sharing their own, the group reinforces the concept of caregiver as identity. It's most interesting to note that Karen, the author of that powerful mission statement on caregiving never refers to herself as a caregiver at all: "Remember whether you are driven by duty or by love, it is still an act of grace when you care for someone in need." Gina and Gail, the two moderators who take the strongest line re setting boundaries, staking claims etc. are technically no longer caregivers (Gina's father died in 2006, Gail's parents have also passed within the past 10 years). This matches my observations across a variety of caregiver virtual support groups (Dobbins, 2002, 2007). People keep posting, keep participating, are invested in maintaining their caregiver identity – even when the need for providing family care has passed.

4. Caregiving as Evolutionary

In working through the narratives described in this study, I kept an ear open for new voices, voices other than the Patient, Kin and Advocate voices. I found a multitude of themes and emphases, but none of them clustered together in a way that represented a completely new voice. However, I can bear witness to a voice in progress, as the Caregiver as Advocate voices gradually morphs into two separate voices: a spiritually-oriented voice that speaks of caregiving as a vocation, and a secular but deeply invested voice that speaks of caregiving as a profession. Informal caregiving is now recognized as having legal, medical and economic implications that affect individuals and society at large; this new orientation requires a different kind of voice. It seems that while there is an ongoing need among caregivers for an Advocate voice that positions caregiving as higher calling, that there is also an emerging need for the Caregiver as Professional voice.

What We Can't Say: Limitations of the Present Study

There are limitations inherent in my sample, my analyses, and my own positioning that prevent me from saying all that I would wish to say. Some of those limitations are due to the medium I've chosen to work within: the Internet. The factors that make virtual space a wide open frontier – the lack of physical gatekeepers, and the ability to maintain anonymity in the very act of connecting with others – make it difficult for the researcher to pin down exactly who's there. I spent considerable time in trying to fill in missing demographics for the sample from which my data is drawn; I tracked the 32 participants through every forum on the Empowering Caregivers™ site, looking for clues regarding their age, gender, socio-economic status, etc. As described in the Who's Talking section of this dissertation, I was somewhat successful in terms of gender, age, and marital status, but social-economic status, spiritual/religious affiliation, geographic location and race/ethnicity/culture markers were almost impossible to find. I therefore can't talk about the ways in which the Patient, Kin and Advocate caregiver voices are influenced by these factors and have barely touched upon the implications of gender, race ethnicity and socioeconomics for family caregivers in general. This seems a serious gap in the discussion, as I believe that voice is an important tool in exploring these issues. As Fox, Hinton and Levkoff (1999) note:

> The meanings of illness represented in these caregiver accounts may be a mirror for large-scale social forces at work as they construct lives ravaged by racism, economic exploitation, poverty, loss and cultural misrepresentation. [p. 520]

I'm also aware that in working with a group that a) communicates solely through written exchanges and b) is so strongly identified with caregiving, I'm somewhat stacking the deck in favor of caregiver voice. The participants on the Empowering Caregivers™ site have already identified as caregivers to some extent, and are prepared to voice that identification; after all, that's why they are there. The form and function of message board forums means that I can only capture the voices of those who post. I am haunted by the lurkers, those who read and reflect but who do not post, and whose voices we therefore cannot hear. How would they speak their caregiving? What would it sound like? The only clue is given by those who make the move from lurker to poster, e.g. "I've been reading here for a while, but I had to reply to your post…"

This leads me to a deeper and more pervasive issue, concerning the ethics of Internet-based research. In choosing the medium and the venue for this study, I looked for a group where the message board forum was public, and where the members of the group were aware that they were participating in a public space. Empowering Caregivers™ posts reminders in several locations regarding the need to be circumspect in posting personal information on any of their message board forums, and the moderators reinforce the reminders within the message board forums from time to time. And yet it is clear that people do forget that they are in a public space. What then is my responsibility as a researcher in using their unguarded utterances for my data? For the present study, I formally requested Gail Mitchell's permission to observe the Introduce Yourself group and to collect the data used in the Voices Across the Board analyses. With her permission, I reached out to the participants in the Learning How To Do This thread, and received their consent to use their posts in this dissertation. Gail's reaction to my request was most telling: “I don’t know why you’re asking me this. I can’t stop you from doing it.” As researchers – and most especially researchers in psychology – become increasingly enamored with Internet-based research, we need to stay aware of the invisible but present boundaries between ourselves and our unseen, unknown participants.

And finally, I must take into account my own positioning within this research project. The three voices presented here initially arose out of my own experiences and interactions; I heard them and then looked for what lay behind them. The layered multiple readings that served as my analytical method were all performed by me alone, and of course, the interpretations are mine as well. I am the product of Western culture: an American, Caucasian, middle class, middle aged woman. Further, I am both researcher and caregiver in the making. My positioning as such has shaped the theoretical construction of voice presented, the choices made regarding sample, venue and medium, the analyses I’ve conducted and the conclusions I’ve drawn. I wonder if I am hearing all there is to hear; I wonder if my own “multivoicedness” (Bakhtin, as cited by Dentith, 1995) distorts what I do hear.

What Can Be Done [Next]?

The attempt to address these specific limitations opens up the discussion of where future research might take us. As a next step, I’d love to take this research project offline and onto the streets. My original research design called for a real life component to offset the virtual narratives collected. I planned to conduct interviews with people caring for family members and then apply the vocal analysis described to the transcripts of those interviews. I would suggest that the application of this methodology to a variety of caregiver and non caregiver[25] venues – focus groups, interviews, even laundry-room chats like those that inspired this dissertation – would help to fill in the demographic gaps inherent in the virtual world. This would also open up the potential for hearing new voices in progress.

Another extension of this project would be to broaden the analytical/interpretive audience. This dissertation, like all such projects, represents a work in progress; due to limitations of funding and time, I performed all the multiple read analyses myself. If I had it to do over again, I would pull together a team of reader/analysts to bring their own unique positions and perspectives to the analytical task. As part of the ongoing search for new/alternate caregiver voices, other researchers who hold different positions (e.g. non-Western cultural background, or from the male perspective) might apply the same approach to the construction of caregiver voice as the one described here; their different orientations may allow them to hear different voices. This kind of theoretical and analytical polyphony is essential to the study of informal caregivers as the face of family caregiving shifts, encompassing men and women, children and elders, crossing cultures and socioeconomic backgrounds. As the repertoire of caregiver voices available to us expands, we gain a deeper, richer understanding of how family caregivers come to experience themselves as such.

Reflections

I began this research project in an attempt to reconcile a perceived dichotomy between "research" and "real life" conceptualizations of caregiving. Over time I began to see this divergence between the scientific study of informal caregivers and what family caregivers say to and about each other as a continuum that reflects a range of epistemologies and experiences. This shift was brought home to me through my earlier research on Internet based caregiver support groups (Dobbins 2002, 2007). As I followed the interactions between caregivers on a variety of online sites, striking parallels emerged between the work caregivers were doing within these groups, and my own role as researcher. These caregivers were doing literature searches: looking into medical resources, reading up on treatment protocols, and developing schema for evaluating the information they found. Using themselves as data, support group members engaged in active experimentation, e.g. trying out different strategies, implementing different approaches to their own caregiving scenarios, etc. They would then report back on their results, as any researcher is expected to do. These people were developing their own caregiver knowledge base, their own epistemology.

Sociologist Janet Heaton (1999) suggests an update to Foucault's concept of medical gaze to the *paramedical gaze***:** one that is "no longer the sole prerogative of experts but the shared responsibility of all." This updated gaze is more than an appealing concept; it reflects a practical reality. Marlin Whitmer, retired chaplain and spousal caregiver, once told me: "Assessment is a mutual activity between professionals and non professionals when most of health care is out in the community" (personal correspondence, 2004). Researchers, health care professionals, community workers, caregiver advocates and family caregivers: all are partners in the project of care. And so my work has revealed a new geometric figure to describe the relationship between research and real world epistemologies. I have moved from the <u>dichotomy</u> to the <u>continuum</u> to the <u>hermeneutic circle</u>. The caregiving literatures generated by psychology, medicine, public health, sociology, etc. feed into and are fed by the knowledge and experience of family caregivers as they live their lives. The study of caregiver voices and the processes by which they work is my contribution to this circle.

In this dissertation, *voice* is presented as a viable construct for studying family caregivers and how they create, negotiate and co-construct the family caregiver role. Voice allows the researcher to capture movement in a way more static analyses do not, to follow shifts over time, through illness progression, through crises and maintenance. Voice supports the exploration of what questions are really being asked and answered – and by whom. All participants in the caregiving conversation can be traced, whether they are named as caregivers or not. Voice provides a framework for connecting seemingly disparate positions or orientations towards caregiving that enriches understanding of historical, social, political and individual contexts.

I suggest that this research makes three significant contributions to the psychological study of informal caregivers: the identification of three distinct but related caregiver voices, the exploration of how multiple voices intersect, intertwine, support and negate each other, and the presentation of a methodology that allows these voices and processes to be revealed and examined. The Caregiver as Patient, Caregiver as Kin and Caregiver as Advocate voices each represent a fundamental orientation towards family caregiving, as created and disseminated through public and private discourse. As voices are traced through these discourses, the psychological, social, cultural, economic, and political frameworks that support the discourses are revealed. The revelation of these frameworks through individual and collective caregiver voices allows the researcher to examine micro, mezzo and macro levels of experience.

The exploration of how caregiver voices intersect illuminates the creative ways in which people create themselves as caregivers, alone and in collaboration with others. The unique polyphony created by each caregiver may be as individual as a fingerprint. The examination of polyphony in caregiver voice can help in the identification of coping strategies and identity processes used by caregivers over a wide spectrum of experience. It can also help in the development of psychological support services, i.e. counseling that encourages the caregiver to develop their own unique voice.

The path of analysis used in this research project – the combination of positioning theory with the multiple read method – is potentially a key contribution to the study of family caregiving. The analytical method proved to be both generous and precise, capturing overlaps, disconnections, contradictions and augmentations within and between caregiver narratives. In other words, the path of analysis does justice to the complexity of the phenomenon. I'm not sure that I'm the first to discover this positioning theory/ multiple read method approach, but I believe that I'm among the first to apply it to the study of informal caregivers.

The deeper understanding yielded by the study of caregiver voices can ultimately lead to better research, assessment tools that are truly informative, and interventions that are on target. To listen to these caregiver voices is to tie individual experience to the larger world; to actively study them can be the vehicle for social change.

Endnotes

[1] It’s interesting to note that across the literatures I reviewed, the most popularly cited estimate for the number of U. S. family caregivers was “over 50 million”, citing the National Family Caregivers Association website. The NFCA uses this phrase descriptively, but doesn’t say where the number comes from.

[2] This work, initially published in 1960 and revised in 1980 is a classic in American kinship studies and is cited frequently in current anthropological studies.

[3] Estimates reflect a meta-analysis of five recent studies based on nationally representative surveys.

[4] The multiple read method calls for reading the same text multiple times for different stances or positions.

[5] The healthiest member of the family is elected to assume the caregiver role.

[6] The meaning of caregiving is not always negative. Mendez-Luck, Kennedy and Wallace’s 2008 study on Mexican women caring for elderly relatives used semi structured interviews and phenomenologically-driven analysis to reposition caregiver burden as multi-dimensional. For these women, “burden” was the emotional and physical weight they shouldered in providing care – but it was also viewed as positive sacrifice, an act of love.

[7] This excerpt and all other excerpts of Internet-based communication used as exemplars in the Presenting the Voices section are drawn from a now defunct web-based support channel hosted by AOL.com.

[8] The research literature uses the terms self-help group, self-help support group and peer led support group interchangeably – and so do I.

[9] Safety does not always translate into privacy. Unless specifically set up as a members only site, virtual space is public space; anyone may read what is published there. While most virtual groups clearly indicate the places on the site that are open to the public, participants do forget that they are not always communicating in private. This leads to an ethical dilemma for the research. Implications are discussed in the <u>Limitations</u> section of the dissertation.

[10] A thread refers to an initial post and the all responses and interactions that arise in response to that post, pertaining to a given topic or subject. It does not refer to individual posts or messages.

[11] A Web Ring is a collection of web sites that have agreed to list each other's web links.

[12] Originally as an AOL/IVillageHealth Chat forum, and later as an independent web site hosted by Yahoo groups.

[13] The first and second largest boards are <u>Daily Thought, Affirmation or Quote For The Day</u> (1365 topics) <u>and What Are You Feeling?</u> (904 topics).

[14] Registration entails filling out a web-based form that requests an e-mail address for verification, a screen name chosen by the registrant and optional information on gender, geographic location, occupation and hobbies/interests.

[15] Active participation means posting to the message board in order to initiate or continue a group conversation. I have no way of capturing those who read without responding.

[16] Newcomers as of 2007, during the period of data analysis. I actually collected this data in 2008.

[17] Based on past observation of this web site I would have expected that both moderators would have been heavy posters (see Empowering Caregiver™ history). What we see here is the enactment of the founder/moderator's pulling back from the group at the time of analysis; she no longer responds to every introductory post, but is still present. We find her in the **2-10 post** category.

[18] I've removed these last two members from the following discussion, leaving 30 caregiver/participants.

[19] All variants of these terms were sought: caregiver, care giver, care-giver, etc.

[20] Given the growing media attention family caregiving currently receives, I was curious to see if the term sandwich caregiver popped up at all. Nine members used this term to describe themselves.

[21] There is another possible explanation for this: the impending split of the Advocate voice into two voices.

[22] The precise relationship of Rose to her mother's husband is unclear. Although other group members assume he is her father, she never refers to him as such, nor does she call him her step father. He is always called her mother's husband.

[23] DH is a common web-based support group term for Dear Husband or Darling Husband.

[24] Often but not always. It’s interesting to note that the two participants who choose not to offer their own experiences as part of this conversation are Gina and Gail, the two moderators.

[25] This last seems particularly important, given that those who care for others sometimes resist identifying themselves as caregivers.

Appendix A: Breakdown of Literatures Used for Conceptual Grounding

Key: General = General readers
Professionals = Readers within the discipline
Caregivers = Family Caregivers

Author	**Literature base**	**Audience**
CAREGIVING		
Davis 1992	Nursing	Professionals
Foner (1994)	Anthropology	Professionals
Fox, Hinton, & Levkoff (1999)	Gerontology	Professionals
Gilligan (1995)	Psychology	Professionals
Levine (2002a)	Palliative Care	Professionals
Miller (1999)	Psychology	Professionals
National Family Caregivers Association website	Advocate/ Self Help	Caregivers
Ortiz, Simmons & Hinton (1999)	Gerontology	Professionals
Parsons, T. (1951)	Sociology	Professionals
Pearlin, Mullan, Semple & Skaff (1990)	Gerontology/ Sociology	Professionals
Radley (1999)	Social Psych/ Ethics	Professionals
Schiller (1993)	Anthropology/AIDS	Professionals
Schneider (1980)	Anthropology	Professionals
Strang (2001)	Nursing	Professionals
Taylor (2002)	Social Psychology	General/ Professionals
Walker, Pratt & Eddy (1995)	Gerontology	Professionals

Appendix A, continued: Breakdown of Literatures Used for Conceptual Grounding

VOICE, THEORETICAL

Bamberg (1992)	Psychology	Professionals
Brown, Tappan, Gilligan, Miller & Argyrols (1989)	Psychology	Professionals
Davies & Harré 1990	Psychology	Professionals
Dentith (1995)	Philosophy/ Lit Criticism	General
Foucault (1973)	Philosophy	General
Gottlieb (2002)	Feminist Philosophy	General
Heaton (1999)	Sociology	Professionals

CAREGIVER AS PATIENT VOICE

Barer & Johnson,(1990)	Gerontology	Professionals
Beach, Schulz, Yee, & Jackson (2000)	Gerontology	Professionals
Cacioppo, Poehlmann, Kiecolt-Glaser, Malarkey, & Burleson (1998)	Health Psychology	Professionals
Cannuscio, Jones, Kawachi, Colditz, Berkman, & Rimm (2002)	Nursing	Professionals
Esterling, Kiecolt-Glaser, Bodnar & Glaser (1994)	Health Psychology	Professionals
Folkman & Moskowitz (2000)	Psychology	Professionals
Fox, Hinton, & Levkoff (1999)	Gerontology	Professionals
Hall (2002)	Gerontology	Professionals
Kung (2003)	Social Services	Professionals
Marriot (2003)	Journalist/Caregiver	Caregivers
Navaie-Waliser, Feldman, Gould, Levine Kuerbis,& Donelan	Public Health	Professionals

Appendix A, continued: Breakdown of Literatures Used for Conceptual Grounding

CAREGIVER AS PATIENT VOICE, continued

Ortiz, Simmons & Hinton (1999)	Gerontology	Professionals
Parsons, T. (1951)	Sociology	Professionals
Pearlin, Mullan, Semple & Skaff (1990)	Gerontology/ Sociology	Professionals
Reinhart (2004)	Nursing	Professionals/ Caregivers
Vitaliano, Zhang & Scanlan (2003)	Psychology	Professionals
Wight, LeBlanc, & Aneshensel, (1993)	Health Psychology	Professionals
Wrubel & Folkman (1997)	AIDS	Professionals
Wuest (2000)	Nursing	Professionals

CAREGIVER AS KIN VOICE

Alibhai-Brown (2002)	Popular	General/ Caregivers
Ayres (2000)	Nursing	Professionals
Bronte (1855)	Literature	General
Bunting (2001).	AIDS	Professionals
English, (1989)	Feminist Philosophy	General
Foucault (1973)	Philosophy	General
Giddens (1991)	Sociology	Professionals
Gilligan (1982)	Psychology	Professionals
Levine (11/12/2002)	Popular	General
Neufeld & Harrison (1998)	Nursing	Professionals
O'Leary (1998)	Psychology	Professionals

Appendix A, continued: Breakdown of Literatures Used for Conceptual Grounding

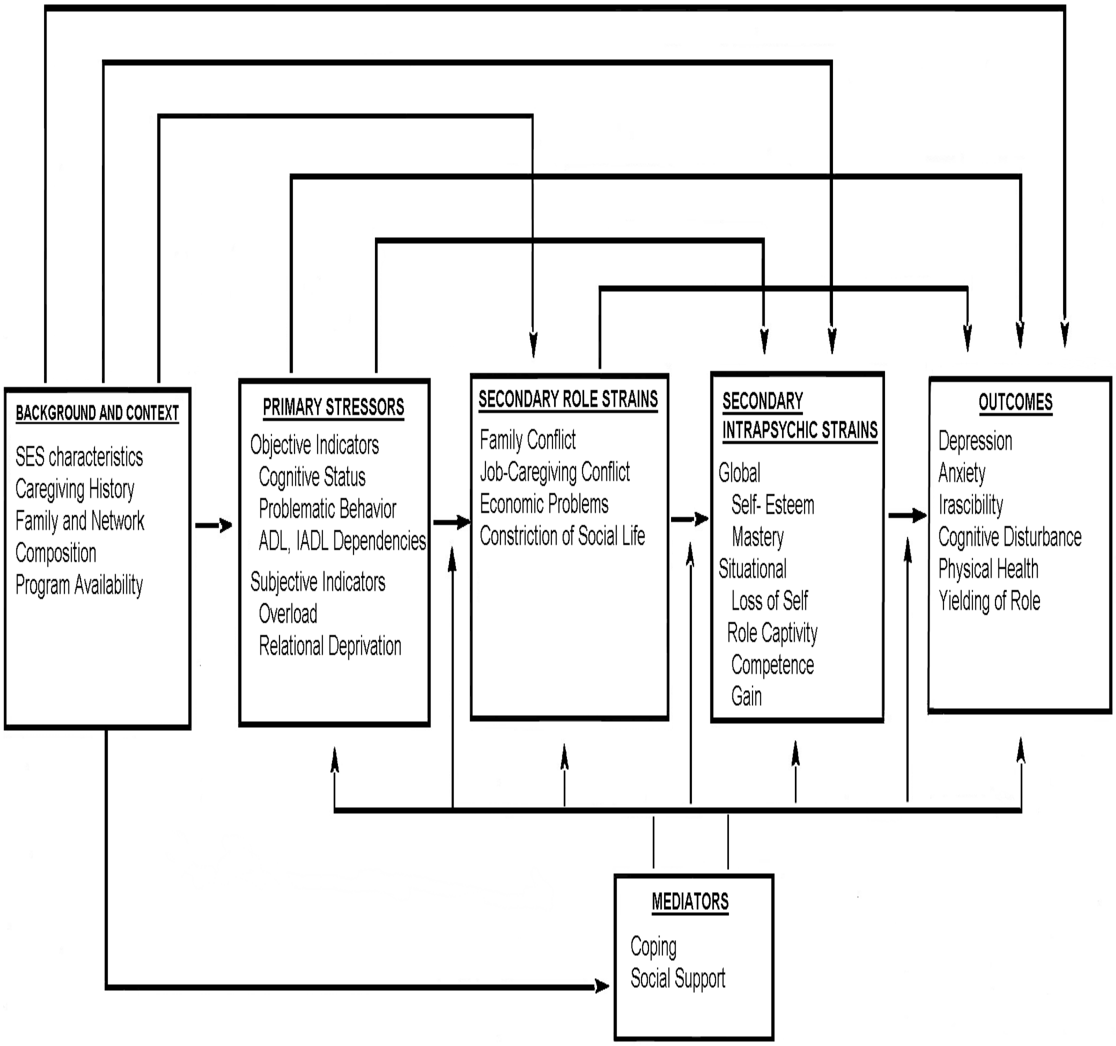
CAREGIVER AS KIN VOICE , continued

Parsons, C.D.F. (1984)	Anthropology	Professionals
Post (1990)	Feminist Philosophy	General
Rothman (2004)	Public Health	Professionals
de Saint Exupéry (1971)	Literature	General
Taylor (2002)	Social Psychology	General/ Professionals
Wilson (1992)	Nursing	Professionals
Wuest (2000)	Nursing	Professionals

CAREGIVER AS ADVOCATE VOICE

Barg (2001)	Self help	Caregivers
Gottlieb (2002)	Feminist Philosophy	General
Hershey (2003)	Disability Studies	Caregivers
Marriot (2003)	Journalist/caregiver	Caregivers
Mintz (n.d.)	Advocate	Caregivers
National Family Caregivers Association (ongoing)	Advocate/Self Help	Caregivers
Toth-Cohen, Gitlin, Corcoran, Eckhardt, Johns & Lipsitt (2001)	Nursing	Professionals
United Hospital Fund (2000)	Public Health	General /Professional/ Caregivers

Appendix B: Pearlin et al. (1990) Caregiver Stress Process Model



<u>Note:</u> “The stress process is made up of four domains: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress.” (Pearlin et al, 1990)

Appendix C: Barg (2001) The Fearless Caregiver Manifesto.

- I will fearlessly assess my personal strengths and weaknesses, work diligently to bolster my weaknesses and graciously recognize my strengths.

- I will fearlessly make my voice be heard with regard to my loved ones' care, and be a strong ally to those professional caregivers committed to caring for my loved one and a fearless shield against those not committed to caring for my loved one.

- I will fearlessly not sign or approve anything I do not understand, and will steadfastly request the information I need until I am satisfied with the explanations.

- I will fearlessly ensure that all of the necessary documents are in place for my wishes and my loved one's wishes to be met in case of a medical emergency. These included durable medical posers of attorney, wills, trust and living wills.

- I will fearlessly learn all I can about my loved one's health care needs and become an integral member of his or her medical care team.

- I will fearlessly seek out other caregivers or care organizations and join an appropriate support groups; I realize that there is strength in numbers and will not isolate myself from those who are also caring for their loved ones.

- I will fearlessly care for my physical and emotional health as well as I care for my loved one's, I will recognize the signs of my own exhaustion and depression, and I will allow myself to take respite breaks and to care for myself on a regular basis.

- I will fearlessly develop a personal support system of friends and family and remember that others also love my loved one and are willing to help if I let them know what they can do to support my caregiving.

- I will fearlessly honor my loved one's wishes, as I know them to be, unless these wishes endanger his or her health or mine.

- I will fearlessly acknowledge when providing appropriated care for my loved one becomes impossible because of either his or her condition or my own and seek other solutions for my loved one's caregiving needs.

Appendix D: Two Caregiver Paradigms

FIG. D1: Traditional Caregiver Paradigm

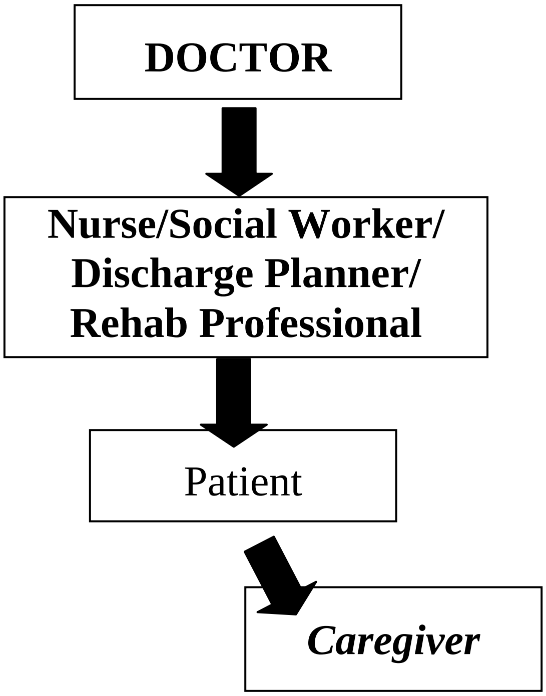


FIG. D2: Fearless Caregiver Paradigm

Appendix E: Empowering Caregiver™ Home page Site Link list, retrieved 11/19/2008

Home
Search
Updates: What's new
Site Map
Community Support
Messageboards/Forums
Chat
Experts
Caregiving Articles
Journal Exercises
Spotlight
Healing Circle of Prayer
Inspiration
Elderly
Humor
Alternative Healing
Suggested Readings
Resources
Greeting Cards/
Post Office
Webrings & Awards
Newsletter
Subscribe to Newsletter

About Us
Our Mission
Evolution of EC
Testimonials
Contact Us
Advertising
Sponsorship
Collaborators
Volunteers
Privacy Disclaimer
Visit www.nofec.org

Appendix F: Empowering Caregivers™ Message Board/Forum List (n.d.), retrieved 11/18/2008

Forum, continued	**Topics**
Updates: What's New At Empowering Caregivers Check here for updates at the site, important events, new editions and much more.	148
Daily Thought, Affirmation Or Quote For The Day Check back daily for our inspiring thought, affirmation or quote. favorites.	1365
Introduce Yourself To Others Here At The Boards Tell us about yourself, what you did prior to caregiving, about your family, your interests, your career, your dreams...	534
Caring For Yourself -The Caregiver	216
What Are You Feeling? Caregivers experience a myriad of feelings and emotions during the caregiving experience. What do you feel?	904
Spirituality In Caregiving Share your thoughts on your own spirituality and growth during the caregiving process. Caregiving offers you the opportunity to transform your beliefs, to forgive, heal and open to love.	46
Caregivers' General Concerns Many of the topics listed here are now continued under other categories. You may post your general concerns that arise during caregiving.	168
How Does Your Caregiving Role With Another Loved One Affect Your Relationship With Your Spouse? Share issues and dynamics that come up between your spouse, the loved one you are caring for and yourself.	24
Caregiving For A Parent Or Elderly Person A safe space to discuss issues regarding the parent(s) you are caring for.	455
Caregiving For A Spouse	117
Caregiving For A Child	15
Sandwich Generation Caregiving Share with others who are caring for a parent(s) and children at the same time.	27
Caregivers' Issues Re: Illnesses & Diseases Post questions and information related to the illnesses and diseases of the one you are caring for.	67

Appendix F, continued: Empowering Caregivers™ Message Board/Forum List (n.d.), retrieved 11/18/2008

Forum, continued	Topics
Family Issues And Communications Communicating with parents and siblings plus getting the support and assistance you need can be extraordinarily challenging...	57
Miracles & Gratitude Daily we experience miracles. Gratitude is one of the most important characteristics we possess...	35
The Lighter Side Of Caregiving Finding and sharing the humor in your experiences is not only a blessing for you but for those who read it.	61
Legal, Financial, & Insurance Issues	64
End Of Life Issues Post your fears, concerns and issues about final stages, experiences on recognizing the need for and accepting hospice and end of life issues.	31
Grief & Bereavement Share with other members who have been supporting you through it all.	61
In Memory: Memorials To Our Loved Ones A sacred place to write of your loved one.	68
News Updates-Caregiving, Health Issues, Legislation & More Feel free to add headlines you feel are valuable for others. You may also respond to the posts.	469
Caregiving Related Research, Interview Requests From Caregivers Students, Non Profit Organizations, Journalists Etc., May Post Requests Here. Please use discretion. Thank you.	97
Poetry & Other Writings From Caregivers A place for caregivers to post their poetry, writing and other unique sharing.	40
Problems with Navigating the HealthCare System, Services etc. Share your experiences Share your experiences with our health care system and services. Information may be used to advocate on behalf of caregivers	2

Appendix G: General Demographics for Introduce Yourself Participants

Table G1: Member by Gender

GENDER [N=32]	# Members	%N
Not Reported	2	6%
Male	0	0%
Female	30	94%

Table G2: Member by Age

AGE [N=32]	# Members	%N
Not Reported	15	47%
Reported	17	53%
AGE REPORTED BREAKDOWN (N=17)		
20-35 years	2	12%
36-50 years	7	41%
51-65 years	8	47%
66-80 years	0	0%

Appendix G, continued: General Demographics

Table G3: Member by Marital Status

MARITAL STATUS [N=32]	**# Members**	**%N**
Not Reported	7	22%
Reported	25	78%
MARITAL STATUS REPORTED, BREAKDOWN (N=25)		
Married	18	72%
Domestic Partner	0	0%
Single	3	12%
Divorced	3	12%
Widowed	1	4%

Appendix G, continued: General Demographics

Table G4: Members by Employment Status

EMPLOYMENT STATUS [N=32]	**# Members**	**%N**
Not Reported	6	19%
Reported	26	81%
EMPLOYED VS. UNEMPLOYED, REPORTED [N= 26]		
All Employed	12	46%
Unemployed	12	46%
Occupation: Caregiver	2	8%
EMPLOYMENT, REPORTED BREAKDOWN [N=26]		
Caregiver	2	8%
Employed, Full time:	7	27%
Employed, Part Time	3	12%
Self Employed	2	8%
Home	1	4%
Student	3	12%
Retired	3	12%
Unemployed	5	19%

Appendix G, continued: General Demographics

Table G5: Posting Frequencies by Member since registration, across all Empowering Caregiver™ forums [N=32]

# Posts	# Members	%N
Single post	3	9%
2-10 posts	12	38%
10-25 posts	3	9%
25-50 posts	5	16%
50-100 posts	1	3%
100-250 posts	4	13%
250-500 posts	1	3%
>500 posts	3	9%

Table G6: Posting Frequencies by Member during 6-month period of analysis, Introduce Yourself forum [N=32]

# Posts	# Members	%N
Single post	9	28%
2-9 posts	20	63%
10-20 posts	3	9%
>20 posts	0	0%

Appendix H: Member/Caregiver Characteristics

Table H1: Care Recipients (Who are these caregivers caring for?) [N=32]

Caring for [N=32]	**# Members**	**% N**
Parents	24	75%
Spouse	7	19%
Adult Child	2	6%
Siblings	1	3%
Grandparents	1	3%
In Laws	1	3%
Friends	2	6%
Not Reported	2	6%

Table H2: Location of care (Where does caregiving take place?) [N=30]

Location of care	**Members**	**%N**
At Home	17	57%
Out of Home	12	40%
Not Reported	1	3%

Appendix H, continued: Caregiver Characteristics

Table H3: Caregiver/Member breakdown by number of care recipients [N=30]

Caring for	**Members**	**%N**
Caring for one care recipient	18	63%
Caring for more than one care recipient	12	37%
Caring for 2 care recipients	10	82%
Caring for more than 2 care recipients	2	18%

Table H4: Member/Caregiver breakdown by relationship to care recipient(s) [N=30]

Caring for	**# Members**	**%N**
Parent	17	57%
Spouse and Parent	4	13%
Friend	2	7%
Parent and Adult Child	2	7%
Spouse	2	7%
Parent and Sibling	1	3%
Grandparent	1	3%
In Law and Spouse	1	3%

Appendix H, continued: Caregiver Characteristics

Table H5: Member/Caregiver Breakdown by Live vs. Deceased Care Recipients [N=30]

Living Vs. Deceased	**# Members**	**%N**
Care Recipient Living[a]	19	63%
Care Recipients Deceased	6	20%
Care Recipients, Mixed[b]	5	17%

[a] Living at time of member participation in group
[b] Mixed = some care recipients living, some now deceased

Table H6: Caregiver Term Reference by Members

Caregiver Term reference	**# Members**	**%**
No Caregiver term referenced	15	50%
Caregiver term(s) referenced	15	50%
Member Breakdown by # Caregiver Term References [N=15]		
Single reference made	9	60%
2-5 references made	4	27%
6-10 references made	1	7%
0ver 10 references made	1	7%

Appendix I: Vocal Presence/Volume scoring rubric by voice

Table 1. PATIENT Voice, scoring rubric

V-score	Criteria/ Positioning	Sounds like…	Volume Category
4	Caregiving as specific threat to caregiver health/well being	The worst has happened; at the end of my rope	High Volume
3	Caregiving as potential threat, impending doom	The worst is coming, Caregiving may be taking a toll	High Volume
2	Direct/Multiple references to stress/strains as per 1 (see below	This is getting harder and harder; not only do I…	Low Volume
1	Indirect reference to stresses/strains on caregiver as result of caregiving	It's been hard since; I've had to…	Low Volume
0	No vocal presence at all		

Appendix I, continued: Vocal Presence/Volume scoring rubric

Table 2. KIN voice, scoring rubric

V-score	**Criteria/ Positioning**	**Sounds like…**	**Volume Category**
4	Caregiver experience and family relationship mirror each other	She never cared for us, why should I care for her?	High Volume
3	Family history referenced to explain current caregiver experience	When we were kids, my brother always…	High Volume
2	Family members/relationships referenced as key part of caregiver narrative	I am the only daughter and they depend on me to…	Low Volume
1	Caregiver experience and family relationship mirror each other	My husband has cancer, and I…	Low Volume
0	No vocal presence at all		

Appendix I, continued: Vocal Presence/Volume scoring rubric

Table 3. ADVOCATE voice, scoring rubric

V-score	**Criteria/ Positioning**	**Sounds like…**	**Volume Category**
4	Strong position of caregiving as job/vocation, with specific roles responsibilities affiliation with others	We caregivers, this is quite a journey we're on	High Volume
3	Detailed list of specific tasks and services; overt search for meaning	I do her bills, her laundry, give her baths, try to keep her going	High Volume
2	Stronger helping vocabulary, more direct reference; sense of above and beyond	I'm caring for, taking care of…	Low Volume
1	Indirect reference to help/services on behalf of care recipient	Since his surgery, dad needs help with…	Low Volume
0	No vocal presence at all		

Appendix J: Voices Across the Board, Vocal Presence and Volume by Voice

Table J1: Vocal Presence By Post

VOICE	Posts	%N
PATIENT [N=138]		
Voice Present[a]	90	65%
Voice Absent[b]	48	35%
KIN [N=138]		
Voice Present[a]	98	71%
Voice Absent[b]	40	29%
ADVOCATE [N=138]		
Voice Present[a]	112	81%
Voice Absent[b]	26	19%

[a] Posts scored as 1, 2, 3 or 4
[b] Posts scored as 0

Table J2: Vocal Presence By Member

VOICE	Members	%N
PATIENT [N=32]		
Voice Present[a]	10	31%
Voice Absent[b]	6	19%
Mixed [c]	16	50%
KIN [N=32]		
Voice Present[a]	13	41%
Voice Absent[b]	2	6%
Mixed[c]	17	53%
ADVOCATE [N=32]		
Voice Present[a]	16	50%
Voice Absent[b]	0	0%
Mixed[c]	16	50%

[a] All posts made by member scored as 1, 2, 3 or 4
[b] All posts made by member scored as 0
[c] Voice is sometimes present (posts scored >0) and sometimes absent post scored as 0) within member posts

Appendix J, continued: Voices Across the Board

Table J3: Vocal Presence By Thread

VOICE	Thread	%N
PATIENT [N=26]		
Voice Present[a]	8	31%
Voice Absent[b]	2	8%
Mixed[c]	16	62 %
KIN [N=26]		
Voice Present[a]	9	35%
Voice Absent[b]	1	4%
Mixed [c]	16	62%
ADVOCATE [N=26]		
Voice Present[a]	14	54%
Voice Absent[b]	1	4%
Mixed[c]	11	42%

[a] All posts made within thread scored as 1, 2, 3 or 4
[b] All posts made within thread scored as 0
[c] Voice is sometimes present (posts scored >0) and sometimes absent (posts scored as 0) within thread.

Appendix J, continued: Voices Across the Board

Table J4: Vocal Volume By Post

VOICE	Posts	%N
PATIENT [N=90]		
Low Volume[a]	66	27%
High Volume[b]	24	73%
KIN [N=98]		
Low Volume[a]	49	50%
High Volume[b]	49	50%
ADVOCATE [N=112]		
Low Volume[a]	42	38%
High Volume[b]	70	62%

[a] Posts scored as 1 or 2
[b] Posts scored as 3 or 4

Table J5: Vocal Volume By Member

VOICE	Members	%N
PATIENT [N=26]		
Low Volume[a]	8	31%
High Volume[b]	3	12%
Both[a]	15	57%
KIN [N=30]		
Low Volume[a]	7	23%
High Volume[b]	6	20%
Both[a]	17	57%
ADVOCATE [N=26]		
Low Volume[b]	8	25%
High Volume[b]	10	31%
Both[a]	14	44%

[a] All posts made by member scored as 1 or 2
[b] All posts made by member scored as 3 or 4
[c] Member used both low volume (posts scored1 or 2) and high volume posts (posts scored 3 or 4)

Appendix J, continued: Voices Across the Board

Table J6: Vocal Volume By Thread

VOICE	**Thread**	**%N**
PATIENT [N=24]		
Low Volume[a]	13	54%
High Volume[b]	1	4%
Both[c]	10	42%
KIN [N=25]		
Low Volume[a]	6	24%
High Volume[b]	8	32%
Both [c]	11	44%
ADVOCATE [N=25]		
Low Volume[a]	5	20%
High Volume[b]	4	16%
Both[c]	16	64%

[a] All posts within thread scored as 1 or 2
[b] All posts within thread scored as 3 or 4
[c] Member used both low volume (posts scored 1or 2) and high volume posts (posts scored 3 or 4)

Appendix K: <u>Learning How To Do This</u> Thread, Retrieved 1/31/2008

Post 1: ROSE

Hello all, my name is Rose. i'm 49 and presently a caregiver to my 72yr old mom who lives with her 78 yr old husband. I am here at this site, hoping to find some information and support. My mom has COPD (chronic obstructive pulmonary disease) Asthma suffers from sleep apnea, HBP and is overweight. I need some help and am crying as I write this. She is on oxygen 24/7 and is mobile but she refuses to do anything. She gets these "bad feelings" and refuses to go to the hospital but then wants everyone to cater to her and sit with her. Both she and her husband were hospitalized 2 weeks ago at the same time. He has been diagnosed with heart failure. He signed himself out of the hospital. My mom and her husband do not get along. He leaves her here most evenings for hours on end. The house is sad, they are sad and I am sad. I have been here helping since Aug 06. My mom controls through her illness'. I have 2 brothers both of whom cannot come and help. They don't understand why I can't just make Mom go to the hospital.

There is so much more I cannot begin to tell you. I feel guilty because I want to leave. It is taking a toll now on my health and well being. She has a housekeeper who has been with her for 20 years but the housekeeper is sick too. My Mom refuses to get a home health aide, yet we have to help her bathe, fix all of her meals, clean, laundry, comb her hair etc. And she won't stay in a room by herself, although she can. I also take care of all her bills etc. One of the issues I have had to deal with is my Mom has not filed taxes in 12 years. Right now, all I can do is sleep and cry when I'm not taking care of her needs. Thank you all for listening.

Post 2: BONNIE

Hi, Rose (is that a unique way to spell [redacted]? - is that how it's pronounced?)

Welcome to a safe corner of the world. First let me give you a big cyber-{{{HUG!}}}.

I hope you have something that you can do for you - journaling, hot baths, long walks. It's important that you get some time alone and just breathe.

My husband spent the better part of 2006 in bed. He had some complications from heart-bypass in 2004, that the doctors didn't acknowledge until about a year ago. He had spells of not sleeping well, not wanting to be alone, not wanting to do anything at all. His dr put him on Zoloft for depression, and that has helped, along with better pain management. He spends almost half his waking hours out of bed now, but still doesn't want to go outside or go with me much of anywhere.

With my DH I had the opposite problem of his wanting to go to the ER whenever he doesn't feel "right." So we have a routine where we check his vitals (BP, pulse, glucose - he's diabetic, temp, etc.) If any of his numbers are in the ranges his dr's gave him as emergency, then we decide whether to go. Sometimes having normal readings is enough to calm him down enough so he can rest. So maybe you can get your mom to agree to go to the hospital if her vitals get too far out of whack.

I'll keep you in my thoughts and prayers today.

Hugs, Bonnie

Post 3: GINA

{{{Hello Rose:}}}

Welcome to the boards Rose. I am sorry to hear of your mother's health and how difficult things have becme for you. It is a heavy load on you.

Bonnie has given you some good advice with journaling etc. It is important to find time to take care of yourself. This will help you find time away from the sadness.

I think that home health care is in order. While she may resist, it is possible that she may hit it off with one. You would be surprised how much influence a third party can have. It is worth a try and it would take a BIG load off of you.

Just know, Rose, that we are here for you. It is not an easy path that you are on. You must get some help caring for your mother or you will burn out...

Meanwhile, take care of yourself!

Love and Hugs from Gina

Post 4: KAREN

Dear Rose, This is horrible, isn't it. When I was sinking while caring 24/7 for my friend J, I finally said, look have arranged for a health aide to come once a week, and this is not for you, it's for me. I was lucky to get someone that he liked, but you might just try your luck and present your mother with a fait accompli. If you do, then stick with it. The first few times the aide was there, Joe was calling me constantly and finding reasons why I had to come back immediately, but now after about five visits he is beginning, just, to be reconciled to the fact that I need time off.

Good luck, sweetie, and remember whether you are driven by duty or by love, it is still an act of grace when you care for someone in need.

Let us know how you get on.

Post 5: ROSE

oh my goodness!! I cannot believe the outpouring of support here. THANK YOU SO MUCH!!!

Bonnie thank you so much for that idea about "checking for vitals." That makes it into something concrete rather than the amorphous "bad feelings." It is a formula; a great idea. I'm going to think of how to apply that with her. Bonnie, thanks for the hug!! I needed that.

hugs, Rose

Post 6: ROSE

Thanks so much Gina. I journal every day but for some reason have not journaled too much about what is going on here with my mom etc. . That is interesting and I'm going to look at that.

Bonnie, thank you for the idea too. Regarding my name yes, it is Rose. I'm told it stems from "[redacted]."

I've been mulling over the idea of a home health aide. Mom absolutely refuses to even consider it. Gina, thanks for sharing your experience and you are so right about it being for the caregiver too. A home health aide would be a relief for all concerned. If any of you have any ideas about how to approach this with Mom, I'd appreciate hearing them.

hugs, Rose

Post 7: ROSE

Karen, thank you for sharing that experience and for the reminder about the act of grace. It is also tough to have to care for someone who was not fond of you as child (but that is another story)

My apologies for replying so many times, I'm learning how to do this. Update: Yesterday, Mom went to her primary physician for an appt. He referred her to a Psychiatrist to give her someone to talk to about her obvious depression. It was good that he recognized this. He had already prescribed Zoloft (at my urging) which has helped her tremendously.

We had plans for Mom to travel to Houston to my brother's house for a visit and to see a Doctor skilled in Asian medicine, Herbalist etc. Mom's Dr is refusing to give clearance until she has a full cardiac work-up and consult with her pulmonologist. Needless to say, Mom threw a fit in his office. It was something to see. Mom acted terribly sick one minute and in the next was caustic and biting. This further reinforced the Dr's idea for her to see the Psychiatrist. I don't think dementia is an issue, I think Mom is having anxiety on top of depression. She came home and sat in the chair for almost an hour, refusing to take her coat and hat off. Her husband came home and she told him that the Dr does not know what is wrong with her. She also yelled at her husband and told him to shut up etc.

Anyway: Thank you so much for the support. I'm so glad I came here. Karen, you are right. I was sinking. I'm going to focus on my self-care for even as I type this, I'm aware that a cold is trying to take hold of me.

Have a great day all, be well.

Post 8: GAIL

Hello Rose... welcome... sending lots of healing energy in your direction...

your mom is very needy... she probably has been all her life, but copd.. can make anyone fearful.. afraid to be alone.. to walk and exert themselves... especially since she is overweight.. she has all she can do to breathe.. her air passages are closing down during this process... some of these tendencies may be why your parents don't have a great relationship but my sense is that there is more to it than meets the eye..

Your dad's chronic heart failure is just as difficult as your mom's copd.. so I am sure he is unable to cope even more.

I would strongly encourage you and your siblings (even if they are unable to help out) participate in a family meeting to discuss what choices are available from all vantage points.

At this meeting, you might want to ask a social worker or priest or someone impartial to mediate. This would be the time you could set some boundaries and take some control. You can point blank say to your mother, that your health is in jeopardy.. if something were to happen to you, who would she have to take care of her and then move on from there.

You explain to her that she has to cooperate by letting a home health care aid come in to care for her and bathe her, etc with your supervision so that you can tend to other issues at hand that she has personally neglected such as the taxes etc.

Bonnie gave you some other ideas.. there are journal exercises here at the site that might help you to process through some of what you are going through as well.

Please be gentle and nurturing to yourself. Your mom beats up on you enough. She cannot make you feel guilty... the guilt is from conditioned patterns you have with her.. you are doing the best you can to help her and advocate on her behalf and you are in need of some cooperation...

please keep us posted... take care

Post 9: ROSE

Gail,

THANK YOU, THANK YOU, THANK YOU

Oh my goodness, reading what you wrote to me was like little xmas light bulbs going "pop," "pop." I am going to follow your advice and the advice of others that have replied. I feel such a relief being here at this site. It feels wonderful and empowering!!

again, thank you so much

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