Abstract

RECOGNIZING COMPASSIONATE FAMILY CAREGIVERS:
MEANINGS, JOURNEYS

BY MARK B. DURIEUX

This study aimed to discover new meanings and uncover fruitful understandings associated with the lived experiences of family caregivers. To that end, and making use of a variety of sensitizing concepts derived primarily from symbolic interactionism and Paul Ricoeur’s hermeneutic phenomenology, in-depth qualitative interviews were conducted with an emergent-theory-driven convenience sample of twenty-eight family caregivers, seven of whom were male, residing in Calgary, Alberta, Canada. These caregivers represented a variety of disabilities and illnesses. Analysis of the interview data, framed against a simple narrative orientation, yielded a grounded theory stressing the centrality of a particular family caregiving compassionate desire, ethic, and promise — that of “being there” for and with traumatized individuals at their “ground zero.” This intention appears to have links to gift giving (both secular and divine) and a number of meaningful and significant ends. Further, “being there” is suggested in important private and public tensions, with implications for an expanded understanding of family caregiver self-identity, friendship, and the humanization of community in general as well as health care in particular.
Thank you to all of the “family” caregivers who were kind enough to share their stories with me. This is for you. I sincerely hope that my appropriation and interpretation of your voices both honors you and extends the life of this crucial conversation.
# TABLE OF CONTENTS

## CHAPTER ONE: INTRODUCTION ......................................................... 1

**BACKGROUND** ............................................................................. 1  
Critique of previous family caregiving research ........................................ 1  
Toward a new research agenda ............................................................. 2  
Grounded Theory, an exploratory methodology ......................................... 3  
Preparatory sensitization .................................................................... 8  

**PAST RESEARCH** ........................................................................ 13  
**SUMMARY** ................................................................................. 27  

## CHAPTER TWO: METHODS ............................................................ 28  

**CONCEPTUALIZATION** ............................................................... 28  
Summary .......................................................................................... 33  

**LISTENING TO LIVED EXPERIENCE** ............................................ 34  

**GENERATING GROUNDED THEORY** ........................................... 38  
Sampling considerations .................................................................... 40  
The study’s participants ...................................................................... 42  

## CHAPTER THREE: BEGINNINGS ................................................. 45  

**TRAUMA, SUFFERING, AND FAMILY CAREGIVING** ......................... 45  

**WHY THEN CAREGIVE?: BEING THERE** ....................................... 46  
Corrine ............................................................................................ 52  
Sandy ............................................................................................... 55
“ORIGINS” OF BEING THERE

The secular gift ................................................................. 59
Unconditional love: the divine gift ........................................ 63
The secular or divine gift?: other tensions .............................. 64

“ENDS” OF BEING THERE ................................................... 65

Being there as instrumental care ......................................... 65
Being there as charisma or advocacy .................................... 67
Being there as honoring ...................................................... 69
Being there as facilitating .................................................... 72
Being there as mentoring ..................................................... 73

CHAPTER FOUR: MIDDLES .................................................. 75

ALIENATION FROM ONESELF ............................................ 75

The quest for balance......................................................... 77
Making their way ............................................................... 85
Help-seeking .................................................................... 89

ALIENATION FROM OTHERS ............................................. 91

CHAPTER FIVE: ENDINGS? .................................................. 107

ECHOES OF FAMILY CAREGIVING ..................................... 109

CHAPTER SIX: RECAPITULATION AND PROSPECT ............ 114

THEORY ............................................................................. 117

Family caregiving: strategic, handy, faithful friendship .......... 117
CHAPTER ONE: INTRODUCTION

BACKGROUND

Government cutbacks, deinstitutionalization and the redefinition of hospitals as acute-care-only institutions, a burgeoning elderly population, and the increased life expectancies of seriously ill or disabled individuals are just some of the factors converging to place the informal, voluntary, or “family” caregiver at the center of the provision of care in many North American municipalities such as Calgary. As such, as an undeniably new variation of a social form that has been with us since the very dawn of human history, family caregiving today provides sociology with both a new object of inquiry and new opportunities for theorizing (Bryant, 1995).

Yet, as care has become increasingly community and family-based, many have begun to express concern over the well-being of the family caregiver (c.f. Keating, N., Fast, J., Frederick, J., Cranswick, K., & Perrier, C., 1999). Indeed, according to a Canadian media source, the Journal of the American Medical Association recently reported that “elderly caregivers who experience stress and strain have mortality rates 63% higher than people in the same age group who do not provide care or whose spouses are not disabled” (“Elderly Caregivers,” 2000). No wonder that it is now commonplace to claim that it is time to “care for the caregiver.”

Critique of previous family caregiving research

According to Jaber Gubrium (1995), this widespread concern has prompted a “voluminous” amount of social scientific research. However, in his recent review of this literature, Gubrium (1995, p. 267) concluded that this research unfortunately tends to second-guess caregivers’ lived experiences.
Models with overly clear components, arranged in highly rationalized causal relationships with predictable outcomes, produce results that belie the often fuzzy contents and borders of caregiving encounters and the identities of the participants. There is little sense that caregiving, as a going concern, may be something subject to negotiation on a daily basis, changing in quality with turns in identity and the developing relationships of those concerned (1995, p. 267).

Echoing Gubrium's trepidation, a policy analyst for the Calgary Regional Health Authority recently allowed that in its analysis of its own family caregiving data, “we’re learning the hard way that the ‘cookie-cutter’ approach to trying to understand the lives of family caregivers just doesn’t work very well” (personal communication).

Media are also calling for recognition of the subjective experiences of family caregivers (Creighton, 1998). And finally, powerful advocacy groups such as C.A.R.P. (the Canadian Association of Retired Persons) have recently recognized that family caregivers are in crisis, being “silent victims in a silent system” (“Caregivers in Crisis,” 1999). In response, this organization has initiated comprehensive attempts to put a human face on home care (Barris, 1999).

**Toward a new research agenda**

Past research, then, states Gubrium, “suggests that the forefront of caregiving research is definitely not more of the same. We need... to move in directions that will lead to the discovery of new meanings and uncover fruitful understandings” (1995, p. 267, emphasis added). This research represents such a move: it sets in place a discovery-oriented, hence open-ended and therefore qualitative, inquiry capable of attending to and exploring the inner lives of family caregivers themselves – their lived experiences,
identities and meaning-makings which are always transformed anew in relation to an ever- and rapidly-changing world – with the intention of generating fruitful, yet empirically grounded, understandings, or theory, of the subjective aspects of that role.

Where can such an investigation begin? Without “jumping the gun” too much, it is important to anticipate later discussions of methodology with a brief “mapping” of the process here. This is made necessary by a need to discuss the issue of “sensitizing concepts,” which give “the user a general sense of reference and guidance in approaching empirical instances... [and] merely suggest directions along which to look” (Blumer, 1954, p. 8), all in preparation for a review of the literature regarding the lived experience of family caregivers. Let us now consider that map.

**Grounded Theory, an exploratory methodology**

There are many different versions of Grounded Theory, and while it is well beyond the scope of this report to review or contrast them, it is important to note that fundamental to all such explorations is an empirically grounded discovery of theory, such that theory “emerges” from the data “readily (not forcibly)” (Glaser & Strauss, 1967, p. 3), where “forcing” instances the doctrinaire application of theory to data (p. 46). The emergence of theory begins with basic pattern recognition, through constant comparison, which, in our case, would revolve around the idea of lived, subjective experience. Pattern recognition, a classificatory and descriptive enterprise concerned with what is going on or how things are happening, is typical of much qualitative research (Gubrium & Holstein, 1997, p. 195). Pattern recognition, for example, would allow us to organize the experience of family caregiving in terms of, say, its positive and negative meanings. The
following two testimonials are quite obviously different and could form an initial attempt at establishing such a pattern.

Nel Noddings (1984), for example, avers: “Joy... accompanies fulfillment of our caring” (p. 6) and “represents a major reward for the one-caring” (p. 132). Also, “the one-caring... is not bored with ordinary life.... She does not ask, ‘Is this all there is?,’ but wishes in hearty affirmation that what-is might go on and on” (p. 126).

Yet from Elsie Helsel, the mother of Robin, a 30 year old multiply handicapped male, we hear precisely the opposite:

Living with a problem for thirty years takes its toll. I get tired of dragging Robin around, making all the special arrangements that must be made before I can go anywhere or do anything. I get tired of lifting that heavy wheelchair in and out of the car. It would be nice just to be free to take off on a moment’s notice and not have to plan ahead (Turnbull & Turnbull III, 1978, p. 100).

The beauty of such work is that it is not overly difficult, at face value, to build consensus as to the presence or absence of this or that aspect in an exploratory investigation, for two reasons. First of all, humans are generally adept at recognizing patterns in similar ways (Azevedo, 1997, p. 102). Secondly, in exploratory work, ambiguity of findings (that is, ambiguity in pattern discrimination as well as in number of cases needed to pronounce a pattern) are not overly problematic. Indeed, as a function of working with qualitative information, such ambiguities are not only a fact of exploratory research, and so acceptable, they are desirable as well. It is, after all, more important to the exploration of unfamiliar territory and later theoretical discovery to allow findings in
than keep them out. When recognized, this norm makes consensus building all the easier since there should be a built-in avoidance of “niggling” differences.

Of course, the risk in building consensus regarding findings in this way is that one may admit, in so doing, a number of ultimately unproductive findings, seeing patterns that aren’t really there. Interestingly, this notion is akin to statistical Type I error which states that “we reject the null hypothesis when it is actually true” (Elifson, Runyon, & Haber, 1998, p. 314). This is tantamount to saying that we reject the idea of a finding being a non-finding – or chance occurrence – when it actually is a non-finding. This is simply seeing something that isn’t there, seeing a “mirage.” But concatenation over a variety of substantive areas and the consequent move to develop formal grounded theory (Stebbins, 1992a) greatly assist in later exposing these mirages, or minimizing these errors, a topic we will return to at the conclusion of this report.

Exploratory descriptive research, then, is generally an enterprise which can garner some support for itself, given the caveats noted above. As well, there is an intriguing “newness” about it, being drawn from metamorphosizing localities and lived experiences. In general, it can then be said that the attractive features of exploratory description stem from its remaining “close” to the data, as ambiguous a statement as that may be.

The same cannot be said for those impulses that lead to and from such description; neither description’s predispositions and sensitizations, on the one hand, nor the emerging theoretical accounting for the patterns, the whys of things being the way and how they are, on the other, are conducive to consensus. Rather, they are subject to personal vagaries and initiatives, rooted in interpretations which are the outcomes of a researcher’s reflexive and creative interrogations of his or her traditions and – with
regard to emerging theory – the data. Indeed, in the case of emerging theory, such interpretations, which necessarily “go beyond the data” without violating them, are the essence of intellectual craftsmanship. As Stebbins (quoted from manuscript, pp. 404-405; in press) notes with regard to the issue of quoting respondents in Grounded Theory:

Nothing seems to more quickly upstage a generalization than a long-winded quotation from a respondent or a string of shorter ones from several respondents…. To be sure, particular statements made by respondents in interviews are the raw materials investigators work with to fashion their generalizations, but subsequently quoting… these statements can never show, validate, or prove the creative leaps the second make during these expressions of intellectual craftsmanship.

In general, then, grounded theorists must remember to “write about concepts not people…. The power of theory resides in concepts, not description” (Glaser, 1978, p. 134, italics in original).

These sensitizing and theoretical impulses, then, are often contentious. But without them, and their links to vital philosophical matters, exploratory description remains mired in the ultimate banality of mere novelty, and the intellectual future of social theory, as Sica (1998, p. 5) implies, becomes lost.

With these considerations in mind, it is fitting to briefly consider the philosophical positions that have colored this investigation’s field encounters and emergent theoretical linkages. Thus, we now turn to a consideration of the sensitization guiding this inquiry into the inner life of family caregivers.
However, before doing so, the reader should note that this is not a philosophical treatise but a sociological study. That is, what follows is a self-conscious, if summary, look at the philosophical traditions chosen to sensitize this research, a point made earlier. This effort, however, does not entail “hunting out a thinker’s exact doctrine [which] eventually seems to end in a constrictive and predatory procedure....” (Fiumara, 1990, p. 74). Rather, such a taking for one’s own use claims, after Gadamer, that: “It is part of real understanding... that we regain the concepts of an historical past in such a way that they also include our own comprehension of them” (Fiumara, 1990, p. 77-78).

This sort of “reading,” by the way, is increasingly common within contemporary hermeneutic practice. Indeed, the emphasis is shifting decidedly in favour of “our own comprehension.” Thus, Derrida is, for example, quick to point out recently that his is a culled and selected reading of Nietzsche, an active and hazardous interpretation, a “following without following” (cited in Caputo, 2000, pp. 72-73). Similarly, Ricoeur (LaCocque & Ricoeur, 1998, pp. xiii-xiv) has noted that it is not the “secret” of an author’s intentions (the “background” to a text) that is of primary concern, but rather the interpretive reception of a text by a community of readers (the “foreground” to a text). Thus, Ricoeur concludes: “We must therefore say emphatically that the foreground outruns the background” (LaCocque & Ricoeur, 1998, p. xiv). And so, much of what follows appropriates philosophical notions without precisely reflecting “true” doctrine.

In closing this section, let it also be noted in passing that a consideration of the other non-descriptive exploratory impulse, namely, emergent theorization, will take place throughout the findings chapters as well as in the final discussion chapter.
Preparatory sensitization

This study approaches the lived experience of family caregivers by encountering what is arguably one of the most consequential distinctions in all of human thought: that of freedom and determinism in human affairs. Thus, are we free creatures, or are our lives externally determined? Indeed, as Christians (2000, p. 133) points out, this is a core question precisely because the Enlightenment dualisms of subject/object, fact/value, and material/spiritual, reflecting the cosmological legacies of Galileo, Descartes, and Newton, have, at their deepest root, a pervasive autonomy, a cult of human personality, triumphant and free.

Human beings were declared a law unto themselves, set loose from every faith that claimed their allegiance. Proudly self-conscious of human autonomy, the 18th-century mind saw nature as an arena of limitless possibilities in which the sovereignty of human personality was demonstrated by its mastery over the natural order. Release from nature spawned autonomous individuals who considered themselves independent of any authority. The freedom motif was the deepest driving force, first released by the Renaissance and achieving maturity during the Enlightenment.

But, as Christians notes (2000, p. 133):

The Enlightenment’s autonomy doctrine created the greatest mischief. Individual self-determination stands at the centerpiece, bequeathing to us the universal problem of integrating human freedom with moral order.

It is at this very point, the point of confronting this “greatest mischief,” that, in terms of this research, we must then ask: are caregivers’ inner lives autonomous of
physical reality and the moral and social order about them, or not? And if so, to what extent? These two questions roughly guide this inquiry and take us directly into that little known realm where events, self-identity, and meaning-making all meet.

Certainly, those who would deny the existence of such an autonomous inner life – or at least regard it as epiphenomenal – are legion. They would assert that the human subject is either entirely or most importantly a product of history and its institutional, cultural, biological and evolutionary forces. The Cartesian cogito, once so self-confident in its modern logocentric claim – “I think, therefore I am” – has been decentered and deconstructed in so many ways by now that, while technically it may be said that something remains, in practice, whatever – if anything – is left is, for those of this persuasion at least, not worth mentioning.

Yet, against this perspective, there is an enormous resistance from individuals themselves who, in grounded, practical ways, sense that there is not only an autonomous reality to their own lives but that it also matters a great deal and so is very much worth mentioning. Their skepticism is reminiscent of the ancient Chinese insight which teaches that despite our epistemic and theoretical ability to halve a stick ad infinitum, in reality, ontologically speaking, we are, of course, obliged to stop short much sooner than that (Grigg, 1994, 192). Consequently, it should not surprise us that despite current post-structuralist pronouncements on the death of the author, for example, a recent review by Richard Sieburth, (cited in Rapport, 1997, p. 8), notes that “the number of autobiographical writings now being published in France is some twenty-five times what it was in the late nineteenth-century.”
This French tendency is by no means unique. Specifically, if one examines the current family caregiving literature readily available through any public library branch, self-help bookstore or internet site one cannot help feeling impressed by the large and rapidly growing collection of personal accounts written by family caregivers\(^1\). Politically, this is an important trend, for it may provide caregivers with some basis for resistance against their possible erasure by those previously mentioned as well as protection against any consequent denial of their right to participate in “care for the caregiver” initiatives.

However, there is a danger in this rising crescendo of autobiography. Ironically, it may only be furthering the very problem it seeks to alleviate: those who would better know the family caregiver – including caregivers themselves seeking a sense of community – are faced with a seeming cacophony of disparate and perhaps even oppositional voices clamouring for recognition. The unfortunate end result may then be a desensitization to the lived experience of family caregivers, social “amnesia,” and the possible erasure of the autonomous element of self-identity.

The position of autonomy is perhaps better represented, then, by enabling the disparate and fragmented voices of family caregivers to converse with each other in some methodical fashion. This suggests a synoptic approach to inquiry that is both capable of recognizing the threads of unity in diversity and outright differences within and between the groupings of autonomous inner lives of family caregivers. This suggests a comparative inquiry that enters the social flow of conversation, initially as listener and

---

\(^1\) A visit to web sites such as amazon.com or bn.com (Barnes and Noble) easily confirms the latter part of this claim.
increasingly as participant, with an eye to increasing the recognition of family caregivers amongst themselves and the community at large. This recognition would be a first and important step in generating social findings and theory of use to family caregivers’ lives and their flourishing.

Recognizing family caregivers, however, must also fundamentally relate to our initial dilemma, which is the overarching one: the contradictory perspectives regarding the autonomy of the inner life vis-à-vis the physical and social world. We can discern from our previous discussion of Christians’ thinking that failing to consider this underlying constitutional tension is, in view of this research, to overlook the very core of lived experience, meaning, and self-identity.

In the interests of a balanced and fair sociological exploration of these forces, which seeks to avoid excess and premature closure of inquiry, then, we are constrained from taking sides on this issue. What we are left with, it seems, is an openness to the possibility of a complementary dialectic as perceived by Paul Ricoeur between tradition and innovation, belonging and distanciation, familiarity and novelty, near and far, ideology ("as a symbolic confirmation of the past") and utopia ("as a symbolic opening towards the future") (Kearney, 1998, 1999, pp. 448-449). The reader should carefully note that the terms on one “side” or the other of this dialectic are not intended to be synonymous (i.e., “tradition,” “belonging,” “familiarity,” “near,” “ideology”; “innovation,” “distanciation,” “novelty,” “far,” “utopia”), but, as interpreted here, are taken to be suggestively and ambiguously parallel, entirely in keeping with this study’s discovery and exploratory tenor.
Further, this dialectic is suggestive of a parallel to the structure and agency dialectic so familiar to sociology: structure being those social institutions (including biological, evolutionary, and cultural traditions) which exist prior to and beyond the life span of any human individual and which have the potential — given an immature or otherwise unreflexive, compliant host — to differentially inscribe themselves very closely upon that life; and agency being the capacity of an individual to actively, self-consciously, and innovatively author their own life in at least some ways — and not merely, passively, narrate it — thereby distancing themselves from society’s structural elements.

Perhaps the importance and eternal difficulty of this dialectic was best summarized by Karl Marx (1852/1954, p. 10):

Men make their own history, but they do not make it just as they please; they do not make it under circumstances chosen by themselves, but under circumstances directly found, given and transmitted from the past.

But what are the manifestations of this difficult-to-express dialectic in real life, in family caregivers’ lived experience? And how do these manifestations work, either in concert or separately? And why do they do what they do how they do it? These are this inquiry’s empirical questions.

In this way, we can exploratorily discover emergent grounded theory that “fits” and “works” to explain (Glaser & Strauss, 1967) the lived and meaning-laden experiences of family caregivers. In this way we can bring the philosophers down to earth. And, if the point is to change the world and not merely philosophize it, as Marx (1845/1956, p. 69) famously observed, then this new empirical direction for the family
caregiving research agenda would serve an important political function, namely, to provide an empirically grounded, nonfictional – and therefore more dependable than the utterly fantastic – foundation upon which mimesis, the bridge between the imaginary and the real, can be built.

PAST RESEARCH

For whatever reasons, a recent review of several hundred sociological, social work, and nursing abstracts by this study’s author reveals that to date and on the whole little has been done to bring about the research agenda advocated by Gubrium in 1995. Yet, some intriguing studies have, indeed, been conducted both prior to Gubrium’s comments and since then. The more salient of these will now be reviewed. Prior to doing so, though, it is worth noting that none of these studies’ authors goes on to self-consciously and carefully investigate the dialectic noted previously (shorthanded here simply as the “ideology-utopia” dialectic), which was earlier held up to be an important basis of lived experience. However, this does not mean that the issue is passed over entirely, as we shall see. As well, it appears that no one thus far has comparatively studied family caregiving simultaneously across both sexes and more than two disability or illness groups, whether in an exploratory manner or not.

We begin with Pearlin and Aneshensel’s (1994) well-known study of family caregivers to Alzheimer’s patients because, at first glance, it appears so relevant. However, for important reasons which shall now be discussed, it is not.

Pearlin and Aneshensel’s (1994) major finding is that the extreme demands and stresses associated with caregiving conform to a “career” trajectory and further entailed a trade-off in crucial self-identity, and often precipitated a loss of self (p. 381). What is
meant by this is that with the increasing demands of family caregiving, caregivers experience an increasing homogenization of their lives into the single role of the caregiver (p. 381). Thus, their subjective career, or the "moving perspective in which a person sees his life as a whole" (Hughes, 1937) becomes narrowed to a single point and a loss of self ensues. Pearlin and Aneshensel then speculate that this self-loss is linked to depression, perhaps through grieving the atrophying of one's life roles (p. 381).

Interestingly, this finding conforms in substance to that obtained by this author in his study of caregiving parents of children disabled by cerebral palsy (Durieux, 1992). That research revealed that the intrusiveness of caregiving, or the extent to which caregiving kept parents from engaging in valued activities, had a moderate total negative effect (p = -.41) upon parental subjective well-being. Thus, it can be said again that as other valued activities or roles are denied the caregiver through their participation in caregiving, so losses in well-being (theoretically akin, perhaps, to self-loss and depression) accrue.

However, despite this important contribution, Pearlin and Aneshensel's study remains largely superficial with regard to informing us of the lived experiences, identities, and meaning-making of family caregivers. Thus, while the general stress literature itself long ago recognized that in the cases of varied and complex stress situations — such a family caregiving — "one person's stress is another's challenge," such that the gap between perceived demand and capacity is a matter of subjective interpretation, this was not a matter of inquiry for these authors. And, with that, from this study's perspective, was lost the further opportunity to explore the workings of the ideology—utopia dialectic in expressing the lived experiences of family caregivers.
Next we consider a study by Hashizume (1998), who provides a fascinating look at the meaning of family caregiving to frail elderly parents in Japan. This meaning, the author contends, is affected by many sociocultural and historical forces just as it is currently changing in concert with Japanese societal change and development. The case of Japanese filial piety is presented, whereby respect and devotion to elders and parents "charges family members to assume responsibility for caring for their elderly relatives" (1998, p. 125). Indeed, "Filial piety is internalized as a cultural value in Japan through moral education beginning in elementary school" (p. 125). As well, "filial piety is further supported by the Japanese value of reciprocity," (p. 125) such that "being nurtured by parents requires a debt of gratitude, and people feel obliged to assist the parents who have cared for them in the past.... Caring for parents from a sense of gratitude is considered a virtue" (p. 126). Finally, filial piety dovetails nicely with another important Japanese value, that of "dependence" among the elderly. Thus:

The dependence of elderly people on the younger generation is natural and desirable in Japanese family relationships, along with the idea of filial piety. This is in contrast to American cultural values that tend to denigrate dependence as a sign of weakness. In Japan, it is common for essentially capable old people to refuse to do things for themselves (p. 126).

Other cultural factors impose meaning upon the Japanese family caregiving experience, reinforcing it even further. We are reminded, for example, of the Japanese value of privacy, such that caregivers "may experience embarrassment and fear when a service provider 'invades' the privacy of their homes" (p. 128). As well, there is a stigma
associated with institutional long-term care: “Public nursing homes are considered to be poorhouses” (p. 128).

Yet for all the positive valence attracting the Japanese to family caregiving there is at least one important value which stands, at some point in time, in fundamental opposition to such a valence. This is the ancient devaluation of unhealthiness, which has its origins in Japan’s history as a poor, preindustrial society where “the value of a human being was dependent on his/her ability to contribute to the community” (p. 129). Thanks to this entrenchment, those with a “fixable illness” are supported, showered with loyalty, love and affection. However, those with “unfixable illnesses,” who are chronically or seriously disabled or ill, such as the frail elderly, are considered embarrassing or shameful.

How does this astonishing contradiction play itself out in the psyches of the Japanese family caregiver? We are given no indication. The potential psychic “fallout” from the interaction between the two conflicting ideologies regrettably cannot be considered since the author’s concerns are solely historical and institutional. Ideology’s effects are favoured so far as to completely deny the existence of an autonomous, authoring individual family caregiver. The dialectic between ideology and utopia remains unacknowledged and unexplored.

Hashizume’s report is, from this research’s perspective, weakened in two other important ways as well. First, no attempt is made to distinguish between the effects of the various forms of Japanese culture upon the sexes. Thus, we do not know whether the effect of ideology (and, indeed, conflicting ideologies) upon the meaning of family caregiving differs for men vis-à-vis women. Second, there is no distinction made between
the various illnesses and disabilities affecting the aged in Japan. As a result, we cannot speculate as to whether the effect of (conflicting) ideologies upon meaning-making is contingent upon various categories of "unfixable" illness or disability. Does the contradiction between positive and negative valence ideologies have a similar effect upon family caregiver meaning-making regardless of whether an aging parent has Alzheimer's or is paraplegic and confined to a wheelchair?

From Hashizuma's single study, with its overwhelming prejudice toward the ideological, we now turn to a small number of studies which have considered, to some lesser or greater degree, the inner world of the family caregiver. Initially, we find that three investigations into caregiver subjectivity reflect, to some small and superficial advantage, the ideology-utopia dialectic. Unfortunately, the research is primarily descriptive and so fails to tap into the promised theoretical richness of the tension between tradition and innovation. Following these studies, we will consider another four inquiries which are revealing both in their treatment of caregivers' lived experience and, more specifically, in their implicit attention to the ideology-utopia dialectic.

Wood's (1991) phenomenological study of the meaning of family caregiving sought to explore the question, "What is it like to experience being a family caregiver?" Ten caregivers were interviewed, eight of whom were female. Nine of the ten individuals requiring care were elderly, while seven of those ten were stroke survivors.

Although Wood's research certainly qualifies as very much "lived experience" research, there is no apparent attempt to explain why the experience of caregiving is as it is. Rather, the data analysis remains at the descriptive level. As a result, the dialectic tension between tradition and innovation is not evident. For example, when attitudes
toward caregiving were examined, a number of motivations for taking up the caregiving role were found. One caregiving spouse spoke of fulfilling the marriage vow (p. 197). Another caregiver, a woman who cared for her father-in-law, provided multiple motivations: “I take care of him because it’s my responsibility. I owe it to him. I was the only one who could quit my job and do it” (p. 197).

In a similar manner, Wood focused on the changes brought on by caregiving, claiming: “Half of the respondents indicated that the closeness [of the caring relationship] had positive and negative results” (p. 197). Unfortunately, this statement is not elaborated upon.

As well, two other themes are noted: “caring for the caregiver” and “positive and negative aspects” (p. 198). Regarding the former theme, one caregiver commented: “I don’t care for myself. I go out for about an hour occasionally, but I wouldn’t want anything to happen to him when I wasn’t there” (p. 198). An intriguing comment, but without further exploration and contextualization we are at a loss to interpret it in terms of the dialectic of interest. Is the caregiver, if female, expressing a guilt that is rooted in her socialization into the caregiving role? Or are other societal pressures being brought to bear upon the caregiver? Is the concern, perhaps, fixed in the struggle to innovate in dire circumstances? Indeed, what other factors on either side of the ideology-utopia divide might be at work? We cannot know.

The same can be said of the latter theme’s treatment. “I get... a little depressed at times,” reported one caregiver. Again, this is lived experience, surely, but without the search for explanation such an utterly descriptive statement lacks the richness that we know is inherent in lived experience.
Enyert and Burman (1999), Cartwright, Archbold, Stewart, & Limandri (1994), and Langner (1995) have all examined the subjective experience of family caregiving from the perspective of the autonomous individual. All begin with Victor Frankl’s (1959) widely known and esteemed studies of human meaning-making in the midst of suffering. Enyert and Burman (1999), after Frankl’s (1966) essay, set out to describe the ways in which the burdens and losses of caregiving are transmuted into self-transcendence, enrichment, and personal growth.

Enyert and Burman (1999) examine self-transcendence in family caregiving, defined as “reaching out beyond the boundaries of the self to achieve broader perspective and behaviors that help one discover or make meaning” (p. 456). This quality is thought to be rooted in freedom of choice: “Even when deprived of both the creative and experiential ways of finding meaning, one retains the opportunity to choose how to face adversity” (p. 456). In terms of our dialectic, it would seem that these authors value utopian notions over the ideological and organize their study accordingly.

Yet, judging by all the accounts these authors provide, self-transcendence is no more attributable to freedom of choice than external, especially social, factors. Thus, even though “one woman defined everything she did for her husband as meaningful to her ‘because my goal was to be there for him,’” (p. 458) it hardly goes without saying, nor is it at all evident, that this noble sentiment has its origins in free, responsible, ethical choice versus, say, the internalized binds of the marriage vow. The data is simply presented as it is, left to lie, from our perspective, theoretically uninterrogated.

Similarly, caregivers’ lack of formal training or education as caregivers is associated with self-transcendence, in that caregivers demonstrate that they can and do
rise above their own limitations. But why does this happen? What motor(s) drive this personal change? There are no attempts to shed light on this linkage, especially, from our point of view, via a closer examination of the ideology–utopia dialectic. Instead we are left with the insipid; that is, left with participants’ remarks such as: “I just learned. I don’t know what prepared me.”; and “But somehow you get the strength, but I don’t know where it comes from. It just kicks in and you can just do it” (p. 459). Repeatedly in this report the dialectic relationship between ideology and utopia is left unexamined – though somewhat intimated. Thus, we are left bewildered.

Rutman’s (1996) two day research workshop for five and then eight caregivers of elders more closely approaches the course we have set for ourselves here. Through an examination of incidents of powerfulness and powerlessness in the lives of caregivers we begin to see tensions arising between the caregiver and others, between self and society. This study informs us, for example, that: 1) caregivers perceived a lack of recognition of, or respect for, their competence and expertise; 2) caregivers perceived a lack of control, for example, over the care receiver’s disease process; 3) caregivers and care receivers values and preferences often clashed; 4) the “system” was overbureaucratic and underresourced [such that] the needs of caregiver and care-recipient apparently did not come first; and 5) caregivers expressed frustration at feeling that they needed to suppress their own emotions even if the situation did not warrant such “reasonableness.”

Clearly, these are important findings concerning caregivers’ lived experiences. Yet again, in terms of the tension between author/agent and society, this study, like those discussed previously, remains merely descriptive. It reveals little about the nature of these experiences of powerfulness and powerlessness in terms of the dynamic tension inherent
in the dialectic. The result, which is consistent with the other studies reviewed thus far, is that we really see very little of caregivers' inner lives. Reported perceptions of powerfulness and powerlessness only hint at the depth, complexity, and tensions inherent in the dialectic between ideology and utopia and the contested ground of lived experience, meaning-making, and self-identity where the battle for the autonomy of the individual is waged. Secondarily, of course, this study is, for our purposes, hampered by a design that does not allow for the comparisons we desire across caregiving groups and gender.

We now turn to four studies which, as noted earlier, reveal the inner life of the family caregiver and do so, importantly, by paying attention — at least implicitly — to the ideology–utopia dialectic. Parsons (1997) conducted a phenomenological study of the male experience of caregiving for a family member with Alzheimer’s disease in order to determine what the experience was like. Interview data collected from five husbands and three sons revealed several common and quite fascinating themes: 1) enduring (i.e., “Oh God, have I got to go through that again?”); 2) vigilance, where, for example, due to the wanderings of the care-recipient, the caregiver had to be vigilant, both day and night; 3) a sense of loss (i.e., the absence of the person known and loved prior to Alzheimer’s); 4) aloneness and loneliness as a result of the increasing estrangement from the care-recipient; 5) taking away, as when the caregiver must withhold objects or aspects of the care-recipient’s life for their own safety; 6) “searching to discover” as much as possible about the disease or its manifestations and workings within the cared for individual; 7) the need for assistance, especially in crisis; 8) reciprocity (i.e., the caregiver’s desire to reciprocate to their parent for the care received during their upbringing); 9) overstepping
the normal boundaries, meaning the transition which sees the caregiver reverse their usual child–parent role for the “parent” –“child” role of caregiver and care receiver.

Parsons' study is replete with fruitful understandings, new meanings, and issues with regard to self-identity within the caregiving experience. Further, if we examine each theme closely enough, we can discern indirect traces of the all-important ideology–utopia dialectic. For example, under the theme of “enduring” one male caregiver describes his estrangement from society: “Five hard years.... I had to do almost everything myself and I couldn’t go anywhere or do anything, and that was hard” (Parsons, 1997, p. 396). The theme of “vigilance” makes passing reference to the fact that respondent caregivers somehow, though this is not discussed, managed to engage the help of neighbours in keeping an eye out for the wandering care-recipient (1997, p. 397). And, of course, in the case of Alzheimer’s, the caregivers’ “sense of loss” increases as the cared-for individual’s cognitive abilities decline and intimate familial ties weaken.

One could go on, of course. The important point is, however, that Parsons’ study is a different breed of research from that reviewed thus far; one that acknowledges, albeit informally, the importance of the ideology–utopia dialectic through its central placement within the reported research.

A couple of final points. Aside from all of this, one may wonder at the seeming exclusivity of these findings to male caregivers: they seem, instead, and to a large extent, theoretically applicable to both sexes. Certainly, such a companion comparison begs to be done. As well, one wonders about whether and to what extent these themes would reoccur among caregivers from other illness and disability groups.
Cartwright et al.'s (Cartwright, Archbold, Stewart, & Limandri, 1994) symbolic interactionist grounded theory examination of enrichment processes in family caregiving to frail elders seeks to uncover processes and elicit meanings in interactions. The authors draw an attractive analogy between alchemy and caregiving: caregivers, too, need to transform the mundane elements of their lives into something precious. This is accomplished within the caregiver-care recipient dyad, embedded in the shared and mutually affirming personal histories of both actors. It is also accomplished within the “frailty trajectories” (encompassing illness, functional, affective, and cognitive domains) of these two individuals. Thus, “caregiving encompasses the intertwining of two frailty trajectories and two histories that span lifetimes” (p. 37).

Yet, against these structural constraints “caregivers are continually attempting to balance these separate but entwined trajectories and histories in the dyadic relationship and the caregiving situation” (p. 37) and create the “potential for invoking memories and creating meanings around daily activities.” Thus caregivers may turn to customary routines in an attempt to creatively appropriate historical meanings. The situation of a man and his wife with advanced Alzheimer's disease illustrates this: “Every morning we have a lesson we study and we have a book that has readings for every morning.... she grew up that way in her home.” And caregivers may develop innovative routine breakers to add meaning: “She can have [natural fruit candy bars], so I bring one of them and I try not to get in the habit of getting them a lot because then it isn’t a treat.” (p. 39)

Despite its precise “micro-sociological” orientations and particular interest in caregiving to the frail elderly, Cartwright et al. nevertheless greatly enrich our understanding of the everyday practices family caregivers develop in order to give
meaning to their lives. That this is done in a way that emphasizes the interplay of tradition, in the form of family ties and obligations, and caregiver innovation, is commendable from our point of view as we see, by implication, the ideology–utopia dialectic coursing through even the tiniest veins of caregiver life.

Kellett and Mannion (1999) more recently conducted an ontological–hermeneutic study of the meaning of family caregiving intended to highlight the human experience of family caring at home. Seven family caregivers caring for an older relative were interviewed. No indication is given as to the breakdown by sex.

Six common themes of meaning are discussed by Kellett and Mannion: 1) sense of family life past; 2) sense of change; 3) sense of engaged involvement; 4) sense of worth; 5) sense of concern; and 6) sense of continuity. For example, a caregiver's “sense of family life past” refers to the background governing how caregivers approach their experience of caregiving, view that experience, and interpret it. Clearly, the emphasis here is on ideology, tradition:

Thus the past is with each family carer and shapes their Being as a family carer. From each tradition of family care and practices... it was possible to speculate how attitudes had been shaped and influenced. A sense of family life past was described in terms of valuing commitment and loyalty of kin, experiencing a sense of family closeness and belonging, and recognizing the importance of sharing and facing life situations together (p. 700).

A caregiver's “sense of change,” on the other hand, seems to illustrate the other side of the dialectic; that is, the utopian, self-reflective, and innovative. As one caregiver put it, contrasting a transition from ideology to utopia:
I don’t think you ever think about it until it happens because you are so used to a person being there and being OK. I never gave it a thought.... [Now, in the caregiving role] sometimes I stand back a little bit and can’t understand why all this is going on, why should I be involved with this type of thing (p. 700).

Indeed, under the theme of adaptation, which is so closely allied to change, we find the unresolved – though not unresolvable – tension between utopia and ideology. Here, caregivers anxiously struggle to innovatively fashion ways in which to maintain their tradition-bound sense of family life:

Anxiety was commonly experienced as family carers sought ways of caring at home, ways of being a carer which provided for a continuing sense of meaningful family life characterized by feelings of attachment and belonging (p. 700).

While it is beyond the scope of this review to dissect Kellett and Mannion’s findings in more detail, it should be sufficient to point out that theirs is a commendable study, theoretically probing caregivers’ lived experiences, oftentimes quite interestingly, employing our dialectic of interest. Nevertheless, theirs is a roundabout treatment of that dialectic and so remains incomplete, haphazard, and vague in that sense.

Langner’s (1995) study of loss and personal growth among family caregivers to aging relatives commits itself to the utopian belief that “finding meaning is an individually derived process... [possibly] rooted in caregivers’ making personal choices about life... valuing positive aspects of the experience, and by... searching for both transitory and deeper meaning in the experience.” (76)

Two common themes related to loss and personal growth emerged from analysis of the data. Not surprisingly, confronting a new reality was the theme related to loss
while rediscovering and redefining the sense of self was the theme related to personal growth.

In loss, according to Langner, we find a confrontation with a new reality. "The turning point" of that reality is "characterized by the acknowledgement of a change in the relationship between themselves and their dependent older relative." (p. 78). Clearly, this is a fairly direct characterization of the traditional, social aspect of the dialectic in a state of flux as once trustworthy social bonds melt into air. And one immediately wonders how caregivers, as potentially capable human agents, respond to the new reality of loss. This question is taken up by Langner in the form of a "paradox" which can easily be seen as another manifestation of the ideology-utopia dialectic:

Oftentimes it is through the experience of separation and loss that one gains a sense of personal autonomy and mastery over life's vicissitudes. Although loss in its various forms is often painful and requires social, physical, and emotional adjustment and adaptation, it can also provide an individual with the opportunity for personal growth (p. 76).

The way out of this paradox is through the theme of rediscovery and redefinition of the self (utopia, innovation, agency, etc., in our terms), a process which begins with elevated levels of self-conscious self-inquiry, not merely low-level self-monitoring of the kind that we do when doing the laundry, for instance. In other words, "radical reflexivity." The following statement made by a woman caring for her husband recently diagnosed with Amyotrophic Lateral Sclerosis (A.L.S.) powerfully illustrates this:

From our first visit [with the researcher], I started thinking, and I really think that for the first time everything started to come into perspective. I cannot believe that
I was so foolish as to think that my life could be put “on hold.” This is a time when I am probably doing more living than ever before. Every day presents a new challenge and a new opportunity to prove to myself that I am really worth something and capable. How could I think that at some future date life would begin again just where I left off a year ago when all of this happened? Everything that has been happening will lend a new dimension to my thinking and feeling.

**SUMMARY**

Let us summarize, then, what a review of the literature has uncovered for us. First, little has been done to realize the research agenda Gubrium set before family caregiving researchers in 1995; examinations of the inner life or lived experience of family caregivers – where events, self-identity, and meaning-making meet – remain a rare commodity. And those that have been done have been limited by their inability to draw comparisons across sex and disability or illness groups.

Second, if we locate the center of an investigation into the inner life of family caregivers within the dynamic tension existing between ideology and utopia (suggested here in Ricoeurian and sociological terms), we find that no formal, explicit study of this dynamic has taken place to date. While the studies reviewed have paid more or less casual attention to this dialectic, and have nevertheless done so in a manner suggesting the fruitfulness, timeliness, and warrant for continuing in such a direction, it will remain for an investigation such as this to explore this important topic in explicit detail.
CHAPTER TWO: METHODS

CONCEPTUALIZATION

Because the ideology-utopia dialectic is central to this study, we now turn to a closer examination of this tension in order to conceptualize this research more thoroughly prior to our engaging the field.

Let us begin with human inquisitiveness, that which inevitably forces a confrontation with the unknown. As Cooper (2000), a prominent local political scientist, pointed out on the first day of the new millenium, the history of human attempts to understand the unknown demands the utilization of a simple, time-honoured strategy:

If there is any historical progress it amounts to figuring out what is intelligible and what is not, and trying to make sense of the latter by analogy with the former.

Of course, the great unknowns do not simply exist “out there” in the physical world. There are a host of unknowns located within each one of us, at the interface of mind, body, soul and world. Chief among these are our inarticulate, libidinal wishes or desires¹. These desires continually press themselves upon our consciousness, seeking our attentions. But though they passionately, emotionally, seek to make their presence known, they are mute, unable to intelligibly express themselves. Thus, they perplex us on two expressive fronts. First, we struggle, lifelong, to inwardly, reflexively, express and

¹ This study follows Carl Jung here in claiming that the libido is a generalized psychic energy, life force, or Will, underlying every kind of wish, intention, or desire, including sexual instincts. This is in opposition to the Freudian view, which finds the source of the libido in the sexual instinct itself (Stein, 1998).
thereby clarify our desires to ourselves. Second, armed with the first struggle’s provisional fruits – self-knowledge – we likewise strain to outwardly express our desires and thereby testify as to their legitimacy within the complex and rapidly shifting interdependencies of the social arena, in order that we may gain their satisfaction.

How, then, do we express our desires? We have at our disposal, as Cooper would doubtless claim, the discerning power of analogy, of which we may identify two broad and oppositional forms: 1) unambiguous-in-meaning (i.e., permitting only standard or accepted interpretations) signs (one meaning), symbols (two meanings), and other nomothetic, archetypal or otherwise deep-seated, social typifications and “master” narratives, including what we might call here life “passages” and life “scripts”; 2) ambiguous, polysemous, idiographic, authorially creative and innovative (for a given individual in contrast to the society in which they are embedded as members) metaphors and personal narratives.

---

1 The notion of inarticulate desires seeking expression in self-clarification and testimony is Ricoeurian (c.f., his “Freud and Philosophy” (1970) and “Oneself as Another” (1992)).

2 This tension is derived from a secondary discussion by Dosse (1997a, p. 237) of Ricoeur’s famous debates with Levi-Strauss. The upshot of these debates is that the fundamental tension in all of human thought is that between theories of sign versus theories of meaning (Dosse, 1997b, p. 450). This study chooses to understand that tension as that which exists between socially prescribed sign, symbol, and narrative, on the one hand, and innovative metaphor and personal narrative, on the other.
With symbols, archetypes, life-scripts, etc., there is a straightforwardness, a lack of interpretive confusion – at least to a particular society’s membership. These things offer members the safety, security, and closeness of a clearly defined ideological system, in the Ricoeurian sense. For these reasons, as culture, they are easily taught, appropriated, internalized, reproduced and transmitted (within the parameters of chance variation), and so are social and shareable forms among participants. With this they assume a rule-bound facticity in our lives, achieving a material quality, as they become part of the very social fabric, hence achieving a longevity that extends far beyond the lives of any individual. The fact that these forms, as forms of “knowledge,” are also so often inextricably bound to the wealthy and otherwise powerful in our society, who control their cultural production (c.f., Bourdieu’s investigations of “cultural capital” (Passeron & Bourdieu, 1977) or Foucault’s (1980) work on “Power/Knowledge”), frequently only further extends and hardens their hold upon the dependent membership, while just as forcefully barring entry to non-membership. These signs and symbols, etc., thus become our ideology – in the hermeneutic sense of “traditions” as well as in the Marxist sense of “illusions.” They become our institutions, our structure.

As such, we can imagine that we turn first to non-ambiguous analogical forms when attempting to express and clarify our desires to ourselves and testify on their behalf to others. This is especially true whenever we leave our ordinary lives and cross into the “strange lands” of liminal existence. For these forms are known to us, familiar, confidently (it seems) shared by a society, much discussed and thus easily accessed by we who have been socialized. They are, we have been trained to think, a safe haven against Chaos.
But ideology ("tradition," and so on) often fails us too. Our critical capacities awaken us to the contingency and contextuality of these forms. With that we begin to sense the broken, leaky margins of these formerly closed systems and realize that they are, in truth, knowledges held together with the "duct tape" of Power and Illusion. With that harsh realization, that cognitive dissonance, we are led into highly self-conscious reflection and critical domains of abstraction, a notion that draws upon Randall Collins’ ideas on "the continuum of abstraction and reflexivity" (1998, p. 787-788). We see now that the ideological forms we had grown dependent upon are, at best, expressively oppressive tools which only satisfice in some ways, but which do not "fit" quite rightly in our attempts to express our desires. Indeed, they deny more insights than they admit. Yet, as much as they leave us unsatisfied (that we have understood ourselves or been understood by others), they remain vital interpretive resources; that is, they may not be the safe haven we hoped for but they remain the life boats to which we cling — desperately — in the face of our unknown desires.

Thankful for small favours, we are nevertheless dissatisfied. Loathe to leave, we must. So torn, we experience a double-consciousness: we live in the one world, never completely free of it, even as we seek to free ourselves from its grip and begin to discover another world, more fully expressive of ourselves.

What is this other world? It is the world of living metaphor and narrative, living in the sense of its freshness and newness for the individual. Also living because the individual has creatively authored it so, working with — appropriating here and there — elements of ideology, now internalized as central aspects of one’s own character, with a firm purpose in mind: the expression of one’s desires through self-clarification and public
testimony. Finally, living because this world’s inherent ambiguity serves as forceful resistance to the “deadness” of ideology, fruitfully admitting more potential insights than it denies, and so promising adaptation and flourishing when previously there was only lifeless barrenness. Thus, its utopian quality.

But this innovative world, this utopia, too, may not be without its own difficulties as well as the potential inherent in ambiguity can be overwhelming and confusing to the expression of our desires. It may become difficult to separate the “wheat from the chaff.” That is, we may find ourselves overwhelmed and sinking in an unstable quagmire of possible expressions for our desires.

Naturally, we seek to tether ourselves to an anchor, a tree, or rock, in such a place. And so, once again we are on the move, nomads, now loathe to leave our freedoms though we must. We attempt to return, once again, to tradition – though it is likely that this is to a new-found (for us) tradition rather than to a prodigal home – seeking stability, risking stultification.

It is thus that in the service of the expression of desires any given ideology may find itself juxtaposed against not only a plethora of utopias but also an equally vast array of other ideologies. In such a scenario the Ricoeurian notion of the conflict of interpretations (Ricoeur, 1974) seems appropriate as desires interrogate both ideology and utopia, while these latter two interrogate each other, intertextually.

And so it goes – and goes. Now it is possible to appreciate how dialogical human agents manage to extend the ideology–utopia dialectic into so many facets of our cultural and psychic lives, from our innermost self-reflections upon our desires to our outermost social interactions in testimony to those desires.
But it is also time to give birth to, to envision, a new type of dialectic. We must relinquish the notion of a great rift or divide or dualism between the two elements, ideology and utopia. Instead we must now see that the two are indissolubly linked, not at all representative of a fragmented reality. We must see that each calls forth the seed of the other, in complementary polarity, as elements in an ever-changing whole. All of this can perhaps best be epitomized in a single timeless word that always has and always will capture the essence of the One’s movement from and to the ordinary and extraordinary. That word, about which more will be said later, is “journey.”

Summary

To summarize: thus far, we have defined a research problem for ourselves, namely that of explaining the lived experience of family caregivers. Doubtless, there are a myriad number of possible ways to approach such a task. Ours, however, builds on a fundamental philosophical issue: the autonomy of the individual within the lived experience, for it is felt that this experiential knot brings us to the essence of any lived experience. Having then noted the important political implications of framing our research problem in this way, we then further specified the philosophical issue as a dialectic between ideology and utopia.

Now, clearly such an explanatory endeavor, given the complexity and nuance of the topic, must be approached, as was pointed out, in an empirically exploratory, inquisitive manner. Armchair philosophizing and theorizing vis-a-vis the lived experiences of family caregivers hold no promise.
Has such an investigation yet been conducted? A review of the literature revealed that this was not the case. Nevertheless, a number of studies gave unspoken empirical warrant for an explicit study such as this.

With that, we began to further conceptualize and refine the ideology–utopia dialectic in preparation for entering the field. Thus, we became “sensitized” to broad, potential manifestations of the dialectic in various “closed,” in contrast to “open,” analogical expressions of human desires and saw that these expressions had two vital functions spanning the societal micro-macro continuum: self-clarification and testimony. We also saw that this dialectic could not be conceived of as dualistic but rather as interpenetrating polar elements, indissolubly linked into a unified whole. In a sense, then, we have developed for ourselves a sort of crude “map” for negotiating the complex terrain of a family caregiver’s lived experience. As Charmaz (1995, p. 49) points out, such sensitization marks a starting point for one’s research, not the end.

**LISTENING TO LIVED EXPERIENCE**

It is time now, given all of the above, to consider the logistics of such a study. First of all, how can the sensitization developed thus far be translated into an actual investigation of family caregivers’ lived experience?

Briefly, we suggest that the essence of lived experience is captured in the struggle over the autonomy of the inner life; that this struggle is captured in the dialectic of ideology and utopia; that this dialectic is expressed in real terms through the contested terrain of our desires; but that such expression, which is the micro-macro pivot around which self-clarification and public testimony are made possible, is only possible through the dialectical compensatory polarity existing between unambiguous symbols,
archetypes, life-scripts, etc., on the one hand, and authorially creative ambiguous, polysemic living metaphor and narrative, on the other. Given these things, we can now look at a family caregiver’s lived experience as a twin process of self-clarification and public testimony of that individual’s desires as expressed through the unambiguous and ambiguous forms of analogy we have discussed.

Simply, in terms of self-clarification, we can ask about: early familial or cultural influences upon the compassionate caregiver; cultural influences such as works of art, philosophy, literature, religion, etc.; the influence of other voices from beyond, such as myths, revelations from a “higher power,” dreams, etc.; the effect of social contacts within the caregiver’s role set (i.e., the care-recipient, physicians, nurses, social workers, etc.); the consequence of a caregiver’s sense of who they are (self-identity and/or life story) upon one’s experience of caregiving.

In terms of public testimony, we can inquire into a caregiver’s “presentation-of-self-as-family-caregiver” within the social milieu; the need for self-advocacy; the problematics of self-attestation as subjugated knowledge as against powerful, dominant discourses; and the sorts of legacies that one would like to bequeath to oneself and others. The representation of these matters can be found in Appendix B. It will be up to our data analysis (which will be discussed shortly) to determine how the compensatory polar opposites of ideology and utopia work as double-consciousness to express family caregiver desires and reveal the deeply involved nature of personal autonomy as lived experience.

But how does one achieve, while in the field, the openness necessary to such an exploratory study?
Consistent with Charmaz' position on sensitization, we must, at minimum, embrace something like Fiumara’s (1990, p. 6) recent philosophy of listening, which stands in stark contrast to “an increasingly arrogant logos, ready even to ignore anything that does not properly fit in with a logocentric system of knowledge.” Rather, empirical inquiry through dialogue would feature a “maieutics of listening” which serves to enhance the creation of language and the growth of the speaking person, thus freeing humans in the making from the forced role of users and imitators of whatever language happens to be most effectively propagated in the market. A maieutics rooted in listening – which is always listening to the person, and not just to the skeletal utterances he or she produces – can make possible the growth of a truly speaking person rather than the assembling of someone ‘spoken’ by the dominant rational language adhered to (1990, p. 167).

With these orientations in mind, this inquiry’s data collection took place through face-to-face, audio taped, semi-structured “long” (McCracken, 1988) interviews. Since even a listening philosophy will not elicit the quality and depth of dialogue required by this research, unless an atmosphere of trust can be established, at the very outset it was of paramount importance to present to the interviewee any ethical approval and research sponsorship statements as well as consent forms to be signed. This placed the locus of control firmly in the respondent’s hands.

Next, it was necessary to begin interviews with the collection of simple face-sheet data (McCracken, 1988; see Appendix C for the face-sheet schedule). This facilitated “breaking the ice” with the caregiver as well as allowing them the opportunity to study the interviewer – the stranger and intruder in their home and life – instead of
immediately being scrutinized themselves. As well, the information collected within this face-sheet exercise was rather innocuous, at least in the early going, since information on birth order, names and ages of siblings, and the like was inquired about.

As trust began to take hold, then, the focus turned to some more open-ended topics, issues near and dear to most people: descriptions of their parents, and, inevitably, the interviewee's relations with them, recollections of family life and an assessment of the respondent's religiosity. Here was our initial attempt to listen and perhaps engage in some idle humorous banter or demonstrate our compassion and empathy for any personal problems that may arise (i.e., "Dad was really distant from us and a real disciplinarian.").

After completion of the face-sheet data collection the interview began. The commitment to listen was reinforced by explaining that the first portion of the interview was designed to allow the caregiver to bring up any topic they wished to talk about with regard to their caregiving. This may have allowed caregivers the opportunity to continue, if they feel the need, to test the interviewer's trustworthiness by presenting some manifest problem while assessing the researcher's response. Whether the researcher "passed" or "failed" may well have determined whether or not latent issues were later revealed. At any rate, given the opportunity to begin wherever they felt comfortable, caregivers were typically put at ease and had little difficulty engaging in conversation.

As the conversation developed, the interviewer noted how certain themes of interest, derived from the theoretical sensitization buttressing this research, were developed (see Appendix B for the full semi-structured interview schedule). Based on this information, after some time, as caregivers begin to demonstrate that they were "running out of things to say," the researcher began to direct the conversation, asking
specific questions concerning themes which had either not been addressed or were only
touched on.

Yet such an approach, as commendable as it is in the clinical setting within which
Fiumara labours, nevertheless runs the risk of producing a cacophony of voices — a
problem addressed earlier. And the solution is the same as before: we need a
comparative, synoptic approach to explanation, through empirical exploration, that can
sort through the richness of data and recognize the threads of unity in diversity and
outright differences within and between caregiving lives. Further, this method should also
be flexible enough to allow theory development to continually become refined or to
change direction as the open-ended data collection and analysis proceeds. What method
is this?

GENERATING GROUNDED THEORY

We refer now to Glaser and Strauss’ (1967) “grounded theory.” True, our
approach here differed markedly from Glaser and Strauss’ in that they contend that one
should initially approach the field with a minimum of preconceptions, something
approaching a theoretical naïveté:

Potential theoretical sensitivity is lost when the sociologist commits himself
exclusively to one specific preconceived theory... for then he becomes doctrinaire
and can no longer ‘see around’ either his pet theory or any other... [being]
preoccupied with testing, modifying and seeing everything from this one angle
(1967, p. 46).

This research, on the other hand, has preferred to approach the field, not in a
theoretically “doctrinaire” fashion, but nevertheless already “sensitized” by certain
established ideas. In this way it is possible to broach certain theoretical explorations which are believed to be particularly fruitful, though this, by no means, implies confirmatory hypothesis-testing. Further, it is, according to the hermeneutic philosophers, impossible to do otherwise. For, as Jameson (1981, p. 9) reminds us regarding the interpretation of any form of communication (including the recountsings of family caregivers’ lived experiences, which we may understand to be “text”):

We never really confront a text immediately, in all its freshness as a thing-in-itself. Rather, texts come before us as the always-already-read; we apprehend them through sedimented layers of previous interpretations, or – if the text is brand-new – through the sedimented reading habits and categories developed by those inherited interpretive traditions.

After that, this inquiry borrowed from grounded theory methodology extensively. Grounded theory is a cyclical, yet spiralling upward toward higher levels of abstraction, theory generating, inductive and deductive process whereby data collection and analysis proceed in tandem. That is, through inductive part-to-whole comparative analysis and classification, the so-called “constant comparative” method codes data “open,” without preconceptions, as empirically grounded indicators of emerging social concepts and processes. These actions for deriving concepts and processes from the data demonstrate increasing levels of abstraction and with that, again referring to Collins (1998, p. 787-788), we are not surprised to find concomitant increases in researcher self-reflection. But this self-consciousness nevertheless retains its loyalty to empiricism.

It should be noted at this point that although respondent quotations represent accurate transcriptions of interview data, the interview tapes were not transcribed
verbatim in their entirety due to constraints upon time and financial resources. As a result, the coding and analysis of the data, while attempting to follow the “spirit” of the constant comparative method and open coding, did not rigorously pursue a line-by-line coding of the data as some proponents would advocate (c.f. Strauss, 1987). Rather, reflecting the practice favored by Barrett (1996, p. 217), each interview was listened to repeatedly while copious notes were taken. These notes in turn were studied as forerunners to “bursts of insight” (Barrett, 1996, p. 221) which guided the development of emergent theory.

Sampling considerations

We arrive now at the deductive whole-to-part nature of the Grounded Theory methodology. This is known as “theoretical sampling,” which is essentially sampling driven by emerging theory. Here, discovered abstractions lead the researcher to address remaining or newly recognized gaps in the developing theory through carefully considered and directed returns to the field for further data collection. These new forays may be typically concerned with whether what has been found so far holds within and between various groups. In our case, for example, having found, say, a particular form of symbolic relationship between a female caregiver and her spouse, perhaps suffering from Alzheimer’s disease, we might then ask whether and to what extent this form holds true for other female caregivers with similar patients.

Beyond that, we might then look between groups, asking whether that form can be found in male caregivers to their similarly affected spouses. This is perhaps the more fruitful aspect of theoretical sampling in that we may quite self-consciously maximize differences and thus suggest “the most general uniformities of scope within [one’s
emerging] theory” (Glaser and Strauss, 1967, p. 56). But more than that, because such a generalization of scope “is usually considered uninteresting, since it requires no modification of the theory” (Glaser and Strauss, 1967, p. 63), such between group study can, more importantly, establish the contingencies and contexts of one’s theory:

Maximizing brings out the widest possible coverage on ranges, continua, degrees, types, uniformities, variations, causes, conditions, consequences, probabilities of relationships, strategies, process, structural mechanisms, and so forth, all necessary for elaboration of the theory (Glaser and Strauss, 1967, p. 57).

This reflects the complexity of the situation, establishing the credibility of future analyses as a result of the investigator’s sensitivity to the dynamics at work in the world. In a similar fashion, we might also ask whether and to what extent that symbolic form can be also found in caregivers to those otherwise ill (chronically or acutely) or disabled.

It is clear from the above that theoretical sampling bears no resemblance to the random sampling methods typically associated with confirmatory, hypothetico-deductive correlational research. Indeed, our sampling was not an attempt to probabilistically represent or model a population of caregivers and thereby generalize results to that population. It was, rather, primarily a purposive and, depending on the availability of subjects at any given point in time and turn in theoretical orientation, often a word-of-mouth or convenience variety of sampling designed to:

maximize discovery of the heterogeneous patterns and problems that occur in the particular context under study. Purposive and directed sampling... increases the range of data exposed and maximizes the researcher’s ability to identify emerging
themes that take adequate account of contextual conditions and cultural norms.

(Erlandson, Harris, Skipper, & Allen, 1993, p. 82)

At no time during the study was it therefore possible to specify what the total number of respondents would be since recruitment accords with emerging theoretical concerns. Consequently, “in research carried out for discovering theory, the sociologist cannot cite the number and types of groups from which he collected data until the research is completed” (Glaser and Strauss, 1967, p. 50; emphasis in the original).

The study’s participants

Having completed the research, however, it is now possible to report that 28 compassionate family caregivers were interviewed, seven of whom were male. Twenty-three were actively involved in family caregiving at the time of interview. Recruitment of study participants proceeded along three main avenues: first, through contact with various agencies which forwarded information regarding the study to known family caregivers, who then chose to contact the author personally; second, through word of mouth; third, through the author’s personal contact with family caregivers in settings such as caregiver workshops and meetings. There were only two criteria for inclusion into the study. First, respondents needed to have extensive lived experience with the family caregiving role, and second, they needed to feel comfortable in discussing that experience with the author at some length.

The ages of the female respondents ranged from 35 to 75 years of age while the ages of the male respondents ranged from 52 to 75 years of age. All of the caregivers appeared to be of Canadian, American, or European ethnicity. The respondents ranged in socioeconomic status from unemployed and working class to upper-middle class.
Seven of the respondents, one of them male, cared for individuals having some form of dementia, including Alzheimer's and, in one case – the male’s – Pick’s\(^1\) disease. Five people cared for stroke survivors, and in one of these instances stroke had lead to dementia. Two of the stroke caregivers were male. Four people (one male) cared for those who were brain injured. Two female respondents cared for individuals suffering from Amyotrophic Lateral Sclerosis\(^2\) (A.L.S.) while one male interviewee cared for a male friend distressed by an A.L.S.-like undiagnosed degenerative neurological disorder. Three female respondents cared for terminally-ill cancer patients. Two respondents (one male) cared for individuals living with Multiple Sclerosis. Two female respondents cared for a frail-elderly relative. One male respondent was caregiver to a variety of H.I.V./AIDS patients living in the community. One female respondent cared for a diabetic and brain injured relative.

It should also be noted that in a sense two encounters with respondents had a longitudinal component or feel to them. In the first instance, a caregiver was reinterviewed a few months after the death of the care-recipient. This was seen as a

\(^1\) Pick's disease is a rare brain disorder causing progressive deterioration in mental functioning in a manner similar to Alzheimer's ("Pick's Disease," 1997).

\(^2\) "Amyotrophic lateral sclerosis (ALS)... is a disease of middle to late life that results in the progressive degeneration of motor neurons (nerve cells) in select areas of the spinal cord. This, in turn, results in the progressive loss of voluntary motor functions. The underlying cause for ALS is still unknown." ("Amyotrophic Lateral Sclerosis," 1997)
potentially useful endeavour since an analysis of the first interview suggested some important themes which may have foreshadowed subsequent relations between these two individuals as death approached the latter. In the second instance, a longitudinal approach was made necessary since the caregiver’s daily duties were so great that interviewing had to be conducted via several emails over a period of some weeks.
CHAPTER THREE: BEGINNINGS

Analysis of the interview data first considered it from a simple narrative perspective: the role of family caregiver was ideally thought to have a beginning, a middle, and an end. This led to the following analytic questions: in orienting to and taking up the role of family caregiver, what personal desires seek expression in self-clarification and testimony using the tools of the ideology–utopia dialectic as conceived here?; how are these desires expressed in the terms just set out?; and why is this so? This study then asked the same set of questions, but with regard to role performance, in the subsequent findings chapter (Chapter Four), and again, with regard to role exit — if there is indeed an exit — in the third of three findings chapters (Chapter Five).

If we but remember that roles, with their beginnings, middles, and ends, all take place within complex social reality, and all the while against, ambivalent to, or in concert with other desires, then this manner of engaging the interview data propels the notion of a moral, valuing-yet-struggling self onto centre stage.

TRAUMA, SUFFERING, AND FAMILY CAREGIVING

By and large, acute pain and suffering are the short-term outcomes of trauma. Trauma also has two important secondary effects. First, it introduces the problem of chronic, medium-to-long term care, whether that is in the sense of rehabilitation or not. Second, because of trauma, individuals experience separation from and/or loss of their life trajectories, the intentional forward movement or progress we all hope for in our lives. As a result, wounded individuals are left with some form of prolonged physical or psychical retrogression or, perhaps, drift, resulting in lingering forms of pain and suffering.
In response to physical suffering at least, the medical profession and its allied technologies have moved aggressively to claim the jurisdiction of acute trauma care (i.e. hospital care) as their own. As well, medium-to-long term care now falls under the purview of community health services. In both instances we find an increasing dependence upon the family caregiver. For, on one hand, advances in medical knowledge and technology and the incursion of fiscal realities are resulting in shorter hospital stays and so shifting the margins of acute care into community care and family caregiving. And, on the other hand, community care, as it expands its role vis-à-vis acute care, is nevertheless also constrained by limited financial, property, and human resources, and so likewise dependent upon the family caregiver. In the end, then, it seems that there is a fairly direct functional and supportive relationship between the prevalence of family caregiving and the rise of both acute and chronic community care. Is this then why family caregivers orient to the role and take it up as they do? Is it because systems require them to, while setting up various prescriptions and expectations, norms, and even rewards, in order to ensure compliance?

**WHY THEN CAREGIVE?: BEING THERE**

It would seem that with acute and chronic, community care – and the family caregiver – “at their side,” so to speak, the trauma victim is well cared for. But are they? Certainly, if our prima facie duty as a society is to relieve suffering (Mayerfeld, 1999), then it would seem that the care-recipient is, potentially, in the best possible hands.

But if we consider that human beings are storytellers too, and not just bodies to be fixed, and that much of who we are is constituted in the *process* of creating our life story, perhaps it is time, along with Arthur Frank (1995), to view the traumatized person, the
care-recipient, as a “wounded storyteller.” From this perspective, the storyteller’s story is embodied, ontologically, through their wound. Hence, the teller is thrust into a strange land that is all and only their own and from which they may, or may not, recoup or reinvent a positive trajectory. Arriving at this point we can only ask: need the teller’s journey be so lonely, bereft of even the simplest compassionate audience and companionship? Is there not, the relief of suffering aside, a place for the compassionate desire to “be there” for and with the wounded storyteller, at their “ground zero?”

Fern, who was the primary caregiver to her father until he died from Alzheimer’s disease, knows the answers to these questions, unequivocally, from the heart. “I had absolutely no regrets in the journey that I took with him,” she proclaims. Indeed, we can only assume that Fern speaks her truth twofold: she now cares for her mother, who is in the disease’s early stages.

1 The term, “ground zero,” is liberally borrowed from Vela-McConnell (1999). Some readers may object to this metaphor in that it is one of violence and annihilation. However, the metaphor, creatively appropriated, has the potential to yield a great many things, including the implication, as with trauma, of both “endings” and “beginnings.” Politically too, this may be an opportunity to recast something once war-like into something, as with family caregiving, more life affirming. Perhaps here we may be reminded of 'Isaiah' 2:4: “They shall beat their swords into plowshares, and their spears into pruning hooks: nation shall not lift up sword against nation, neither shall they learn war any more.”
Alison, too, knew the answers to these questions. A long time friend and visiting caregiver to Mae, who suffered from the late stages of Alzheimer’s disease and who was institutionalized, Alison set out to clarify for herself the importance of being there, while also testifying to that insight. She did so by contrasting the alienating actions of Mae’s family members to those of her own and noting her disappointment in the former’s actions.

Those in Mae’s family are, according to Alison, “the bone pickers,” scavengers who celebrate death, not life, disconnection, not connection. They pick over Mae’s home for its valuables, “taking her stuff out” and “getting what they want out of her,” yet very, very rarely – if ever – visiting; “not really being there for her.” Alison’s own family, on the other hand, despite its own challenges (notably, parental divorce and a brother who is severely mentally retarded and institutionalized), always offered its members a sense of closeness, warmth, and companionship against life’s travails:

I think it’s basically I can’t imagine doing that to someone. And my family background – even though we were fairly dysfunctional – we always had this sense of family.... I just can’t imagine not wanting to see someone.... I don’t know. I just find it disappointing.

What is particularly noteworthy about Alison is the fact that she has taken a set of values learned in her home and, as non-kin, bravely crossed consanguineal lines, bringing with her that understanding, refusing to have it subjugated by Mae’s uncaring family. Indeed, Alison’s “being there” for and with Mae, a gravely wounded storyteller, subverted an atomistic modern – and increasingly familial – ideology. As Alison puts
it: “You know, the world is getting so cold and people are getting so distant from one
another.”

It is also significant that Alison’s interventions took place within a formal, institutional
care setting, with the blessing of the unit nurses.

In talking to the nurses, they were saying that that’s all she [Mae] really needed. She
didn’t need to have someone talking about lots of stuff. Just being near and not
saying anything was ok.

It seems likely that the nurses’ tacit approval of Alison’s being there for Mae signals the
reality put forward here: that the relief of suffering is not enough. It may also signal the nurses’
acceptance of their own limited ability to intervene in this needed way, a thought entirely in
keeping with this study’s contention regarding the real compassionate nature of family
caregiving, and certainly consistent with much of the critical literature on nursing homes (c.f.,
Millar, 1993; Diamond, 1992). We will return to this theme shortly in a discussion of being
there as Charisma.

One further observation: this desire is so substantial that we must recognize it for what
it is – a promise of great magnitude. For example, in a subsequent interview,
conducted a few months after Mae’s death, Alison showed the integrity of the promise to
be there – even as Mae lay unconscious at the very end of her life.

mbd: At one point in our first interview you mention that it’s satisfying enough to
just rub [Mae’s] back or something like that.

Alison: Ya.

mbd: Because she knew that, you know, a friend was there?.
Alison: Ya. And *that's what it basically got to be* [emphasis added). Like just holding her close and getting as close as I could to her and *still*\(^1\) rubbing her back. And while she was in bed, like holding onto her hand, and – an’ – ‘n stroking her hair. Like talking into her ear and just, you know, saying things to her, ‘n, ‘n just letting her know that someone was, was close by, so, ya.

But let us now pause for a moment; let us begin at the very beginning. For though the promise of being there, as we’ve seen, forms the true point of origin for the role of family caregiver – the role’s *raison d’etre* – it would be advantageous to consider *how* family caregivers first come to their role.

In fact, the promise to be there at ground zero represents a complex “calling.” It is a calling which may arise in response to a cry for help from the traumatized person, the wounded storyteller. Yet, it may, as well, not be so; there may be no such plea.

Regardless, the moral call to be there is evoked in response to a message from “the other side of life” – or rather a message *about* “the other side of life.” It is a message originating not in ordinary life but in the extraordinary, not in the typified existence but the atypified. And here it is vital to remember that typification, as interpretation, so often involves putting a subjective “gloss” over what is, in “reality,” *atypical*.

\(^1\) Unless otherwise indicated, the use of italics within quoted interview material denotes original speaker emphasis.
Yet at some point, glossing the atypical into our typified existences can no longer be sustained. Ideology crumbles. At that point, we are capable of recognizing the atypical, the extraordinary, the unexpected, the unintended, the utopian. At that point, we are sensitized to a message about the other side of life and we may be called, finally, as family caregivers, across a threshold and into a journey to the (bed)side of the wounded.

Thus, although in many instances the moral call to caregivers to be there is straightforward and cannot be denied — as with the stunning suddenness of heart attack or stroke — in some few but informative cases, it may not be. Frederik, for example, had so looked forward to a peaceful and happy retirement with his wife, Rose — “We had our vacation planned and everything” — that subtle, atypical occurrences went largely “unnoticed,” glossed into this idyllic ideology. And this is not denial, as in an unwillingness to “see” or heed the moral call. It is, rather, a matter of being thoroughly comfortable in the hope for the future and in one’s life course (c.f., Gubrium, Holstein, & Buckholdt, 1994), in the great Western industrial society ideology of “Happily Married And Happily Retired.”

And so it took years and only the occasional benign overlooking of the “crinklies” (the crumpling-of-cellophane-like sound that Rose alone, infrequently, claimed to hear) and the “angels” (visions Rose would sometimes have during the middle of the night) before Frederik came to realize that these mysterious episodes, which would come and go so quickly, were really the dark harbingers of something truly horrific — Pick’s disease. Indeed, the call about the other side only came months after Alzheimer’s had been ruled out; when finally, after a telling CAT scan, the neurologist gravely announced: “We have to operate — and now.”
But aside from these difficulties, which are so revealing in themselves, we shall now be reminded once again, as we were with Fern and Alison at the fulfillment of their Promises, of the robust nature of this commitment: for the promise to be there at ground zero is there from start — with the call — to finish. Further, it is there, in a hardy manner, negotiating our highly involved geohistorical world all along the way, with the family caregiver’s ultimate destination being the (bed)side of the wounded storyteller.

But, with that promise, coming to the role may exact a price: family caregivers risk entry into various strange lands of their own. Specifically at this point, we will examine three such lands: 1) social disengagement; 2) alienating emotional reactions; and 3) liminal existence at the (bed)side of the care-recipient.

Corrine

Corrine’s story of coming to the family caregiving role illustrates two of the three strange lands listed above, namely, social disengagement and liminal existence at the (bed)side of the care-recipient. Corrine has been a “co-primary” caregiver (along with her step-mother) to her brain-injured brother, Ron, since the fateful night several years ago when he was nearly killed in a motorcyle accident. Corrine and Ron had always been exceptionally close. As Corrine put it: “Our family wasn’t as functional as it could have been, which certainly made Ron and I that much closer.”

As well, Corrine had already known great loss when her boyfriend, her “true love,” took his own life. So when Ron bought his motorcycle, Corrine told him, “I can’t go there again. Please be careful.” Indeed, on the occasions when Corrine would ride on the back of Ron’s bike, she claims to have frequently thought that “if something happens to him on this bike, I want to be on the back of it. I don’t want to be without him.”
Corrine was, however, separated from Ron by some three hundred kilometres the night of the accident. Ironically, she was busy being there to two other family members who were ill in two different hospitals in this faraway city: her mother, Nancy, who had burst a bowel, been intubated\(^1\), and who had undergone at least two major surgeries; and a step-uncle who was terminally ill with a brain tumor.

But something was amiss! Corrine was paged quite mysteriously to phone Calgary, but no number was left. So she phoned a close friend who had no news for her. Uprooted from her usual visiting routines, likely feeling socially disjointed, Corrine fully senses that she was about to cross a threshold into a strange new existence. Displaying an uncanny sense of narrative identity, Corrine half-jokes to her friend: “I don’t know what’s going on, but I want Meg Ryan\(^2\) to play me, ‘kay?” A subsequent phone call to an acquaintance of Corrine’s father revealed that Ron had been in an accident, but Corrine could find out nothing more.

It was almost midnight when Corrine hurriedly said her good-byes to her step-uncle. Sadly, she was never to see him again, as he passed away only days later.

Next came a drive to Nancy’s bedside, where Corrine informed her mother that “you’ll have to settle on your own tonight, mom.” The usual practice had been that Corrine would stay at the bedside until Nancy fell asleep.

\(^1\) To “intubate” is to “insert a tube into (an orifice or hollow organ, as the larynx) for the administration of gases or to admit air” (Webster’s New World College Dictionary on PowerCD, 1995).

\(^2\) Meg Ryan is a contemporary actress well-known for her melodramatic roles.
Torn from her usual caregiving duties in order to be there for and with her brother, the drive home in the early hours of the morning was memorable: stormy, foreboding, and pitch-dark. With every passing kilometre, Corrine had but one timeless request: “Please let me see him alive.”

At the hospital, Corrine’s father intercepted her. “You can’t see him,” he told her repeatedly. Corrine recalls: “I was so angry at him. I just wanted to shoot him!”

Finally, having negotiated her way to the Intensive Care Unit (I.C.U.), Corrine peers through two doors and down a corridor. “I see this light. It’s dark except for this one light...and I just – it’s like I see him at the end of it, and I just – walk to him.... And I was just so happy to be with him.”

However, not even her happiness can allay the “seeping reality” of the incredible world which Corrine has entered at Ron’s bedside. This is her remarkable account, relived in vivid detail:

And then I just started asking questions. You know, “What’s this machine do?” Umm, well, first, “Can I touch him?” And then I could, which was really great. And he’s naked, ummm, covered with this little towel. They’ve shaved half his head. He has this little tube coming out of his head, which is for the cranial pressure. And he’s got staples down his tummy. And staples down his arm. And he’s covered in this yellow antiseptic. And mud. And blood. ‘Cause they haven’t cleaned him up at all yet. So there’s mud and blood in what’s left of his hair. And he’s intubated. And there’s, you know, the collar, ‘cause this is all the stuff off the highway, right?... Like they collar you on the highway and he was intubated on scene. So this is not this pristine white stuff. It’s the stuff they put him in on the
highway. And he’s got these balloon kinda things on his legs to help with the circulation. And, you know, all the i.v.’s. And all that stuff is going.

Nevertheless, despite the extraordinary ideological world Corrine has encountered at her brother’s side — an “objective” biomedical world where the ruptured body-as-object is probed, assessed, and repaired dispassionately — she remains true to the caregiving desire and promise to be there at ground zero. Corrine must conclude, expressing that desire inter-subjectively, spiritually, and transparently through human contact: “But as long as I could touch him, I was o.k.”

Sandy

Sandy is a long-distance caregiver. Her journal account of coming to the role poignantly conveys the promise of being there for and with her mother, who is dying of brain-stem cancer.

I am jolted awake...by the shrill ringing of the bedside telephone. These darned new burgundy phones... have been nothing but bearers of bad news since I first heard mom was sick with vertigo over a month ago. I’d decided to stay home from work... today because I knew I’d hear the catscan news from dad this morning. Harry [Sandy’s husband] takes the call and starts to cry. He passes the phone to me. Dad, too, is crying, “It’s bad, Sandy, really bad — a mass in her lung spread to her brain”. I go numb. Harry holds me and he cries but not me. I am in a complete state of numbness and disbelief. Despite this disbelief, however, my body still reacts and I know that I must get to mom as quickly as possible.

We see in the above paragraph not simply Sandy’s great desire to be there for and with her mom but also the beginnings of her social alienation: Harry’s symbolic gesture,
his caring embrace, as old perhaps as humanity itself, is not a “text” that Sandy can use for self-clarification or testimony in this moment of profound loss. Nor can she otherwise find social, textual resources to express herself to herself or anyone else for that matter. Her shock is too great. What she feels is simply inexpressible, inchoate. At this precise moment, Sandy’s emotions have alienated her from all of the interpretive resources a society normally furnishes to its members. Sandy is quite literally speechless; unable to find or appropriate speech. She is lost and alone in her grief. We also sense the other strange land often associated with keeping the promise to be there, that of social disengagement: Sandy’s body “reacts.” Her desire to be with her mother is total, embodied. She must leave her life here and go to her mother immediately.

Sandy’s grief remains profound as she makes the necessary preparations to fly to her mother’s side. Yet, she is no longer speechless. Sandy has recovered the universal gesture that allows her to understand her grief and express it socially – tears. She writes: “I cry to the teller at the bank. I cry to the travel agent” [emphases added].

However, this testimony, this language of her grief, only alienates her further from what she perceives to be the defining ideologies of a modern, and later, festive society. She thinks of the teller and the travel agent: “They are having a normal Friday, probably looking forward to the weekend. Already I am entering another world of which they are not a part. They are kind and sympathetic but they can’t feel my pain.” And at the airport, “there are many happy faces – people going on a holiday or returning home after a Christmas visit. It is very noisy and bustling....” But, Sandy writes, “I am serious, I am sober.” And “I see these people moving in seemingly slow motion. I feel that they
look at me and can see into my soul. They know that I am not like them. It seems that many are staring at me.”

But Sandy is far from helpless. Instead, she is a creative agent who honors her sorrow by actively selecting her social milieu and those who may enter it. At the passenger agent’s booth, she reports:

I ask for a seat where, if possible, I can have a bit of privacy on a semi-crowded plane. I just can’t bear to sit beside some happy, chatty passenger. I don’t want to talk about trivia and I don’t want to be forced to explain my situation to a stranger. I simply don’t want to let anyone into my world unless they understand. Who will understand? Only those who know the subjugated yet universal language of sorrow and tears:

I get on the plane and go to the back to take my seat. A bubbly, blonde flight attendant says, ‘Hi, welcome aboard, how are you today?’ My eyes fill with tears. She is totally surprised, takes my hand and I explain to her about mom. Something about her gentle eyes and the fact that she is a little older and seems sincere makes me want to open up to her.... The flight attendant is extremely kind. She seats me, brings me a pillow and a blanket and takes care of me with little treats throughout the trip. She smiles and looks compassionately at me every time she comes down the aisle. Her name is “Wanda” and she too is best friends with her mom so she understands. She is a great comfort to me — another daughter who loves her mother so much that she can feel my pain.

It is possible to perceive Sandy’s social disengagement, too, in her narrative identity, which comes to the fore during her grief as well. In a moment of storied clarity,
Sandy reflects on her life course, which, as Gubrium, Holstein, & Buckholdt (1994) reminds us, is a social typification, and concludes that things are decidedly “off” the secure ideological “track”:

Sure, I knew this day could come but that would be some day. It would not be now, not this soon and not as such a profound shock. We bemoan our seemingly “boring” existence sometimes but we long for tedium when life throws us an unexpected and painful curve-ball.

Finally, Sandy also shows us something of the caregiver’s strange land at the (bed)side of the care-recipient, where familiar words are juxtaposed in unsettling ways:

Marilyn, my favorite nurse... will be coming for a visit with mom and I. I’m glad but wish the words “palliative” and “mom” were not being used in the same sentence.

And later, Sandy looks upon her mother lovingly as she sleeps, but struggles to retain the idyllic image she has summoned up:

I hold her hand, cherishing these favourite times where we are just being together.... As she sleeps, I drink in her peaceful, little face. I think “Is this how she will look in her coffin?” Then I recoil from thoughts like that and just savour how sweet she appears to be at this moment in the present.

This is one effect of impending death: Sandy, whose personal voice has always been (in the past), and always is (in the present), existentially, vividly linked to her mother’s in traditional closeness, security, and belonging, and, as such, who desires to be there for and with her mother, is confronted with the paradox – the utopian, innovative, chaotic “impossibility” – of her mother’s cold, abstract demise. That particular future is
a rupture of the continuity Sandy thrives on. It cannot express her fundamental desire to
be there (except as a negation), neither clarifying Sandy’s desire to herself, nor testifying
to that desire. It only alienates Sandy from herself and from her mother. Is it any wonder,
then, that Sandy rejects that future, recoiling from it?

“ORIGINS” OF BEING THERE

Having suggested the underlying centrality of the family caregiver’s desire, ethic,
and promise to be there, as well as something of the strange lands they encounter on their
way to the side of the traumatized person, the wounded storyteller, this study now
considers the affinity which this promise appears to have with gift giving, both in its
secular and divine forms. Here we must introduce an important caveat. That is, in
keeping with the ambiguous nature of this exploratory enterprise and complexity of
reflexive, human subjectivity, we must consider the following question indeterminate: are
respondents – or this study which appropriates and interprets respondent voices –
speaking of the origins of being there vis-à-vis gift giving in “real,” naturalistic terms, in
terms of seeking self-clarification with respect to being there, in terms of seeking public
testimony with respect to being there, or in terms of any combination of these three
possibilities?

The secular gift

Is a caregiver’s desire to be there for and with another obligated in some way? In
one positive and worldly sense, it most certainly can be. That is, it is not unusual to hear
caregivers relate that they “owe” it to the person in care to be there for and with them.
This naturally implies that the two individuals have a history together.
And what is the nature of that history? Frequently, it is based on the notions of gratitude to the care-recipient for kindnesses received from them and, in turn, a felt, but voluntary\(^1\), obligation to reciprocate or give back kindnesses to that individual. These are, of course, the hallmarks of a gift relationship, a subject of long-standing sociological interest beginning with Marcel Mauss’ classic study, *The Gift* (Mauss, 1954).

In Terry and Gary’s case, Gary had been very much the “knight in shining armor,” delivering Terry, by her own admission, from a “very painful, rebellious, bad time” in her life. Terry’s discussion of the tensions involved in deciding whether to place Gary in some more formal care setting unmistakeably reveals the gift relationship behind her wish to continue to be there for him as his caregiver, despite her failing health and his escalating needs. We also observe, most trenchantly, the sense of unfinished business – and the intense struggle which that imparts – when the gift relationship is terminated prematurely:

mbd: I’m not sure where the tension is coming from because on, on one hand you realize that you’re getting to this point and it can’t go on, so it would seem – and listening to the professionals it would seem like this is a fairly simple decision to make – and yet, on the other hand, what is causing the tension? The fact that you feel a sense of obligation? Or, the

\(^1\) Although the obligation to reciprocate is largely involuntary and socially conditioned, the forms that the gift, as reciprocation, take and the times taken to reciprocate are largely left to individual conscience — recognizing, of course, that one’s conscience is a product of social negotiation (c.f., Godbout and Caille, 1998).
fact that you might be failing Gary? Or putting him into a situation where he won’t be as happy? Or....

Terry: All of that. All of that. Ummm, uh, yes, I, I feel, ummm, I feel very, very much that I’m letting him down by even thinking about doing this. Ummm, I feel like I should have been able to do it for a lot longer. Ummm, uhhh, I guess there is a certain sense of obligation – like I, somehow, I feel like I really owe it to him because look at the years that he looked after me. And I feel that if the roles were reversed here I’m sure that he would look after me.

The gift relationship – and the gratitude upon which it is built – also appears to be especially prevalent when adult children discuss their reasons for being there as caregivers to their ill or frail elderly parents. In these cases the familiar refrain, often heard within the community of family caregivers, is: “They’ve done so much for me. How can I turn my back on them now?”

Of course, any human gift relationship is an eminently self-interested, materialistic, rule-bound, and so ideological affair. As such, gifts in general, and the gift of family caregiving, may take unusual and less than idyllic forms as the norms of gratitude and reciprocity are violated for whatever reasons.

Candice, for example, has taken care of her mother, Mary, who is diabetic, and consequently physically and cognitively disabled, for some thirty years. Perhaps this explains in part why Mary routinely fails to show any gratitude for Candice’s singular contributions. Or perhaps Mary’s lack of gratitude is partly due to resentment of the fact that she is chronically dependent upon her daughter. Regardless, as Candice remarks:
It's frustrating, ‘cause when you give a gift, you want somebody to say, “Oh, thanks!” And when they go, “Oh, it’s not really there. You didn’t really give me anything” it makes it hard to keep giving. And so sometimes you just feel like saying, “Well, go to hell.”

As with unrequited love, then, the unrequited gift is difficult to tolerate and so seems to lead to fervent attention seeking, such that now, although Candice still regards her caregiving as a gift, it is as a gift given in the hopes that Mary will someday feel obliged enough to at least notice the reality of Candice’s contributions, if not show gratitude. Quite remarkably, whereas the obligated reciprocation of traditional secular gift-giving is truly ideological and rule bound, in Candice’s case the gift of caregiving becomes an act of quiet, utopian, innovative and hopeful desperation, designed to resist Candice’s erasure, as a moral and steadfast person, by her own mother.

Yet, in case we are tempted to look upon the secular gift as all culture, in the purely social sense, and therefore dismissable as social construction, it seems likely that the reciprocity inherent in gift-giving is at some point, in some instances, deeply, ethologically rooted in the bonds of human attachment. Perhaps this explains, in part, why two caregiving daughters to terminally ill mothers passionately remarked on the special gifts of life and love each had received from their mothers and how each was morally bound, in the most profound, heartfelt ways, to give back and be there in their caregiving. As one of these caregivers, Sandy, remarked: “[I am reminded] of how my mother loves me and how I, her only daughter, love her back.... There is a bond between mother and daughter that spans space and time. My mother is my soul mate.”
Unconditional love: the divine gift

Despite the ubiquity of human gift relations across history and cultures, there are caregivers who specifically repudiate the gift, and all of its ancient traditions, as the basis of their being there. After all, they insist, given the ideological dynamics of a gift relationship – the constant give and take, the obligation to reciprocate which nurtures and perpetuates the relationship (c.f., Godbout and Caille, 1998, p. 10) – is it fair to expect that the cared-for individual give back?

And so, it seems, these caregivers prefer to characterize their being there as a gift that is more purely voluntaristic than the secular version; an unconditional, divinely-inspired Christian love. This divine, utopian gift – so contrary to the Marxian view of Christianity as an ideological opiate of the masses (Marx, no date) – inherently suspects gift-giving among persons (cf. Exodus 23:8: “And thou shalt take no gift: for the gift blindeth the wise, and perverteth the words of the righteous.”) while recognizing the many ways in which God gifts His children with various talents. As such, Christianity enjoins its believers to realize God’s Will by voluntaristically heeding His Call to utilize those gifts unconditionally for the benefit of others, in self-perfecting, “pass-it-on,” service (cf. James 1:17: “Every good gift and every perfect gift is from above, and cometh down from the Father of lights...”; I Timothy 4:14: “Neglect not the gift that is in thee.”; Acts 20:35: “It is more blessed to give than to receive.”).

It is possibly thus that, Christine, the caregiver to Stephen, her now adult step-son brain injured in a cross-walk hit-and-run, remarks: “Perhaps God gave me the gift to be able to do this. I think He perhaps gifted Trevor, James (June’s husband), and myself with the ability to do what we’ve done – the ability and the desire.”
Susan, the spousal caregiver to Brad who is in the later stages of A.L.S. and a devout Christian, writes: “I wouldn’t characterize [my] assistance as a gift relationship.... I don’t feel I am reciprocating an obligation; I want to help him [Brad]”. Further, “I probably have some sense of Christian obligation... and I see helping Brad as part of obeying our command to love one another.”

“Also,” Susan continues, tying the theme of being there as divine gift to facilitation (which we shall shortly explore further):

I find expressions like ‘gift relationship’ to romanticize the situation of coping with a debilitating disease. It is more just the practical reality of what is: one of us is able-bodied and one isn’t, so the able one helps the other.

And finally, for Susan, the idea of a secular gift relationship’s expectation of reciprocation – which really valorizes Western traditions of able-bodiedness and independence – exposes Brad to the social stigma associated with helplessness. As a result, Susan asserts: “I think this sort of simple practical outlook helps the person receiving assistance to not feel so ‘helpless’, if you know what I mean.”

The secular or divine gift?: other tensions

Perhaps one of the more interesting indications of the tension between being there as secular gift compared to being there as divine gift can be found in the opposing ways in which the marriage vow is used to express the “origins” of being there among married couples. Some family caregivers represent their being there and care in terms of the marriage vow’s secular gift-like reciprocity, captured metaphorically in the exchange of wedding rings, or in the notion of a “marriage contract.” Others emphasize that their love,
service, and promise, as with their marriage as a whole, is unconditionally "until death do us part."

Yet another fascinating manifestation of the tension between the ideological secular and utopian divine gifts of being there lies in the contrast between the notions of "neighbourliness" and "mutual aid." For example, John, the husband to Paula, who has suffered some brain injury as a result of two strokes, notes that his rural, Christian family life, growing up in Montana, emphasized an unaffected, voluntary, private and personal neighbourliness. Some other caregivers, however, who also had grown up in rural settings, felt that watching the constant interplay of neighbour-helping-neighbour, in obligated and public displays of mutual aid and reciprocity, had early on set the tone for their own approach to being there as a family caregiver.

"ENDS" OF BEING THERE

As with the previous section, it is necessary to again invoke the indeterminability caveat. That is, we now explore some of the ways in which being there seeks expression as some form of "end." Whether that is as an actual physical manifestation in the world, a public testimony, an attempt at self-clarification, or some combination of these three possibilities, we cannot say.

Being there as instrumental care

Being there and the provision of instrumental care are often closely linked. When Jean's grandmother, Sophia, who was frail and visually impaired with cataracts, broke her hip, Jean was quick to be there for Sophia, providing the vital daily care. "My goal was to be there for my grandmother," Jean says. "I'm just thankful that I could give her the care she needed."
This possible link between being there and the provision of instrumental care seems as natural and as old as humanity itself. Hippocrates, the venerable physician of Ancient Greece, may have expressed much the same notion when he wrote: “For where there is love of man, there is also love of the art [of healing]” (Hippocrates, *Precepts*, Ch. 6, cited in “Bartlett’s ‘Familiar Quotations,’” (1980, p. 79, 15th ed.)).

But the connection may not be so straightforward as these examples lead us to believe, for at least two reasons. On one hand, caregivers may so fully equate the “end” of their being there with the time-honored tradition of providing instrumental care that they have difficulty freeing themselves from that framework. But at times they must. For in some settings, such as a rehabilitative one, a caregiver’s willingness to go the “extra mile” with instrumental care, in order to express their desire to be there, may ironically create tension and distance, as the care-recipient feels that their own initiatives are being “smothered.” Winston, for example, readily admits that when his wife, Bonnie, was undergoing rehabilitation as a stroke survivor, he was “over-doing it” and had to learn to “take a big step back” in order to give Bonnie some “breathing room.” This, of course, signals a couple of important points, namely, the idea that only in *some* cases, not all, will family caregivers find that instrumental care provides an adequate expression of their desire to be there, and that the expression of this desire is, as with the expression of all desires, a socially negotiated accomplishment.

On the other hand, for other family caregivers, the care-recipient’s medical needs may be so great that being there has little means of expression other than through the “end” of instrumental care. This, in itself, is oppressive, as other meaningful and perhaps highly intimate expressions of being there are treated cursorily, or worse, trivially. But
further than that, heavy demands for instrumental care undoubtedly can exhaust a caregiver to the point where “taking the next step forward,” so to speak, in order to be there in actuality, becomes impossible. Thus, instrumental care becomes increasingly “robotic,” and, as a consequence, the link between it and being there attenuates. With that, the true moral compass guiding a family caregiver’s instrumental care is lost. Indeed, it is at this point, it seems, that family caregiving becomes only “auxiliary hospital” care, having lost touch with its original ethic. With that, caregivers often look ruefully to the alternative ideology of placement in a formal care setting, or wishfully to the more recent option of hiring expensive in-home professional caregivers, in the hopes that with such an intervention they may once again recover the ability to really be there.

**Being there as charisma or advocacy**

Max Weber, the eminent German sociologist, noted many years ago (Weber, 1968/1946, pp. 18-19) that bureaucratic and patriarchal structures (and, we may add, capitalistic structures, which are a modern hybrid) are institutions characterized by permanence and given to meeting recurrent needs in either calculable or workaday daily routines. But, says Weber, providing for needs which go beyond those of everyday routine, meeting needs which ask more of these institutions than they can give, has a charismatic foundation. Thus, throughout history individuals have come forward as “natural” leaders, holding neither bureaucratic office nor relevant “occupation”, having neither requisite expert knowledge nor serving for remuneration, all in times of psychic, physical, economic, ethical, religious, or political distress, in times of extraordinary need.

How do charismatic leaders hope to satisfy exceptional needs? Weber notes that “The natural leaders in distress have been holders of specific gifts of the body and spirit;
and these gifts have been believed to be supernatural, not accessible to everybody” (p. 19). With that, the charismatic leader develops a following made up of, firstly, those who look to him or her for the satisfaction of their great needs, and secondly, an entourage of disciples intent upon spreading the good news (p. 21). Finally, it goes almost without saying that the continued authority of natural leaders depends very much upon their eventual success in satisfying the needs of their followers (p. 20).

Though the fit is not perfect, for want of a better term we must identify many family caregivers as charismatics. True, they neither speak in tongues nor perform miracles. Neither do they they boast a “following,” though health authorities across North America and Europe are quick to sing their praises. Family caregivers do, however, as we have already abundantly seen earlier in this chapter, possess a rare attribute: the great desire and ability (through the promise) to be there for and with the wounded storyteller at his or her ground zero when other institutional aspects of society, all the way from family to formal care to government, will not or cannot do likewise.

Family caregivers may also, of course, act as advocates for the care-recipient. By “advocate” this study means to differentiate between a family caregiver’s charismatic actions, taken, as we have seen, when care-recipients’ needs are extraordinary to existing services or institutions, and those actions a caregiver takes when needed services or institutions in fact exist but may be unknown or inaccessible to the care-recipient. Thus, advocacy, as an “end” to being there, assists with finding or opening doors to already available services.

By way of example, Emma, whose brother, Richard, was diagnosed with a brain tumor, spent endless hours attempting to determine the best available treatment options,
the various means to accessing them, costs involved, and so on. Certainly, advocacy, as such, is all too-well known to family caregivers. And we will return to further discussions of both advocacy and charismatic activity in Chapters Four and Five.

**Being there as honoring**

Of course, being there as a companion to a care-recipient likely conveys with it an enormous quality of respect and honor for that individual – a quality actively subjugated in today’s competitively “cut-throat” and monopolistic market-driven economies. This impression, which had been gathered from the first interview with Alison, was fed back to her at the follow-up, which, not incidentally, was held in a coffee shop. Her powerful emotional response in a crowded public place certainly seems to attest to the significance of this aspect of being there:

mbd: I wrote down... just a few brief phrases that I thought [were] kinda summarizing what I was getting out of, out of your transcript. And, forgive me if it sounds really poetic, but uh....

Alison: Ok.

mbd: We honor someone, show their worth, by being there with them, making them a part of our lives. And that’s our gift to them: an expression of the relationship and –

Alison: [sobbing]

mbd: I’m sorry.

Alison: No, it’s true. Yes. You can finish it. [collecting herself with a small, self-conscious smile and laugh – “ha” – as if she had surprised herself]
mbd: An expression of the relationship and its further nourishment. So the gift [of one's being there] not only expresses the quality of the relationship but further nourishes that relationship.

Alison: Yes, yes. That is true.

One suspects that the following account not only reflects, once again, being there for and with the wounded storyteller, as he or she confronts the mystery of dying in solitude, but also, with the presence of a specific cast of family members (daughters and son and their partners) and fondest embracing and touching, the deepest love, respect, and honor for the individual and his or her life. Dorothy says:

My mom actually died in my arms.... Myself, my brother, his wife, my sister, her husband, and my husband were all there when she died. And we were all able to stand there and hold her hand and tell her we loved her. And I actually sang to her [chuckling], which might have been painful for her because she always used to tell me I had a terrible voice [laughing]. But anyway, I didn’t really sing, I kinda hummed.... Singing to a person who is dying is very soothing.

This “end” of a caregiver’s longing to be there in companionship and honour of another is not a recent or unique invention conjured up in the face of mass, anonymous society. Rather, it signals a modern day resistance to that anonymity through a perpetual return to secure and time honored traditions — as expressions of relational desires — spanning time and space. We need only look to the historical record for evidence of this. Witness Mahatma Gandhi’s (Gandhi, 1927, p. 26) life-long shame in discarding such an

---

1 These ideas are taken from a reading of Godbout and Caille (1998, p. 10).
opportunity and cultural tradition, at the final moments of his father's death, in favour of fleeting nuptial pleasure:

I ran to my father's room. I saw that, if animal passion had not blinded me, I should have been spared the torture of separation from my father during his last moments. I should have been massaging him, and he would have died in my arms.

Of course, it should not surprise us that due to a caregiver's desire to be there, in companionship or in honor, from beginning to end, they are frequently invited to be among the first and foremost in eulogising the deceased, another public testimony to their relational desires, and yet another act of resistance against the kind of cold anonymity so prevalent in mass society (Castoriadis, 1997, p. 155):

And three minutes (three milliseconds, rather) after your disappearance, the surface of the waters closes upon itself again, the hole disappears, society continues, and you are not missed.

But more than that, there are knotty circumstances, especially with highly developed dementias, where the care-recipient's identity seems irretrievably lost. Who is there for the memory of a care-recipient who is still among us, yet cannot represent themselves to anyone, let alone themselves? Once again, we find the family caregiver taking the lead.

In the following exchange, for example, we can well imagine that Terry, the spousal caregiver to Gary, who suffers from stroke-related dementia and who is only a very small shadow of the person he used to be, understands the need to be there for him in terms of honoring his lost identity. There seems little doubt that although Terry is quick to refer to her husband in the past tense she does so with great fondness — as a
lover of Christmas and family life — to the interviewer and, we can surely know, she will do likewise to her own children and grandchildren in the coming years.

Terry: I’m sorry for my kids. I’m sorry for my grandchildren because Gary was a wonderful, wonderful man and my grandchildren are missing a wonderful grandfather. They are. And I’m really sorry about that. You know, he, he ummm, I guess two years before he had the stroke we wanted Nathan [one of Terry and Gary’s sons] and his family out here for Christmas so we could all be together and, ummm, Dierdre, my daughter-in-law, phoned and said that she didn’t think the car was going to make it. Their car was not in very good shape. And she was very nervous about driving in winter conditions. And Gary said don’t worry about that. He just jumped in the car and drove out to Vancouver, got them all, and brought them here for Christmas.

mbd: Huh!

Terry: ‘Cause he wanted to be with his family. That’s the way — that’s the kinda guy he was. Didn’t even bat an eye. That was nothing to him, to do that, you know, so...

Being there as facilitating

Individuals who suffer, to an extensive degree, from the debilitating effects of a disease such as A.L.S., or live with the more severe forms of a disabling condition such as cerebral palsy — whose active minds, souls, and identities are “trapped” inside their bodies — often require that family caregivers’ being there express itself, as an “end,” through the latters’ acting as a creative and somewhat self-effacing (in consistently taking
on the role and identity of the Other) facilitator or expeditor of the care-recipients’ volitions. In these types of cases, the family caregiver may have great difficulty even accepting the label “caregiver” since it does not seem to capture what they do or are. Thus, Susan indicates:

Brad has stated that he wants to be treated ‘like a normal person’. This was more in response to those people who make too much fuss about his being sick. [Y]ou know, the overly sincere, “[H]ow are you?” that we often get. He kept working for a long time, even when he was struggling along with a walker, because he said it made him feel ‘normal’. Therefore, I just simply, as I said earlier, see myself as an ‘able bodied extension’ for him (emphasis added), because that approach is one that doesn’t make a big deal about his illness and helps him to be treated ‘normally.’

Being there as mentoring

Finally, a family caregiver can be there for someone disabled or ill by mentoring to that individual. For example, with her mother’s impending death, Dorothy, who has “done some real strong spiritual work the last few years” in trying to combat depression (which is linked to some very difficult years as an adolescent), also hopes to be there for her mother as a teacher, counsellor, and guide – even into the hereafter. In this way, it is clear, as it was with Alison, that Dorothy resists the atomism and social alienation that seems to pervade our modern world. Further, she sees her own mother, spiritually adrift, as being an unfortunate product of that world. Being there now for her mother, then, represents a final attempt to remove ultimate doubt and fear from her mother’s heart, to help her as she crosses out of this life:
My mom did not come from a place of spirituality. So that was hard for me to accept. She said to me one day, she said: “What’s all this God stuff anyway. I don’t see God helpin’ anybody.” So she had a bit of a negative attitude about getting help. She would not ever ask anybody to help her. She just believed she had to be tough and strong. And if she had a downfall, that was it, `cause I don’t think asking for some help or some love from someone is... is wrong.

But Dorothy “really felt that what I’ve learned I could give on to her and take away all the fear of death.” With that, Dorothy unabashedly declares to her mother, in her being there, as the final chapter of their story together on this earth, what she knows to be true: “The one thing that I’ve learned is that people need love. They need compassion. They need caring. And they need peace.” Further:

If you can die in dignity and peace and feel that you’re being loved by your family why should you fear death? You’ve lived a long time and you’re ready to go. And who knows what we’ll meet up with? I believe it’s going to be peaceful, flowers, waterfalls [laughing] and it’s going to be all right.

As a result, Dorothy tried to express these things to her mom on her deathbed:

Every time I talked about death, I’d say, “You know what, mom? You’re going to see a tunnel. You’re going to see a white, warm light. And you’re going to see everybody who’s died before you – if you want to see them. If you don’t, you don’t have to.” And – she just smiled.
CHAPTER FOUR: MIDDLES

ALIENATION FROM ONESELF

Thus far we have seen that the need to be there for and with a traumatized person at their ground zero is a primary desire and promise for family caregivers and the systemic, charismatic point of entry for taking up the family caregiving role. With so much depending on one person, is it any wonder that caregiver accounts resonate with a concern for achieving a “selflessness” or “self-perfection”?

Susan, for example, devotes herself tirelessly to the many duties associated with Brad’s care and to being there for and with him as an extension of his yet keen mind and will. For inspiration, she reports contemplating the writings of Mother Teresa “during some of the more menial and thankless tasks that I perform. Her philosphy that doing these tasks, even if unrecognized, is still quite important has helped me to carry on, even when unrecognized or facing criticism.”

Fern, too, links self-perfection and caregiving:

My goal is to see that I’ve been a good – almost like a parent but only I’m a daughter. But I’ve had a good relationship with my mother and I’m satisfied with that…. But it’s all pressure really put on myself…. I want to do what’s right. And maybe that’s a spiritual thing too. Maybe I feel like you have to answer to God for what you’ve done with your life. And if I feel like I’ve done everything I possibly could and I’ve done the best job that I can do, then that’s my reward. There’ll be an end to it, and that… will be my goal. And I’ll have said, you know, “Hey, that was nice of me. That was good of me to do that. And I’m happy that I did it.”
Despite such commitment, though, human beings are, of course, never motivated by a single, independent desire. Nor are the many desires we do possess ever fully and completely satisfied. Thus, it seems that gnawing feelings of lack are, to some extent, a perpetual feature of our lives. And our desires are never mutually exclusive of each other but are intricately interwoven. Our desires, then, are an enormous and complex Gordian knot.

For family caregivers, then, it is ironic but understandable that in promising to be there, in pursuing this good, caregivers quite typically feel the sting of misfortune and suffering themselves. That is, in being there either passionately or for any substantial amount of time, caregivers too often come to know the trauma and frustration of being separated from, or even losing, a good part of their own way, a good part of their own life trajectory, a good part of what others take for granted — the freedom to approach, exit, and occupy multiple and valued roles. Caregivers consequently know the intrusiveness of their endeavor upon the rest of their life’s project, despite the fact that being there for another is obviously implicated in such a larger project.

This cannot be a passing concern since there is no easy resolution, no quick fix. Caught “betwixt and between” these crucial longings, to step one way or the other for too long is to risk alienating oneself from an important part of oneself. So, while we have seen that in coming to the role family caregivers may embark on a number of journeys, it can also be said that as caregivers perform their role they set out on yet another remarkable and challenging journey. This is the journey to recover or reinvent a fuller flourishing of their way while remaining all the while faithful to their promise to be there.
This is the most difficult quest for balance which seems to lie ahead of many caregivers. While superficially this quest may resemble a grand tension between Self and Other, it is, in reality, a tension between differing selves, as we shall see. And whatever the “balanced” solution may be, it stands opposed to a divided, discordant, and fragmented self on the one hand, and, on the other, a fearful, cut-off-from-the-world “island” of a self. Ultimately, this is a quest to innovatively fashion for oneself, through an engagement with the dialectic of ideology and utopia, a contemporary caregiving experience quite unlike anything witnessed by previous generations.

The quest for balance

The quest for balance begins with the self-conscious bittersweet realization that as noble as one’s being there is, it is not enough. For example, at one point in her interview, Terry noted with some pride:

Ummm, I remember seeing a social worker at the hospital when Gary was — when I was getting ready to bring Gary home, and at this point we thought that he was going to be wheelchair bound for the rest of his life — he wasn’t walking yet. And, ummm, ummm, she asked me if I had a place in mind for him to go. And that blew me out of the water. I said, “Well [modelling laughing in disbelief], I’m taking him home with me.” And she said, “It’s so refreshing to hear someone say that.” She said, most women, whose husbands are as bad off as your husband is just say, “Oh, I can’t look after him now.” And I never gave it a — I never thought that ever, you know.

But after caring for Gary for a number of years — even through her own health problems (breast cancer, depression, and chronic fatigue syndrome) — and despite her
committed desire to be there for him, Terry began to feel “boxed,” “stuck,” or “trapped” in the caregiving role, terms certainly reminiscent of other female caregivers’ impressions\(^1\). And, as a result, an enormous ambivalence sets in as Terry considers the painful possibility of placing Gary in a nursing home:

And, ummm, that’s why it’s so difficult for me now to start telling myself that maybe I’m not going to be able to do this anymore. You know, at times I feel like I can. At other times I feel like I can’t. Sometimes I want to. Sometimes I feel like, “Oh, I don’t want to do this anymore. I just – I’m so tired of doing this.” You know, and I am tired of doing it. But at the same time I feel like, ummm, “How can I let him go?”

This is an ambivalence that is terribly difficult for Terry to come to terms with. As she puts it: “And I don’t know how I’m supposed to feel. And I, I guess I’m trying to make myself be a robot with no feelings.”

The implications for Terry’s self-identity are enormous. The following passage highlights not only her confusion over who she thinks she is vis-à-vis the caregiving role, but also what that stands for in the social arena – a bounded, tightly circumscribed, mini-constellation of familial, mostly care-providing, roles:

\(^1\) The reader may recall Elsie Helsel’s comments presented earlier, whereby, after thirty years of caregiving, Elsie’s son’s wheelchair became a metaphorical “anchor” weighing down her life. Also in this regard, Appendix A details a remarkable dream of entrapment conveyed by a study participant, Rita, who is the caregiving spouse to Don, a now moderately disabled stroke survivor.
Ummm, [three second pause] and I feel truly like ... I don’t have an identity. If you ask me today, “Who are you?,” I’m the person that looks after Gary. And as far as anything else, I’m my kids’ mum, I’m my grandchildrens’ grandmother, I’m my brothers’ sister, and... [four second pause] that’s who I am. I don’t know, other than that I don’t know who I am. I don’t know what I want. I don’t know, uhhh – I don’t think about that. I don’t know that. I just don’t know that. [Sniffle and four second pause] I don’t even know what I, what I want to do with my life, and I still have some life left.

Finally, what is perhaps most disheartening of all is that Terry has a profound sense of deja vue with regard to this theme of entrapment. Having grown up in the “big, old house” belonging to her “Queen Bee” grandmother, and having observed her own mother’s dutiful caregiving to her chronically ill husband over many years in that same house, Terry realizes too well that she is simply the living reproduction – a third generation – of a deeply entrenched ideology: the gendered division of labor. In no way is she crafting her own life story:

I feel kinda like I’ve taken on my mother’s role. ‘Cause she looked after her husband. I’m looking after my husband.... I look at myself in the mirror and... I see myself in my mum. And, uhhh, I don’t like that because I see a person who gave her life away completely. And I didn’t think that was fair. And now I find myself in the same box, and, ummm, [four second pause] I guess it does make me angry.

Terry’s comments have been referred to at length because they saliently represent comparable comments made by other female participants in this study.
Marilyn, whose husband died from “early onset” Alzheimer’s, similarly finds martyrdom unacceptable. She reports that she would attend support group meetings and feel left out because many of the elderly caregivers there seemed endlessly devoted to caring for their husbands:

And here I was ready to seek other professional help and thinking, “My gosh, if they can do it, why can’t I do it?” And comparing myself to them. And certainly, being an older person, I think, you know, coming from a generation of my mother’s, they didn’t have an outside life. Where I was still trying to hang onto my own outside life and look after John, these women, that was it. Their life was caring for them [their husbands], where I had another life.

Analogously, in the following passage Dorothy testifies to a suspicion of her mother’s martyrdom. Yet, it is clear that she simultaneously appreciates her mother’s altruism. Here, quite remarkably, we see along with Heilbrun (1999, p. 52), “that the mother is seen not only in her inadequacy as a model, but also as a secret bestower of possibility.” As such, Dorothy writes her caregiving story, as Heilbrun would say (1999, p. 52), “with and against” her mother. At the same time, she clearly indicates that the unsettled footing characteristic of her own quest for balance may require an intensely self-conscious approach to self-clarification that also departs considerably from the conventional.

While I was looking after my mom I took a clown course. So what I learned about myself was, ya, you need to really look at yourself, examine yourself, then you have to create your own character. So one of the characters I created was a mime, so I don’t have to talk. I can be a clown, but I don’t have to talk. I can play and
have fun. And for me that's very healthy because I sometimes talk too much and I get exhausted.

And I think part of that is caregiving. You know, trying to help people, trying make people understand, trying to be there for them. You forget to look after yourself.

That's what my mom taught me, though. She taught me to worry about others, look after them, and then look after yourself last. So, that I didn't like. But what I did like was my mom was a caring person. She was compassionate. She was — if anybody was hurt she would be right there to help them. And she was very devoted to us kids when she was raising us. Like, I don't remember her buying a new dress all through the years of [my] living at home.

Finally, it is noteworthy that these sentiments (and especially those that buttress the notion of the quest for balance) were expressed perhaps most strongly by the three study participants who had been providing care for the longest periods of time — each over twenty years. Two of these respondents had cared for their parents since childhood. And so, by the time they were well into middle age, they had literally and figuratively grown up and into the role. Thus, the transition to family caregiver had been quite seamless in comparison to virtually every other caregiver in this study. Nevertheless, both women, perhaps more passionately than any of the other caregivers, felt that their time was well overdue.

Fern, for example, whom the reader may remember is now taking care of her mother who has Alzheimer's — after doing the same for her father, who died from
complications associated with the disease – wonders if she has given too much of herself away as she contemplates the later years of her middle age:

I know that the day she [Fern’s mom] dies, I’m going to have to look at my own life and say: “Gee, where do I go from here?” Which is a very scary thing for me right now…. I have friends who are taking courses. Like Melanie [a friend] is now going back for her Master’s degree….Similar age to myself, and I see what she’s doing with her life, and she’s really going somewhere. And I think sometimes my mind is just deteriorated [laughing]. And with both my parents suffering from dementia, you know I don’t know what my future is going to be.

The third respondent is Gillian, aged sixty, who has been the primary caregiver to her husband Eric, a Multiple Sclerosis victim, for over twenty years. Further, during much of that time Eric has been verbally abusive toward Gillian. Gillian summarizes her quest for balance as follows:

I don’t know if I can live like this for the rest of my life. Like, there are many times when I feel like I’m drifting; like I’ve missed it [Gillian’s life].

Of course, not all family caregivers are on this quest for balance. But, the possibility of martyrs aside (and this study found none), the reasons for this only lend more credence to the idea of this quest: those who are not in search of a fuller life trajectory are those who, quite simply, have already tasted from this grail. They have experienced or are experiencing this flourishing, and seek – without losing that accomplishment, its memories, and satisfactions – to commit themselves more wholeheartedly to being there.
The older, retired caregiver, for instance, may have fulfilled their pursuit of a career and other interests, and so looks forward to being there without any distractions, comfortable in her or his life’s accomplishments. Such is certainly the case with Peter, a semi-retired carpenter who continues to work out of the home while devotedly serving as primary caregiver to his wife, Sylvia, who has Multiple Sclerosis. It was also the case with Martha, whose husband, Graham, contracted A.L.S. in his seventies and died soon after. Martha, by her own account, had enjoyed a happy and productive career and family life in partnership with Graham. Hence, she had little trouble devoting herself to being there for and with him.

The same holds true for those caregivers who are in the midst of a productive career yet can afford to curtail, suspend, or otherwise work around their activities in these areas in order to devote themselves more fully to providing care. Winston and Dennis, for example, care for their wives who are both stroke survivors. Both of these men enjoy fulfilling careers which nevertheless allow them the independence to set, or otherwise “flex,” their schedules in order to accommodate their caregiving.

Perhaps though, Susan, Brad’s caregiving wife, is most instructive in this regard. The reader may recall from the previous chapter that Brad is in the later stages of A.L.S. and the prognosis for this particularly insidious disease is always negative, with death usually occurring within five years or so of diagnosis. Susan and Brad are both professionally trained, in their early forties, and have been married for four years as of this writing. With Brad’s diagnosis confirmed only within the last two years, and the disease’s current state of advancement, it appears that Brad’s physical decline has been rather rapid.
Because of Brad’s prognosis then, and because Susan is confident that given her age and her marketable skills she will be able to pick up the pieces of her life when the time comes, it is therefore not surprising to learn that Susan is not particularly concerned with any separation from the rest of her life. That issue has simply been tabled for the meantime, with her life trajectory neither separated from nor lost to her.

With these observations, and the quest to find or maintain balance (hereafter, as before, simply the “quest for balance”) which they engender, in mind, we are in the end led to the feminist utopian hope and vision that all humanity might learn to question, cross, and blur the ostensibly inviolable ideological gendered division which confines nurturing (and so, being there at ground zero) to the bounded mythic home and women’s practice, while assigning the unbounded exploration of the larger world to the fully individuated and fantasized figure of the father (Cornell, 1998, pp. 134-135). Certainly, we have seen this hope and vision in the reflexive knowledge and self-testimony of family caregivers who fear their martyrdom, who desire to question, cross, and blur this gendered division, moving from home to larger world, moving from the “inside-out.”

But, not to be forgotten, we have seen that same hope and vision in the complimentary, opposite movement of caregivers such as Peter, Martha, Winston, Dennis, and Susan, who have travelled from the “outside-in.”

---

1 In fact, Susan’s inclinations may have been prescient: Brad passed away peacefully at home just five months after Susan’s interview.
Spurred by the promise to be there at ground zero and yet, all the while, questing for, or holding to, a fuller, two-sided life, how do family caregivers proceed? We turn now to an exploration of how some caregivers have made, or are making, their way.

Making their way

Whether moving from the “inside-out” or the “outside-in,” the refusal to martyr oneself to the promise to be there at ground zero is, of course, central. We have seen the former situation in several accounts thus far. But even someone like Winston, moving from the “outside-in” to care for his wife, Bonnie, a stroke victim, can awake to the realization that, after immersing himself in caregiving for some time and with great devotion, he was in danger of martyring himself:

I thought I could do it all myself.... I lost a bunch of weight. I remember clearly... that about a year into the process [of caregiving] I’m looking in the mirror one day, shaving, and suddenly saying to myself, “Wake up, you jerk. This is forever.”

With this sort of realization comes a heightened reflexivity or self-consciousness, which we also have already seen. And out of that comes a questioning of the ideological assumptions one has been living under as well as a utopian impulse to either invent a new caregiving or else experiment with the appropriation of other, previously existing, forms — or, of course, do both. Dorothy’s integration of clowning into the promise to be there might be considered such an innovative hybrid.

Nevertheless, self-consciousness here, for the family caregiver, is generally conducted very much “catch-as-catch-can” simply because of the constant demands associated with being there. Therefore, some read snippets from inspirational or
philosophical works and the like. Some go for contemplative walks. Some listen to music. Some keep journals. Some turn to the sympathetic and patient ear of a dear friend, support group member, or their god. Some, sadly, can only cry in the shower. But all must reflect upon themselves and their place in the quest for balance. Without that, true self-care, which is the long and arduous process of self-clarification (and not mere self-monitoring), and self-testimony, is impossible.

Beyond that, though, the caregiver immediately faces three enormous challenges. The first challenge is that of health maintenance, for without this, keeping one’s promise to be there through family caregiving simply becomes impossible. Yet, with it, keeping one’s Promise often becomes difficult since such endeavours often take the caregiver away from the (bed)side of the care-recipient.

The second challenge is that of managing, or perhaps controlling – if not curing – the care-recipient’s disability or illness. This challenge is largely dependent upon the nature of a particular disability or illness, and so seems to be a matter of straightforward instrumental care. However, this is not entirely so. Hope, and its counterpart, denial have their place too. Thus, in the liminal spaces of rehabilitation or recovery (how much is possible?), chronic disability or infirmity (will it always be this way?), or terminal illness (can’t we “buy” more time?), a caregiver’s promise to be there may align itself with various other ideologies and utopias and create unusual difficulties.

For example, when Cindy’s mother, Clara, was diagnosed with lung cancer, Cindy wanted desperately to be there for her mother, as did other family members. Somehow, though, being there became transformed into a veil of loving ignorance, as family members appear to have conspired, knowingly or not, to maintain an idyllic
family life for Clara, all the while utterly failing to obtain an accurate diagnosis and prognosis regarding the disease. Much to everyone's shock and dismay, then, the day arrived far too quickly when Clara had to be rushed to the hospital. She never returned home, dying two days later.

Corrine, too, saw her being there at Ron's ground zero affix to a particularly comforting star, the ancient— in certain religions— cosmology and ideology of "Love And Miraculous Cure":

I just thought that we would figure this out, that we would be closer after this was over, and that this was just an "oop." You know, I've said "I love you" [to Ron, in the past]. Here's my chance to show it, and whoop the dirt out. Like I really— I thought that if I loved him enough, I could heal him. Like I really just had this, ummm, vision that I had the magic key and that love was all it would take. And that I had enough. I had an unending flow of that. And that it would be fine. Like, I really— I was very delusional.

The third challenge is that of managing any additional roles which may need to be shouldered. In marriages, by way of example, this means that the caregiving spouse not only maintains her or his usual roles but also takes on those cast off by the care-recipient as a result of the latter's debilitation, as well as, of course, those associated with caregiving. As demanding as this may be, for some caregivers these extra responsibilities can be somewhat liberating— at least for a time— as ideological gender boundaries are crossed. Thus, in a clear "inside-out" move, Rita notes that if her husband, Don, had not had his stroke she would never have had to take charge of the family finances, coordinate a move to the city and renovations to their new house, and so on. Nor would she have
ever become an avid member of a women’s Bible study group or in other ways met an expanding circle of friends. In short, “I’d still be trailing along behind him on the golf course.” And Rita is not alone in this respect. Wendy overcame much the same difficulties when her husband, Ken, was left partially paralysed ("left side neglect") as a result of a stroke. She, in fact, moved her family from the Atlantic Coast out West, designed their new house with rehabilitation in mind, and successfully began her own home-based business.

In somewhat the same vein, Winston, displays an “outside-in” move, crossing his own gender boundaries, largely as a result of the influence of his nurturing mother. He notes that his “voices of moral conscience” may be rooted in the values he has learned from his parents:

They were religious. Good Dutch Christian Reformed Church. Good Calvanists. Good work ethic. Be on time. Give a dollar’s work for a dollar. Those values were certainly ingrained in us.

But when Winston differentiates between his parents, it is clear that, as far as caregiving is concerned, he “absolutely” identifies with his mother rather than his father. Winston’s family followed a “very European model,” such that:

My father goes to work, comes home, slaps the table, says “Where’s my supper? And what’s your name again?” But the mother is, you know, the “glue.” My father I would never go to if I had a problem — even in later years.... As far as [being] the nurturing and caring father who would... bond with you, get a life!

Nor is Winston the only male to move from the “outside-in” and, in so doing, seem to identify with his mother. Peter, the semi-retired carpenter, recalls, with the
greatest admiration, his mother, Frances, who single-handedly brought up her children after his father was disabled on the job. Frances was multi-talented and throughout her life modelled crossing ideological gender boundaries to her children. A nurturing and loving mother who, while raising her children on “relief,” taught them frugality yet generosity (in contrast to Frances’ “bombastic, cheapskate” brother, a minister). Frances was also a perennial nail-driving champion, as well as, in later years, a noted regional journalist.

Now, it is true that many self-help books and other media delineate and address these three challenges of health maintenance, illness or disability care, and expanded role care, in one way or another. Thus, further exploration of this particular subject matter will be left to the interested reader. However, it is also true that successful self-help – whether in these areas or beyond – assumes both spiritual and sociological dimensions in one self-transcending consequential notion, help-seeking, a topic to which we now turn. For the most obvious fact is that no one individual can surmount these challenges single-handedly.

Help-seeking

With regard to the help-seeking aspects of spirituality, certainly almost every primary caregiver who participated in this study spoke of having an extremely close relationship to the Christian God (or, in a few cases, the Universal Creator or Creative Soul) and seeking assistance from that higher power on a daily basis. Terry provides some penetrating and poignant reflections on this matter. When asked about the Christian resources she turns to, she replied:
I think that, ummm, uhhh, that I’ve gotten a lot of insight from the promises in the Bible. One being, ummm, “Fear not, for I am with you. Be not dismayed, for I am your God. I will strengthen you, I will help you, I will uphold you with my strong right arm of righteousness.” And, uhhh, and then there’s other things, uhhh, you know, if you need wisdom, that you ask for wisdom, and God gives it without finding fault. And, ummm, “when you go through the waters I’ll be with you. You will not be drowned. When you go through the fire, the fire will not consume you.”

Other places where, ummm, one of my favorites is in Jeremiah, where, ummm, He said, “I went down to the potter’s shed” and there was a thing formed on the potter’s wheel. But it was not satisfactory to the potter. So he... broke it and re-shaped it and made it into something that could be used. And, ummm, I feel [beginning to cry] like, ummm, like I’m like that clay and if God wants me to be a caregiver He will be the one that shapes me and molds me and fills me with what I need to be that.

But for most, help-seeking cannot end with supplications to God; it also requires a human practical element, namely, that social resources be explored, that pathways to the outside world be developed. In so doing, caregivers proceed outward from ground zero, beyond kin, friends, and community relations, to increasingly encounter involuntary and impersonal forms of assistance primarily tailored to meeting the needs of mass society. And though these latter forms can be “individualized” to some extent, they nevertheless remain, at base, professionalized, formalized, rationalized, bureaucratized, and governmentalized. It is this divided terrain that family caregivers, guided by the promise
to be there at ground zero and the quest to find or maintain balance, must ultimately traverse, negotiate, and strategize if they are to realize their hopes of weaving together the assistance they require.

**ALIENATION FROM OTHERS**

If there is a single most forbidding and unstable place in the social terrain from which a caregiver can choose to seek help in keeping their Promise as well as finding their balance, it may be, in certain situations, at ground zero. For when cognitive dysfunction produces long-term personality change and lengthy or repeated bouts of fear, depression, indifference, or even truculence, the caregiver comes, it seems, to fear that his or her two most cherished enterprises will amount to nothing. After all, the caregiving promise is one made to someone in particular, is it not? And when that particular someone is "gone," is that then the end of the Promise and the Quest? And what if the Promise-recipient isn't really "gone"? Thus when the desires associated with the Promise and the Quest seek expression through such a care-recipient in terms of their actions, gestures, and words — in short, texts — it may be that where the caregiver hopes for self-clarification and testimony he or she finds only inchoateness and perplexity.

For example, Winston’s wife, Bonnie, struggled in her rehabilitation to regain lost and most basic cognitive skills such as reading, spelling, and math. But her personality was left largely intact. Thus, Winston concludes that, despite the occasional bout with depression, they were “lucky” because “Bonnie’s always had a great attitude and tons of motivation.” As a result, this couple has reorganized its affairs and priorities, grown tremendously together, and tried “every non-invasive therapy known,” with sometimes gratifying results. The fact that they are on the “same page” as a result of their mutual
willingness to support each other makes it that much easier for Winston to feel validated in his Promise and Quest, through his “reading” of Bonnie’s up-beat personality and rehabilitative actions-as-text. These texts, of course, conform nicely to Western society’s closely held values of personal responsibility and work ethic, all of which Winston himself echoed earlier.

Dennis and Claire, on the other hand, continue to face major rehabilitative challenges more than two years after Claire’s stroke. Claire’s personality has been markedly affected. Whereas before her stroke, she had been an avid dancer, outdoor enthusiast, and very social, she is now sullen and withdrawn, drinks too much, and exhibits suicidal tendencies. This is a constant worry for Dennis, who notes that “it’s a long, boring day for Claire” since he does have to work away from the home and Claire, perhaps, in part, because of her aphasia, has lost all of her friends who “don’t know how to talk to her.” Furthermore, Claire now displays a general lack of affection and compassion toward others, including Dennis, which Dennis sees as due to the stroke itself. Indeed, Claire can, in fact, can be quite rude. This makes it understandably difficult for Dennis: “I still want to be appreciated, loved – even desired” he says softly.

Yet, on the other hand, Claire has made some important advances. She has regained her ability to drive a car – although she can become lost easily – and certainly

---

1 In a parallel fashion, Cheryl describes similar effects upon her partner, Raymond, seriously brain damaged as a result of his latest stroke. “Ray’s very volatile” and “can be abusive,” she states. Also, he “can no longer ‘bite his own tongue.’ It’s kind of like whatever pops into his brain falls out of his mouth.”
enjoys her participation in various arts and crafts groups. In this sense then, Dennis feels a certain gratification: one of the ways in which he can be there for and with Claire is to give her the gift of a positive quality of life, and this includes encouraging her to take risks, explore, and grow.

So it's a “mixed bag” for Dennis. On the one hand, Claire’s gains - which are, in many ways, the couples’ gains - as text, can be interpreted by Dennis as a self-clarifying and testifying validation of his Promise and Quest; that is, his twin desires can continue to live and thrive in large part because they achieve expression through the text of Claire’s gains. On the other hand, the text of Claire’s personal relationship with Dennis does not, perhaps cannot, allow for a similarly hopeful validation. This is indeed a strange, liminal sort of social place for any family caregiver to find themselves in.

The implications for all of this are important. As uncertain as Dennis’ reading of Claire is vis-à-vis his Promise and Quest, there is still, at times, a sense of the person Promised-to. But when does this sense of the Other cease to exist? This study suggests that it may be at those very moments when the caregiver finds that they can no longer seek help from the care-recipient, as a textual resource, in understanding and testifying to their desires to be there and find a balance. The care-recipient’s text is inchoate, neither recognizable as ideology nor as any radical, utopian departure from that.

At these moments, the Other-as-text opens up to become an enigma of immense proportions, something akin to the caregiver’s own desires. And the solution is the same as with the desires: apply textual resources to this unknown (this time we may call the effort “intertextual”) in an effort to express it, however tentatively.
In this application, we find the caregiver drawing upon more-or-less ambiguity; that is, utopian or ideological texts. For example, when Cheryl describes her partner, Ray, after his latest and most debilitating stroke, she clearly likens him to something less than human:

You’re with someone, you know. You fall in love with a certain person and then at the drop of a hat [that person is] gone. And you’re left with this thing. And I didn’t like that thing, I really didn’t like that thing, you know. So you’re grieving what you’ve lost, [and] you’ve got to learn to like the thing that you got stuck with, and that, in itself, is a trip.

Now, it may be significant that Cheryl is one of the few caregivers to categorize herself as religiously “inactive,” professing not a personal relationship with God but rather a rudimentary belief in a supreme being. Perhaps this is why, when confronted with the puzzling text that is Ray, she draws upon what seems to be an age-old humanistic anthropocentrism, casting the severely disabled or ill as something other than human. The fact that Cheryl further realizes that this position places her in opposition to an unspecified other value system (New Age Spiritualism? Christianity? Nature Mysticism?) which would maintain that one should “learn to like the thing” further complicates Cheryl’s experience of caregiving. Clearly, regardless of what traditions these may be, it is apparent that Cheryl is caught between competing value spheres, in Weberian terms, and that this experience is a “trip.”

When Terry talks about Gary, her husband, who suffers from stroke-related dementia, in the past tense, we may be witnessing not Terry’s cruelty (which would misrepresent the obvious love and gratitude she has for her husband) but rather, perhaps,
her attempt to understand the mystery of Gary-as-text in terms of the ideology of a utilitarian framework\(^1\). Gary was, at one time, a long-distance trucker and the family's only source of income. He was always so *useful*. Here is Terry plainly describing Gary’s former utility to the children:

Like dad is strong, dad is... dad is the provider, the protector, dad is all of these things. And they could never, ever accept that dad was not that strong man anymore, you know.... He went from being a very big strong healthy truck driver to a very weak – a weak person who was very sick.... And he gradually got some of it back, but like I said before, his personality changed. And the kids didn’t understand ‘cause they didn’t see him often enough and they couldn’t figure out how come dad was so moody, except that he wasn’t working anymore.

And here we see Terry clearly describing Gary’s former utility to her:

It’s hard. We went from Gary being my, ummm, my companion, and my confidant, and my lover, my friend, ummm, my protector, my provider. Ummm, he went from being all of those things to being the person that I’m looking after. And, ummm, he’s not my husband anymore.

Can we not conclude the thought for Terry? “My husband is dead,” would surely have to be her next thought, the logical interpretive conclusion, given everything previous. And, as we saw earlier still, to Terry’s way of thinking, Gary *is*, indeed, sadly, dead.

\(^1\) Thanks to Harry van Bommel, family caregiver and noted author and speaker in the area, for suggesting this interpretation (personal communication, August 29, 2000)
Corrine was faced with a similar problem. Initially, she believed that her brother, Ron, brain-injured and comatose for several days as a result of a motorcycle accident, had "returned" but was perpetually angry with her for unknown reasons. At this point, Ron is clearly not the "old" Ron and this is an enormous mystery, perplexing indeed. Is this Ron at all?

And I did think he hated me. And I thought every bad thing I did to him growing up — you know, he's really mad at me. Umm, he felt betrayed. I felt that he felt — and in a sense I still think he might feel — betrayed by me because I promised to take care of him and I didn’t. And then I promised that it would be o.k. And I promised: "Please, listen to my voice and come back to me. I promise it will be o.k."....

But Corrine is soon given cause to creatively appropriate other unusual (for her) and yet ancient — and yet ambiguous — traditions, the traditions of reincarnation, when she learns the awful "truth."

Because I would say "Ron" — like he kept talking about that "other guy." And I would say, "Ron." And he would say, "I'm not him! Ron's that other guy. He's dead." And I would say, "No, Ron, that's you." And he would say, "No. I was watching and he was in really bad shape. I could see him."

So he was telling me that he was watching. He was looking down at him [Ron] and "he's dead. He was in really bad shape and he's dead."

But I have now come to a belief that — I don't think this happens to all people with brain injury — but I got to think here — but I do believe that Ron, my
brother, died. That soul went somewhere else. And now I have someone else in
his body. And he’s an o.k. guy, but he’s not my brother.

In the case of a condition such as Alzheimer’s, which often produces comorbid
illnesses resulting in loss of consciousness and eventual death, we again find the puzzle
of the Promise recipient’s true status as a person. In the excerpt below, Alison had been
by Mae’s bedside until the very end. When asked if she detected or even imagined any
communication from Mae as she lay unconscious and close to death, Alison, in her
intertextual “reading” of the enigma of Mae, reveals her ties to a venerable spiritual
tradition. And, in that, we also find a consistent (for Alison) resistance to human
mechanistic alienation, rendered in the nurses’ previous comments about Alison’s
Grandma:

Well, the last week, holding onto her h-hand, like, you know, and feeling her hand
tighten. And just, you know, ‘n just go – it was like when my Grandma died, it
was the same thing. Like she was in a coma. And the nurses say, “Well, she’s not
responding to you. It’s just her nerves.” And I go, “No. It’s my Grandma saying
‘goodbye.’”

So, I don’t know if Mae did that at all, but in talking to her and just feeling
her hand tighten, for me it was, it was a good thing – [crying, seven second
pause, resumption through tears] – especially that, that last day, that, that
morning I was to see her, and that’s when I was holding onto her hand, and could
feel her squeezing it [Alison’s hand], so I, I think that’s – for me that was her…
saying goodbye. [Crying resumes, and through the tears] I thought I was over this.
As caregivers move outward from ground zero they encounter family and other kin relations, friends, neighbours, and grassroots community. Here, the caregiver’s desire and promise to be there is broadly legitimated.

Perhaps it cannot be otherwise, given the widespread current popularity of an ideology, falling under the broad rubric of Attachment Theory, which stresses the developmental dependency of human children upon their parents or some parent surrogate. That is, without parent-like attentiveness and being there for and with children, it is now held in many sectors of society that successive generations of affectively flourishing human social life would simply not be possible. Thus, the validity of being there appears factually linked. Because of that ideological facticity, being there achieves public familiarity and thus sanction. And, in the text of every thriving child we find that that sanction has come to fruition.

It is only a short step thereafter to attest to the importance of being there for and with any dependent human being. And since we are all dependent upon each other in some way, being there achieves a nearly universal status. Being there consequently symbolizes so much of human safety, security, and flourishing. As such family members, friends, and community, as social members, can only perpetuate such an ideology and laud its existence as perceived in the actions and daily activities of caregivers themselves. As Candice, the long-time caregiving daughter to her diabetic mother, Mary, puts it: “All my friends tell me I’m a saint.”

But, as many caregivers note, there is a world of difference between lauding the role of the family caregiver in word and supporting it in deed. And this is where we see the deficient holding power of the doctrines of Attachment Theory and its offshoots.
That is, within the stock of knowledge that constitutes ideology, Attachment Theory and its relations constitute but one doctrinal expression of one core desire. But there are, as we have claimed earlier, even among caregivers, competing desires and the myriad possibilities of their expression. One such desire which we have found at work in caregivers — and which neither caregivers nor anyone else has reason to limit to only caregivers, given the ubiquity of its expression — is the human desire for personal individuation.

With this in mind, caregivers may, on one level, understand that others will not be quick to respond to their help-seeking, and so seem sadly resigned to old friendships wasting away. But, on another level, the bigger question is this: if kin, neighbours, and the like are so like family caregivers in their desire for individuation, why do they appear to be so different in terms of their commitment to being there? Family caregivers try very hard to have it both ways. Why not the rest of the world? These are difficult questions, to which this research can provide tentative suggestions through a brief analysis of the puzzlement caregivers themselves feel.

Here, in a manner analogous to caregiver attempts to solve the enigma of the Promise recipient, then, caregivers tend to borrow from certain well-known ideologies — as expressions of individuation — to try to “read” the text of those who do not help. Their readings invariably seem to incorporate references to laissez-faire Individualism and acquisitiveness. Marilyn, for example, very clearly sees those friends who have left as “partyers” and “activity” friends. Fern somewhat similarly describes those of her friends who do not help out and who offer inane “advice” (such as “I don’t know how you put up with your Mother. Why don’t you let her go?”) as upwardly mobile professionals.
So too, Fern is neither surprised nor quick to blame her young adult children when they come forward to ask that she vow, in writing, that she will not ask them to care for her later in life. The children have seen firsthand the seemingly endless caregiving difficulties associated with Alzheimer’s disease – and the family history. So Fern understands: they are young, with their lives ahead of them, she notes.

Family caregivers, in a way then, do understand the lack of support they receive. Somehow, too, they understand that there is a qualitative difference in the expressions of individuation put forth by caregivers as opposed to others. Somehow, the ideological interpretive resources which caregivers choose to draw on and react to (perhaps in utopian fashion) don’t quite have the “edge” of other ideological or utopian expressions of individuation. Caregivers “want it,” but not that bad! Why is this?

For caregivers, it may well be simply a matter of intimacy – and personal history. As Miller [1979, p. 159] points out, intimacy is based on accident: “accident is important for intimacy, for [intimacy] needs accident to become more than mere accident [itself].” Let us rewrite this in the more familiar terms of caregiving and trauma: “trauma is important for caregiver intimacy, for [that intimacy] needs trauma to become more than a mere ‘fluke’ [itself].” In other words, Miller (1997, p. 159) concludes, “What we are suggesting is that some... notion of history is needed if we wish to make an important distinction between intimacy and mere togetherness.”

So, although caregivers desire individuation, they are “held back” from clarifying it to themselves and publicly testifying to it as many others do – with an “edge” – because of their intimacy with the care-recipient, regardless of whether that intimacy is reciprocated. We are back to the inescapable Promise.
Thus, it seems plausible to suggest that those who have not seen another’s accidents or trauma can’t be intimate, and so be there – either as caregivers themselves or as supports to caregivers – because there is nothing, no history, to transcend. And why do people fail to see another’s accidents, trauma? Alison would have a ready response: “Because the world is so cold, and people are so distant from each other. We’re all too busy to really see each other.”

Consequently, it is perhaps for these very reasons that family caregivers know that support does not come easily from one’s immediate circle of acquaintances. Rather, support comes from fellow caregivers – intimates who have been to someone else’s ground zero for and with them – or from friends who have a “history,” as survivors of personal misfortune, and are therefore simply empathetic to the challenges of family caregiving. In either case, support comes from “survivors” who have “been there, done that, and got the t-shirt” – a surprisingly familiar refrain among family caregivers in this community, and the kind of ideological fragment or marker which undoubtedly enables true caregivers and friends to recognize one another.

It seems to be this set of convictions which motivates family caregivers to join caregiver support groups. Here they find compatriots who truly understand their Quest and their angst, not the well-meaning individual who claims to “know what you’re going through” in some clumsy attempt to “connect” over coffee. To these latter folks, Terry has a blunt message:

I get very angry. I blew up at a close friend of mine, ummm, shortly after Gary had his stroke. And, ummm, she said to me, “Oh, I know what you’re going through.” Well, I lost it. And I just, ummm – I was very angry, and I said, “You
know, do you? Sure you know. When your husband can’t get up in the morning and go to work, when he can’t come home at night and take you to bed and make love to you, when you guys can’t go on a trip together and you can’t sit there in the car and he can do some of the driving,... when you can’t do things together anymore, and when he doesn’t even know who you are in the middle of the night, then you come and tell me that you know how I feel. ‘Cause you don’t have the slightest idea.

Furthermore, within a support group, caregivers find some solace in knowing that they are not as alone or isolated in their lived experiences as they had imagined. This emergent “sociological imagination,” where biography and history meet in a fusion of horizons that leads to new understanding, is very often a key component in animating a collective voice for positive change in the more formal and distant reaches of family caregivers’ social topography.

All the more confident now in their commitment to being there — if there ever was a doubt — family caregivers begin to negotiate their way through a maze of formal support services and institutions. These entities generally take longer to access than kin and proximate community, and, of course, one must travel farther geographically and politically (in terms of chains of command, informational or referral networks, and so forth) to do so. This, then, is the region where family caregivers must get out and, in Winston’s terms, “kick some rocks.”

But more importantly, family caregivers negotiate this terrain very much informed by their ethical promise to be there at ground zero. Thus, they will appreciate as supportive, favorably evaluate, gravitate toward, and advocate for the existence of those
professionals (doctors, nurses, social workers, psychiatrists, personal care attendants, etc.) who have good bedside manner at ground zero and who can either truly be there or provide a decent, humanizing and compassionate facsimile – something perhaps comparable to a “mother’s wit” (as Diamond [1992, p. 17] calls maternal feelings and skills of caring) – despite the systemic constraints these devoted people work with. On the other hand, caregivers feel nothing but disdain and exasperation for those professionals who work at ground zero but have poor bedside manner. Indeed, in the course of this research, a variety of illustrations were advanced by caregivers in this regard: doctors who, without permission or consultation, routinely experiment with various psychotropic drug treatments upon the frail elderly and confused; aides who forcefeed the severely dependent and perhaps resistant [i.e., Alzheimer’s] patient; the neurologist who offers a terminal diagnosis so matter-of-factly as to write off all hope – and the patient – in one fell swoop; the Intensive Care Unit nurses who refuse to talk to a coma patient “as if” that person, that soul, is still “present” somehow\(^1\); and so on.

\(^{1}\) This is not just a “parlor game.” In this regard, Harry van Bommel (personal communication, August 29, 2000) notes that a “life-affirming” spiritual belief system attached to caregiving has two crucial advantages: first, it makes caregiving easier; and, second, it “puts fewer people at risk of an early death.” Indeed, it might well be claimed that if Corrine and her step-mother, a nurse, had not so believed they would never have been able to alert inattentive I.C.U. nurses and physicians to the formation of a blood clot which threatened Ron’s life.
And there is no quarter given even as one moves even farther away from ground zero into governmental and executive officialisms. Being there, as a humanizing principle, should apply throughout all of society. Where it exists, it must be accessed – and here caregiver advocacy plays its part. And where it does not exist it must be made to do so. Thus, we return to the notion of the caregiver as a charismatic.

Further, the object of their change efforts, along with the larger social machinery (for example, bureaucracies, for profit nursing homes, etc.), is very often the personal, the individual: the particular administrator or bureaucrat who disallows and medicates away largely harmless behaviours, like habitual pacing, because of insurance perturbations; the nursing home owner who will not pay attractive enough wages to keep good staff, when others do; the x-ray technologist who manhandles the frail elderly parent; and so on.

This is not to say that family caregivers are always successful in breaking new ground. In fact, many know the frustrations of being ignored, talked down to, even overtly belittled. Some develop their own peculiar illness that comes with crossing the border between informal and formal systems – “formitis,” as one caregiver put it, meaning the chronic mental fatigue induced by filling out literally hundreds of bureaucratic forms. At about this point, some family caregivers do throw up their arms and hands and cry out: “I give up. I concede. It’s no use. If I can’t find help, I’ll just have to go it alone.” Such is their commitment, that at such a time they would martyr themselves before giving up on the Promise.

Interestingly, this research suggests that those caregivers who experience the most difficulty in crossing the border between informal and formal support systems may be
those who have depended primarily upon family and neighbourly support of their endeavours. This seems particularly true of those caregivers who have moved from or been raised in rural settings stressing mutual aid. But it also appears to be the case among more older caregivers who grew up holding professionals, especially physicians, in the highest possible regard and are therefore loathe to question the latter’s authority. In either case, it appears that caregivers struggle mightily in their help-seeking as they encounter and read the texts of alien, formal support systems.

Neither of these groups appear to have the one requisite skill for survival in modern mass society, which is, as one caregiver put it, the attitude and knowledge to say to an individual far removed from ground zero: “If you can’t or won’t help me out, then I’ll find somebody who can.” Who was this caregiver? Wendy, a former nurse.

Another former nurse, Christine, also acknowledged the value of her training and self-education insofar as providing her with an advantage in communicating with professionals:

Because of my education and because I’ve read so much there’s not a lot I don’t understand. So I can do the “medical-speak.” And I can do the “legal-speak.” And I can do the “rehab-speak.” But I can also do the “caregiver-speak.” So I guess I’m just multilingual [chuckling]. But I can also invite professionals to talk in simpler terms, too. Humour works well there.

---

1 Christine is the primary caregiver to her adult brain-injured step-son, Stephen. The “legal-speak” is a reference to years of litigation brought against the hit-and-run driver who struck Stephen in a cross-walk.
Indeed, it seems that nurses, social workers, and males (most especially those with managerial or executive training, who know how to exercise power and intimidate) – in short those who are familiar with this terrain and know how to “tweak” it to get what they want – are much more successful in doing just that.
CHAPTER FIVE: ENDINGS?

The promise to be there for and with another who is in need of assistance is likely one of the more powerful commitments that one human being can make to another. Indeed, assuming, of course, that family caregivers can still be active in their role outside of the home (i.e., in nursing homes, hospitals, etc.), the caregivers in this study who had concluded their role did so only as a result of the death of the care-recipient or that person's successful rehabilitation. But, of course, we know too that termination of the role is frequently due to the caregiver's ill-health. Nevertheless, the commonality in all three of these exit scenarios should not be lost to us: family caregivers, once they have taken up the role, tend to occupy that role for as long as they are capable or needed.

But what about life after caregiving?

We have seen that family caregiver's quest for balance is a difficult, often precarious, balance to strike. The image of an almost perpetually leaning tight rope walker comes to mind. Here the acrobatic caregivers find themselves constantly being pulled over to the side of the promise to be there, perpetually facing the real possibility that their next tilting step will plunge them into Martyr’s Abyss. As a result, with an absolute fear for their psychic survival, caregivers struggle desperately to right themselves, to seek the necessary balance in their lives before it is too late. However, this righting mechanism, for all its necessity, is not powerful enough to establish a successful equilibrium. The moral call to be there while a loved one remains in trauma means that the desired attention to the caregiver’s own life trajectory is paid only the minimum practical heed, while the frustration of such negligence only heightens that desire. As Terry reports of her life story:
It's not, it's not *anything like* I ever thought my life would ever be. At all. And I just find that, ummm, I live it one day at a time. Any plans I ever did have are gone. Ummm, any thoughts of things when I was a girl that I wanted to do or wanted to be, none of them ever happened, and ummm, they never will, so... No I'm not the least bit happy with the way my life has been. If I had the chance to do it over again, boy – .

After caregiving, then, should we not expect that, given the opportunity, the ex-caregiver will make every effort to attend to the unfinished business of looking after his or her own life trajectory? Absolutely. And so caregivers return to or seek out careers or life trajectories that are unrelated to caregiving and bring out their dormant or neglected talents.

But an intriguing number of caregivers, it seems, cannot simply “walk away” from the role “cold turkey.” The role, in and of itself, as the practical, eminently useful expression of the promise to be there (which animated it) has provided to the caregiving self the real-world individualistic language and texts (complete with built-in limitations) for clarifying the desire to be there to the caregiving self. By the same token, the role has provided caregivers with the social language, texts, and the like needed to express themselves, to testify to the validity of their desire to be there within the social arena, as they now understand it. As such, the role, despite its termination, achieves profound meaning, and an elevated status in the psychic lives of some caregivers. Echoing, reverberating, the caregiving role has transcended the finitude of its own demise to become a narrative force, an animating spirit that keeps the story going, sustaining and
revitalizing, through its defining "moment," the caregiver's narrative identity, and, indeed, his or her life story.

**ECHOES OF FAMILY CAREGIVING**

As such, despite its many difficulties, the valence of the family caregiving role remains high long after the caregiver has quit it. Perhaps an object-relations perspective would predict that caregivers, anxious to maintain proximity to the lost role, seek to involve themselves in replications or facsimilies of the role. Against this, then, caregivers need to deal with the perpetual problem of their life trajectory.

It is here that integration, more than ever before, becomes the viable and preferred solution. Contrary to postmodern ideological notions of an anomic, indeterminate, and fragmented self-identity, some caregivers, in line with the above thinking, intentionally and creatively author for themselves — praxically, as best they can given the scarce resources of their everyday lives — life trajectories which metaphorically resemble the utopian patchwork of a quilt. But upon closer examination it becomes evident that the jumble is not a mere miscellany. Rather, there are certain strategically-placed features in the arrangement which demonstrate that the central theme of being there at ground zero is vibrantly alive and well in various, quite miraculous, spin-offs, embedded within that quilt. We need only approach the quilt from the proper perspective to see this "life-defining" truth about the role.

Alison's mother, Carol, provides an admirable illustration of this. When her son, Jim, was tragically and severely brain damaged at the age of four, Carol attempted to care for Jim at home. But the personal and familial strain was too great. Medicine and State then intervened, institutionalizing Jim some three hundred miles away. Denied the
opportunity to participate in the usual family caregiving role, reduced to the role of a
casual visitor to a by now severely retarded adult male who has never recognized his own
mother, Carol has nevertheless faithfully travelled the distance virtually every weekend
over many, many years to be there for and with her son.

Is this guilt? After so many years? Alison is convinced otherwise, pointing to the
kind of person her mother has always been. Carol has always been there for anyone or
anything injured, for instance. And here we are regaled with marvelous tales of Carol’s
nursing injured birds, cats and other creatures back to health and, indeed, in some
instances, having these creatures and their offspring return to establish a close proximity
to Carol. “Do you see the design echoing through my mother’s life-quilt?” Alison might
well ask.

In much the same way, Edna, who cared for her husband for many years until his
death from Multiple Sclerosis, now frequently volunteers her time to various groups who
are interested in the opinions of a former family caregiver. These include the local Family
Caregiver Centre and a recent conference aimed at the helping professions who work on
the front lines with family caregivers. Representing caregivers is Edna’s way of being
there for them, her compatriots, in what she knows from her own experience is their great
need.

Other former caregivers have taken to publishing their personal accounts of their
experiences. Three such caregivers were interviewed for this study. And while,
admittedly, putting out works such as these has now become something of a cottage
industry for small publishers, none of these authors is now wealthy as a result of their
disclosures. Rather, as with Edna, there is a clear and definite desire to impart their
learning, this time to other caregivers in need. Still others volunteer their time to other caregivers as telephone or visiting “buddies,” ready to listen, talk, mentor, or refer at almost any time of the day or night.

Finally, there is a new breed of former caregiver who is not only committed to being there for current caregivers and their care-recipients but who is also fervent in his or her espousal of the being there at ground zero family caregiver philosophy in general. This philosophy stands firmly opposed to the deprivatizing (c.f. Holstein & Gubrium, 2000, p. 153) influences of formal and informal sectors of society, such as Medicine, Welfare, Capitalism, Bureaucracy, and Government, on the one hand, or generalized communal apathy, on the other.

These ex-caregivers, then, perform two valuable duties: 1) they advocate for improved access to existing humanizing (being there at ground zero) services and resources; 2) they charismatically lead and thereby garner the social support required to lobby for or independently establish needed but non-existent humanizing services and resources.

An example from each of these areas of work is informative.

In the informal, community setting one can find these caregivers advocating on behalf of a particular caregiver by helping him or her find and evaluate available community services, such as respite care. And charismatic efforts have taken the form of going door to door within a community in an effort to enlist aid in supporting a neighbour living alone and just diagnosed with a terminal cancer.

In the formal sector, these former caregivers have charismatically petitioned the local health authority to establish a much-needed Family Caregiver Centre, offering
information, education, referral, and support to caregivers who have become lost in a rapidly and ever-changing maze of service and resource (mis)information. They then were instrumental in keeping “the ball rolling” by helping to organize a full-day caregivers’ seminar to which over one hundred family caregivers attend – a resounding demonstration of the collective sociological imaginations of family caregivers.

Finally, in the formal sector we might find these caregivers advocating for improved consultation with family members and caregivers regarding treatment and care, because certainly, the resources already exist for such an initiative. In nursing homes, for instance, it would be to everyone’s benefit, it seems, if family members were invited to consult with front-line staff regarding, at minimum, so-called “problem behaviours.” Yet frequently this does not happen. The consequences can be unfortunate.

Thus, according to one such advocate, care assistants once battled daily to entice an elderly gentleman in the later stages of Alzheimer’s disease to take a bath. But every time this man laid his eyes upon the steaming water, he would thrash about hysterically, yelling “PIG! PIG! PIG!” as if his very life depended on avoiding that bath. Staff became increasingly irritated and frustrated until finally the patient’s wife was consulted. The man, it turns out, was once a pig farmer. At one time, pigs were butchered by lowering them into boiling vats of water!

The solution? Showering.

And so, in a sense, we have come full circle. What Alison’s mother has done as a solitary moral soul for so many years, others are increasingly arguing for and creatively authoring and implementing as an ethical code of resistance to the so-called “objective,” hyper-rational, and dehumanizingly distant-from-being-there-at-ground-zero juggernauts
of mass institutional society. Indeed, it seems that family caregivers may find themselves standing on the brink of history in this perplexing (post)modern age, ready to help humanity recognize itself anew.
CHAPTER SIX: RECAPITULATION AND PROSPECT

The overall objective of this study has been to develop an emergent theory that would generate insights into the lived and meaningful experiences of family caregivers. To that end, a specific sensitizing perspective was developed which held out the promise of bringing into greater view the libidinal desires deeply embedded within the family caregiving experience. The related phenomenological struggle of caregivers who seek not only to clarify such desires to themselves but also testify to their growing comprehension of those desires in the social milieu was also attended to through that sensitizing perspective, as was the notion that such self-clarification and testimony are fuelled by a complex faith in and suspicion of the ideological and the utopian hermeneutic resources required for such personal projects. All in all, such an approach was designed to bring into higher relief the ways and extents to which the subjects of this study might be viewed as actively engaged in the construction of their own, most difficult, caregiving role.

This sensitizing perspective in the end yielded a generous fund of life-world data which were subsequently analyzed using simply narrative techniques as a point of departure. With that, this investigator, as a listener and participant in the ongoing conversation of family caregiving, perceived an emerging story of a fundamental caregiving desire, existing situationally (that is, enmeshed in many social and moral difficulties), yet authorially transmuted (through the strategic use of the interpretive ideology–utopia dialectic) into an everyday, practical, sociological, flesh-and-blood Promise of compassion.
More specifically, for many family caregivers in this sample, coming to their caregiving role appeared to be an expression of a deeply-rooted desire to be there for and with esteemed or loved ones, at the latter's ground zero; that is, the place and time of trauma to the care-recipient's physical and mental capacities and life trajectory. This desire, this being there at ground zero, associates with a number of significant "ends" for the caregiver such as providing instrumental care, charismatically acting or advocating on behalf of the cared-for, honoring that individual, mentoring to she or he, and so on. It has also been noted that this primary family caregiving inclination appears to have an affinity to gift giving, which may have secular or divine inspirations.

Yet, we have also seen that being there at ground zero is not without its own difficulties. First among these is that this impetus often intrudes upon the overall trajectory of a caregiver's own life, causing much consternation and suffering. To allay this pain, caregivers often embark on a quest for balance, seeking to satisfy both their desire to be there at ground zero and maintain, or perhaps create anew, their life's trajectory.

This Quest, however, is a peculiar, quintessentially practical balancing act, one portrayed metaphorically here as akin to walking a high wire - with the added condition that the performer is constantly being pulled off-centre and precariously close to a fall into Martyr's Abyss by the enduring promise to be there. True, attention to the rest of one's life trajectory may temporarily right the high wire artist just enough to take a next halting step, but a full balance is never achieved as long as the care-recipient's needs are great, and this is particularly so in the cases of terminal illnesses, and most especially so when death is near.
There are, of course, in this “high wire” metaphor, hints of altruism, defined as “a
tendency to see the needs of others as more important than one’s own and to therefore be
willing to sacrifice for others” (Johnson, 2000). And, with that, we are reminded of
Durkheim’s classic treatment of “altruistic suicide” (Durkeim, 1985, p. 107):

Having designated as “egoism” the condition in which the ego pursues its own
life and is obedient only to itself, the designation “altruism” adequately expresses
the opposite condition in which the ego is not its own property. It is blended with
something other than itself, and the goal of conduct is external to itself, that is, in
one of the groups in which it participates. Thus we call the suicide caused by
intense altruism “altruistic suicide.”

But, clearly, though altruism is a crucial element – indeed, perhaps the dominant
element – in the family caregiver’s Quest, that Quest is not an entirely altruistic one.
Indeed, in eternally attempting to “right” themselves and avoid Martyr’s Abyss, or
“altructive suicide” in the psychical, if not literal, sense, this study’s caregivers, more than
in past generations it seems, appear to be performing a thoroughly modern “act.”

A second difficulty associated with being there at ground zero relates to the fact
that family caregiving is a particularly burdensome role. Yet, despite this obvious truth,
the caregiver searching for help often finds little of that forthcoming from the care-
recipient, kin, members of the community, or formal services, for reasons which have
been explored in some detail.

A third difficulty exists with respect to formal services in particular, since being
there at ground zero is a powerful moral viewpoint which not only perceives the social
landscape in its own colours but also provides an impetus which puts the caregiver into
difficult opposition with many of society's institutional forms, even after the role is properly terminated. Thus, we have seen that caregivers resist and confront the increasingly impersonal, routinized and rationalized human services of mass society by supporting each other, advocating for improved access to existing resources and services and charismatically leading the way toward the creation of needed but previously non-existent resources and services.

THEORY

In terms of a search for an exploratory, empirically grounded, yet sensitized, theory of the lived experience and meaning of family caregiving, we have seen the animating centrality of the desire to be there at ground zero for and with a traumatized other, as well as some of the unique trials and tribulations which that promise must endure. What then is the essence of this promise? Here we might do well to recognize that family caregiving, as we have seen here at least, may well be a special form of friendship.

Family caregiving: strategic, handy, faithful friendship

Aristotle distinguished between the amorality of friendship-in-pleasure and friendship-in-utility as against the moral, virtuous nature of "perfect friendship," or "that friendship of [people] who are good, and alike in virtue; for these wish well alike to each other qua good, and they are good in themselves" (cited in Reed and Johnson, 1999, p. 182).

By now, we cannot doubt the morality and virtue of many family caregivers' friendships. But unlike Aristotle's "perfect" friendship, the "alikeness" ingredient may
well be missing; that is, the care-recipient, so wounded and alone on their desperate journey, may not, in fact, be a part of Aristotle’s social recipe for a perfect friendship.

We cannot call the family caregiver, then, a “perfect” friend in the Aristotelian sense. Nevertheless, the caregiver’s friendship is a noteworthy one, achieving, as Miller reminded us in Chapter Four, an intimacy through a transendence of the accident of trauma. As characterized here, then, the “family” caregiver, whether kin or not, should likely be termed a *faithful friend*, with the term “friend” etymologically rooted in the Middle English “frend,” and akin to the German “freund,” which is itself tied to the older German “frijon,” all related to the Old English “freon,” meaning “to love.”

Consistent with this thinking and above all, the family caregiver is, according to this study at least, one who out of gratitude and appreciation, or out of divinely inspired love, is intimately on the care-recipient’s side in their journeyed struggle, and so, a special sort of companion, never enemy but rather ally, supporter, sympathizer, or helper. Further, the family caregiver is *resolutely* such a friend, faithful in the sense of maintaining a seemingly indefatigable allegiance; being constant, loyal, dutiful, reliable, and conscientious in attendance to the cared-for.

Admittedly, this characterization smacks of an armchair philosopher’s romanticization of one of society’s most difficult roles – an idealized type indeed. But, instead, this typification, while undoubtedly one of many possible interpretations of this study’s data, nevertheless retains an honesty about it, having emerged from and being found consistent with an empirical base. Consequently, while no claim is being made that the “faithful friend” characterization is the only one possible, it does seem to be an entirely worthy one to report. Furthermore, we have seen repeatedly that this typification
is not at all ideal. After all, it is under constant assault from a virtual plethora of both private and public tensions.

What we may have then in today’s family caregiver is a strategically faithful friend, postmodern in the sense of possessing fragmented selves, selves often divided against themselves, as well as against society, yet “bricoleur” or handyman enough (c.f. Holstein & Gubrium, 2000, p. 153) to be able to intentionally, practically, and cleverly work with that fallout, as found material, in the service of the demanding promise to be there at ground zero. Thus, just as our whirling, frenetic times provide the centrifugal force that threatens to rip the self apart and separate out ancient from modern traditions and selves, powerful promises such as that of being there seem to provide just enough centripetal strategic gravity (Joy, 1997, p. 37) to innovatively emplot these often opposed elements into some sort of comprehensible – if tenuous – storyline and, with that, caregiver narrative identity.

These, then, are not easy times for the family caregiver. Max Weber (1919/1958, p. 155) boldly envisioned them many years ago:

The fate of our times is characterized by rationalization and intellectualization and, above all, by the “disenchantment of the world.” Precisely the ultimate and most sublime values have retreated from public life either to the transcendental realm of mystic life or into the brotherliness of direct and personal relations. It is not accidental that our greatest art is intimate and not monumental, nor is it accidental that today only within the smallest and most intimate circles, in personal human situations, in pianissimo, that something is pulsating that
corresponds to the prophetic *pneuma*, which in former times swept through the
great communities like a firebrand, welding them together.

But neither are these hopeless times. Though Weber surely had the big picture
right, we have seen that the *pianissimo* pulses passionately within some – and possibly
many – family caregivers. This is attestation to the fact that these individuals, as
strategically handy faithful friends motivated by the promise to be there, are ready to
resist the powerful and discourses of Professionalization and Deprivatization (Holstein &
Gubrium, 2000, p. 154) so epidemic over much of the social terrain. They are also ready
to offer up the Promise as a particular, vibrant, *irrational* antidote to the hyper-rational
disenchantment of the world.

Yet it should be noted that this commitment to the irrational Promise, as we have
seen so amply demonstrated, neither signals that family caregivers represent an
essentialist “caring” feminism (c.f. Noddings, 1984; Gilligan, 1982) nor a radical
departure from same. Rather, in their quest for balance, this study’s caregivers seem to
occupy a delicately leaning, often broken-and-repaired, liminal and entirely subjugated
middle; a lived, experiential understanding of self and society, utopia and ideology,
which leaves the family caregiver avowing “both – and” something else. And that
something else, like the wooden sailing ships at sea perpetually battered by storms but
also perpetually rebuilt plank-by-plank by the mariners aboard, is praxically always
“under construction.”

The nourishing waters of the well of faithful friendship have always been and will
always be available to us, in the form of the Promise, even though the ever-shifting,
unstable and liminal path to that well is something family caregivers must discover and
negotiate anew for themselves each and every day. This is the caregiver's own heroic journey. And when the boon is finally seized for however long — when the nourishing waters are finally drawn — all society is made better for that. Our own pilgrimmage, perhaps, is to lift the veil keeping us from recognizing and appreciating in gratitude the gift which the family caregiver's odyssey holds out to us.

**IMPLICATIONS**

Re: the family caregiving literature

This open-ended, exploratory, empirically grounded study has been characterized by its small, non-probabilistic and theoretically driven sample, its clinically-based method of data collection which employed a fairly unique researcher skill-set, and, in its interpretive analysis and reporting, an unabashed overdetermination of abstract and ambiguous social concepts and theory juxtaposed against an underdetermination of fact — a mix, which, according to Alexander (1996) is entirely distinctive of social, as opposed to natural, science in general. The result of such an idiosyncratic, elastic process is, and can only be, suggestive during the short term, pending concatenation of the research in future studies (a topic we will soon consider), since there are no statistical grounds for generalization to any larger population of family caregivers.

In the meantime, as suggestive, this study's findings and emergent theory are intended to provoke conversation, to open up parameters of debate and intimate conceptual bridges. They are perhaps, then, for some readers, the untidy antithesis of a confirmatory, logocentric, tightly conceptualized perspective. This, though, is only as it must be given the very particular nature of this inquiry.
As a consequence, this investigation’s empirical findings do not readily lend themselves to evidential comparison with respect to the many other studies comprising the available family caregiving literature. For example, rather than pre-framing caregivers’ experiences in terms of the “standard” model of care, which centres on concepts of burden, stress, and psychological adaptation, this study’s interviews have opened to view the richly textured and biographically-mediated meanings of the caregiving experience.

In a similar fashion, in this study’s earlier review of the literature, Parsons (1997), Wood (1991), and Hashizume (1998) all, in some form, cursorily acknowledged the existence of filial obligation and piety in the caregiving role. Sandy’s unparalleled story reported herein serves, however, to remind us that when considering such issues we might be wise to also more deeply and openly probe the importance of both the gift relationship and the gift’s ties to human irrational and affectional bonds. And, referring again to this study’s literature review, we encountered the notion of a caregiver’s desire to “be there” for the care recipient, but only briefly mentioned by Enyert and Burman (1999, p. 458). This inquiry, however, regards the image of “being there” as central to the lived experience of the caregivers interviewed, achieving a complex implicative and narrative force in their lives. All of this is to the good as it leads directly to a consideration of the real strengths of this exploratory inquiry, which shall now be addressed.

What are those strengths? What then can this study claim as its principle contributions to the burgeoning family caregiving literature?
Jeffrey Alexander (1996) has observed that what best distinguishes the social from the natural sciences is the former’s greater emphasis upon discursive, as opposed to empirical, referents. Indeed, it is these discursive elements which give contrasting versions of social science and theory their distinctive evaluative content (1996, p. 25), often carrying “significant implications for the desirable organization and reorganization of social life” (p. 25).

Relatedly, it may be in much the same sense of evaluative comparison and, further to that, critique that Charles Lemert (1993, p. 1) claims that “social theory is a basic survival skill,” a public activity (p. 10), having its roots in social disruption (p. 11) and debate, available to potentially all members of a society and not just the academic elite.

With these things in mind, it might be offered (and again only suggestively, since family caregivers, as members of the community of practising social theorists, must also have their vital, authentic say) that this study’s strengths are most especially found in its discursive and evaluative elements. It is these elements – the central, animating compassionate and moral desire to be there, transmuted into the Promise, and thence into an ethical community movement, conflicted both in relation to other aspects of a caregiver’s self-identity as well to the Other (whether that Other be the care-recipient, family relations, neighbors, community workers, medical professionals and entrepreneurs, or legislators) – which speak of a family caregiver ethnography of – no, autopoiesis, or self-making, in – institutional life which the new phenomenological and ethnomethodological directions set by Gubrium (1995) for a family caregiving research agenda must now heed and nurture further.
Re: policy and practice

Given the discursive and evaluative elements of this study, what are some of the implications for policy and practice?

A preliminary starting point for addressing these concerns might be that this inquiry’s subject matter, findings, and emergent theory have already *discursively* contributed a good deal to the local conversation surrounding family caregiving and hold further promise in that regard. For instance, from this inquiry’s initial interviews, caregivers have, in many cases, gratefully implicated – without prompting – the in-depth and open-ended nature of the interviews and the subject matter itself in affording them the unique opportunity to truly and finally discuss their caregiving experiences.

It is clear that family caregivers have a great need to consider their lives in detail as they quite self-consciously seek out self-clarification. Further, it is clear that this is a long and often mystifying process requiring patience, a plethora of interpretive resources, authorial creativity, and usually at least one good listener. Who will be there for the caregiver?!

Since many of the caregivers interviewed professed to having attended various self-help and support groups with at best mixed results, it may well be true that in general such groups are often failing to adequately meet some of the fundamental needs family caregivers have; that is, individuals in such group settings simply may not be getting the lengthy “air time” they need to move toward self-clarification and public testimony.

---

1 Also, there may be an historical effect at work as well: some of the veteran caregivers interviewed for this study revealed that they had stopped going to support
One alternative might then be for agencies to thoughtfully "buddy" caregivers who have survived their journey with those who are now thoroughly engaged in their own. Further, this buddying should take place on more than the usual ad-hoc, crisis driven basis, and agencies should monitor the ethics and quality of such interventions. Another alternative might be for therapists and counsellors to develop a specialty niche in more fully comprehending, and thus better serving, family caregivers.

This research has also contributed to local conversation regarding family caregiving issues in that as emerging understanding of other caregivers' lived experience was brought forward to successive interviews, the value of that understanding was frequently validated, conditionally or unconditionally, by a caregiver's willingness to engage certain notions and appropriate them in their own projects of self-clarification and testimony. This "fusion of horizons," where biography and history meet, and the consequent creation of a particular sociological imagination within the consciousness of the caregiver, speaks distinctly to the relevance of this research in discursively meaningful terms to other caregivers in the community as well as to planners and policy makers.

To this end: at various points toward the middle and end of the field experience, emerging understandings were presented informally or formally to others in the group meetings precisely because there was a group expectation that, as long-time caregivers who had "ironed-out" many of their own issues long ago, their role in the group was to act as an important resource to the "rookies." As a consequence, they felt that their own needs were often neglected.
community. Frequently, for example, other family caregivers who were not actual study participants were told, in ad hoc conversation, of preliminary findings. These caregivers’ supportive remarks once again helped to extend the meaningfulness and usefulness of the findings outward into the community. This also proved to be the case for more formal presentations made to, firstly, heart and stroke survivors and their caregivers, and secondly, to a team of local health authority community health practitioners and planners. It is anticipated that in similar fashion this study will continue to implicate itself as a discursive and evaluative survival tool within local family caregiving circles.

With regard to further implications concerning policy and practice, let us return to the original problems motivating this research; that is, the increasing centrality of the family caregiving role in the provision of care in our society, and the question of how we, as a society, can better care for the family caregiver.

This research suggests first and foremost that professionals, as agents of rationalized and bureaucratized deprivatization in our society, must now concede not only the vital instrumental function of family caregivers as an extension of the various planned human services (this has never been in doubt) but also the latter’s moral and ethical autonomy in providing that which these professionals cannot – the solace and faithful friendship of being there at ground zero. This can only make for difficult relations between informal caregivers and professionals. For, on the one hand, family caregivers are increasingly being accepted and depended upon by the various health-related professions as an integral part of the care delivery team and a humane approach to case management. Yet, on the other hand, family caregivers themselves reject the
dehumanizing model of care which they labour under and which cannot and will not make time and ways for being there.

Of course, family caregivers are not alone in their rejection of such dehumanization. Feminists such as White (2000) find that the increasing professionalization of health care is at root a pervasive manifestation of paternalistic expertise standing in dire need of a just and democratic overhaul. This stream of thought, coupled with the compassion of committed family and other informal caregivers, which in itself reveals a morality of friendship free of the limitations of filial and other consanguineal obligations and thus a being-with-and-for-others that makes caring a society-wide-and-deep reflexive project, may provide the impetus needed, on a large enough scale, to dramatically dignify, at both the micro and macro levels, the expert-only provision of care we now know. And, suffice it to say, such a sociopolitical convergence of forces and consequent dissemination of compassionate culture into the larger social milieu would go much further in meeting the burgeoning challenges of eldercare, for example, than would a philosophy proposing that the values of filial obligation be somehow imported to the West from Asian countries such as Japan (c.f. Peterson, 1999).

In the meantime, however, society must support caregivers such as those portrayed here in their earnest crusade while also understanding the tensions and, indeed, the great threats to a caregiver's personal identity which invariably accrue along the way. Hence, those helping professionals who have been drawn to their careers because they believed in being there for others (i.e., nurses, physicians, social workers, and so on) would do well to recognize and honour in their actions and interactions with caregivers their kindred humanity. They must also (as hard as it may be to put aside The Schedule)
attempt to listen to the meaning of the family caregiver’s life. Hopefully, this study, among others, will suggest some ways to approach this critical task.

But further than that, communities (support groups, neighbours, friends, and relations) too have a special part to play in this movement, for they alone can aid the family caregiver’s quest for balance in ways in which the formal system cannot. For example, it may well be that only close relations and friends can rally around the caregiver who needs to pursue other dreams while holding fast to their Promise. Who, from among this circle, will come forward to form part of a voluntary “team” that will support such a one as Fern in clarifying and realizing her very personal life-long ambitions? As June Callwood (1986) seems to amply intimate, there is a vast and immeasurably meaningful potentiality in assisting primary caregivers with their quest for balance through the formation of such informal caregiving teams. This, Callwood asserts, is an impressive example, of “the human tribe functioning at its best.”

Re: further research

Having presented a few tentative recommendations for policy and practice, it is nevertheless necessary to recognize that future progress in these areas will greatly depend on developing the current state of knowledge and understanding concerning the lived experience and meaning of today’s family caregivers beyond its present infancy. To this end, a further program of research can now be elucidated.

We begin with Stebbins (1992a) notion of “concatenated” research activity. This is the set or chain of linked exploratory field studies which presents a continuing (longitudinal) capacity for interstudy comparisons, whether within or between substantive research areas. As long as these studies remain within the rubric of a particular
substantive area, in this case family caregiving, the linked substantive grounded theories emerging from each study may grow in theoretical reflexivity and abstraction while still retaining their capacity to "fit" empirical situations and "work" to provide social researchers and laypeople alike with relevant and useful theory. The "end" product, a concatenated cumulative substantive grounded theory, is perhaps the most imminent practical extension of any beginning exploratory study such as this one.

As such, concatenation in the substantive area of family caregiving should see this and other studies' theories carried forward as further sensitizing concepts into broader and more diverse geopolitical, socioeconomic, cultural, ethnic, and gendered communities of family caregivers. We need to hear the voices of family caregivers in other regions and nations, urban and rural settings, classes, ethnic enclaves, and so on. And, of course, it is imperative to hear from more male caregivers in all of these contexts as well, who are coming into the role in increasing numbers, especially later in life and ostensibly even less well prepared for the role than the women we have seen in this and other studies, but about whom we understand very, very little. Finally, all along the way, it would be most fruitful, in theoretical terms, if exploratory studies of professional careproviders (i.e., physicians, nurses, and perhaps most interestingly, private for-profit contracted caregivers) could be done for comparison's sake.

But beyond this, a substantive grounded theory which achieves a certain level of theoretical abstraction (whether that is the result of a cumulative and concatenated process as just outlined or an exploration begun at a higher level of abstraction through the use of certain sensitizing concepts, as was the case with this study) may generate important enough general implications and relevance to be taken to apply to other
substantive areas. With that, a substantive (possibly concatenated) grounded theory almost automatically becomes a springboard or stepping stone to concatenation between substantive areas and, hence, to the development of a grounded formal theory.

An exemplar of this movement from substantive to formal grounded theory via concatenation between substantive areas is Stebbins’ definitive *Amateurs, Professionals, and Serious Leisure* (1992b) which offers such a formal theory of amateurs and professionals based on research in eight substantive areas. Similarly, this research, with its level of theoretical abstraction, suggests that we begin to explore the lived experiences and meanings of other “faithful friends” – those members of the human race who seek to “be there at ground zero” for and with others who are highly dependent and perhaps traumatized and suffering, or stigmatized, marginalized, shunned, abandoned, alienated, and so forth.

These people might be the Guardian Angels who voluntarily combat crime in the streets, the volunteer coaches who work with underprivileged children, the unpaid community activists or organizers, as well as the volunteer search and rescue workers, or even the grandparents intimately involved in raising their grandchildren because, for example, the childrens’ parents both work. And of course, faithful friends need not only befriend people. Indeed, they may desire to be there for any living entity. Thus, it may be productive to study the “bird lady” who rehabilitates injured hawks, eagles, and so forth, as well as radical environmentalists who would claim to befriend Gaia Herself.

Studying any form of friendship has never been an important part of the sociological agenda. This is a particularly costly omission – at least in terms of faithful
friendships – which must be rectified. For, as Shlapentokh (1989, p. 172, cited in Pahl, 1996, p. 99) notes of extremely close friendships in Russia:

Friendship is an obstacle to the absolute dominance of the state over the individual. Moreover, friendship frequently constitutes the basis for the creation of underground organizations and anti-governmental activities.

In our own way we have made a similar claim here: faithful friendships have the potential to transform modern day health care and society for the better – if not move mountains.
While on "Paxil," an antidepressant, Rita is impressed by the "incredible" dreams she was having and their "great detail":

One was ridiculous. We were going to a wedding and the kids were still at home [Rita’s children are, in reality, grown up and married with children]. And I was all dressed up in this lovely white pretty dress. And the coal man came.

Now, you won’t even know what a coal man is.... But... when I lived in England as a child, we had coal fires.... We had a fire and it was made of coal. And the coal man used to come and he’d deliver about ten hundred weight of coal about once a month, or once every two months.

And we had a coal cellar at the back of the house, so he’d go ‘round the house with this big coal bag on his — the house was built with a coal cellar. And he’d tip all this into the coal cellar. And we’d fill our coal scuttles and coal bins from there and carry them into the house.

And [referring back to the dream] the coal man came. But he didn’t deliver it into the house. He just tipped it out all over the street. And there were mountains of this stuff. There was huge — it was up and down the street and none of the neighbours could get by and it was all up the driveway. And I don’t know what house we were in.

And all I could think of was: “Here I am, all dressed up and I can’t do it. I’ve got to get to this wedding and I am in this lovely dress and I’m all clean and I can’t shovel this bloody coal anywhere.” I said to him: “What a day to come!” [Rita laughs.] And it bothered me.
And then one of Ned’s, my eldest son’s, friends… Stanley, was there. So I gave him a shovel and I said to him, “Can you help me out? Can you shovel some of this coal off the street so the neighbours can get by while we’re at the wedding? And I’ll help you when I come back.” And he said, “Oh, yes, sure.” And that was the end of the dream.

What follows is Rita’s interpretation of the dream:

mbd: It was a messy problem.

Rita: Ya. A big, black, dirty problem…. And where Stanley came from, I don’t know. He was always willing to help. I remember that. Always willing to do anything for me…. The only thing is, you know, that it just seems that there is a big problem in my life. There is a big thing that’s happening that’s not pleasant, which would be the stroke. You know, it’s not normal. This is an abnormal thing. Because that wasn’t ten hundred weight of coal. It was millions of weight of coal. It was huge. It wasn’t the normal thing. It’s the only thing I can think of.

And I go along from day to day and make the best of things and pretend there’s nothing wrong. This is my life. I have to live this way now…. But I suppose every now and again I find that it is larger than life [emphasis added].
APPENDIX B: FAMILY CAREGIVER INTERVIEW GUIDE

(©2000 Mark B. Durieux)

1ST THEME – EARLY INFLUENCES

* Can you name anyone you know who has served as an informal caregiver? What impressions do/did you have of their caregiving experiences?

* Are there other people from your past or present who might have influenced you one way or another as a caregiver?

* Are there any works of literature, art, music, inspirational works of religion, philosophy, new age thought, spirituality, etc., that have had an important impact on you as a caregiver?

* Are there any "voices of moral conscience" that speak to you from somewhere beyond yourself (either from somewhere distant or close by) concerning caregiving in general or your caregiving in particular? Here, we might be talking about dreams, or revelations from God....

* Or is it your impression that caregiving "just comes naturally," is "instinctive," or "genetic," or, in some way, biological or evolutionary? That is, to your way of thinking, is caregiving a product of nature, not nurture? Or is it some combination of nature and nurture?

2ND THEME – SOCIAL CONTACTS

* Can you please sketch some of the more important people that you come into contact with as a caregiver? (if not mentioned, probe for the cared-for individual, other patients; physicians, social workers, nurses, other health care professionals; friends, mentors, other caregivers;....)
* Concerning the people you have just mentioned, what are/were your most vivid reactions to these encounters? How do/did you feel about being with these people? (i.e., did you feel like an alien in strange company in some of these relationships? Which ones and why? In others did you feel like a friend or relation, perhaps, in old familiar company? Why?) (Probe if not brought up during conversation)

* What are some of the more vivid recollections you have about the expectations that may have been placed upon you by these people? And what are or were you learning about yourself as a result?

* How do/did these reactions and insights colour the caregiving experience for you as a result?

3RD THEME – SELF-IDENTITY/LIFE STORY?

Now I'd like to learn about your life more generally. Like our faces, our life stories share a lot of features with other people's. But they're completely unique, too.

* Please tell me about your life, in about 20 minutes or so if you can. You can begin with whatever you'd like. (Check that the following years have been mentioned: childhood, adolescence, young adulthood, the respondent's 20s, 30s, 40s, ... etc.)

- How does/did the caregiving experience fit into, or not fit into, your life story? Please tell me about those places where you recognize(d) parts of your life story in caregiving, and those other places where you hardly recognize(d), or don't/didn't recognize at all, your life story in caregiving.

4TH THEME – PRESENTATION OF SELF

Now I'd like to return to the people we looked at at the beginning of this interview.
* Knowing what you do about yourself and how caregiving fits into your life, how easy or hard is it / has it been for you to advocate for yourself; that is, to influence others, such as those people we talked about previously, to understand, respect, and support who you are and your situation?

* Do/did you come away from these encounters feeling that the understanding you have of your life (i.e., life story) and your caregiving harmonizes or clashes with other "stories" or understandings "out there" (dominant discourses)? And where does that leave you?

**5TH THEME – INFORMING OTHERS**

Thank you for your generosity and patience. We are almost finished. Now, considering all the ground that we have covered today....

* if you were presented with the opportunity to voluntarily take on the caregiving role once again, would you? Why or why not?

* just for the sake of argument, let's imagine that you had decided to take on the caregiving role again. What sorts of things would you try to remember or try to do in order to help yourself through the experience?

* finally, if you had to "map out" the experience of caregiving for an inexperienced caregiver about to face a situation somewhat similar to yours what advice could you give them? Is there anything specific to the relationship between an individual's sense of who they are and the experience of caregiving that they should be prepared for?
APPENDIX C: FACE-SHEET INTERVIEW SCHEDULE

Today's date: __ (yr) __ (mo) __ (dy)

Place: ____________________________________________

Time: __:__ (am / pm)

Subject's Name: ________________________________

Sex: ___

Birth Date: : __ (yr) __ (mo) __ (dy)

Birth Order: 1 __ 2 __ 3 __ 4 __ 5 __

Brothers:

<table>
<thead>
<tr>
<th>first name</th>
<th>present age</th>
<th>now lives in</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sisters:

<table>
<thead>
<tr>
<th>first name</th>
<th>present age</th>
<th>now lives in</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Parents:

mother's age now or died in what year your age then

__________________________  ____________________________  ___________

father's age now or died in what year your age then

__________________________  ____________________________  ___________

Parents' Marital Status: divorced (Y / N)

Your age then ______

mother remarried when you were _____

father remarried when you were _____

lived with mother between what ages ________________

lived with father between what ages ________________

Special Comments:


Occupation of:

mother ________________ stepmother ________________

father ________________ stepfather ________________

Respondent's education:_________________________________

Highest level: __________

emphasis/specialty (if any)

_____________________________________________________

Occupation: ____________________________________________

Married what year: __________________________
Divorced what year: ____________________

Remarried when: ________________

Respondent's children (ages and sex):

name  age  sex  now living (y/n)

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

Religion: _________________________________

How religious: Strong  moderate  inactive  indifferent

how often worships: daily ___  weekly ___  monthly ___

    several times a year ___  yearly ___

    once every few years ___
REFERENCES


