Enrichment in Family Caregiving to Frail Elders

by

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A bit of advice
given to a young Native American
at the time of his initiation:

"As you go the way of life,
you will see a great chasm.

Jump.

It is not as wide as you think."

Joseph Campbell, 1991

This research is dedicated to my father,

John R. Palmer

who inspired my love of ideas and

passion for learning,

and who has always encouraged me to jump.

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TITLE: Enrichment Processes in Family Caregiving to Frail Elders

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This dissertation reports findings from an exploratory study of enrichment processes used in family caregiving to frail elders. Proposed is a theory of enrichment that explains how some families use pleasurable or meaningful experiences in their caregiving roles, and what antecedent and consequent factors are associated with the enrichment process.

Purposeful sampling for dyads--caregiver and care recipient--believed to be personally knowledgeable regarding enrichment in family caregiving to frail elders aged 65 and older guided identification of the participants. The investigator used the grounded theory method to analyze responses to open-ended interviews conducted with 20 caregivers and 4 care recipients. Participant observations of caregiver--care recipient interactions supplemented the interviews. Caregivers also completed a questionnaire measuring variables believed to be associated with the presence of enrichment.

Interview and observational data were analyzed using the method of constant comparative analysis. The resultant coding paradigm described antecedent and core variables for enrichment, and consequences for members of the dyad.

The metaphor of alchemy explains how the convergence of three core elements transformed ordinary activities into events with special meaning: *customary routines* that help provide structure to the caregiving day, and *innovative routine breakers* that provide a change in daily patterns. The *quality of the dyadic relationship* and the nature of the *caregiving situation* are antecedent factors affecting enrichment processes. Core elements influencing the nature of enriching events include *acquiring meaning*, *performing activity*, and *fine tuning*. Consequences of enrichment are dyadic *relationship sustenance*, *identity sustenance* for both caregiver and care recipient, *comfort* for the care recipient, and *rewards of meaning* in the caregiving role for the caregiver.

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Introduction

This dissertation is composed of two papers for publication and a series of appendices describing aspects of the work that are not included in the papers.

Paper 1: Enrichment Processes in Family Caregiving to Frail Elders

This paper provides an overview of the dissertation research findings. The grounded theory method of analysis guided development of a theory of enrichment processes used by some family caregivers to frail elders. Open-ended interviews and participant observations were conducted with a purposeful sample of 20 caregiver-care recipient dyads. Revealed were antecedent conditions and intervening factors for endowing the caregiving with special meaning or pleasure for both members of the dyad. The metaphor of alchemy explains how the convergence of three core elements transformed ordinary activities into events with special meaning. Two categories of enriching activities were identified: customary routines that help provide structure to the caregiving day, and innovative routine breakers that provide a change in daily patterns. Participants who perceived enrichment in their caregiving situation experienced positive individual and dyadic consequences.

Paper 2: Fine Tuning: A Process Component of Enrichment in Family Caregiving Over Time

Described in detail is one component of the enrichment process, *fine tuning*. Fine tuning refers to accommodation of frailty trajectories and personal histories of both caregiver and care recipient in an effort to enrich the caregiving situation. The dissertation research revealed that fine tuning is necessary in order for enrichment to occur over time and across physical, cognitive, affective, and functional changes experienced by both care recipients and caregivers. Factors which influence the selection of fine tuning strategies include context, knowing the other, and resources. Identified are five strategies for fine tuning that facilitate the ongoing presence of enriching activities across changing frailty trajectories and personal histories.

Appendix A: Review of the Research Literature

Summarizes relevant research literature related to enrichment.

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Summarizes non-research papers related to enrichment in family caregiving.

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This appendix describes the coding paradigm for enrichment processes that emerged from the research. Cited are exemplar data bits illustrating the codes.

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Interviews and observations of family caregiving dyads revealed methodological issues which may be unique to this population. These concerns are described along with strategies that were used for their management.

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Listed are the five criteria for evaluating the credibility of a qualitative study according to Lincoln and Guba. Included is evidence for how these criteria were met in this study.

Appendix J: Informed Consent

Copies of the informed consent forms used for both the pilot study and the research are included along with a discussion of how the ongoing informed consent form was not used as had been initially anticipated.

Appendix K: References

Listed are all references cited across the papers and appendices.

Paper One

Enrichment Processes in Family Caregiving to Frail Elders

Introduction

With an expanding aged population, health care providers have increasingly focused their practice and research interests on the phenomenon of family caregiving to frail elders in the community. Considerable research has focused on what activities family caregivers perform (Stephens & Christianson, 1986; Stone, Cafferata, & Sangl, 1987), and the burdens or strain they feel (Given, Stommel, Collins, King, & Given, 1990; Knight, Llutzky, & Macofsky-Urban, 1993; Pearlin, Mullan, Semple, & Skaff, 1990). Limited attention has been given to the way in which family members provide the care, or to the positive meaning associated with providing care. This paper reports findings from an exploratory study of enrichment processes used by family caregivers.

Enrichment has been identified by Archbold and Stewart (1988) as a critical dimension in the quality of family caregiving. They suggested that nurses might assist families to develop enrichment interventions to enhance meaning and satisfaction in caregiving. Stewart and Archbold directed Levine, Cartwright, and Inoue (1991) in reviewing transcripts of caregiver interviews to develop a measure of enrichment as one component of the quality of family caregiving. Enrichment was eventually defined as the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient. In the course of developing the measure of enrichment it became apparent that knowledge was limited regarding the processes by which families create meaning or pleasure in the situation of caregiving to frail elders. Therefore, the grounded theory method was used to develop a theory of enrichment in family caregiving that explains how some families use pleasurable or meaningful experiences in their caregiving roles, and what antecedent and consequent factors are associated with the enrichment process.

Review of the Literature

Increasingly, researchers are recognizing family caregiving as a complex and multi-faceted phenomenon. Some investigators have focused their attention on management of family relationships within the caregiving situation. Identified as central to the care provided are caregiver concerns and efforts to maintain the dignity, self-identity, and emotional well-being of the care recipient (Abel, 1990; Bowers, 1987; Hasselkus, 1989). Some caregivers endeavor to maintain their self-identity, and to affirm the meaning and value of their relationship with the care recipient (Orona, 1990; Corbin & Strauss, 1988).

Mutuality, the positive quality of the relationship, has been examined as a critical variable in family caregiving (Archbold, Stewart, Greenlick & Harvath, 1990; Hirschfeld, 1983). Archbold and colleagues found that mutuality was associated with lower levels of some dimensions of caregiver role strain even after controlling for variables that had been identified as predictive of role strain by other investigators. They suggested that mutuality may be greatly underestimated as a factor that may ameliorate negative outcomes of caregiving. Walker, Martin, and Jones (1992) indicated that the quality of the relationship was one of several situational factors contributing to perceived costs and benefits for both care recipient mothers and caregiver daughters.

Researchers of caregiving have explored the ideas of Frankl (1985) in finding meaning as essential to the human spirit. Valuing positive aspects of the caregiving experience was the most frequently cited strategy of caregivers for finding meaning through suffering (Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken, 1991). Elders derived a sense of life meaning by engaging in activities which were perceived to make a difference, to be helpful to another, and to be positive in nature (Trice, 1990). Thus, while studies have identified positive aspects and outcomes in family caregiving, little is known regarding the actual processes through which enrichment occurs in the situation of caregiving to frail elders.

Method

My goal was to propose a theory of enrichment processes that captured the broad range of experiences reflecting enrichment while staying faithful to the everyday reality of the people whose situations I was analyzing (Strauss & Corbin, 1990). Grounded theory methods for data collection and analysis were therefore selected. Symbolic interactionism, the theoretical foundation for grounded theory, is particularly appropriate for research that seeks to uncover processes and elicit meanings in interactions (Blumer, 1969).

Procedure

Three sets of data were collected and analyzed. The pilot study was based on interviews with six caregivers. Secondary analysis of three interviews recorded for the Caregiver Measurement Project (Stewart & Archbold, 1991) augmented this portion of the study. Interviews with 11 additional caregivers and 4 care recipients were conducted later in the analysis. The interviews ranged in length from 1 hour (care recipients) to 6 hours with most lasting 2 to 3 hours. Using an open-ended interview guide, the interviewer encouraged participants to talk at length regarding their situation. All interviews were tape recorded and transcribed verbatim. Field notes supplemented the audio-tapes. Participant observations were conducted at the convenience of the dyad–caregiver and care recipient, and tended to arise spontaneously. Examples included participating in a birthday celebration, shared meals, and an afternoon of singing. Informal interviewing occurred during these periods. Detailed field notes were recorded immediately after these sessions.

Sampling

During the initial period of data collection the primary sampling goal was to identify a representative range of caregivers who were personally knowledgeable regarding enrichment in family caregiving. Community based nurses, case managers, and support group leaders were asked to identify dyads who might be interested in participating in the study. As the analysis progressed, theoretical sampling based on emergent concepts directed the data collection. For example, later interviews focused on the probes related to frailty trajectory and the historical quality of the dyadic relationship.

Analysis

Constant comparative analysis across the transcripts and field notes, and use of a coding paradigm ensured conceptual density in interpreting the data (Strauss, 1987). Emergent categories were developed to include salient properties and dimensions. An axial coding paradigm (Strauss & Corbin, 1990) was used to identify the phases and interactional components of enrichment processes. Negative case analysis, the identification of examples that do not fit the emerging analysis, expanded the representativeness of the theory.

Participants

The caregivers ranged in age from 39 to 86 years, with a mean age of 67. Care recipients (interviewed and not interviewed) ranged in age from 65 to 104 years, with a mean age of 84. Caregiver relationships to the care recipient included primarily daughters ($\underline{n}$ = 7), wives ($\underline{n}$ = 5), and husbands ($\underline{n}$ = 4). Nine (43%) care recipients had diagnoses reflecting dementia. All of the care recipients required assistance with at least three activities of daily living (ADLs). With three exceptions, all of the dyads lived together at the time of the interviews. Based on subjective household observations, the caregivers appeared to belong primarily to low-middle and middle classes. However, three seemed well off, and two appeared very impoverished. Participants were recruited from urban and rural sites. They were primarily of Pacific Northwest, Caucasian backgrounds, which is representative of the geographic area.

Credibility of the Analysis

Transcripts, field notes, and documents were reviewed numerous times to identify recurring patterns. Data bits that did not fit emergent themes were used to expand the representativeness of enrichment as the phenomenon of interest. Detailed field notes and interview probes that elicited thick descriptions provided a dense connection between the data and the analysis. Each category and property reflects multiple quotes which are considered illustrative of the analysis. Members of the dissertation committee and of three doctoral level seminars provided an ongoing peer-auditing mechanism for critical examination of theoretical memos and all data.

Efforts to transfer this analysis to other settings should be tempered by recognition of the small number of participants and the nature of their caregiving situations. For example, while all of the care recipients were quite dependent in ADLs, only one was so functionally impaired as to be bedridden.

Findings: Grounded Theory of Enrichment

In considering the process of enrichment, it is helpful to recall the analogy of alchemy. Alchemists desired to turn mundane elements into gold. They tinkered with various substances combined in different amounts and sequences in their efforts to change common objects into something precious. Enrichment processes operate in a similar fashion. Mundane activities are made special for caregiver and care recipient through the convergence of several critical elements. A caregiver's descriptions of shared activities illustrates this process:

> CG:....but we watch *Family Feud*. It just depends how my day's goin'...I try to make sure I can sit and watch at least a half an hour with her and that just makes her day.....We enjoy the TV shows and then at night, after I've had my shower, I usually go over and watch

Wheel of Fortune. We try to guess the puzzles. So, that's her enjoyment before she goes to bed.

INT: How did these two particular shows come about for you to share?

CG: Cause they're on at that time...they just happened to be on.

INT: Again, what cues are telling you that she's enjoying this, when you're there with her for those two shows?

CG: Oh, just kind of laughing and trying to guess it and maybe I'm wrong and she'll laugh at me and she's wrong, I'll laugh at her and just kind of giggle, you know, and sometimes you're right and "yea" and, you know...she enjoys it.

INT: How about you? How do you feel about doing that with her?

CG: Oh, I, I enjoy it.

In the preceding situation, the caregiver was the adult daughter of an 87-year-old woman with diabetes and neuropathies that severely restricted her mobility. The mother had lived in a small trailer adjacent to her daughter's modest, rural home for the past 4 years. The daughter, married and with multiple sclerosis and many household related responsibilities, assisted her mother in numerous personal ADLs and all instrumental activities. This dyad had turned the ordinary, TV game shows, into the special: twice daily periods of laughter and mutual pleasure in each other's company.

How do these 20th century alchemists work their magic? What are the critical elements and interactions that transform the ordinary into the special? Figure 1 depicts relationships among the *antecedent factors*, *core elements*, and *consequences* of *enriching events*. The following discussion provides a framework for understanding essential components to enrichment in family caregiving.

Antecedent Factors

Both caregiver and recipient come into the care situation with unique *personal histories* which have developed over time through interactions between personality traits and life experiences. These histories intersect to create the *quality of the dyadic relationship* that reflects past and current knowledge of each other, including values, preferences and meanings. The conceptualization of biography as the temporal component to identity (Corbin and Strauss, 1991) was helpful in my thinking about personal histories as dimensions in family caregiving. As an illustration, one caregiver, the sister of a woman with advanced Alzheimer's disease, described the role of music throughout their separate and shared lives. Both women had been musicians, participating in numerous church and social activities that emphasized their musical talents. This sister recalled happy times involving music for both herself and the care recipient.

The positive quality of the dyadic relationship was commonly described in interviews where enrichment occurred. Some participants reported a longstanding history of closeness: "the things we liked to do together were quiet things. I guess that you could say we like the same things and we like things to go pretty much the

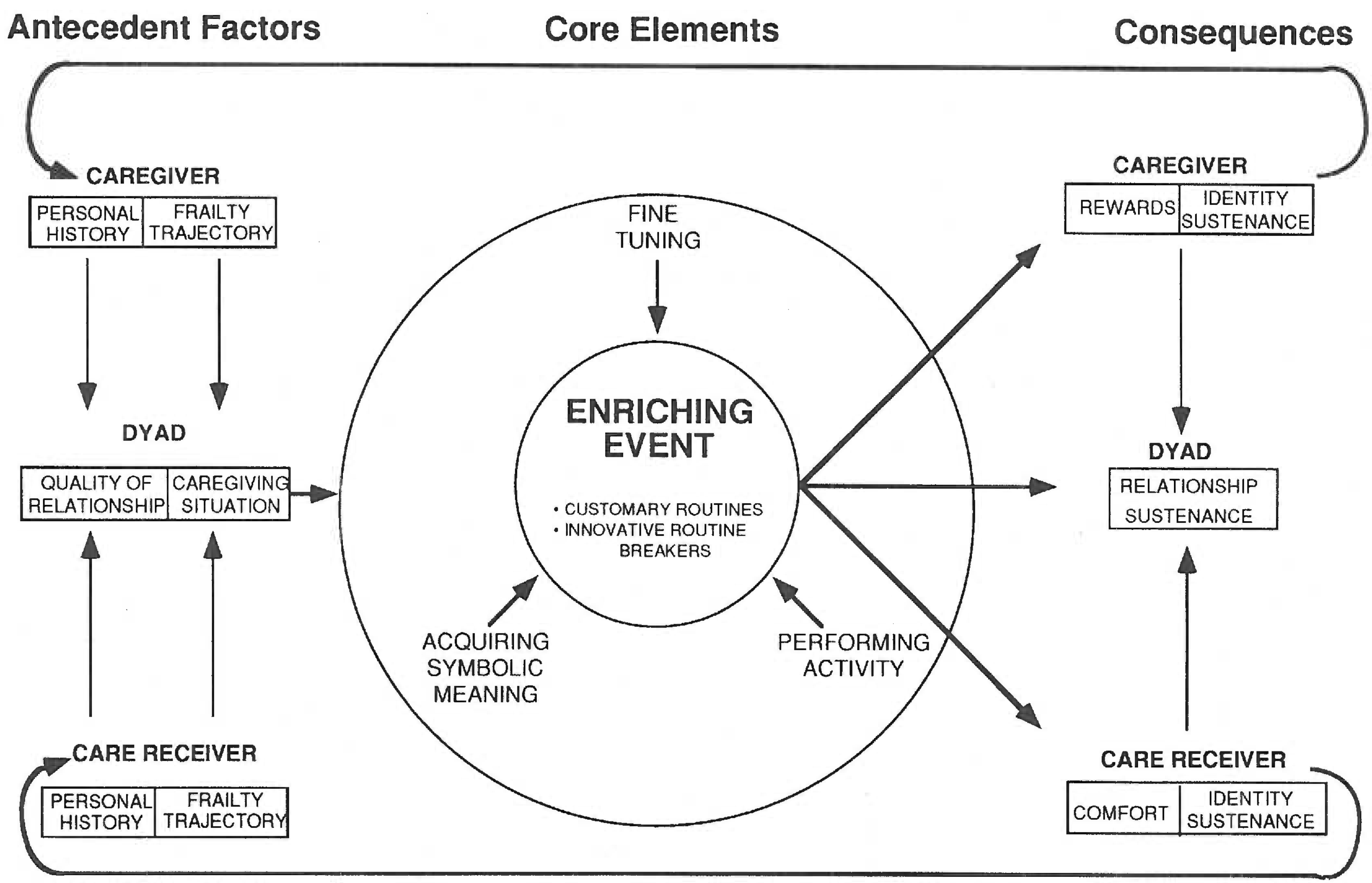

Figure 1. The process of enrichment in family caregiving to frail elderly

same way." Others described the emergence of shared pleasurable activities since the advent of the caregiving situation:

> When she first came, well, we made up, I feel, what I missed [in our past mother-daughter relationship], and probably what she missed, too. You know, we really enjoyed ourselves the first years, when she was really mobile and got around...and we still enjoy doing things and she's satisfied and I am, and we just get along great.

Both members of the dyad bring to the caregiving situation their own *frailty trajectories*: physical, cognitive, emotional, and functional states which change over time. Corbin and Strauss (1988) found that care recipients may be viewed within the context of an illness trajectory. This analysis expands the notion of trajectory to encompass functional, affective, and cognitive domains besides illness. Additionally, early in the data collection experience it became apparent that caregivers to frail elders also have frailty trajectories vis a vis their own functional limitations and/or pathophysiology: " You know, I wear nitro patches because I have angina attacks; I take high blood pressure medicine. So, all in all, I think that we do quite well considering everything."

The transcripts revealed that caregiving encompasses the intertwining of two frailty trajectories and two histories that span lifetimes. Caregivers are continually attempting to balance these separate but entwined trajectories and histories in the dyadic relationship and the *caregiving situation*. The frailty trajectories provide overall structure for the nature of the day by identifying how much and what type of personal and instrumental care is needed, and medical regimens that must be followed. The quality of the dyadic relationship creates the potential for invoking memories and creating meanings around daily activities. Together, the caregiving situation and the quality of the relationship provide a framework in which enrichment may occur as an additional form of structure in the day.

Transformation of Three Core Elements

The enrichment process represents the coming together of three core elements: *acquiring symbolic meaning, performing activity, and fine tuning.* These elements combine to create an activity with special meaning for each member of the dyad that is individually fashioned around dyadic histories and frailty trajectories.

Acquiring symbolic meaning refers to the significance, value, or intent of an activity or object, and may change over time. The symbolic property reflects meaning that transcends the utility of an object or event (Gusfield & Michalowicz, 1984). Historical knowledge is sometimes used to acquire symbolic meaning, however, special meaning can also emerge from the current situation. Music, frequently cited in the interviews, serves to illustrate the salience of acquiring symbolic meaning. One woman described singing duets with her sister who had advanced Alzheimer's dementia: "It's the only thing that we can do together anymore...I enjoy singing. It brings back memories." In the same situation, the care recipient's husband perceived music as representative of his wife's and his own losses:

> Her singing and playing the flute...you think about this all the time, it affects you some. So I just try to [block] it out. Why dwell on that? It was so nice and good but I don't want to just sit and listen and try to remember that song or this song, like that.

The same activity held quite different meanings for the care recipient's sister and husband.

Performing activity refers to observable behaviors in the caregiving situation. One caregiver described noon time dinner for her and her husband who had aphasia and hemiplegia:

> At noon, we don't have television on. That's the time that I talk and he listens. It's kind of our time to visit. We talk about what we get in the mail and we talk about the different things that we're going to have to take care of during the month. I try to keep him up on what I'm doing about the banking...I tell him about what I've seen going on out here in the complex, you know–just whatever happens during the day.

The food, carefully prepared from scratch, included a hot entree and dessert. Flowers decorated the table. Each member of the dyad had a specific role during the meal. The acquired symbolic meaning in this situation reflected efforts by the couple "to keep our life as much the way it was as we possibly could." The opportunity to act out the customary roles of husband and wife was provided and made special through the mundane symbols of dinner.

Fine tuning[1] involves efforts over time to accommodate the frailty trajectories and histories in creating enrichment (Cartwright, 1993). The following data bit illustrates how personal histories and frailty trajectories can be accommodated. The wife of a man with hemiplegia, limited speech and vision, and insulin-dependent diabetes described a day visit with old friends from camping:

> CG: We still went hunting and camping til, oh, five years ago. What we did mostly was sit in camp and visit with the other people, because they'd gone every year to the same camp. We went to the campground and met the same families, the same four or five couples.
>
> INT: So there was less of the hunting and fishing and more of the social?
>
> CG: Yes (laughs). So that was fun for us. In fact our daughter and her husband took us to the campground last fall one day. We got to visit some–that was fun. That kind of made up for missing it. Took the place of it, I guess, to visit the people at the campground. We just visited with the people in camp, asked if they'd gotten their deer. We enjoyed that. He was very pleased with that. We were hoping we could do it again maybe this year, because we'd enjoyed last year. And on our anniversary card my daughter wrote something about it. So we might go.

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[1] I wish to acknowledge and thank Dr. Virginia Olesen, Professor, School of Nursing, University of California San Francisco, for suggesting the term *fine tuning*.

The above example demonstrates fine tuning through accommodation of camping, which was important in the history of the dyad. The caregiver never learned to drive and her husband had multiple functional limitations. The annual outing of camping and visiting with old friends was modified into a day trip. Fine tuning permitted accommodation of the activity while retaining the essence of the experience–communality among friends.

In considering how the three core elements come together to form an enriching event it is useful to return to the analogy of alchemy. Valence is a property that alchemists considered when mixing elements. Derived from the Latin "*valentia*", power or strength, valence refers to the capacity of elements to unite, react, or interact (Merriam-Webster, 1965). In the situation of enrichment, valence represents the degree of attraction among acquiring meaning, performing activity, and fine tuning. This attraction influences the existence and shape of the enriching event. When the valence of one of the three elements for the others is weak, an enriching event may not occur, or may be discontinued. However, if valence is strong, then previous, new, modified, or substituted enriching events may emerge in the caregiving situation. One caregiver described how church attendance changed over time for her and her husband with advanced Alzheimer's disease: "We couldn't go to worship anymore. He would just say he couldn't go in. We started in the nursery. I just knew that there's always a need for someone to hold babies! And he was very useful." In this example, resources for fine tuning combined with an activity that retained the symbolic meaning of participating as a productive member of the church community. Some other caregivers for whom the combining power of acquiring symbolic meaning, performing activity, and fine tuning was weaker reported that church participation discontinued when managerial problems heightened.

Categories of Enrichment

Two categories of enrichment processes have emerged. *Customary routines* refers to patterned and predictable parts of the day. These activities include rituals or ceremonials whose known and anticipated patterns of familiarity breed a sense of comfort. The events are comforting by virtue of their presence in the daily rhythm. Their absence would create discomfort. This category emerged from participant responses to questions such as "Are there any things in the day that you both look forward to?" Responses included daily worship activities, bedtime rituals, and mundane endeavors such as specific television shows. The common denominator among these examples is the regularity with which the incident occurs and its patterned structure. Customary routines are similar to the concept of patterned family interactions as described by Wolin and Bennett (1984). Like patterned family interactions, customary routines help provide structure to the day and affirm participants' shared identities.

Innovative routine breakers represents the second category of enrichment processes. This refers to activities that are not routine, that add a bit of stimulation to the day. One caregiver acknowledged the importance of not engaging in these activities regularly.

> 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. You know, you can only do so much for her and that tickles her, so I try to do that every once in awhile. I don't make it an everyday habit. I make it a treat.

Both customary routines and innovative routine breakers may emerge from very simple and ordinary activities. The balance in use between these two categories of enrichment varies. Some dyads relate a predilection for routine in their lives. Others seek stimulation. A complicating factor is that the preferences of two people, often with very different energy levels, frailty trajectories, and interests, must be considered in creating a rhythm to the day's events. Some caregivers express frustration at the paucity of stimulation in their lives due to care recipient frailty limitations or preferences for routine.

Consequences

This study identified several consequences of engaging in enrichment. Enrichment processes provide a forum for maintaining or strengthening the dyadic affiliation. One woman remarked that the caregiving experience was an opportunity to develop the mother-daughter relationship that historically had been weak. This outcome is labeled *relationship sustenance* to reflect its nurturing, growth enhancing dimension.

Another potential consequence is care recipient feelings of self-esteem or of *identity sustenance*. A daughter reported:

> She has all those beautiful things. Saves for company. But who's coming? Why not use them? So I'll get a glass, a nice glass. She'll say, 'no, just get one of those' [everyday glasses]. And I'll say 'Why? Aren't you special? Yeah, you are special. You're the lady of this house.' Eventually she will say 'Oh yes, I am special. Right, bring that [glass] on.' [laughs].

Comments by caregivers suggested that enriching events sometimes generated feelings of their own enhanced identity sustenance. One adult son described an afternoon routine of sitting in their garden and reminiscing with his elderly mother about his childhood and their home.

> We sit there and talk about some of the old days...You know, what a character I was when I was young; how she put up with me. It brings back a lot of memories to me when I was a kid...I enjoy it....[we] laugh about it.

Some care recipients seemed to experience *comfort* from enriching activities, particularly those that reflected customary routines. The wife of a man who was cognitively intact but aphasic and hemiplegic described his bedtime:

> There's a little routine when I put him to bed. I just tell him that I hope he has a good night and that he'll sleep well and to call me if he needs me and that I love him. That's just about the same thing every night. We go through the same routine. If I miss one thing, he knows it and he sort of reminds me that I've missed one of those

> things...he'll look at me and grins and shakes his head 'no', and I know that I've missed something.

That caregivers may experience *rewards of meaning* in their role was suggested by frequent expressions of 'a job well done' related to enrichment events. One caregiving daughter remarked, "You know, she's always just been special. I want to do everything I can to make her life special. It makes me feel good [to create special mealtimes], cause I love my mother."

While this research did not focus on comparing caregiver experiences between cognitively intact versus demented care recipients, some differences were noted between these two groups. The caregivers to people with dementia tended to rely heavily on their historical knowledge of the care recipient in planning enriching events. These caregivers frequently interpreted the care recipient's pleasure based on historical knowledge and/or on very subtle behavioral cues. One caregiver described his wife's pleasure in listening to music: "We've always liked good music--the old masters, the big bands, the vocalists. They seem to dig out memories with her more than just talking about the old times. Some of the things we did are fading now." This analysis supports Orona's (1990) finding that memory based activities are valuable for maintaining the identities of both caregiver and care recipient with Alzheimer's disease.

Discussion

The preceding discussion is not meant to romanticize family caregiving. Rather, these findings demonstrate the process of enrichment that can occur in the family caregiving experience, given the availability of core elements. Enrichment involves engaging in individually fashioned activities whose symbols reflect special meaning or pleasure for the caregiver and care recipient. Enrichment processes are not, in and of themselves, costly in time or money. The participants in this study related use of symbols that were free or inexpensive, and readily available to them.

A more complex consideration for the presence of enrichment processes involves the necessary antecedent and concurrent factors. Data bits suggestive of mutuality in the relationship were commonly found in interviews where enrichment occurred. Frequently cited were feelings and activities reflecting aspects of mutuality similar to dimensions which have been identified by other investigators of caregiving: shared values, reciprocity in the relationship, affection, and shared pleasurable activities (Archbold, Stewart, Greenlick, & Harvath, 1992). Feelings of empathy, the ability to experience vicariously another's emotions (Staub, 1978), were suggested in the comments of some participants. Caregivers who engaged in enriching activities frequently expressed identification with the feelings of the care recipient, even in situations where the care recipient was no longer articulate. In summary, for enrichment to happen, certain conditions need to be in place, including either an existing positive relationship or the motivation to improve the relationship.

A limitation to this study is that in most families only the caregiving member of the dyad reported his or her perception of the situation. Also, the primary strategy for data collection, the interview, may not adequately capture enriching behaviors which are performed but not spoken by the participants.

This analysis raises questions for additional research. What happens in families where enrichment does not occur or diminishes over time? What is the nature of enrichment in situations where care of the body is a major focus of the caregiving? What kinds of enriching behaviors and symbols might be revealed with greater use of participant observation for data collection? What is the role of formal agencies in ensuring that caregivers have adequate support resources to enhance the quality of the caregiving experience? Finally, this investigation provides the foundation for a longitudinal study that examines the development of enrichment in family caregiving over time.

As our body of knowledge related to family caregiving expands, attention will be increasingly placed on the quality of the experience. Nurses, by virtue of their intimate involvement with families across a broad range of daily living activities, have the unique opportunity to help caregivers incorporate enrichment into the caregiving experience. The findings described in this paper represent a preliminary effort to understand the quality of family caregiving through knowledge of related enrichment processes.

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Paper Two

Fine Tuning:
A Core Element in the Process of Enrichment in Family Caregiving to Frail Elders

Introduction

With an expanding aged population, family caregiving to older people is increasingly common. The U. S. Senate Special Committee on Aging (1991) reported that between 79% and 84% of long term elder care is provided by family members, primarily wives and daughters. Analysis of the National Long Term Care survey revealed the ongoing and intense nature of family caregiving: 80% of caregivers provide assistance 7 days a week; the average daily time spent in caregiving tasks is 4 hours with 25% reporting greater time commitments; and 1 in 5 caregivers has been providing care for 5 or more years (Stone, Cafferata, & Sangl, 1987). Thus, the majority of elder care in this country is provided on a long term basis by women with personal knowledge of the care recipient.

An exploratory study of enrichment processes in family caregiving revealed that some caregivers make continuous adjustments in their caregiving to reflect the changing frailty conditions of both care recipient and caregiver in order to endow the situation with special meaning or pleasure (Cartwright,1993). The efforts by the caregiver to accommodate changing frailty trajectories with personal histories has been labeled *fine tuning*[1]. While fine tuning is necessary for the ongoing occurrence of enrichment in family caregiving to frail elders, it may also be a critical condition for competence in performing other care activities. This paper describes antecedents,

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[1] I wish to acknowledge and thank Dr. Virginia Olesen, Professor, School of Nursing, University of California San Francisco, for suggesting the term *fine tuning*.

intervening factors, and strategies for fine tuning, a core element for enrichment processes in family caregiving.

Method

The findings reported in this paper are part of a larger study which explored enrichment processes in family caregiving using the grounded theory method (Cartwright, 1993). This analysis is based on tape recorded interviews which were transcribed verbatim, and participant observations where detailed field notes documented the visits. An open-ended interview guide with probes for special meaning or pleasure in the caregiving situation guided the interactions. Participants were encouraged to talk at length regarding their general caregiving situation. While this strategy resulted in lengthy interviews (2 to 6 hours), it was intended to decrease the potential for investigator invoked reactivity that may arise from focusing solely on the phenomenon of interest, enrichment. Observations tended to arise spontaneously and included participation in a birthday celebration, shared meals and/or coffee, and an afternoon of singing. Anonymity was protected by eliminating personally identifying data from transcripts and field notes, and destroying the interview tapes after they were transcribed.

Participants

Purposeful sampling of caregivers believed to enrich their situations guided recruitment of 20 participants through community agencies that assist caregiving families in urban and rural communities of the Pacific Northwest. The participants were providing personal and instrumental care for relatives, mostly spouses ($\underline{n} = 12$)

or parents (n = 6), who were at least 65 years old (M = 84 years). Length of time providing care ranged from 3 months to 25 years (M = 5.5 years). The caregivers were primarily women (71%) and ranged in age from 39 to 86 years. The care recipients lived with their caregivers in all but three cases, and reflected a variety of medical diagnoses, cognitive abilities, and functional limitations. Subjective household appraisals suggested that the families were primarily of low-middle and middle class backgrounds.

Data Analysis

The conceptualization of fine tuning was developed using the constant comparative method of analysis described by Strauss and Corbin (1990). While reading the transcripts, I used open coding techniques to identify data bits that reflected my understanding of enrichment. The incidents identified as enriching were then examined for similar patterns. Repeatedly, caregivers described adjustments required to engage in activities which they recognized as pleasurable or meaningful for the care recipient and themselves. These adjustments occurred in the management of frailty, in the nature of enriching activities, or in the selection of settings where enrichment occurred. When accommodation or fine tuning was not achieved, the activity was discontinued.

The deductive analytic strategy of Strauss and Corbin (1990) was used for confirmatory comparison among data bits. Negative cases, instances that deviate from the proposed explanation of factors and relationships, expanded the representativeness of the analysis (Strauss & Corbin, 1990). For example, the intervening context category of *physical safety* was identified late in the study using negative case analysis. One caregiver remarked on her concerns for the care recipient's safety while grocery shopping. This was a shared, pleasurable activity, but the elder's increasingly unsteady gait and slow ambulation worried the caregiver, and ultimately influenced shopping together. Both new and existing transcripts were subsequently reviewed for evidence supporting the presence of caregiver concern with safety as part of the enriching experience. While identified towards the end of the analysis, recognition of physical safety as a contextual factor influencing fine tuning added to the explanatory power of fine tuning.

Theoretical sampling for concepts related to fine tuning was discontinued when new transcripts revealed no additional categories, conditions, or properties. At that point, theoretical saturation of the concept was considered to have occurred.

Credibility of the Analysis

The primary evidence for plausibility of this analysis rests on the consistency of the themes which are detailed across the different accounts. For example, references to social tolerance were expressed in each data bit which reflected a public situation. I have attempted to weave a dense connection between my interpretation and the data through heavy use of participant quotations. Each identified condition, property, and dimension has at least two, if not multiple quotes which may be considered illustrative of the analysis, although this report includes only brief samples.

Findings: "Things Change As Things Go Along"

Fine tuning is the process of aligning or accommodating the frailty trajectories and histories of both caregiver and care recipient in an effort to create an experience that has special meaning or pleasure for both members of the dyad. Figure 1 illustrates critical *antecedents, intervening factors*, and *strategies* for fine tuning that result in an *enriching event*. Characteristics of both members of the caregiver-care recipient dyad and of their situation influence the type of strategy that is selected to accommodate enriching activities across time. When the interactions of antecedent and intervening factors do not lead to fine tuning strategies, the activity is deleted from the caregiving situation.

Antecedent Factors

Frailty trajectories and *histories* are antecedent factors reflecting care recipient and caregiver characteristics (Cartwright, 1993). By frailty trajectory is meant the physical, cognitive, emotional, and functional conditions which change over time for the individual. Although frailty status is usually considered in relation to the care recipient, this analysis revealed that caregivers also have frailty trajectories: "I went up to see [MD] and my multiple sclerosis–everything was worse than when he detected it in early '89. And he says, 'What have you been doing? What's going on?'"

Personal history refers to a person's current and past ways of achieving meaning and/or pleasure. Awareness of another's personal history provides a basis for engaging in activities that were or still are considered meaningful or pleasurable

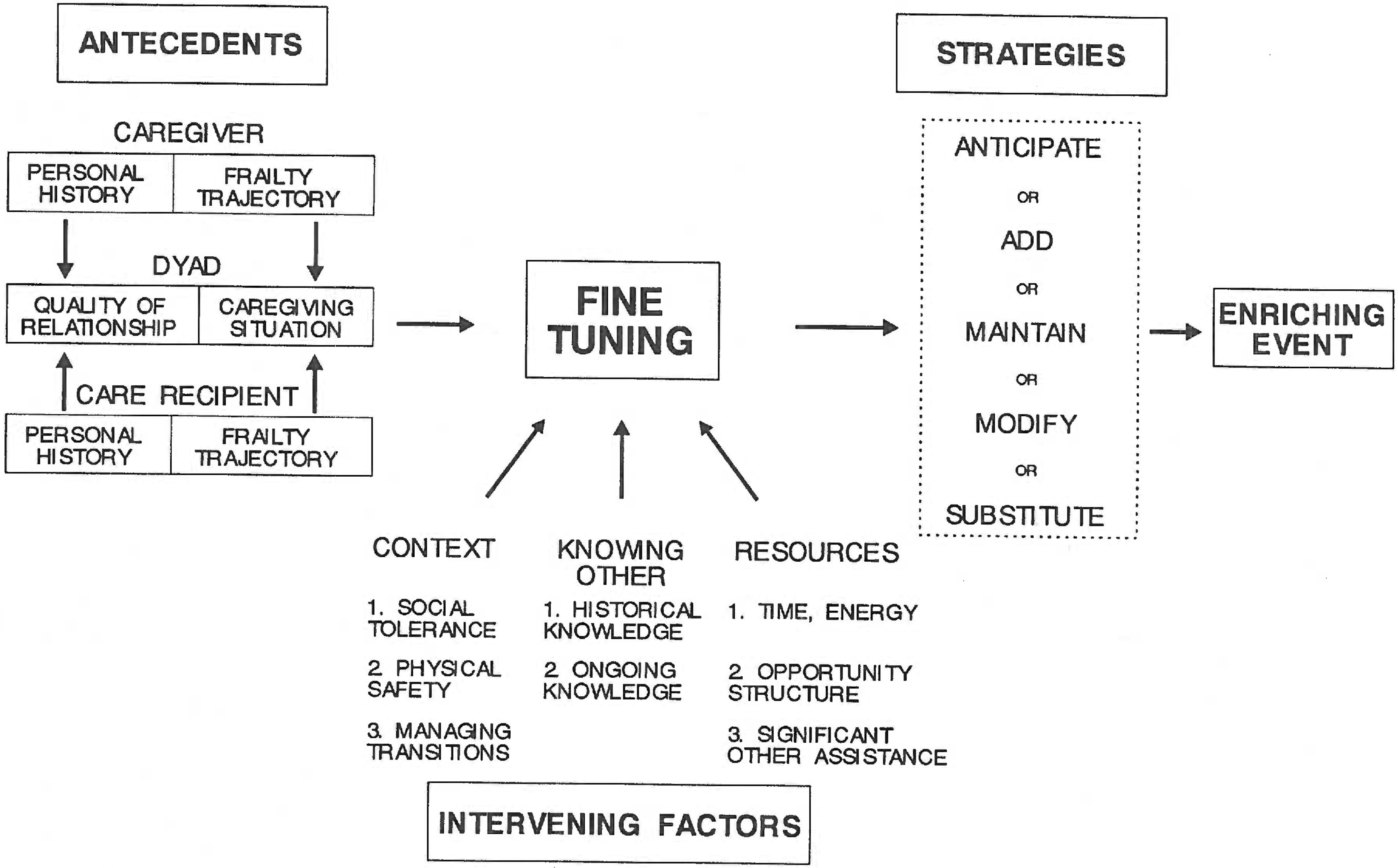

Figure 1. Fine Tuning: A Core Element in the Process of Enrichment in Family Caregiving to Frail Elders

to that individual. Because family caregiving generally emerges from a past or ongoing relationship, caregivers usually have access to knowledge of the care recipient's history. In situations where the personal histories of the caregiver and care recipient entwine in a positive fashion, the participant may report closeness and/or shared pleasure in the *quality of the relationship.* The presence of an historically positive dyadic relationship between caregiver and care recipient is illustrated in the following description by a caregiver:

> I moved up here with her and lived with her for a couple of years and she took care of me and I kind of took care of her. And she showed me–we went out berry picking places everywhere–she knew the time, the date when to go and pick berries, and we would just bring them home by the bucket loads and then sit and clean them and talk and clean and talk and store them away.

Examining participants' efforts to enrich the *caregiving situation* revealed attempts to align or fit activities that were considered meaningful or pleasurable with the changing physical, cognitive, emotional, or functional conditions of both members of the dyad (Cartwright, 1993). The following data bit illustrates how enriching activities were fine tuned or adjusted to accommodate the changing situation:

> We did quite a bit of hiking and bird watching. We'd take our binoculars and go out and bird watch, had our bird books. That was our main activity for the last five years before he got sick. A lot of

> times we'd drive way out by the river some place and just bird watch...[later] while we were still in the house, we had bird feeders out by the windows and he'd watch the birds, but here, we just don't have birds. Sometimes I read aloud to him, if I have an article about birds I find, that he's interested in.

In this example, after a stroke left the care recipient with multiple physical and functional impairments, he became reluctant to leave their home. His wife, realizing how much pleasure the outdoors had once brought to her husband, developed ways to bring the world of nature to him, given the limitations of their caregiving situation.

STRATEGIES

Five strategies for fine tuning evolved from constant comparison of enriching events across interview transcripts. These strategies represent different ways of incorporating meaningful or pleasurable activities into the caregiving situation over time.

Anticipatory fine tuning occurs in contemplating potentially enriching activities. Caregivers think through the proposed activity to gauge its logistical feasibility. The daughter of a woman with Alzheimer's dementia described her plan to take the care recipient, a minister's wife, to church:

> We're having a women's day celebration next Sunday. I'm trying to get her, I've already started talking to her about it. I'm going to get her clothes together. Who knows? I think she would enjoy it. It's

> going to be a special program. Two of her granddaughters are co-chairs of the program. I think, I know, she'd be so proud.

Adding new enriching activities can happen as a result of a changing frailty status. One caregiver began to use feeding on an intermittent basis as a way to bring pleasure to the situation of eating for the care recipient. This activity arose after an acute illness, where the care recipient was unable to feed himself. While the care recipient was regaining independence in this activity of daily living, "If I have time and he needs that little extra comfort, I'll feed him. I'll say 'you like that', and he'll say 'yes.'"

Maintaining the activity occurs when an ongoing event is continued despite changes in the frailty status of the care recipient or caregiver. A woman whose parents both have Alzheimer's dementia reported on a weekly routine of dining out: "We take them out to dinner quite a bit too, and they enjoy that. Mostly to the Chinese restaurant because its easy, there are no steps, and they can eat it...that was one of their favorite cuisines when they were younger."

Modifying the activity occurs when adjustments are made in the way the activity is performed while retaining an essential component of pleasure or special meaning. One caregiver described his and his wife's past pleasure in weekend trips to an artists' beach community for people watching. Her dementia had curtailed this activity.

> You can see every type of person on the face of the earth if you go to [beach community]--they're bound to pass you on the street! [Now], I

> can get the same results by going down on [local main street] and we watch the people go by...her enjoyment is as good one place as another...[it] is very pleasant.

Substituting is used when a pleasurable or meaningful activity can no longer occur. Something new is developed as replacement. The daughter of a woman with severely limited mobility described sharing the progress of her home remodeling:

> When I got my bedroom done, she said, 'Oh, I'll never get to see your bedroom. I'd love to get to see it.' I said, 'Mom, when we get done I'll take pictures." And I mean that satisfies her. Course she knows what it looked like before, you know, so that satisfies her, too."

In this situation the house was very small with narrow doorways and several entry steps that precluded the use of a wheelchair to give the care recipient a tour of the bedroom. Photographs enabled the mother and daughter to share pleasure in the remodeling.

Intervening Factors

Early in the analysis, several factors were recognized that influence the selection of strategies for fine tuning. Three intervening factors are critical in determining the nature of fine tuning: *context*, *knowing other*, and *resources.* Context refers to environmental conditions that influence the presence of an enriching event. Context is evaluated by considering the setting in terms of *social tolerance*, *physical safety*, and *managing transitions* in frailty status. *Social tolerance*, the caregiver's comfort with how the care recipient behaves in a public situation, was consistently cited by participants:

> Mom loves music...I take her to the symphony concerts at the college. This year our seats are on the front row and it's frustrating to me because Mom is so friendly that she's sitting there waving at all the players that are in the orchestra and there's two men that just about fall off the chairs in laughter...If they can't get me tickets back farther I'm not going to go again because it's embarrassing to me.

Caregivers varied in their estimations of when social context necessitated a change in the strategy being used to achieve an enriching experience. The wife of a man with advanced Parkinson's disease reported "Most of the time I say, if people don't like what they see, that's their problem." In contrast, another caregiver mentioned her embarrassment at the movies: "We've been going to matinees...but, she has to go to the bathroom so often...I'm embarrassed because we have to disturb the people around us to get out."

Physical safety is another factor in determining the nature of an enriching event. The wife of a man with advanced Alzheimer's disease described her increasing concern for his safety while hiking with a local senior's group:

> We were climbing around on that mountain. We got stuck one day...we got to this one point and it was a big, high boulder and no way could I get him over that boulder. I was beginning to get upset because I could [envision] this [rescue] helicopter coming. What I did

> in the end was I built a place to put your foot and had him turn around so he couldn't see the drop-off and we walked along the ledge of this cliff, and got onto the other side of the path. We were all relieved when that was over.

Managing transitions involves considering the amount and type of effort required to bring about the enriching event over time and a changing frailty condition. In a follow-up interview, the wife of a man with advanced Alzheimer's disease acknowledged how drives, previously identified as a pleasurable activity they could still share, were becoming difficult:

> Yesterday [sigh] I couldn't get him in the truck. He wanted to go, but he couldn't figure out what he was doing wrong, and he wouldn't pay attention to what I was telling him to do--couldn't do what I was telling him to do--whatever. Got annoyed with me when I wanted him to come back in the house.

Knowing other refers to use of knowledge, both *historical* and *ongoing*, regarding what is pleasurable or meaningful, and ways in which the other has achieved meaning or pleasure in the past. This factor recognizes the identity of the other beyond their role in the caregiving situation. As illustration, the adult daughter of a woman with numerous complications of diabetes and marked limitations in her mobility remarked:

> My Mom is the type, she don't make friends real easily, and she doesn't play cards...she doesn't sew, she doesn't knit, she never did.

> She was a workaholic. She never really had what you'd say a social life...But, uh, we watch TV and that satisfies her and then the grandbaby comes out. That's all she wants. She don't care if she ever goes anywhere. Like I say, we wheel her outside. She does like to go outside and sit. But she seems to be real satisfied.

The care recipient mother confirmed her daughter's observations:

> I could go [shopping or drives with caregiver] cause they'd take me--her husband is just as good to me as she is, and he'd take me any time I'd want to go. I'd rather stay here. I'm so scared of falling and getting hurt again, that it's just not worth it. And I have my TV and I watch my TV.

Ongoing knowledge derives from the caregiver's interpretation of current behavioral cues of the care recipient. One woman, whose mother had diminished conversational skills, described the cues that reflect her mother's pleasure in enriching events: "Oh, laughing, and she likes to kiss and hug. Doing that lets me know she's happy...I know she feels good when that's going on."

Historical knowledge of the other is particularly critical in situations of dementia. Caregivers to persons with Alzheimer's disease rely heavily on their historical knowledge to provide pleasure or meaning, and to interpret care recipients' responses to the enriching activity as positive. When asked how she knew that her husband with very advanced Alzheimer's dementia enjoyed their daughter's visits, one caregiver replied: "He's always glad to see her. He always wants to know what she--you can't understand him [care recipient] anymore, but he's saying 'where are you working?' and so she [daughter] just tells him."

Resources are the third critical factor influencing fine tuning. Resources include *time* and *energy*, *opportunity structure*, and *assistance from significant others*. The following data bit illustrates the salience of sufficient *time and energy* for enrichment to occur:

> Now it just depends how my day's going...a lot of times I've got stuff I've gotta get done and of course my own work and I've always got wash and I try to get everything I have to do done in the morning because I--afternoons I do not function well.

As with social tolerance, caregivers report a range of time and energy levels. One woman who reported very little enrichment in her caregiving situation remarked "I'm tired lots of times. And its because I'm leaking energy." However, several caregivers whose caregiving days seemed subjectively quite demanding, and who routinely incorporated enriching activities into their care echoed the following comment: "I have enough [time and energy]. The Lord gives me just what I need for each day, so that's what I depend on." Critical, minimal levels of time and energy may be necessary for enrichment to occur, or be fine tuned, at all.

The notion of *opportunity structure* emerged early in the analysis when a rural caregiver described her husband's visits to nearby neighbors driving a motorized golf cart. This type of activity could not occur in an urban setting. That some caregivers utilize unique properties of their situation in creating enrichment is reflected by opportunity structure. One man used his wife's poor memory as an opportunity for enrichment:

> Evenings we depend on the television to entertain ourselves. She'll say 'I haven't seen this before.' And that's good–that aspect of Alzheimer's is good. Because she won't be bored with it. She won't say 'I won't see this, I've seen this a dozen times.' And the good shows, I like seeing again–there's a good story–kind of like visiting an old friend again.

The final property of resources is *significant other assistance*: the participant's perception of help from other people in providing enriching experiences. An adult daughter described an Easter cake her mother has enjoyed for decades:

> [Friend] always make this, what they call torte, for Easter and never fails to make an extra one too for Mom. Mom can't eat them that much because the nuts–that's why she makes a special one for her, and she calls me to come get it and bring it to her [Mom].

In another situation, the daughters of a wheelchair bound man were instrumental in helping him and his wife enjoy an afternoon outing: "Well, those streets are terrible in [town]. They said, 'oh, no problem.' They just each took one side of the wheelchair and carried him along! We had quite a day."

While this analysis focused on the presence of fine tuning in enrichment processes, its absence was also evident in the data. Some caregivers were unable to fine tune an activity, and events which had been identified as meaningful or pleasurable were deleted from the caregiving situation. The following example illustrates how the intervening factor of social tolerance precluded the ability of one caregiver to successfully strategize a way to continue attendance at church:

> We would always go to church together. But the last time, she had a purse--she had a purse in a purse. She may have had 4 purses. One inside the other, with zippers. Zip, zip, zip. Everybody was turning around--what was going on. So I just got to the point that I didn't tell her that it was Sunday.

Discussion

Fine tuning is a complex process that provides the mechanism for accommodating two sets of frailty trajectories with two separate and entwining personal histories. The caregivers interviewed for this study were very aware of the changing nature of their care recipient's frailty condition, and that strategies for providing meaning or pleasure had to be adjusted accordingly. The three intervening factors of context, knowing other, and resources were used to fine tune enriching events in order to sustain individual identities and/or the quality of the dyadic relationship within the caregiving situation (Cartwright, 1993).

Corbin and Strauss (1988, 1991) found that chronic illness management extends beyond disease care to include management of everyday living activities, relationships, and biographical work. They developed an illness trajectory framework that is useful in thinking about the dynamic nature of family care for frail elders over time. Their notion of an illness trajectory is expanded in the situation of elder care recipients, who often have frailty trajectories reflecting functional changes separate from chronic illness. The findings in this study elaborate further on the research of Corbin and Strauss by recognizing that two individuals, caregiver and care recipient, have frailty trajectories which must be accommodated within the context of everyday living and relationships. Finally, Corbin and Strauss found that couples, through management of chronic illness, can shape the course of the illness trajectory. This research reveals that, through fine tuning, caregivers also use their knowledge of care recipient and caregiver frailty trajectories in strategizing ways to create or preserve enriching events.

The ideas of Lawton regarding environmental press and the elderly are confirmed and expanded in this analysis. Lawton (1982) discussed the concept of environmental press in relation to individual competence and adaptation by older people. Adaptation has been described as a state of balance between the level of external stimulation (environmental press) and personal competence. The greater the personal competence, the more press is required to achieve stimulation. Individuals with low levels of competence, which includes persons with physical, cognitive, and/or affective limitations, are sensitive to small changes in environmental press acting in a stimulating manner. In this study the attention provided to physical safety revealed awareness of the influence of environmental press on enrichment. Caregivers and care recipients expressed concern for environmental factors associated with safety when strategizing ways to enrich a situation.

The optimization principle developed by Wohlwill (cited in Lawton, 1982) represents the ideal or balanced zone between competence and level of press. This study confirms Lawton's notion that relatively small changes in press may be sufficient to achieve a zone of optimization for frail individuals. Repeatedly, caregivers described use of ordinary activities such as music, drives, and simple food treats to enrich the caregiving situation. Enriching activities often encompassed mundane aspects of everyday living that had acquired special meaning for both caregiver and care recipient (Cartwright, 1993). Finally, environmental press may explain the challenge of creating enrichment in dyadic relationships when members have different competence and adaptation levels based in part on their differing frailty conditions.

Implications of the Findings

While this study explored fine tuning in relationship to enrichment, the concept may be critical as a basic social process related to the quality of family caregiving in general. Enrichment as a dimension in the quality of family caregiving is distinguished by the special meaning assigned to specific activities or objects. Competence, the property of having the necessary knowledge, skill, and resources to provide the required care, has also been identified as a critical dimension in the quality of family caregiving (Archbold & Stewart, 1988; Levine, Cartwright, & Inoue, 1991). What role does fine tuning play in care related competence, particularly as the frailty trajectory of the care recipient changes over time? When fine tuning occurs in the absence of special meaning, is this a form of caregiving task competence?

A limitation to this investigation is that generally only the caregiving member of the dyad was reporting their perception of the situation. Also, the primary strategy for data collection, the interview, may not adequately capture enriching behaviors which are performed but not spoken by the participants. Efforts to transfer this analysis to other settings should be tempered by recognition of the small number of participants and the nature of their caregiving situations.

This research suggests additional areas for study related to the phenomenon of fine tuning. What happens in situations where fine tuning does not occur or ceases? Can families be assisted in using the fine tuning process? How can nurses facilitate families' use of this process specifically for enrichment, and also for competence in tasks related to caregiving? Are there antecedent or intervening conditions that preclude the use of fine tuning?

Nurses and other health care providers are increasingly concerned with the quality of the experience of family caregiving to frail elders. The concept, fine tuning, suggests antecedent and concurrent conditions that may be desirable for families to evaluate as they provide care in a situation that changes over time. By recognizing critical antecedent and intervening factors, nurses may help families select strategies that create or sustain enrichment across changing frailty trajectories, and help them to use personal history knowledge or acquire necessary resources to facilitate ongoing enrichment.

This study proposes that fine tuning is one element that may be critical for successful caregiving over time. While this research focused on fine tuning in relation to enrichment, the broader implications of this concept for family caregivers and nurses have also been identified.

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Appendix A

<u>Review of the Research Literature</u>

Appendix A

Summary of Selected Reports in the Research Literature Related to Enrichment in Family Caregiving to Frail Elders.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Abel, 1991. The purpose of this study was to explore the experience of family caregiving from the framework of public policy.	The exploratory descriptive design used in-depth interviews guided by grounded theory methodology.	Purposeful sampling from support agencies resulted in interviews with fifty-one women. Seventy-five percent cared for an elder with a diagnosis of dementia. Most of the caregivers used formal services substantially. Open ended questions addressed attitudes and experiences in caregiving, use of formal services, social networks, and relationships with care recipients.	Emerging themes included concern for care recipient's dignity, frequently through protection and preservation of recipient's former self. Caregiving was perceived in terms of maintaining the recipient's overall well-being rather than as a series of tasks.	Supports presence of enrichment processes as a mechanism to preserve the personhood of the care recipient. A limitation to the study was the disproportanately high amount of community services used by these caregivers as compared with the caregiving population in general.
Archbold, 1982. The purpose was to describe the impact of parent caring on Caucasian women.	This exploratory descriptive study used grounded theory methodology.	Thirty Caucasian adult women participated through intensive interviewing, participant observation, and completion of the OARS Multidimensional Functional Assessment Questionnaire.	Parent caring may be categorized into two general roles: provider or manager of care. Managers identify more benefits to the relationship: a sense of meaning, satisfaction, and increased knowledge of aging.	One of the earliest studies suggesting that caregivers perceive positive aspects in caregiving.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Archbold, Stewart, Greenlick, & Harvath, 1990. The purpose was to identify how well mutuality and preparedness for caregiving predict caregiver role strain after accounting for other variables.	This descriptive correlational study involved structured measures administered through in-person interviews at six weeks and nine months post care recipient hospital discharge.	A convenience sample of 78 caregiving dyads who were affiliated with an HMO was obtained. All care recipients required assistance in at least one personal activity of daily living. Structured interviews conducted at six weeks and nine months included: mutuality in the relationship, preparedness for caregiving, amount of direct care required, degree of cognitive and physical impairment, caregiver role strain across nine dimensions, gender of caregiver, and kin status of the relationship. Hierarchical regression analysis was used to analyze the relationships among the predictor variables with role strain.	After accounting for all other variables except preparedness, mutuality explained between 4% and 24% of the variance in role strain at 6 weeks (median value of 12%). The nine month variance was similar. Mutuality appeared to ameliorate strain from direct care, tension, and global role strain but had little effect on strain from worry, strain from lack of resources, or economic burden.	While mutuality has been described though anecdotes as salient to the caregiving relationship, this study reflects a pioneering effort to quantifiably demonstrate the significance of mutuality in predicting caregiver role strain. This study supports the need to further explore enrichment processes, which appear related to mutuality in the caregiving experience.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Blieszner and Shifflett, 1990. The purpose of this study was to explore the relationships over time for spousal and adult child caregivers of persons experiencing Alzheimer's disease.	The longitudinal exploratory design involved four, in person, structured interviews during the first 18 months post Alzheimer's diagnosis. Structured measures were also administered.	A convenience sample of 11 caregivers (six spouses, five adult children) was recruited from an Alzheimer's support group. Care recipients were in the early stages of the disease. The interview schedules included retrospective and ongoing information regarding personalities, family roles, support systems, symptoms, & coping strategies. The Miller Social Intimacy Scale (Miller & Lefcourt, 1983) was administered at each visit.	Coping methods described one year after diagnosis fell into three categories: redefining positive and negative aspects of the relationship, needing to put closure to the relationship, and changing role from partner in a close personal relationship to caregiver role. Positive aspects in the new relationship including finding pleasure in little things.	The finding that redefining positive aspects in the relationship includes little things has implications for examination of enrichment processes in family caregiving. This is a rare study from a longitudinal perspective.
Bowers, 1987. The purpose of the study was to generate a theory of intergenerational caregiving based on the caregiver's perceived purpose.	This exploratory-descriptive, theory generating design used grounded dimensional analysis (a form of grounded theory methodology).	Twenty-seven parents and 33 caregiving adult children were interviewed separately. Preliminary questions asked about becoming a caregiver and stressful aspects of the role. Later questions focused on consequences of failed caregiving and strategies for invisible caregiving.	"Invisible" describes the bulk of caregiving to mildly impaired elders. Protective caregiving was the most universally experienced, the most difficult, and considered the most important type of caregiving. Protective caregiving involves protecting the parent's emotional well being and identity from threats.	Contributes to rational for examining enrichment processes as potential mechanisms for maintaining care recipient self-worth. Care recipients were mildly impaired cognitively, which limits generalizability of findings.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Cameron, 1991. The purpose was to investigate the effects of caregiving on elderly husbands of physically impaired, disabled wives.	This descriptive correlational study used semi-structured interview guides combined with a scaled questionnaire.	The sample consisted of 34 elderly Anglo-Canadian husbands who were the primary caregivers to frail wives. Visits on two occasions were used to conduct the interviews (Leininger's Cultural Health Care Assessment Tool; Concept of Caregiving; & Support Services guide) and administer the questionnaire (Caregiver Burden Interview scale, Novak & Guest, 1989).	The questionnaire revealed a majority of respondents in the range of slight burden, particularly in the area of time-dependence. Analysis of the interview data supported this finding but also revealed that most caregivers perceived good relationships with their wives, and that caregiving sometimes enriched their lives. Qualitative analysis suggested rewards outweighed negative experiences.	Supports presence of enrichment in caregiving. Limited information re. psychometric adequacy of measures, procedures for data analysis, or selection of sample.
Corbin & Strauss, 1988. The purpose was to examine chronic illness care as a work process from the perspectives of the caregiving couple.	This descriptive, theory generating design used grounded theory methodology.	Purposeful sampling of 60 marital couples representing a range of ages, medical diagnoses and socio-economic backgrounds. Theoretical sampling guided in-depth interviews of 2-3 hours' length regarding the work involved in managing chronic illness and daily lives for married couples.	Lines of work and illness trajectory emerged as the central concepts. Management in process refers to maintaining relative equilibrium among the lines of work. Sustaining commitment, one type of management in process, means sustaining shared understandings regarding the illness trajectory, lines of work, and each other's cherished identity. Sentimental work sustains cherished identities through making the other feel important, needed, and loved despite the illness.	This study emphasized the processes of managing care. Enrichment as a process may be related to sentimental work and sustaining commitment.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Dunkle, 1985. The purpose of this study was to explore the relationships between spousal versus adult child care provider households, and elders' depression.	For this descriptive correlational study, structured measures were administered in person to elder care recipients.	Impaired elders ($\underline{n} = 410$) were obtained from caregiving families selected for a larger study in terms of location, race, and structural composition. Scales included the Zung Self-Rating Scale for depression; self-rated health, perceived degree of need, perception of behavior of primary caregiver, and elder non-financial contributions to the household. The latter item included activities such as remembering birthdays, giving gifts, visiting with, or entertaining others. Demographic data were also collected.	Elder's perceived contribution to the household was significantly, inversely related to level of depression even after considering demographic, health, and kinship variables ($\underline{B} = .318$, $\underline{p} < .05$ for spouses; $\underline{B} = .924$, $\underline{p} < .05$ for child-parent relationships).	The items used to measure elder non-financial contributions suggest enrichment type processes were invoked by the elders. A limitation to the study was its exclusion of severely disabled elders, and the convenience sampling strategy used.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Erikson, Erikson, & Kivnick, 1986. The purpose of this study was to describe the psychosocial processes for vital involvement in living used by older persons.	For this exploratory descriptive study structured, open-ended interviews were based in part on information from a 50 year longitudinal study of families in Berkeley, Ca. Informant responses were organized by Erikson's developmental life stages.	The locally available surviving parents (n = 29) of 50 children from the 1940 Berkeley Guidance Study were invited to participate in two part interviews. The interviews, approximately two hours in length, covered reflections on past family events and current life views.	Elders' memories and current perspectives were analyzed across the eight life stages. Caring experiences, both remembered and existent, were used to ameliorate regrets from past, painful situations. Reminiscence brought to life feelings from an earlier time and was helpful in filling current emotional voids. Sense of identity involved both personal life review and strategies to create memories of the elder for younger generations. Sensory stimuli such as photos were helpful in evoking a sense of identity.	Excerpts from the interviews illustrate participants' strategies for reconciling their lives at each stage of the lifespan. These strategies may be related to enrichment from the care recipients' perspectives. Limited information regarding methods for analyzing the interviews. The participants tended to be well educated and life-long members of a middle to upper income Caucasian community that is dominated by a major university.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991. The purpose of the study was to answer the question, how do caregivers find meaning in the caregiving process?	For this exploratory descriptive design structured interviews were analyzed for thematic categories of finding meaning.	The volunteer sample of caregivers (n = 94) represented 34% wives, 32% husbands, 24% daughters. All care receivers had a diagnosis of Alzheimer's disease or another form of irreversible, progressive dementia. Two hour in-home interviews were conducted with the caregivers. The structured format included several scales and open-ended questions regarding difficult and pleasant aspects of caregiving, how caregivers continue in their roles, and what their lives are like now.	Four major themes emerged. Valuing positive aspects was the most frequently cited response (90% gave responses in this category). Valuing included family and social relationships, their caregiving as good care, experiencing the care recipient's love, and maintaining a positive relationship with the recipient. Searching for meaning included finding meaning in the caregiving experience.	Supports the presence of positive aspects in caregiving. The notion that caregivers choose their personal responses suggest the potential for interventions to facilitate positive meaning in the situation. Information not included regarding methods used to quantify interview responses for correlation with scaled responses.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Harvath, 1990. The purpose of this study was to describe concepts central to the management of problem situations for caregivers of family members with dementia.	The exploratory design used grounded theory methodology to identify and develop a model of filter and situational variables related to caregiver management of potentially problematic situations involving care receivers with dementia.	Purposive sampling of caregivers for persons with dementia who were exhibiting potentially problematic behaviors yielded 10 female caregivers ranging in age from 51 to 80. The interviews were based on a semi-structured interview guide. A structured questionnaire regarding caregiver stress and affect along with a demographic survey provided additional data. Constant comparative analysis, theoretical sampling, and theoretical memoing guided the development of concepts and their relationships.	Filter variables were used by family caregivers in determining whether or not a caregiving situation was perceived as problematic. These variables included perceived mutuality between caregiver and recipient; guidelines for care used by the caregiver; caregivers' reflections on their care; emotional and psychological empathy for the care recipient; and knowing the care recipient. Caregivers were less likely to perceive the dementia situation as threatening to their well-being when higher levels of mutuality, empathy, knowing the care recipient and reflections on care were present.	Supports the salience of perceived quality of the relationship as influencing the nature of the caregiving experience. Caregiving is not necessarily a negative or burdensome experience in and of its self. Additionally the concept, knowing the care recipient, has relevance in thinking about enrichment as a personally designed phenomenon.
Hasselkus, 1989. The purpose of this study was to understand the meaning of daily activity to family caregivers for the elderly.	This exploratory descriptive design used ethnographic interview methods to construct taxonomies of the domains of caregiving as defined by the caregivers.	Fifteen family caregivers were interviewed. All care receivers required daily personal and/or instrumental care. Four interviews, each one hour in length, were conducted. Initial questions were descriptive regarding the caregiving day; later questions were specific.	Three broad goals of caregiving activities were generated: 1) getting things done, 2) achieving health and well being for the care receiver, and 3) achieving health and well being for the caregiver. Part of achieving health and well being for the care receiver included feeling responsible for a variety and balance of activities in the care receiver's daily life.	Suggests that caregivers are concerned regarding the quality of the caregiving experience for both members of the dyad. Supports need to examine enrichment processes as part of the caregiving situation.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Hirschfeld, 1983. The purpose was to explore factors influencing families' abilities to live with and care for an older individual with dementia versus to consider institutionalizing the care recipient.	This exploratory descriptive design used grounded theory methodology.	A non-random sample of 30 demented elderly and family caregiver dyads was obtained. Care recipient age ranges were 59 to 92 years, 60% were males; 64% severely cognitively impaired. Caregivers were 73% female; two thirds were spouses. The OARS Multidimensional Functional Assessment Questionnaire (OMFAQ) was used along with in- depth interviews and observations. Both caregiver and care recipient were interviewed and their verbal and non-verbal interactions observed.	Mutuality emerged as the major factor in families' abilities to care for the elder. Mutuality grew from the caregiver's ability to find gratification in the relationship with the care recipient, and meaning from the caregiving situation. Mutuality, rather than sociodemographic or impairment variables, influenced the decision to institutionalize. Management ability, morale, and tension correlated strongly with mutuality, and also contributed to the decision to institutionalize.	Enrichment may be a process by which mutuality is sustained or enhanced.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Levine, Cartwright, Inoue, 1991. The purpose of this research was to develop a measure of quality in family caregiving.	This methodological study analyzed qualitative data from semi-structured interviews to develop indicators of quality of caregiving.	The convenience sample of 11 caregivers represented spouses and adult children; women and men. Care recipients included persons with a variety of cognitive and physical deficits. Data collection: Interviews covered aspects of the caregiving day, and caregiver approaches to specific activities. Scales measuring preparedness for caregiving, mutuality in the relationship, caregiver role strain, and rewards in caregiving were also administered.	Rating scales were developed to measure caregiver self report regarding competence, enrichment, and predictability in caregiving. Inter-rater reliability estimates using repeated measures ANOVA were .71 for predictability, .85 for competence, and .92 for enrichment. Preliminary evidence suggesting construct validity of the enrichment scale was revealed by correlational analysis of enrichment with rewards in meaning (Kendall's tau-b = .57, p = .018).	Content analysis revealed preliminary evidence for at least three types of enrichment in family caregiving: use of ceremony in caregiving tasks, intermittent integration of personalized, aesthetically pleasing activities in caregiving, and use of ritual or ceremony in the general caregiving relationship. Further work is needed in refining the concepts and the measures.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Morgan, & Laing, 1991. The purpose was to explore the early impact of a diagnosis of Alzheimer's disease from the perspective of the spouse.	This exploratory descriptive study used ground theory to reveal spousal perceptions of events surrounding the first few months of diagnosis.	Nine spouses of newly diagnosed AD patients were recruited from an outpatient clinic. Several unstructured interviews were conducted with the participants for the purposes of identifying salient themes and verifying emerging concepts.	Two categories of spousal responses emerged: the Grief group and the Role Strain group. The former group was most distressed by the relationship loss engendered by the diagnosis, and demonstrated an empathic approach to their spouse. This group reported a close marital history. The Role Strain group were most overwhelmed by their increasing responsibilities. This group reported a historical marital relationship characterized by conflict and lack of intimacy. For both groups, the prior relationship influenced motivation to provide care, ability to tolerate and manage the care, and perceived levels of burden.	While this study does not address enrichment per se, it does support the significance of historical context as impacting on the caregiving experience.
Motenko, 1988. The purpose was to describe husband caregivers' perceptions regarding the nature and meaning of caregiving and their use of respite services.	This exploratory descriptive study used in-depth interviews and observations in the home.	The sample consisted of six men with a mean age of 73 years. Length of caregiving time was either 3-6 years or 14-16 years. Wives were all severely disabled and dependent in ADLs. Taped interviews were transcribed for analysis. Field notes were kept. No additional information regarding data collection or analysis.	Caregiving was perceived as a positive experience which provided an opportunity for reciprocity and a means to maintain a loving relationship. While negative aspects were identified (monotony and decreased socialization) positive aspects predominated. Husbands experienced a sense of pride and responsibility for their caregiving.	Analysis of enrichment in family caregiving may reveal the processes by which reciprocity and sustained loving relationship are achieved within the caregiving dyad.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Myerhoff, 1978. The purpose of this study was to describe the lives and meanings of elderly Jewish immigrants affiliated with a Jewish senior citizen's center.	This exploratory descriptive design used intensive interviewing and participant observation over a two year period.	The membership and activities surrounding the Senior Center were studied in depth. Members were elderly, mostly immigrants from Eastern Europe during World War II, generally impoverished, in poor physical health, and had limited contact with their adult children.	The center was a constructed reality which reinforced self views of its members. Rituals and myths were used to create and preserve personal and collective meanings of one's life and one's heritage. Through shared symbols and activities, doing became believing. Rituals heavy with sensory symbols (food, music, stories) transformed improbable claims into reality. The notion of preserving personhood by remembering the person's past achievements was apparent.	The values and uses of ceremonies and symbols to sustain self within the senior center community have implications for family caregiving situations.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Orona, 1990. The purpose of this study was to describe the impact of the caregiving experience over time on self and other's identity for caregivers to people with Alzheimer's dementia.	Grounded theory methods were used to develop a theory of temporality and identity loss in family caregiving to people with Alzheimer's disease.	For the pilot study, five relatives caring for a person with Alzheimer's disease were interviewed in-depth. Later, open-ended interview techniques were used with ten relatives providing care for at least several years. Data were also collected from weekly case conferences at a memory clinic, and participant observations at two separate adult day health centers.	As the disease progressed, caregivers lost portions of their own identities (as well as care recipient identity loss) because the care recipient was unable to reciprocally participate in the dyadic relationship. Caregivers used memory keeping strategies to maintain self and other identities as the disease advanced. Memory keeping rituals, re-enactments of everyday living, were used to both normalicize and make special the caregiving situation.	The findings reveal the presence of activities which fit my definition of enrichment. This paper also suggests possible outcomes of enrichment vis a vis identity maintenance for caregiver and care recipient in the situation of caregiving for people with Alzheimer's disease. A limitation to this study, which examines identity loss over time, is that the data were collected through single interviews with respondents.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Parsons, Cox, Kimboko, 1989. The purpose was to determine relationships between elder care recipients' perceptions of the caregiving relationship and their level of functioning in situations of adult child caregiving.	This descriptive correlational design used structured and open-ended interviews. This paper reports only care recipient findings.	The convenience sample of 33 care receivers proportionately represented three ethnic populations (Black, White, Hispanic). The OARS Multi-functional scale measured level of functioning. Quinn's 1984 Components of Relationship measured affection, open communication, and perception of caregiver's feelings of affection. A single item, 10 point scale assessed satisfaction with caregiving arrangement. Open ended questions elicited general attitudes re. the caregiving arrangement.	No significant differences were found by ethnicity or gender. Level of social functioning was related to affection behaviors ($\underline{F} = 3.92$, $\underline{p} < .05$); open communication ($\underline{F} = 3.56$, $\underline{p} < .05$); & perceived caregiver affection ($\underline{F} = 14.59$, $\underline{p} < .001$). Level of satisfaction correlated significantly with all 3 components. Satisfaction did not correlate statistically with level of functioning. Open-ended responses revealed elders' concerns that they are burdens and of limited value in the caregiving household.	One of few studies from the care recipient's perspective. No descriptive demographic data. No information regarding psychometric adequacy of measures. Small convenience sample limits generalizability.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Phillips, & Rempusheski, 1986. The purpose of this study was to develop a theory of caregiving dynamics which accounts for the quality of the relationship, and has implications for nursing interventions.	This exploratory descriptive study was based on grounded theory methodology using intensive interviewing techniques.	"Good" (n = 28) and "abusive" (n = 50) caregivers were recruited through advertisements in three communities. Women and men, and spousal and adult child-parent caregiving relationships were represented. Theoretical sampling guided the interview questions. Interviews continued until theoretical saturation of the evolving theory occurred.	Caregiver role beliefs were influenced by their definition of the situation. Factors influencing definition included perceived personal identity of the elder, reconciliation of past with present identity, image of caregiving, and reconciliation of proscribed caregiving with perceived reality. "Good caregivers" tended to have normalized images of the care recipient. "Abusive" caregivers experienced divergence between their proscriptions and perceived realities. "Good" caregivers exhibited nurturing-supporting roles behaviors while "abusive" caregivers were monitoring and controlling.	The emergent theory of caregiving dynamics was developed in part by contrasting "good" and "abusive" caregiver characteristics. The proposed enrichment study may represent a complementary approach to examining caregiving processes.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Scharlach, 1987. The purpose was to examine the impact of caregiver adult daughter role strain on the quality of emotional support and psychological well-being perceived by care recipient mothers.	The correlational descriptive design involved questionnaires administered to both caregiving daughters and their mothers.	A convenience sample of 40 daughters was recruited. Twenty-four mothers were interviewed also. Caregiving activities were primarily instrumental with some personal ADL assistance provided. Zarit's Burden Interview (1982), Bengtson's Affectual Solidarity Scale (1981), and a two item, likert scaled measure of perceived role overload were administered to the daughters. Mothers completed the Bradburn Affect-Balance Scale (Moriwaki, 1974) and several likert-scaled items related to perceived loneliness and happiness.	Mothers' scores correlated highly, therefore were combined and standardized as psychological well-being. This variable was inversely correlated with daughter's role strain ($n = 24$, $r = -.47$, $p = .09$). All three of the daughter predictor variables accounted for 38% of mothers' psychological well-being ($n = 24$; $p = .05$).	Causality cannot be inferred. A limitation of the study is the relatively mild impairment of the care recipients.
Swanson, 1991. The purpose of this study was to develop a factor-naming theory of caring.	The descriptive design used phenomenological methods to inductively derive the theory from open-ended interviews and participant observations.	Participants ($n = 47$), obtained from three separate studies, included women care recipients and family as well as professional care providers. The care recipients were women in the childbearing cycle. Care providers were attending to either these women or to babies in the newborn intensive care unit. In-depth interviews were guided by ongoing data analysis.	Five caring processes were identified and refined: knowing, being with, doing for, enabling, and maintaining belief. The definition of caring which emerged emphasizes recognition of the specialness of the care recipient in providing care: "Caring is a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility" (1991, p. 165).	Intriguing findings in light of the range of caregivers who provided the data for these findings: women and men; family and professional caregivers.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Walker, A, Allen, K., 1991. The purpose was to explore outcomes in intergenerational family caregiving using a social exchange paradigm.	This qualitative descriptive study used semi-structured interviews.	Daughter and unmarried mother dyads ($\underline{n} = 29$) responded to an ad. Levels of care provided were low. Average age of daughters was 55 years; of mothers, 80 years. Semi-structured, open-ended interviews included questions regarding mothers' health status, nature of the caregiving activities, the situation in general, and the nature of the dyadic relationship. Data were analyzed for positive and negative caregiving patterns and sorted for themes using social exchange theory.	Three distinct relationship patterns emerged: intrinsic, ambivalent, and conflicted. Intrinsic pairs ($\underline{n} = 13$ pairs; 45%) were distinguished by their mutuality, participated in mutual, beneficial activities, and described themselves as equals. For ambivalent pairs ($\underline{n} = 10$; 34%) rewards were experienced with significant costs for at least 1 partner. For conflicted pairs ($\underline{n} = 6$; 21%) both partners experienced few rewards, frequent costs, and great conflict in the relationship. Intrinsic pairs had shorter caregiving careers ($\underline{F} = 3.78$, $\underline{p} = .04$), with daughters reporting fewer children ($\underline{F} = 8.02$, $\underline{p} < .002$) than the other two groups.	Mutually meaningful, shared activities distinguished the intrinsic dyads. This supports the presence of enrichment as defined by Cartwright, et al. (1991). Limitations to the study were the sampling criteria of cognitively intact care recipients, and the minimal levels of caregiving provided.

Author/Purpose	Design/Method	Sample/Data Collection	Findings	Comments
Walker, Martin, & Jones, 1992. The purpose of this study was to examine caregiving outcomes using the concepts of costs and benefits from social exchange theory.	The longitudinal correlational design used structured interviews at two months intervals.	A convenience sample of 141 pairs of mother/adult daughter caregiving dyads was recruited. Levels of parent care primarily involved instrumental assistance and bureaucratic mediation. All of the care recipients were free from diagnosed cognitive impairment. For daughters, demographic and situational variables such as mother's perceived need for care, daughter's health status, and perceived intimacy were measured against 7 potential caregiving benefits and 28 potential caregiving costs. Mothers completed similar scales.	For daughters' responses, three caregiving cost factors were identified using principal components factor analysis: insufficient time, frustration, and anxiety. None of the benefits items loaded in the analysis. For mothers, the following factors were identified: helplessness, feeling loved, and anger. Block regression analyses revealed predictor variables for the factors. For daughters, intimacy was a significant, negative predictor for insufficient time ($\underline{b} = -.30$, $\underline{p} < .0001$); and for anger ($\underline{b} = -.67$, $\underline{p} < .0001$.) For mothers, intimacy had a significant negative effect on anger ($\underline{b} = -.55$; $\underline{p} < .0001$.)	Because the perspectives of caregivers and care recipients regarding the care experience may differ, there is a the need for research which includes data from both groups. The findings suggest that situational factors versus demographic factors may be important in explaining caregiving outcomes. A limitation to the study is the sampling criteria of cognitively intact care recipients, and the minimal level of care required.

Appendix B

Review of the Non-research Literature

Appendix B

Summary of Selected Papers in the Non-research Literature Related to Enrichment in Family Caregiving to Frail Elders.

Author/Purpose	Major Points	Comments
Archbold and Stewart, 1987. The purpose of this presentation was to conceptualize caregiving and its importance to nurses.	Discusses the notion of the caregiver role as going beyond specific tasks. Suggests that caregiving may involve ritual activities that incorporate meaningful, individualized patterns and aesthetics to provide enjoyment for both caregiver and recipient. Cites Gadow's ideas regarding ritual time which emphasize individualized texture and patterns of caregiving as salient to the meaning of the experience. Suggests that significant ceremonies for caregiving dyads include predictability, aesthetics, and personally meaningful activities.	Summarizes the salient ideas of Archbold and Stewart regarding ceremony in family caregiving. Provides rational for an exploratory study of the enriching aspects of family caregiving.
Beck, 1988. The author describes her experiences in caring for her mother-in-law diagnosed with dementia.	After several decades of an uneasy relationship, reconciliation occurred as daughter and mother-in-law came to know each other through the caregiving experience. The essay describes several incidents that reflect use of rituals and little extras in the caregiving experience. These incidents frequently involve meaningful activities for the care receiver, pleasures based on past preferences, and use of humor.	A particularly interesting account in light of the fact that emotional attachment was not a paramount factor in the relationship in earlier years.

Author/Purpose	Major Points	Comments
Corbin and Strauss, 1991. Describes a nursing model for chronic illness management based on a trajectory framework that emerged from a grounded theory study of chronic illness.	The trajectory framework emphasizes the temporality of chronic conditions: that their course is varied and changing over time. Living with chronic illness affects everyday life and sense of identity. The course of chronicity can be shaped through proper management, most of which occurs in the home by the ill person and/or their family, and therefore within the context of everyday living activities. Conditions which influence management of chronic illness include resources, motivation, care setting, life style and beliefs, interactions and relationships, physiologic involvement, including symptoms, and the political and economic climate. Biography, the temporal dimension of identity, can be affected by illness or its management. The role of nursing in chronic illness management includes helping to shape the illness trajectory while maintaining quality of life. Nurses use "supportive assistance" in helping clients integrate proper management of illness with their biographical needs and the performance of everyday living activities. Supportive assistance is ongoing. It shifts in relation to changes in the illness trajectory, the client's and family's biographies, and the context of everyday living. Guidelines for nurses to use the trajectory framework in providing ongoing care to clients with chronic illness are identified. Emphasized is the idea that quality of life is an overriding goal of care; and the goal of blending illness management activities with biographical and everyday life activities.	The ideas described in this model seem salient to the notion of fine tuning by family caregivers. Fine tuning involves a similar balancing process in which frailty trajectories and personal histories are accommodated or aligned. Frailty trajectory, while similar to illness trajectory, is a broader concept, encompassing functional and affective changes that may occur separately from any specific pathophysiology. Personal history is similar to biography, but emphasizes the story or experiences which comprise the lifespan. These experiences, alone or in the dyadic relationship, provide a framework for knowing the other. Fine tuning addresses efforts by the family caregiver to accommodate two sets of frailty trajectories and personal histories while the chronic illness framework emphasizes the role of the nurse in accommodating a single client's illness trajectory with biographical and everyday activities. Quality of life is emphasized in both frameworks, although with fine tuning quality of life is viewed vis a vis enrichment. The ideas expressed in this paper, while providing a framework for nurses, are complimentary to fine tuning for enrichment in family caregiving.

Author/Purpose	Major Points	Comments
Dell, 1991, Personal Communication. The "Partners" program for caregiving dyads at an adult day care center was described.	A structured group program was developed to help caregivers relate to their loved, cognitively impaired elder in a positive way. The program includes recognition of both partners' strengths, integration of sensory stimuli to provide pleasure (cooking, music, etc.), and identification of ways in which the care recipient can contribute in a meaningful fashion to the relationship.	Reminiscent of family enrichment intervention programs, but adapted for situations of caregiving to frail elders.
Evenson, Evenson, & Fish, 1986. The purpose of this paper was to describe a family enrichment program for non-dysfunctional families recovering from the mental or physical disability of a member.	Structured enrichment programs are preventive and help families actualize their individual and collective potential. Organized activities rather than didactic strategies provide experiential learning for the family regarding their strengths and potential. Enrichment programs are being developed for non-traditional family situations such as single-parent families, expectant couples, and substance abuse families.	The concepts which are central to family enrichment programs may be applicable for considering enrichment which occurs in the situation of family caregiving to frail elders.

Author/Purpose	Major Points	Comments
Frankl, 1985. The purpose of this book was to describe Frankl's personal experiences with finding meaning while living in a Nazi concentration camp. These experiences and his observations of others influenced Frankl's ideas regarding meaning in life and how individuals achieve meaning under extraordinary circumstances.	To find meaning is a primary motivational factor in life. Finding meaning involves taking responsibility to find the right answers to one's problems. Self-transcendence involves finding meaning by going into the world, going out to others. Self-actualization is a "side effect" of self transcendence. Three strategies exist for finding meaning: Through creating work or deeds; through experiencing something or someone; through one's attitude towards unavoidable suffering.	Enrichment may represent a way of finding meaning in caregiving by loving behaviors to the care recipient. These behaviors may be considered both creating work and experiencing the other as forms of finding meaning. Care recipients may find meaning also through deeds, or through their attitudes and behaviors towards unavoidable suffering.
Gadow, 1983. The purpose of this paper was to discuss the concept of frailty in aging.	Frailty is an inevitable part of human existence. The meaning of frailty varies: infant (tender devotion) vs. aged (burden). From the rationalist perspective, the spirit (subjective: self, essence) and body (objective: flesh, transient) are separate. Frailty becomes problematic when the body "decays". In existentialism frailty may be viewed as either a "grim" or a "laughing, dancing" existence where one embraces all of life, including suffering (Nietzsche). Gadow suggests frailty may be seen as an intense experience which brings new life.	May provide a framework for viewing rituals of care as part of enrichment.

Author/Purpose	Major Points	Comments
Gadow, 1984. The purpose of this paper was to describe how technology and touch can co-exist in the caring situation through use of an empathic paradigm of mutuality between care provider and care recipient.	Patients are diminished to the status of objects when they are no longer at the center of their experience. The scientific paradigm, in emphasizing technology, views the body as machine. The empathic paradigm distinguishes between body as object versus subject by distinguishing between physical phenomenon as symptoms versus symbols. Symptoms reinforce the scientific, objective view of the body. Symbols emphasize the personal meaning of the experience to the person. Bodily difficulties become symbols of needs rather than symptoms of failure. Physical care can be viewed symbolically through the phenomenon of touch, which affirms the subjectivity of the individual. The symmetry of empathic touch involves mutual gift giving, the care recipient giving the gift of trust to the care provider.	May provide a basis for use of rituals in family caregiving to frail elders.
Gadow, 1986. The purpose of this paper was to describe three views of time which may be viewed in geriatric rehabilitation. Strengths and limitations for each of the views, limbo, linear, and ritual time, were discussed.	Physical disability and aging are situations where altered time perspectives may influence outcomes for rehabilitation. Limbo time refers to experiencing the present. Older persons may perceive themselves as trapped in the moment, with no foreseeable end to present suffering. Ritual time refers to a specially fashioned and personally meaningful pattern of experience, designed around the body's particular strengths and frailties. In ritual time, the body is considered a partner in recovery. It is "enjoyed and redirected; made comfortable and urged to exertion; listened to and spoken to" (p.5, 1986). Subjective vitality for the individual occurs with the ritual of care.	Ritual may be a type of enrichment.

Author/Purpose	Major Points	Comments
Geach, 1987. To discuss bedtime ceremonial activities and their role in human development with emphasis on the psychiatric setting.	Daily living is imbued with "ceremonials", routines that mark how things are done by the individual. While ritualist behaviors can be symptomatic of obsessive-compulsive disorders, rituals can also be meaningful cultural constructions with positive consequences.	Ritual activities may have positive dimensions that reflect the place of the individual in the family, community, and/or culture. In considering enrichment, activities that incorporate ceremonial elements may have positive consequences for the participants.
Gusfield and Michalowicz, 1984. The purpose of this paper was to review the literature analyzing symbolic and non-symbolic actions in three areas of secular life: institutions including politics and law; ceremonial events such as sports; and everyday life such as consumer goods and foods.	Reviews classical writings related to symbolism. Symbolism is denoted as something that stands for something else (Firth, 1973); as meaning that transcends the means-goal relationship (Lane, 1981); as that which is latent--not immediately apparent but perceptible. Symbolic analysis identifies different levels of meaning. The metaphysical approach separates signs into three kinds: icons, indices, and symbols. The latter have no inherent relation to their referent except through convention. Another approach to symbolism is found in considering context. Symbols are defined by contrasting them with the nonsymbolic. The salience of meaning in the eye of the beholder is emphasized in considering when meanings are symbolic: what is symbolic and metaphoric in one context and for one audience may be literal and mundane for another group. Additionally, the same object or activity may possess multiple meanings and consequences, depending on the perspective.	The salience of perspective in recognizing symbolic meaning is critical to an understanding of enrichment in family caregiving. Informants identified as imbued with symbolic significance objects and activities that an observer might consider mundane and literal. For example, TV shows and meals had symbolic meaning for some informants beyond mundacity or manifest purpose. Ricoeur's description of metaphor, while illustrative of how symbols operate, also supports use of alchemy in describing enrichment: "The metaphor surprises: It redefines reality by creating points of resemblance between actions and objects normally understood as unrelated or contradictory."

Author/Purpose	Major Points	Comments
Harvath, Gadow, Hagan, Brody, Schook, Archbold, & Stewart, 1991. This paper describes local and colonial knowledge in family caregiving to frail elders.	Local knowledge represents the skills and understandings that families bring to the caregiving situation based on their historical relationships and experiences. Colonial knowledge refers to "formal" knowledge the health care providers bring to the caregiving situation. Both types of knowledge provide complementary perspectives on the situation that can be used to develop effective caregiving interventions.	Suggests that personal knowledge of the care recipient by the caregiver can influence the nature of the care experience. Nurses can help families tap into local knowledge to improve the quality of their caregiving. The salience of the perspectives of members of the caregiving dyad vis a vis enrichment is reinforced by the ideas in this paper.
L'Abate, 1990. The purpose of this book is to describe a theory of interpersonal competence for use with families.	Discusses family intervention strategies that are primarily preventive in nature. Suggests that strengthening existing family interpersonal competence, through programs designed to tap both individual and collective strengths, is an essential component for preventive mental health care. Suggests that intimacy is the most vital of all family attachments. Intimacy requires love and negotiation skills, both of which can be enhanced through specific exercises.	Provides a theoretical framework for enrichment as a specific intervention that strengthens healthy families. Cited clinical examples do not include families caring for an aging or frail family member.

Author/Purpose	Major Points	Comments
Lawton, 1982. This paper discusses the relationships between competence, environmental press, and adaptation for older people.	Adaptation level represents a state of balance between the level of external stimulation (environmental press) and the sensitivity of the individual's sensory, perceptual, and cognitive state (competence). The greater the competence, the more press is required to achieve stimulation. Individuals with low levels of competence are sensitive to smaller changes in environmental press. Understimulation may result in boredom; overstimulation in maladaptive or negative behaviors. However, some stimulation acts to challenge maximum performance. Optimization principle refers to the balance between stimulation level and competence.	The notion of environmental press supports analysis of interviews with caregivers that suggest relatively small changes may be "enriching" to individuals who are frail. Environmental press may also explain the challenge of creating enrichment for a caregiving dyad whose members have different competence and adaptation levels based in part on differing frailty levels.
Low, 1987. The purpose of this article was to discuss the use of ritual time in rehabilitation of aged persons. Ritual time may be more appropriate to facilitate patient motivation than linear (future oriented) time with older persons.	Uses Gadow's classification of limbo, linear and ritual time as the basis for describing ritual time as an appropriate strategy when working with older persons. Habits based on new rhythms and rituals related to the limitations inherent in the existing body are most effective for "engagement in the world" by the patient, and for avoiding entrapment in limbo time, or condemnation to a limited future. Suggests several strategies for rehabilitation based on Gadow's ideas: 1) "little things" or small, short term goals; 2) daily activities based on their meaningfulness to the patient; 3) use of sensory stimulation based on historical meaningfulness to the patient; 4) facilitating a sense of control wherever possible.	Provides clinical applications for Gadow's ideas regarding ritual time.

Author/Purpose	Major Points	Comments
Myerhoff, 1984. The purpose of this paper was to discuss the relationships among ritual, time, and aging.	Rituals: 1) provide predictability in areas of anxiety and uncertainty; 2) reveal ideas, beliefs and dreams through "doing is believing" which emphasizes sensory and symbolic stimulation; 3) connect past, present and future; and 4) link self with self, self with others, self with community [Turner's communitas], or self with cosmos. There has been limited research into rituals during this life stage. There appears to be less ceremonial role specificity associated with old age than with other life stages. Rituals related to aging could provide a paradigm for the future during a period of great anxiety and social-biological tension.	Provides a theoretical framework for examining the presence of enrichment from the perspective of ritual in aging.

Author/Purpose	Major Points	Comments
Roberts, 1988. The purpose of this paper was to provide background information regarding ritual based on perspectives from anthropological and family therapy.	Key components of anthropological ritual include use of symbols, the concept of specialness in the ritual event, action as a necessary component, coordination of order and spontaneity, and a physiologic component. Ritual supports strong emotions, acts to coordinate individuals, families, communities, and to link past, present, and future; supports transitions and enhances social cohesion through increased individual limbic activity during shared ceremonies. Therapeutic and cultural rituals differ primarily in terms of extent of historical context. Therapeutic rituals are less embedded in ongoing family history. This provides greater flexibility for creating meaning, but may lack historical meaning. An advantage of historical meaning is its linking of past, present, and future. Family therapy builds on anthropological ritual. Family therapeutic ritual should incorporate multiple meanings and a variety of levels of participation.	Primarily a theoretical discussion. Numerous clinical anecdotes are used to illustrate the theory.
Silverman, 1990. The purpose of this paper was to describe ways to combine spirituality and science in the practice of medicine.	The curative medical paradigm is of limited value for persons with chronic or terminal illness, or the frail elderly. Distinguishes ceremonies from rituals as organized activities involving a community of persons and integrating subjective experience with objective reality through use of symbols, metaphors, and sacraments. Ceremonies have the potential to reconnect older persons with society by creating meaningful activities related to important aspects of the elder's life. Appropriate materials which are used as symbols during the ceremony are items which affect the senses.	Distinction between ceremony versus ritual is insufficiently developed. Builds on Myerhoff's ideas that rituals may be of value for individuals and society to deal with changes that occur in the aging process.

Author/Purpose	Major Points	Comments
Stegner, 1971. This passage is taken from a fictional account of the settlement of Grass Valley. The passage describes, in first person, the bath--bedtime ritual of the tale's narrator.	The protagonist, a middle aged writer, has paralysis of all limbs and is totally dependent on others for all his activities of daily living. The bath--bedtime ritual is a comfortable, predictable evening activity that closes each day. Sensory components of the ritual are emphasized: the pain in transferring; hot bath water that makes the "cicatriced stump prickle and smart"; cool pajamas; intimate toweling of the body dry. Symbols (objects with multiple meanings) abound. The night cap is a reward for the work of the evening as well as closure to the day and mild sedative. The bath and night cap reflect a convergence of the two individuals as equals versus employer-employee; caregiver--care recipient; frail versus sound.	Stegner responded to an inquiry regarding the caregiver's (Ada) point of view in this passage. He acknowledged that the passage was written solely from the protagonist's (Lyman) perspective but surmised that Ada would view this time, while "work", not with distaste; that the night cap routine was soothing and equalizing for them both. This anecdote demonstrates the elements of ritual as described by Wolin and Bennett regarding daily interactions; the open parts referred to by Myerhoff, and the individual fashioning of a personally meaningful pattern according to Gadow.

Author/Purpose	Major Points	Comments
Wolin & Bennett, 1984. The purpose of this paper was to review theoretical bases that delineate the place of ritual in family life. The clinical and research value of recognizing ritual behaviors in families was also discussed.	Family ritual is defined as "a symbolic form of communication that, owing to the satisfaction that family members experience through its repetition, is acted out in a systematic fashion over time" (p. 401, 1984). Functions of rituals include: establishing and preserving a sense of family identify, stabilizing this identity, delineating family boundaries and rules for the family, and providing a shared sense of belonging. Rituals may be categorized as 1) family celebrations; 2) family traditions; and 3) family interactions. The power of rituals includes the bonding effect that occurs among participants and the learning experience--one's place in the family, society, the cosmos. A key factor in maintaining meaningful family rituals is the notion of flexibility: the ability to incorporate change in the ritual without significantly altering the value of the ritual.	The typology of ritual categories may be of merit in looking at enrichment in family caregiving. Subsequent articles by Wolin and Bennett discuss their quasi-experimental research into family ritual and intergenerational transfer of alcoholism.

Appendix C

Support for the Analysis in Interview Data Bits: Enrichment in Family Caregiving to Frail Elders

Appendix C

Support for the Analysis in Interview Data Bits: Enrichment in Family Caregiving to Frail Elders

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
PERSONAL HISTORY Caregiver Care recipient Past Present	Past & current ways of achieving meaning or pleasure. Derives from lifespan interactions between personality traits and experiences. Similar to concept of biographical identity as used by Corbin & Strauss (1988), but emphasizes the stories or anecdotes that comprise biography.	"Well yes, she used to sing a lot. "Her and her sister used to sing duets together. The whole family is musical, you see. She liked it, that's what she liked to do. They used to sing for funerals, weddings." (OR011) "He just likes home-cooked, anything that's homemade. He was a bachelor for many years and so he appreciates cooking now. He cooked for himself for a long time." (OR020)
Empathic quality	Ability to vicariously experience the other's emotions.	
DYADIC RELATIONSHIP	Entwining of the histories of care recipient and caregiver.	"Uh, she and I were best friends. Spent a lot of time together--just go shopping--just do all kinds of things together...we like to shop--she loves to shop, I do to. We go shopping, window shopping, then have lunch. We like to do that. We don't do that anymore." (S054)
Mutuality	Positive quality of the relationship between caregiver and care recipient (Archbold et al., 1990)	"I moved up here with her and lived with her for a couple of years and she took care of me and I kind of took care of her. And she showed me--we went out berry pickin' places everywhere...she knew the time, the date when to go and pick berries and we would just bring them home by the bucket loads and then sit and just sit and clean 'em and talk and clean and talk and store 'em away and make whatnot like that..." (OR041)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
FRAILTY TRAJECTORY Caregiver Care Recipient	Physical, cognitive, emotional, and functional conditions of care recipients and caregivers that change over time. Most care recipients have a frailty trajectory that is in gradual decline.	"She calls–well she doesn't call him anything now. All our childrens' names begin with "J" so she'll call them all John, but the last few months, she doesn't call them anything.... Yeah, she's not on a plateau at the moment, on a down slope." (S150) "I can't get in and out of the car. It hurts me so bad it's not worth it....Well, I used to go to town with her every day shopping and going to stores with her and I don't know what" (OR050A) "I went up to see him [MD] and my MS–all the tests he gave me–everything was worse than when he detected my MS in early '89. And he says, 'What have you been doing? What's going on? What are you under?'" (OR050) "Well he's gotten so where he can help himself with a lot of things a lot more. So it makes it a lot more easy for me. At first I had everything, so I didn't have time to take care of the house and things–I was doing something all the time. But now, he does a lot for himself." (OR060)
Slope Direction	The slope may be steep or gradual. The direction of the trajectory may be upward, downward, or level.	
CAREGIVING SITUATION	Demands and requirements of the care recipient's and caregiver's frailty trajectories. Some situations have a pattern or rhythm, a harmony, to the day.	"She gets up in the morning, gets me ready to go. She gets my clothes...I can't [dress] myself..she puts them on me...twice a week I take a bath. [She] sits me down in the [shower] chair, gives me a bath. And I come out here, and I sit." (ORO60A)
Structure Predictability	Property of organization or patterning to the caregiving day. Extent to which activities or events in the caregiving day are anticipated.	"That's...it's about the same, everyday...You know, it's just everyday things....everything seems so cut and dried and the same every day, you know. I guess I've taken care of him so long now that it's just kind of a second nature." (OR020)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
ACQUIRING SYMBOLIC MEANING Value Intensity	Significance of an activity or object to the individual. Can change over time. The symbolic dimension reflects meaning that transcends utility. May be positive, neutral, or negative. Magnitude of feeling by the individual for the meaning.	"When I brought her down [here to live] and made up, I feel what I missed and probably what she missed, too...we made up for at least three years there, and now we're--we're still enjoying a few things now." (OR050) "She plays violin and she plays piano. That's what I miss now--she can't do it anymore...I just keep out of my mind, some of the things she used to do, I just try to blank them all the time, I don't want to dwell on them...it was so nice and good but I know what she did and that's it, but I don't want to just sit and listen and try to remember that song or this song." (OR011) "He was really happy to get to do that; to see all those people in the campground he'd know for years...So that was fun for us [day trip to old camp site]." (OR060)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
SYMBOLS	Objects or activities with meanings that have an abstract component which transcends utility; that may differ among individuals. (See Appendix E: Symbols Used in Enrichment)	"I still, I still hold up, you know, the [music] book when we're sitting here. I hold it up so you know--she can't read--no she can't read at all. [Why do you still hold up the book?] Just to make her feel normal, maybe..." (OR011SIS) "I read those [birthday cards] to him every day. I'm going to put a sign up after awhile that says, "Happy Birthday," and one of the grandkids wants to come by and have a piece of cake. We'll do that." (S053) "This is a beautiful tray, it will make her want to eat what she has on there. So I'll get a glass, a nice glass. She'll say 'No, jut get one of those.' And I"ll say, 'Why? Aren't you special? Yeah, you are special. You're the lady of this house. You're special.' Get that for her. I think it would make her feel better....Save, save for company. But who's coming? And then eventually she will say, 'Oh yes, I am special.' I'll say, 'You sure are. Right!' And she'll say, 'Right, bring that on!'" (S054)
Aesthetics	High ----> Low	
History	Have always done ----> Spontaneous	
Concreteness	Object ----> Event	
Meaning	What the symbol represents to caregiver and/or care recipient	

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
PERFORMING CAREGIVING ACTIVITY	Observable behaviors that are fashioned around the caregiving situation.	"At noon we don't have television on. That's the time that I talk and he listens, you know. It's kind of our time to visit." (OR020)
Pattern	Presence of sequencing or structure to the activity.	SIS asked CR if she would sing for me--that I had come to hear her sing. CR replied something like "wellll,uhhh." She looked a little uncertain. SIS said, "well, let's all sing." SIS went into the kitchen and returned with a handful of papers--words to songs; not notes. I joined them on the love seat---SIS was in the middle holding up the sheet music...CR usually started singing several words after SIS. Her voice was very clear, she knew all the words--to songs that contained multiple verses. On several songs, CR harmonized beautifully. During the singing, SIS held up the sheet of words. CR looked at the sheet music sometimes. Sometimes she looked at her lap. Always singing clearly, and not particularly softly. Her expression was not animated during the singing. (OR011SIS; Field Note)
Occurrence	Frequency with which the activity is performed. Ranges from often to rarely; regularly to spontaneously.	The care recipient spends every Thursday with her sister. "And is it usually in the afternoon that it [singing] happens?" "Yes. If I start the words, then she can sing...we can sing a couple of hours, two maybe, with a nap in between." (OR011SIS)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
FINE TUNING	The process of aligning or accommodating the frailty trajectories and histories of both caregiver and care recipient in an effort to create an experience that has special meaning or pleasure for both members of the dyad.	"I bought *Modern Maturity* in here too and the songbook and CR was sitting--I'm sitting here and CR was sitting here, and uh, we sang for awhile and then, pretty soon, she was sleeping and so I got out my *Modern Maturity* and read [laughs] and then she'd wake up, so I'd get the book again and we'd start singing and...we can sing a couple of hours, two maybe, with a nap in between." (OR011SIS)
Context Knowing other Resources Strategies	See Appendix D: Support for the Analysis in Interview Data Bits: Fine Tuning.	"We did quite a bit of hiking and bird watching. We'd take our binoculars and go out and bird watch, had our bird books. That was our main activity for the last five years before he got sick. A lot of times we'd drive way out by the river some place and just bird watch...[later] while we were still in the house, we had bird feeders out be the windows and he'd watch the birds, but here, we just don't have birds...sometimes I read aloud to him if I have a book that I think he is interested in...an article about birds I find, that he's interested in." (OR020)
CAREGIVER REWARDS OF MEANING	One positive consequence of enrichment for the caregiver. Reflects pride of accomplishment in caregiving role. The presence of enriching activities may be associated with higher levels of rewards of meaning. This term (*rewards of meaning*) derives from the work of Archbold, Stewart, 1988)	"...you could just tell she enjoyed it. She just enjoyed the day, you know, so that made me enjoy it, too." (OR050) "It makes me feel good, uh hum. It does. It makes me feel good, cause I love my mother. You know, she's always just been special. I want to do everything I can to make her life special as I can..." (S054)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
CAREGIVER IDENTITY SUSTENANCE	One positive consequence of enrichment for the caregiver. Reflects self affirmation separate from caregiving role.	I: "So, you enjoy music as sort of background for the rides or during your day, but you're not sitting there listening for all the nuances in the music as much as it's a pleasant background?" CG: "I think that's a fair statement." I: "Okay. And it may trigger memories from when you were younger?" CG: "A lot of it. Yeah, we hear music that ties in, reminds you of that - very much." (OR021) "We sit there and talk about some of the old days...You know, what a character I was when I was young; how she put up with me. It brings back a lot of memories to me when I was a kid. I enjoy it. [We] laugh about it." (OR031)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
RELATIONSHIP SUSTENANCE	One positive consequence of enrichment for both members of the dyad. Reflects maintenance or nourishment of positive dimensions in the relationship.	"There's little things that work now like music. The old masters--the big bands, the vocalists....they bring back memories. They seem to dig out memories with CR more than just talking about the old times." (S151) "It brings back memories and, uh--back in our day, singing and playing the ukeleles was [laughter], you know. We, we made our own entertainment....It's [singing together] the only thing that, uh, we can do together anymore." (OR011SIS) "I then generally, um, get into bed with him for a while [they have twin beds] and we love each other up and we say our morning prayer and then we get up and he makes breakfast. I make the beds...." (111) "She picked a bunch of berries and it was--she loved it, you know. We came back and bought a beer--a bottle of beer--and shared a bottle of beer as we went home. It was kind of neat...really a cherished moment." (OR041)
CARE RECIPIENT IDENTITY SUSTENANCE	One positive consequence of enrichment for the care recipient. Reflects self affirmation separate from care recipient role.	"There's usually three men and they sit here and talk about things that have been happening over there, you know, and he listens and laughs, and he knows what's going on. They bring him up to date on everybody that he knew over there....The friends he's had for a long time and they just tell him all the news and they just treat him like he was going to talk with them." (OR020)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
CARE RECIPIENT COMFORT	Care recipient experiences solace in the enriching event.	"And when I come home, my daughter had my little Christmas tree decorated and the house all decorated for Christmas. I was so glad to get back home that...she's the sweetest little one I ever met. She sure was good to me.... Yeah, it was sure a night....I sat down and cried...a little Christmas tree about this high and she had it decorated and the house all decorated so pretty." (OR050A)
ENRICHMENT PROCESS	The convergence of three core elements, *acquired symbolic meaning, performing activity*, and *fine tuning* to create an activity with special meaning or pleasure that is individually fashioned to accommodate the dyad's frailty trajectories with their biographies.	Alchemy is a metaphor for understanding enrichment processes. The alchemists desired to turn mundane elements into gold. They tinkered with various substances combined in different amounts and sequences in their efforts to change common objects into precious metals. Similarly, mundane objects and events are made special through enrichment in family caregiving. Valence, a property that alchemists considered when mixing elements, reflects the interacting or uniting power of the three core elements in enrichment: assigning meaning, performing activity, and fine tuning. Enrichment in family caregiving reflects a process of transforming everyday objects and events into something special through the interaction of the core elements.
ENRICHING EVENT	An activity with special meaning or pleasure that can be described and observed, and that encompasses behavioral (activities), affective (meanings), and fine tuning (cognitive) processes.	"Then I go over a lot in the afternoons, but she sits and watches those soaps and they make me nervous. I mean, I can't sit and enjoy them. I don't know why. I'm just not a soap opera person....She'll say a lot of times now, 'You be over here by 7:00; you get around.' So I hurry up and try to have dinner and a lot of times I have to leave half my dishes so I can hurry up and get in the shower and get my jammies on so--and half my dishes sit, but I usually make it over there to watch that show with her....Oh, just kind of laughing and trying to guess it and maybe I'm wrong and she'll laugh at me and she's wrong, I'll laugh at her and just kind of giggle, you know, and sometimes you're right and 'yea!', you know." (OR050)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
Sub-categories of Enriching Events 1. CUSTOMARY ROUTINES	Activities that are patterned and predictable parts of the day. Includes rituals or ceremonials whose known and anticipated patterns of familiarity breed a sense of comfort. Comforting by virtue of the activity's presence in the daily rhythm.	"There's a little routine when I put him to bed. I just tell him that I hope he has a good night and that he'll sleep well and to call me if he needs me and that I love him. That's just about the same thing every night. We go through the same routine. If I miss one thing, he knows it and he sort of reminds me that I've missed one of those things." (OR020) Friday night is Jack Daniels time. We have popcorn and drinks. She'll have a drink and she might not even drink. I'll have my second drink. [Do you have a special room? Special glasses?] Right here [this room]. Well, we have some good ones--they're big. Yeah, we have special glasses for our cocktails. We might have the TV on--*Crossfire*. If not, we'd have the radio on. (OR021) "Every morning we have a lesson we study and we have a book that has readings for every morning. I read that and then I give a prayer afterwards, see. She used to pray but she...she doesn't want...I kept on until finally she said 'No, you do it.' And I didn't push it then. So, she'll tell me she knows all about it. Of course, she grew up that way in her home." (OR011)

CATEGORY & PROPERTIES	DEFINITION	EXAMPLE
2. ROUTINE BREAKERS	Activities which are not routine, but which add a bit of stimulation to the day.	"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. You know, you can only do so much for her and that tickles her, so I try to do that every once in awhile. I don't make it an everyday habit. I make it a treat." (OR050) "If I go in to get a cup of coffee, I go in to get her a drink, or pop corn, something like that, she's sitting here all comfortable, just give her a kiss, or pat her on the cheek as I go by. Just keeps the flame burning, you might say." (S151) "I always make a big deal out of what we're eating. A couple of weeks ago we were going out to dinner, so I made them a candle light dinner. You know, they thought that was great! I'm not sure how romantic it was, but it was different." (081)

Appendix D

Support for the Analysis in Interview Data Bits:

Fine Tuning

Appendix D

Support for the Analysis in Interview Data Bits: Fine Tuning

CODE	DEFINITION	EXAMPLE
PERSONAL HISTORY	See Appendix C	
DYADIC RELATIONSHIP	See Appendix C	
FRAILTY TRAJECTORY	See Appendix C	
CAREGIVING SITUATION	See Appendix C	
INTERVENING FACTORS	Situational conditions of *context*, *knowing other*, and *resources* that influence the nature of an enriching event.	See specific situational conditions for exemplary data bits.

CODE	DEFINITION	EXAMPLE
CONTEXT	Environmental conditions that influence the selection of strategies for fine tuning. Includes *social tolerance*, *physical safety*, and *managing transitions*.	See specific environmental conditions for exemplary data bits.
Social tolerance	Caregiver comfort with care recipient behaviors in a public situation	"Mom loves music...I take her to the symphony concerts at the college. This year our seats are on the front row and it's frustrating to me because Mom is so friendly that she's sitting there waving at all the players that are in the orchestra and there's two men that just about fall off their chairs in laughter...If they can't get me tickets back farther I'm not going to go again because it's embarrassing to me." (022) "We would always go to church. We would go together. But the last time, she had a purse, she had a purse in a purse. She may have had 4 purses. One inside the other, with zippers. Zip, zip, zip. Everybody was turning around--what was going on. So I just got to the point that I didn't tell her that it was Sunday." (S150) "Most of the time I say, if people don't like what they see, that's their problem." (111)

CODE	DEFINITION	EXAMPLE
Physical safety	Evaluation of safety factors related to care recipient participating in an enriching event.	"And she used to love to go shopping. I'd take her grocery shopping. She is so slow. I'd say, gee, everyone is in a hurry, and she'd hold onto the cart for balance. And I thought a cart would protect her, but I thought, God, I'd never do that again. It really frightened me. I thought people would run into her." (S051) "We were climbing around on that mountain. We got stuck one day....we got to this one point and it was a big, high boulder and no way could I get him over that boulder. I was beginning to get upset because I could see this helicopter coming...What I did in the end was I built a place to put your foot and had him turn around so he couldn't see the drop-off and we walked along the ledge of this cliff, and got onto the other side of the path. We were all relieved when that was over." (S053) "I guess that's the only way it could be done, except try to get her up the stairs, and I just--I just don't ever want her to fall. I don't want to have to go through all that again." (OR050) [Reference to showing remodeled bedroom to care recipient.]

CODE	DEFINITION	EXAMPLE
Managing transitions	Amount and type of effort required to bring about the enriching event during changes in the frailty status of the care recipient.	"Anymore, I have to put my leg under him so he doesn't miss the seat. And then we have to get his heavy legs in, and it's difficult...Yesterday [sigh] I couldn't get him in the truck. He wanted to go, but he couldn't figure out what he was doing wrong, and he wouldn't pay attention to what I was tellin' him to do--couldn't do what I was telling him to do--whatever. Got annoyed with me, when I wanted him to come back in the house [chuckles]." (S053) "She can even walk down that ramp and walk out in her walker, except the last couple times we did it she got so tired, and you could tell she did. So, then it got so I said, 'well, I should get the wheelchair' so, either my husband or son or son-in-law goes in and wheels her out." (OR050) "Well I used to go to town with her every day shopping and going to stores with her...I can't get in and out of the car. It hurts me so bad, it's not worth it." (OR050A)

CODE	DEFINITION	EXAMPLE
KNOWING OTHER	Refers to the use of information, both historical and ongoing, regarding what is pleasurable or meaningful to the other; and ways that the other person has achieved meaning or pleasure in the past and now.	See specific sub-categories of *historical knowledge* and *ongoing knowledge* for exemplary data bits.
Historical knowledge	Knowledge based on historical information.	"I would take him to air shows because he flew an airplane and he likes--he loves the noises." (S053) "The only think I ever remember my Mom doing is working...her big thing, I guess, was to go to Reno with my Dad. Her and my dad would go to Reno, that was her big thing. Or shopping. They never went out shows, she's just never had a social life at all, she never knitted, she never sewed, she never--you know, so I think that's why she's so satisfied...." (OR050)

CODE	DEFINITION	EXAMPLE
Ongoing knowledge	Knowledge based on present cues.	"I tried to take her to town a couple times after she got home and she gets real dizzy and I kind of think she's kind of going into an anxiety attack--so she don't wanta ride in the car." (OR050) Oh, laughing and, um, she has a good sense of humor and just her laughter, and you know, as I said, she likes to kiss and hug--doing that. That lets me know she's happy. Whenever she sees you, want you to greet her, kiss her. That's happy, makes her feel good. She wants that. I know she feels good when that's going on." (S054) "She loves to go for a ride. She enjoys a ride in the car...she's just sitting there, looking at everything, seeing how beautiful the sky is. She likes the blue sky." (S151)

CODE	DEFINITION	EXAMPLE
RESOURCES	Critical factors that shape the enriching activity. May act to either constrain or facilitate enrichment.	See specific factors of *time, energy*, *opportunity structure*, and *significant other assistance* for exemplary data bits.
Time, Energy	Perceived extent and amounts available to caregiver for providing enrichment.	"Now it just depends how my day's going...a lot of times I got stuff I've gotta get done and 'course my own work and I've always got wash and I try to get everything I have to do done in the morning because I--afternoons I do not function well..." (OR050) "Like I say, some nights I can't [watch TV]. Like if he gets home late from work and I'm running late or--sometimes I can't watch the program but I do go over every night so I always let her know..." (OR050) "I have enough [time and energy]. The Lord gives me just what I need for each day, so that's what I depend on." (S053)

CODE	DEFINITION	EXAMPLE
Opportunity Structure	Unique properties of the situation that are used to facilitate enrichment.	[How did these two particular shows come about for you to share?] "Well, cause they're on. Cause they're on at that time...they just happened to be on." (OR050) "I told the doctor, 'there's one thing I'd like to ask as a favor--is it all right if she goes to the maternity ward before she goes in to have her surgery?' He looked at me, and I said, 'Just last night her first great, great grandson was born. She would really like to see him'...The nurses were all lined up and they said, 'Here she is.' She said, 'How come you all know my name?' And they took her up to see him and it was real emotional. She wanted to hold him. She said, 'One comes and one goes.' The thought was there...The next day was her 91st birthday." (S052) "Evenings we depend on the television to entertain ourselves. She'll say 'I haven't seen this before.' And that's good--that aspect of Alzheimer's is good. Because she won't be bored with it. She won't say 'I won't see this--I've seen this a dozen times." (S151)

CODE	DEFINITION	EXAMPLE
Significant Other Assistance	Perceived assistance from other people either in providing enriching experiences or in providing assistance which frees the caregiver to have sufficient time and energy to engage in enrichment.	"[Friend] always makes this, what they call a torte, for Easter and never fails to make an extra one too for Mom. Mom can't eat them that much because the nuts. That's why she makes a special one for her, and she calls me to come get it and bring it to Mom." (S052) "The girls, they're really thoughtful about--when they are going to do something, they almost always invite us to go along...Last weekend they had a big yard sale in [town]. Well, two of my daughters decided we could go [laughs]. I said, 'well those streets are terrible--its terrible in [town].' They said, oh no problem. They just each take one side of the wheelchair and carry him along! He liked that! (OR060)

CODE	DEFINITION	EXAMPLE
STRATEGIES FOR FINE TUNING	Ways of incorporating meaningful or pleasurable activities into the caregiving situation over time. Selection is based on antecedent conditions and intervening factors.	See specific strategies for exemplary data bits.
Anticipating Strategy	The caregiver thinks about potentially enriching activities that might be incorporated into the situation.	"[Daughter] came over the other day and had this book about Alaska cruises, the inland passage. And she said 'when would you like to do it?' And I said, 'Well, I don't know'. And she said they had the boat very well equipped for handicapped. They even carry their own wheelchairs. I said I don't know, and CR said 'Yes. I would like to. I've always wanted to do that.' So she booked us! So maybe--you don't know how things go." (OR060) "I'm trying--we're having a women's day celebration next Sunday. I'm trying to get her, I've already started talking to her about it. I'm going to get her clothes together--who knows." (S054)

CODE	DEFINITION	EXAMPLE
Adding Strategy	An opportunity to incorporate a new type of enrichment evolves as the frailty status changes.	"Now, I kiss her good night, tell her good night like she used to do with the kids. Tell her that she's going night night...when the kids were little, she would say 'fahnani', which is Swiss, I suppose. And I will say 'fahnani', and she will close her eyes like a little kid....It stopped when the kids got older. It just started up naturally [with wife]. It seems like it was kind of a similar situation now, but tucking [wife] in instead of the kids." S150) "But if have time and he needs that little extra comfort, I'll feed him...I'll say 'you like that', and he'll say 'yes.'" [Use of feeding on an intermittent basis as a way to bring pleasure to the situation of eating for the care recipient. Originally started during an acute illness for nourishment; now used as an occasional treat.] (081)
Maintaining Strategy	An enriching event is continued despite changes in the frailty status of care recipient or caregiver.	"We take them out to dinner quite a bit too, ad they enjoy that. Mostly to the Chinese restaurant because it's easy, there are no steps, and they can east it...that was one of their favorite cuisines when they were younger." (081) "We sit here on the couch [watching TV] and he holds my hand...he did that before he had his stroke too. It was just one of those things" (OR020)

CODE	DEFINITION	EXAMPLE
Modifying Strategy	Adjustments are made in the way the event is enacted while retaining the essential pleasure or meaning.	"I told her that the huckleberries were just extremely thick, just a really, really wonderful crop this year. She goes, 'Oh, God, I wish I could go.' I said, 'Well, you can.' She says, 'Aw, I can't walk out there." I says, 'We can figure something out. I want to show you it anyway. It's really abundant." ...I had a Pontiac car at that time, and it kind of sat low and it was easy to get her into and I put her crutches in there, and threw her dog in there and we headed up to [berry patch]...I put down a lawn chair for her, she just sat down on the lawn chair..." (OR041) "You can see every type of person on the face of the earth if you go to [beach community]--they're bound to pass you on the street! The last two, three times that I took her, we just sat in the car. [Now], I can get the same results by going down on [local main street] and we watch the people go by...her enjoyment is as good one place or another...[it] is very pleasant."(SF151)

CODE	DEFINITION	EXAMPLE
Substituting Strategy	When a special or pleasurable activity can no longer occur, something new is developed as replacement.	"There's a little routine when I put him to bed. I just tell him that I hope he has a good night and that he'll sleep well and to call me if he needs me and that I love him. That's just about the same thing every night. We go through the same routine." (OR020) "When I got my bedroom done, she said, 'Oh, I'll never get to see your bedroom. I'd love to get to see it." I said, 'Mom, when we get done I'll take pictures." And I mean that satisfies her. Course she knows what it looked like before, you know so that satisfies her too." (OR050)

Appendix E

Symbols Used in Enrichment in Family Caregiving

Appendix E

Symbols Used in Enrichment in Family Caregiving to Frail Elders[1]

ACTIVITY	SO51	SO52	SO53	S054	S150	S151	OR01A	OR020
SINGING		X						
MUSIC	X	X			X	X		
CHURCH				X				
HOME WORSHIP								
MEAL TIMES				X				X
SPECIAL FOODS	X	X		X	X			X
HAPPY HOUR								
WAKE ROUTINE						X		X
SLEEP ROUTINE					X			X
FRIENDS		X						X
FAMILY		X						
WALKS			X	X		X		
DRIVES			X		X	X		

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[1] This table identifies selected objects and activities around which enrichment is fashioned.

ACTIVITY	SO51	SO52	SO53	S054	S150	S151	OR01A	OR020
TRIPS								
OUTINGS								
EATING OUT				X				
SPORTS EVENTS								X
TV						X		X
CLOTHES			X			X		
HAIR CARE						X	X	
REMINISCENCE		X		X		X		
HOLIDAYS		X		X				X
BIRTHDAYS		X	X	X				
POETRY		X					X	
WORK			X					
CONVERSATION								X
FLOWERS								
BIRD WATCHING								
SPECIAL EATING UTENSILS				X				

ACTIVITY	OR030	OR050	OR060	OR011	11SIS	OR021	OR041	081	022	111
SINGING					X					
MUSIC					X	X			X	
CHURCH				X						
HOME WORSHIP		X		X						X
MEAL TIMES								X		
SPECIAL FOODS		X						X	X	
HAPPY HOUR						X				
WAKE ROUTINE								X		X
SLEEP ROUTINE	X		X							
FRIENDS										
FAMILY	X	X	X							
WALKS				X				X		
DRIVES						X		X		

ACTIVITY	OR030	OR050	OR060	OR011	11SIS	OR021	OR041	081	022	111
TRIPS	X		X			X				
OUTINGS	X	X	X			X	X			X
EATING OUT	X			X		X		X		
SPORTS EVENTS			X							
TV		X	X							
CLOTHES										
HAIR CARE	X							X		
REMINISCENCE	X									
HOLIDAYS		X								
BIRTHDAYS	X	X								
POETRY										
WORK										
CONVERSATION	X	X	X			X				
FLOWERS		X								
BIRD WATCHING	X		X							
SPECIAL EATING UTENSILS						X				

Appendix F

Study Participants

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[1] I wish to acknowledge and thank Drs. Patricia Archbold and Barbara Stewart, Oregon Health Sciences University School of Nursing for allowing me to use their Family Caregiving Measures in this study.

Appendix F

Study Participants

Caregiving dyads were recruited for the study using two strategies: purposeful sampling through formal agencies that provide caregiver and senior programs (n = 18), and snowball sampling of friends (n = 2).

Criteria for participation in the study included:

- Care recipient is 65 years of age or older.
- Caregiver is personally knowledgeable regarding the care recipient.
- Caregiver assists with at least one of the following: bathing, meals, transfers, transportation.
- The care is believed to be provided in ways that make the situation special or meaningful.

Twenty caregivers were interviewed over an 18-month period. One caregiver had been providing care for two elderly parents. Interview data related to the recently deceased parent were not analyzed for this study. In two situations, two caregivers were providing care for the same elder. The data summarized in the following tables reflect information regarding 20 caregivers and 18 care recipients. In summary, 20 caregiving dyads encompassing 20 caregivers and 18 care recipients were examined.

Table F-1 displays demographic information regarding the caregivers and care recipients. In terms of caregiver relationship to the care recipient, ages of the dyadic members, and length of time providing care, the participants in this study were similar to the caregivers and care recipients analyzed in the National Informal Caregivers Survey by Stone, Cafferata, & Sangl (1987).

At the conclusion of the initial interview, participants were asked to complete, at their convenience, a questionnaire comprised of four scales developed for the Family Caregiver Relief Study (Archbold and Stewart, 1988). The questionnaires were number coded to protect anonymity, and returned to me by mail. Table F-2 lists item responses by frequency for the participants. Table F-5 summarizes psychometric information related to the scales.

The caregivers in this study were compared with caregivers from the Alzheimer's Disease Center of Oregon (ADCO) study on scores for the following scales: mutuality, rewards of meaning, preparedness for caregiving, and global strain (see Table F-3). Mutuality, rewards of meaning, and preparedness for caregiving were believed to be required in order to have enrichment. The enrichment study group scored significantly higher on the mutuality, rewards of meaning and preparedness scales ($\underline{p} < .01$), and lower on the global strain scale ($\underline{p} < .05$). These findings are interesting in light of the purposeful sampling plan to interview caregivers who make special or meaningful their caregiving situation for the enrichment study. In explaining the purposeful sampling criteria to gatekeepers, I asked them to identify "successful" caregiving dyads–caregivers who seemed to be doing a good job, who were making special their caregiving situations. The scores on preparedness, mutuality, and rewards of meaning suggest that the enrichment study informants met the purposeful sampling criteria to a greater extent than caregivers in the ADCO study who, while not randomly chosen, were not selected using criteria related to enrichment.

Simple correlations were performed among the scale scores and with a subjective rating of enrichment (see Table F-4). The subjective rating of enrichment ("subj.enr") was assigned by me on the basis of reading the transcripts and field notes prior to inspecting participants' responses to the other scales. Participants were assigned scores ranging from 1 to 10 based on the nature and amount of enrichment that was subjectively appraised to exist in the caregiving situation. The higher the score, the greater the appraised presence of enrichment. For subjective enrichment, the mean score assigned was 6 with a standard deviation of 3.3. Scores ranged from 1 to 10.

This analysis supported the findings of Archbold et al. (1990), Levine et al. (1991), and Stewart et al. (1993) that mutuality and rewards of meaning are highly and significantly correlated. In this study, mutuality and rewards of meaning demonstrated a shared variance of 46% ($r = .68$; $p = .001$). The investigator assigned rating of enrichment correlated significantly with mutuality ($r = .54$, $p = .011$), rewards of meaning ($r = .59$, $p = .005$), and scores for global strain ($r = -.45$, $p = .035$). Interestingly, global role strain, while correlating significantly with the subjective enrichment score and preparedness for caregiving ($r = -.48$, $p = .025$), did not correlate significantly with mutuality ($r = -.37$, $p = .07$) or rewards of meaning ($r = -.26$, $p = .15$). However, the magnitude and direction of these correlations are similar to other studies (Archbold et al., 1990; Stewart et al., 1993). The absence of statistical significance for these correlations may be due to the small size of the sample in this study.

Archbold and Stewart (personal communication, October, 1991) and Levine, Cartwright, and Inoue (1991) hypothesized that enrichment in family caregiving may lead to greater levels of mutuality and rewards of meaning, and to diminished levels of global strain in the caregiving role. While the statistical analysis reported here is offered only to more fully describe the qualitative study participants, the significant relationships among mutuality, rewards of meaning, global strain, and subjective enrichment scores are promising, and consistent with hypothesized associations.

Table F-1

Demographic Data Regarding Caregivers and Care Recipients

Caregiver age	M = 67 yrs	SD = 11.9 yrs	Range = 39-86 yrs
Length of time in caregiving role	M = 5.5 yrs	SD = 5.4 yrs	Range = 0.25-25 yrs
Caregiver gender	71% female	---------	---------
Caregiver relationship to care recipient[1]	24% wife	19% husband	33% daughter
Care Recipient age	M = 84 yrs	SD = 10.7 yrs	Range = 65-104 yrs
Care Recipient gender	67% female	---------	---------
Care Recipient has a cognitive deficit diagnosis	43%	---------	---------

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[1] 5 (24%) = "other" (2 daughters-in-law; 1 son; 1 sister; 1 grand-nephew)

Table F-2

Informant Responses to Caregiver Scales: Item Responses

Preparedness for Caregiving

We are interested in your present view of how well prepared you think you are to do each of the following even if you are not currently doing that activity. For each of the following questions, please CIRCLE the number that matches the response that best describes you.

	NOT AT ALL PREPARED	NOT TOO WELL PREPARED	PRETTY WELL PREPARED	VERY WELL PREPARED
1. How well prepared do you think you are to take care of your family member's physical needs?	0	0	9 (43%)	9 (43%)
2. How well prepared do you think you are to take care of your family member's emotional needs?	0	2 (10%)	10 (48%)	5 (24%)
3. How well prepared do you think you are to find out about and set up services for your family member?	0	0	8 (38%)	10 (48%)
4. How well prepared do you think you are for the stress of caregiving?	0	3 (14%)	12 (57%)	3 (14%)
5. Overall, how well prepared do you think you are to care for your family member?	0	0	12 (57%)	6 (29%)

(table continues)

<u>You and Your Family Member</u>

Now we would like you to let us know how you and your family member feel about each other at the current time. Please read the following questions and **CIRCLE** the number that matches the response that best describes you.

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
1. To what extent do the two of you see eye to eye?	0	1 (5%)	3 (14%)	5 (24%)	7 (33%)
2. How close do you feel to him or her?	0	1 (5%)	0	3 (14%)	13 (62%)
3. How much do you enjoy sharing past experiences with him or her?	0	0	4 (19%)	2 (10%)	11 (52%)
4. How much does he or she express feelings of appreciation for you and the things you do?	1 (5%)	1 (5%)	4 (19%)	4 (19%)	8 (38%)
5. How attached are you to him or her?	0	1 (5%)	1 (5%)	3 (14%)	13 (62%)
6. How much does he or she help you?	5 (24%)	4 (19%)	3 (14%)	3 (14%)	3 (14%)
7. How much do you like to sit and talk with him or her?	0	2 (10%)	4 (19%)	6 (29%)	5 (24%)
8. How much love do you feel for him or her?	0	0	1 (5%)	4 (19%)	13 (62%)
9. To what extent do the two of you share the same values?	2 (10%)	1 (5%)	1 (5%)	3 (14%)	11 (52%)
10. When you really need it, how much does he or she comfort you?	4 (19%)	2 (10%)	4 (19%)	4 (19%)	4 (19%)
11. How much do the two of you laugh together?	1 (5%)	3 (14%)	4 (19%)	3 (14%)	6 (29%)

(table continues)

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
12. How much do you confide in him or her?	4 (19%)	2 (10%)	3 (14%)	5 (24%)	4 (19%)
13. How much emotional support does he or she give you?	5 (24%)	3 (14%)	1 (5%)	4 (19%)	5 (24%)
14. To what extent do you enjoy the time the two of you spend together?	0	2 (10%)	3 (14%)	4 (19%)	8 (38%)
15. How often does he or she express feelings of warmth toward you?	1 (5%)	3 (14%)	3 (14%)	5 (24%)	6 (29%)

(table continues)

Informant Responses to Caregiver Scales: Item Responses

Your Reactions to Caregiving

This section focuses on rewards of caregiving. The list of questions that follow are about rewards other caregivers have identified. Please read the following questions and **CIRCLE** the number that matches the response that best describes you. **CIRCLE** "NOT AT ALL" if the question doesn't apply to you.

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
1. To what extent is caring for your family member rewarding for you?	0	2 (10%)	4 (19%)	5 (24%)	7 (33%)
2. To what extent does caring for your family member help you feel like you are doing something important?	1 (5%)	0	2 (10%)	5 (24%)	10 (48%)
3. To what extent does caring for your family member help you feel good about yourself?	1 (5%)	1 (5%)	4 (19%)	2 (10%)	10 (48%)
4. To what extent does caring for your family member add meaning to your life?	1 (5%)	1 (5%)	3 (14%)	5 (24%)	8 (38%)

(table continues)

Informant Responses to Caregiver Scales: Item Responses

Your Experiences with Caregiving

For each question, **CIRCLE** the number that corresponds with your response.

1. From our discussions with many caregivers, we know that for some people, caregiving is very confining, while for others, it is not. How confined to you feel because of all the caregiving things you do for your family member?	Not at all confined 1 (5%)	Confined a little 6 (29%)	Somewhat confined 6 (29%)	Confined a lot 3 (14%)	Extremely confined 1 (5%)
2. How often would you say that taking care of your family member is very difficult?	Never 2 (10%)	Rarely 5 (24%)	Sometimes 7 (33%)	Much of the time 2 (10%)	Always 0
3. How much stress do you feel because of all your obligations, including taking care of your family member? Do you feel	No stress 2 (10%)	Very little stress 0	Some stress 11 (52%)	A lot of stress 4 (19%)	Over-whelming stress 0
4. In the balance, would you say that the positive aspects of caring for your family member outweigh the negative, that the negative aspects outweigh the positive, or that the positive and negative aspects are about equal?	Positive outweighs the negative a lot. 8 (38%)	Positive outweighs the negative somewhat. 1 (5%)	Negative and positive are about equal. 6 (29%)	Negative outweighs the positive somewhat. 2 (10%)	Negative outweighs the positive a lot. 0

Table F-3

Comparisons of Scores on Caregiver Scales: Enrichment Study Group Versus Alzheimer's Disease Center of Oregon Study Group (ADCO).

	Comparison Groups						
	Enrichment Study			ADCO Study			
Scale	n	M	SD	n	M	SD	t
Mutuality	18	2.80	1.00	194	2.16	.94	2.62**
Rewards of meaning	18	3.07	1.06	198	2.04	1.03	3.96**
Preparedness for caregiving	18	2.32	.40	196	1.89	.59	4.14**
Global strain	17	2.08	.49	191	2.28	.74	1.67*

* $p < .05$ (1-tailed significance)
** $p < .01$ (1-tailed significance)

Table F-4

Correlations Between Scores on Cargiver Scales[1]

	1	2	3	4	5
Preparedness	1.0	.37 p = .06	.42 p = .04	-.02 p = .46	-.48 p = .025
Mutuality		1.0	.68 p = .001	.54 p = .01	-.37 p = .07
Rewards of Meaning			1.0	.59 p = .005	-.26 p = .15
Enrichment (subj.)				1.0	-.45 p = .035
Global Strain					1.0

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[1] Correlations among all measures were based on 18 participants except for the correlations for global strain scores that were based on responses from 17 participants.

Table F-5

Psychometric Information for the Caregiver Scales.

				Reliabilities	
SCALE	n *	M	SD	Alpha	Test-retest
Mutuality	194	2.16	.94	α = .94 T1 α = .95 T2	r = .92 [1]
Preparedness	196	1.89	.59	α = .83 T1 α = .86 T2	r = .81
Rewards of Meaning	198	2.04	1.03	α = .85 T1 α = .89 T2	r = .82
Global Strain	191	2.28	.74	α = .73 T1 α = .72 T2	r = .83

* Total Sample at Time 1 (T1) = 202
Retest Sample at Time 2 (T2) = 99

STUDY SOURCE: Oregon Family Caregiving Survey (Stewart, Archbold, et al, 1993)

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[1] All test-retests were conducted at 1 month intervals (T1, T2).

Appendix G

Methodological Issues Related to Use of Intensive Interviews and Participant Observations in the Home with Caregiving Dyads

Appendix G

Methodological Issues Related to Use of Intensive Interviews and Participant Observations in the Home with Caregiving Dyads

Issue	Description	Discussion
Gaining entree to family caregivers and to frail elder care recipients	Difficulties in gaining access to participants were encountered at the gatekeeper level and when talking with potential participants.	▸ Levels of support from formal gatekeepers varied. Community nurses, while voicing interest in the topic, were least helpful in identifying potential participants. Reasons cited included heavy caseloads which precluded time to think about the research, and lack of access to families that met the purposeful sampling criteria. Social services personnel, particularly case managers, were most helpful. ▸ Talking with formal agency personnel about the study, including details regarding the methodology and human subjects protection, along with sharing a short abstract of the research seemed most effective in garnering agency support (see attachment). Follow up reports were provided to agencies that requested information regarding the findings. ▸ Families identified the following reasons for not participating in the study: ● refusal to be audio-taped; ● reluctance to allow a stranger (the investigator) into their home; ● refusal to sign any papers (informed consent); ● unwilling to share personal information with interviewer; ● difficulty arranging for time to participate in the interview; ● unavailability of another person to stay with the care recipient during the interview; ● care recipient was considered too frail to be separated from the caregiver. ▸ Investigator "legitimization" by formal gatekeepers and, in the situation of snowball sampling during the pilot, common friendships among the informant, the investigator, and a third party, were helpful in allaying some informants' concerns related to participating in the study.

Issue	Description	Discussion
Gaining entree (cont'd)	Difficulties in gaining access (cont'd)	▸ Methodological memos about the investigator's anxiety related to stifled access were useful in sorting out strategies for gaining entree and alleviating a sense of personal rejection (2/13/92; 2/17/92; 3/14/92).
Investigator invoked reactivity	The sustained participant–investigator relationship that developed through intense interviewing may have influenced caregiver or care recipient responses to questions, or behaviors during observations.	▸ One caregiver did not complete the mail survey regarding mutuality, rewards in caregiving, preparedness for caregiving, and global role strain. This individual wrote a detailed letter describing their inability to answer the questions. This incident was discussed at length with the dissertation committee. Issues around social desirability and the intense nature of the investigator–participant relationship in this study were discussed. A theoretical memo was written on the incident (12/14/92) ▸ The following strategies were used to minimize the risk of investigator invoked reactivity: ● Prolonged engagement (caregiver interviews lasted from 2 to 6 hours), ● repeat visits, ● interviews with multiple participants in the same household, ● investigator assurances of confidentiality related to the interviews, ● privacy for the interviews, and ● number-coded surveys to minimize the risk of reactivity. ▸ Transition to less structured, more open-ended interviews may have minimized the potential for reactivity. With the exception of some probes related to enrichment, participants were encouraged to talk at length about their caregiving situations in general.

Issue	Description	Discussion
Investigator role conflict	Families frequently had questions regarding nursing and medical care of the care recipient. Paradigmatic assumptions for this research did not include investigator objectivity or neutrality. Therefore nursing information and community resources were shared with participants. An additional dilemma arose when the investigator's nursing assessment of the care situation suggested interventions were needed.	▸ During the course of the interviews, questions sometimes arose regarding symptom management for the care recipient, or sources for help. The investigator provided time to discuss and answer participant concerns. In several instances where the investigator did not have answers, follow up phone calls or letters with the information were made to the participants. ▸ On three occasions the investigator was concerned that care recipients might require additional medical follow up. In each case the concern, with specific recommendations, was shared with the caregiver. In two of the cases, the gatekeeper agency was also appraised of the investigator's concerns. ▸ The Human Resources Committee at Oregon Health Sciences University required the investigator to include a statement in the informed consent addressing her obligation to report suspected abuse. ▸ The writing of Taylor (1991) regarding close relationships in special research situations was helpful in clarifying concerns that arose in the process of interviewing and observing caregiving dyads.

Issue	Description	Discussion
Doing friendship	The intimate nature of the interview and participant observations led to an interjecting of social niceties with the research. Bosk's strategies for doing friendship were invoked to maintain a balance in these gift relationships.	▸ The ideas of Bosk (1979) vis a vis doing friendship and of Finch (1984) regarding trust versus exploitation were helpful in maintaining awareness regarding the risks of over-rapport, and over-indebtedness. ▸ Strategies for minimizing investigator over-indebtedness included sharing professional information and resources, bringing small gifts to follow-up interviews, writing thank you notes for all interviews, selective sharing of personal information, and a listening ear when the participant wandered beyond the focus of the interview. ▸ Strategies for minimizing over-rapport included writing field notes and memos that detailed investigator feelings engendered in some interviews and discussing these feelings with experienced field researchers. Time and distance also served to attenuate feelings of over-rapport. ▸ The risk of over-generalization was addressed by seeking confirmatory data bits from two or more participants for all analyses, and by use of a research team acting as audit mechanism to review and critique theoretical memos and findings. ▸ Concerns regarding collective exploitation (Finch, 1984) of caregivers who enrich was addressed by framing the findings in their full contexts. The salience of antecedent and intervening conditions was specifically recognized in writings related to the findings in an effort to minimize romanticization of caregiving.

Issue	Description	Discussion
Doing friendship (cont'd)	When interviewing vulnerable populations, the concern exists that participants may not assume a self-protective role in the research situation (Archbold, 1986).	▸ The balance between developing sufficient rapport to facilitate participant comfort in sharing their experiences and feelings, and exploiting the loneliness of frequently isolated individuals was addressed in the following ways: ● Discussed with Dr. V. Olesen in preparation for the pilot study was the possibility for potentially sensitive conversations. We agreed that if interviews seemed to be moving into a sensitive area, the investigator would stop the interview and specifically ask the participant if they were comfortable proceeding with the conversation; with sharing this information. ● Participants were invited to review their situations which were used to illustrate specific concepts in the papers. No participants indicated discomfort regarding the content or manner in which their situation was portrayed in the papers, or a reluctance for the information to be shared in a paper. ● Personally identifying information was deleted or altered in manuscripts.

Issue	Description	Discussion
Investigator uncertainty in the role of participant observer	The isolated nature of family caregiver became apparent early in the interviews. The investigator experienced feelings of discomfort as a potential intruder on the caregiving scene unless specific activities were identified for observation. The notion of "hanging out" was uncomfortable to the researcher.	▸ Kleinman's advice (1991) to recognize feelings as a resource for understanding the phenomenon under study guided recording of reflective memos regarding this issue (1/18/92; 11/93) ▸ The dissertation committee helped the investigator think through the nature and purpose of participant observations. Strategies for proposing selected "hanging out" with participants were identified. These were ultimately not used in this study as the data collection period ended prior to the opportunity for additional planned observations. ▸ Dr. Arlie Hochschild, who has used participant observation in the home, was consulted. Dr. Hochschild affirmed the discomfort that frequently accompanies "hanging out" in another home, and indicated that boredom is an additional issue. Strategies for blending in to the setting were suggested. These included pitching in with chores and bringing snacks for the day. ▸ Jules Henry's account (1971) of participant observation in households with mentally ill children was read. While Henry devoted little space to describing the method or its challenges, his narrative revealed the extent of his participation in other's homes.

Issue	Description	Discussion
Relationship negotiation among strangers	For most of the interviews, a "re-emergence" phase occurred while saying good bye after intense discussion about the caregiving situation. On one occasion where the leave taking was cut short, the investigator experienced significant discomfort around inadequate closure of the relationship.	▸ Realization that the interviews involved strangers engaging in intense discussions regarding intimate feelings and experiences occurred early in the data collection. A recurrent exit phenomenon was noted: both participants and investigator engaging in re-emergence talk. In the process of saying good-bye, general topics were brought into the conversation. These topics included family photos and mementoes on display in the home, the weather, the community, the investigator's family. ▸ One particularly intimate interview where this activity did not occur (multiple phone interruptions for caregiver) was later resolved through re-emergence talk in a subsequent interview. ▸ The phenomenon of relationship negotiation was identified during the pilot study. Time for re-emergence talk was allocated in all subsequent interviews.

Appendix G

Abstract Attachment

for Gatekeepers

ENRICHMENT PROCESSES IN FAMILY CAREGIVING TO FRAIL OLDER PEOPLE

INVESTIGATOR: Juliana Cartwright, RN, MN, doctoral student, School of Nursing, Oregon Health Sciences University, (503) 899-8141.
SUPERVISOR: Patricia Archbold, RN, DNSc, Professor, School of Nursing, Oregon Health Sciences University, (503) 494-3840.

PURPOSE: To identify enrichment processes used in family caregiving to frail elders. Enrichment refers to those activities which provide meaning or pleasure in the situation. These are generally activities that are personalized in nature, or that have been developed to make special some aspect of the caregiving situation. The goal for this research is to understand the processes which enhance the caregiving relationship--processes that might be the basis for caregiving interventions by nurses and other care providers.

METHOD: Interviews, observations, and questionnaires. If possible, interviews and observations will be conducted with both the caregiver (CG) and care recipient (CR). CG interviews are anticipated to last between 1 and 2 hours, although experience reveals that caregivers frequently <u>want</u> to talk--therefore the interviews may last longer. Permission to return for additional interviews may be requested.

Questionnaires will be left with the CG to complete and return via mail to the investigator. The questionnaire takes about 15 minutes to complete.

SAMPLING STRATEGY:

1. Study criteria:
    - CR over 65 years.
    - CG is personally knowledgeable re. CR.
    - CG assists with at least one of the following: bathing,meals, transfers, transportation.

2. The caregiver is articulate--willing to talk to the investigator.

3. The care is believed to be provided in ways that make the situation special or meaningful.

4. Ideally, the participants will consent to be audio-taped, and will consider being observed during selected aspects of their CG situation (special routines, interactions, etc.)

5. Ideally, the CR is willing to talk and is capable of signing an informed consent; or a responsible party is willing to let CR talk with the investigator, and is willing to sign a consent.

PROTECTION OF PARTICIPANTS:

All interviews will be transcribed with personally identifying information deleted in the process. The tapes will then be destroyed. Transcripts and questionnaires will be tracked by code numbers. The participants will be invited to review the analysis of their situation. Only the investigator and the dissertation committee will have access to transcripts. Abstracts for any presentation will be mailed to the participants.
Approval for this study has been received from the Oregon Health Sciences Committee on Human Subjects (7/2/92).

Appendix H

Interview Guides

Caregiver Interview Guides

Care Recipient Interview Guides

Table H-1

Revisions in the Interview Guides Over the Course of the Study[1]

Change	Rationale	Comments
Wording change to emphasize "making special" *I'm interested in learning about ways that the caregiving day and activities are made special or pleasurable for both of you.*	The original probes used "personalize" or "specialize" in reference to the caregiving. "Making special" was thought to capture the nuances of activities that transcend the caregiving more than the original wording, which elicited responses related to how care was individualized.	
Addition of probes for time and energy *How much time and energy do you see yourself as having?*	Caregiver time and energy were identified during the pilot study as critical resources for the presence of enrichment. Probes were added to elicit caregiver estimates of their levels of time and energy.	
Addition of a probe regarding the presence of assistance from significant others *Is there anyone that the care recipient counts on and looks forward to seeing or being with?*	During the pilot analysis people besides the primary caregiver were identified as participating in enrichment efforts with the care recipient.	A terminology concern arose in developing this label. Social support was specifically avoided. Rather, the goal was to select a term that suggested "important others" who were family or friends.

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[1] Special thanks and acknowledgement for the ideas of the following people are in order: Drs. P. Archbold, B. Limandri, V. Olesen, B. Stewart, and C. Tanner.

Change	Rationale	Comments
Addition of probes regarding how enriching activities were modified over time *How did you come to be doing this activity?* *Have you had to change or modify how you do this over time?* *Have you had to stop certain activities that were once enjoyable?* *How do you feel about these changes?*	The temporally dynamic nature of caregiving, including enrichment processes, was identified early in the analysis. Participants continually referred to their changing situations, and how they needed to modify their approaches.	This probe was critical in eliciting information that helped develop the notions of fine tuning and frailty trajectories.
Addition of probes to elicit evidence for CG/CR feelings *If I were in your shoes, how would I have a sense that care recipient is enjoying this activity?*	Added to elicit evidence for special meaning or pleasure by either CG or CR. The behaviors and comments elicited by this probe were critical in evaluating the plausibility of the analysis.	Used whenever an enriching incident was cited to garner evidence for meaning/pleasure.
Addition of a probe regarding if or how the care recipient ever initiates enriching activities *Does care recipient ever initiate specific activities that you both enjoy?*	During the pilot, participants were citing anecdotes that demonstrated care recipient initiated enrichment. Therefore a probe was added to capture this phenomenon.	Care recipient-initiated, enriching anecdotes are present in the data but have been minimally analyzed to date.

Change	Rationale	Comments
Modification in the care recipient interview guide Probes that attempted to elicit stories of the care recipient as a person and the nature of the care recipient--caregiver relationship were added.	Care recipient interviews were brief and elicited less description than caregiver interviews. This may have been related to limited participant articulation in some cases. However, comparison of the CG and CR interview guides revealed that CRs were given little opportunity to talk about their situations in a general sense, unlike the caregivers.	Probes were added that provide increased emphasis on the care recipient as a person, and on the nature of the relationship with the caregiver. These have not been used to date.

CARE GIVER INTERVIEW GUIDE

Questions guiding initial interviews with caregiver and care receivers regarding enrichment in the caregiving experience.[1]

CAREGIVER QUESTIONS:

1. Could you start by telling me a little bit about care receiver [CR] as a person, both before s/he needed your help and now?

2. I am interested in how your day goes in caring for CR. Could you describe to me what a typical day (perhaps yesterday) is like in providing care to CR? Imagine that I am coming to take care of CR and you want to make sure that I understand how to do things your way. I'd like to hear as much as possible about the beginning of the day, when you wake up--to the end of the day, when you fall asleep, for both CR and you.

While a lot of research has looked at the tasks that caregivers perform, we know very little about how families personalize these activities to make their situation meaningful or pleasurable. I'm interested in learning about ways that the caregiving day and activities are specialized or enjoyable for both of you.

3. I'd like to know more about how you personalize or specialize the caregiving for both CR and your self. (Probes reflecting back to specific details of situation described in #2. Preliminary content analysis by Cartwright et. al., 1991, suggests key situations may be meals, morning care, outings, evening time.)

4. Are there any things you do because they are special to you or to CR?
    How did you come to start doing this?
    How do you feel when you do this?
    How do you think CR feels?

5. Are there times of the day that you spend with CR that you or CR especially look forward to?
    Could you tell me about what happens during these times?
    How did you come to be doing this activity?
    How do you feel when you do this?
    How do you think CR feels?

6. Are there things you do for CR just because you think that s/he likes or enjoys

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[1] The ideas of Pat Archbold and Barbara Stewart were especially valuable in helping me develop a preliminary interview guide for exploring enrichment in family caregiving.

December, 1991

it? Could you tell me about what happens during these times?

How did you come to be doing this activity?
How do you feel when you do this?
How do you think CR feels?

7. Are there any other aspects in the caregiving that you especially look forward to or enjoy? Could you tell me about these times or events?

PROBE: These activities could be things that you do every day, or only occasionally–maybe at special times of the week or year.

PROBE: Sometimes families may not even realize how they are personalizing the care, but they do certain things because that's the way they've always done them in their family. For example, one person mentioned that he always gives the CR their morning coffee in a special mug–a mug that is only used by CR, and only at breakfast time because it has a special memory to them.

How did you come to start doing these things?
How do you feel when you do this?
How do you think CR feels?

PROJECT TITLE: ENRICHMENT IN FAMILY CAREGIVING TO OLDER PEOPLE

CAREGIVER INTERVIEW GUIDE

1. Could you start by telling me a little bit about [CR] as a person, both before s/he needed your help and now?

2. I am interested in how your day goes in caring for [CR]. Could you describe to me what a typical day (perhaps yesterday) is like in providing care to [CR]? Imagine that I am coming to take care of CR and you want to make sure that I understand how to do things your way. I'd like to hear as much as possible about the beginning of the day, when you wake up--to the end of the day, when you fall asleep, for both of you.

Does anybody else help out with the caregiving?

While a lot of research has looked at the tasks that caregivers perform, we know very little about how families personalize these activities for their situation. I'm interested in learning about ways that the caregiving day and activities are specialized or enjoyable for both of you.

3. I'd like to know more about how you personalize or specialize the caregiving for both [CR] and your self. (Probes reflecting back to specific details of situation described in #2. Key situations may be meals, morning care, outings, evening time.)

4. Are there any things you do because they are special or you both enjoy them? Could you describe this activity in detail for me?
   How did you come to start doing this?
   How do you feel when you do this?
   How do you think CR feels?
      If I were in your shoes, how would I have a sense that CR is enjoying this activity? (actual statement by CR/behavioral indicators, etc.)

2/6/92

5. Are there times of the day that you spend with [CR] that you both look forward to?

Could you tell me about what happens during these times? How is this special for both of you?

How did you come to be doing this activity?

How do you feel when you do this?

How do you think [CR] feels?

If I were in your shoes, how would I have a sense that [CR] is enjoying this activity? (actual statement/behavioral indicators, etc.)

Are there any activities you and [CR] did once, but can't do now?

How do you feel about this?

6. Are there things you do for [CR] just because you think that s/he likes or enjoys it? Could you tell me about what happens during these times?

How did you come to be doing this activity?

How do you feel when you do this?

How do you think [CR] feels?.

7. Does [CR] ever initiate or request activities that you both enjoy? Would you tell me a little about what happens in these situations?

8. Are there any other aspects in the caregiving that you and/or [CR] especially look forward to or enjoy?
PROBE: These activities could be things that you do every day, or only occasionally–maybe at special times of the week or year.
PROBE: Sometimes families may not even realize how they are personalizing the care, but they do certain things because that's the way they've always done them in their family. For example, one person mentioned that he always give the CR their morning coffee in a special mug--a mug that is only used by CR, and only at breakfast time because it has a special memory to them.

Could you tell me about these times or events?

How did you come to do start doing these things?

How do you feel when you do this?

How do you think CR feels?

Innovation probe: How did you happen to think about that?

9. Over the time you have been caring for CR, has CR's condition changed in ways that have changed your caregiving? Could you tell me about changes in the way you manage the situation? What about changes in the way you personalize the caregiving?

Probe by specific tasks mentioned earlier--how have you changed the way of personalizing these activities?

Have you had to modify or stop certain activities that were once enjoyable?

(Story strategy: tell me a story about the personalized task--how it started, over time, and now)

How do you feel about these changes?

10 Looking dow the road a piece, what do you anticipate with managing the care situation? Do you have any ideas about what you might do if you can't continue some of the personalized, special activities you've told me about?

11. This is the last question: How much time and energy do you see yourself as having?
[May be woven into the script at earlier questions--or asked now]

12. Is there anything you would like to ask me?

PROJECT TITLE: ENRICHMENT IN FAMILY CAREGIVING TO OLDER PEOPLE

CAREGIVER INTERVIEW GUIDE

While a lot or research has looked at the tasks that caregivers perform, we know very little about how families personalize these activities for their situation. I'm interested in learning about ways that the caregiving day and activities are specialized or enjoyable for both of you.

1. COULD YOU START BY TELLING ME A LITTLE BIT ABOUT [CR] AS A PERSON, BOTH BEFORE S/HE NEEDED YOUR HELP AND NOW?

2. I AM INTERESTED IN HOW YOUR DAY GOES IN CARING FOR [CR].

> Can you describe to me what a typical day (perhaps yesterday) is like in providing care to [CR]?

Imagine that I am coming to take care of CR and you want to make
sure that I understand how to do things your way.
I'd like to hear as much as possible about the beginning of the day, when you wake up--to the end of the day, when you fall asleep, for both of you.

IS THERE ANYONE THAT CR COUNTS ON AND LOOKS FORWARD TO SEEING OR BEING WITH?

3. I'D LIKE TO KNOW MORE ABOUT HOW YOU PERSONALIZE OR <u>MAKE SPECIAL</u> THE CAREGIVING FOR BOTH [CR] AND YOUR SELF. (Probes reflecting back to specific details of situation described in #2. Key situations may be meals, morning care, outings, evening time.)
ARE THERE ANY THINGS YOU DO BECAUSE THEY ARE SPECIAL OR YOU BOTH ENJOY THEM?

Could you describe this activity in detail for me?

interview.cg
8/13/92

4. CAN YOU TELL ME ABOUT SOME TIMES THAT IT MATTERS THAT IT IS YOU GIVING THE CARE RATHER THAN ANOTHER PERSON? SOME THINGS THAT IT IS REALLY IMPORTANT THAT YOU DO, THAT YOU DON'T WANT ANYBODY ELSE TO DO?

How did you come to start doing this?
How do you feel when you do this?
How do you think CR feels?
IF I WERE IN YOUR SHOES, HOW WOULD I HAVE A SENSE THAT CR IS ENJOYING THIS ACTIVITY? *(actual statement by CR/behavioral indicators, etc.)*

HAVE YOU HAD TO CHANGE OR MODIFY HOW YOU DO THIS OVER TIME?

5. ARE THERE TIMES OF THE DAY THAT YOU SPEND WITH [CR] THAT YOU BOTH LOOK FORWARD TO?
Could you tell me about what happens during these times? How is this special for both of you?

6. ARE THERE ANY ACTIVITIES YOU AND [CR] DID ONCE, BUT CAN'T DO NOW?
How do you feel about this?

HOW DID YOU COME TO BE DOING THIS ACTIVITY?
HOW DO YOU FEEL WHEN YOU DO THIS?
HOW DO YOU THINK **[CR]** FEELS? *IF I WERE IN YOUR SHOES, HOW WOULD I HAVE A SENSE THAT [CR] IS ENJOYING THIS ACTIVITY?*

COULD YOU TELL ME ABOUT WHY THIS ISN'T HAPPENING ANY MORE?

7. ARE THERE THINGS YOU DO FOR [CR] JUST BECAUSE YOU THINK THAT S/HE LIKES OR ENJOYS IT? Could you tell me about what happens during these times?

8. DOES [CR] EVER INITIATE OR REQUEST ACTIVITIES THAT YOU BOTH ENJOY? WOULD YOU TELL ME A LITTLE ABOUT WHAT HAPPENS IN THESE SITUATIONS?

9. ARE THERE ANY OTHER ASPECTS IN THE CAREGIVING THAT YOU AND/OR [CR] ESPECIALLY LOOK FORWARD TO OR ENJOY?

PROBE: These activities could be things that you do every day, or only occasionally–maybe at special times of the week or year.

PROBE: Sometimes families may not even realize how they are personalizing the care, but they do certain things because that's the way they've always done them in their family. For example, one person mentioned that he always give the CR their morning coffee in a special mug--a mug that is only used by CR, and only at breakfast time because it has a special memory to them.

Could you tell me about these times or events?

INNOVATION PROBE: HOW DID YOU HAPPEN TO THINK ABOUT THAT?

HOW DID YOU COME TO DO START DOING THESE THINGS?
HOW DO YOU FEEL WHEN YOU DO THIS?
HOW DO YOU THINK CR FEELS?

10. OVER THE TIME YOU HAVE BEEN CARING FOR CR, HAS CR'S CONDITION CHANGED IN WAYS THAT HAVE CHANGED YOUR CAREGIVING? COULD YOU TELL ME ABOUT CHANGES IN THE WAY YOU MANAGE THE SITUATION? WHAT ABOUT CHANGES IN THE WAY YOU MAKE SPECIAL THE CAREGIVING?

Probe by specific tasks mentioned earlier--how have you changed the way of personalizing these activities?

Have you had to modify or stop certain activities that were once enjoyable?

How do you feel about these changes?

(STORY STRATEGY: tell me a story about the personalized task--how it started, over time, and now)

11. LOOKING DOWN THE ROAD A PIECE, WHAT DO YOU ANTICIPATE WITH MANAGING THE CARE SITUATION? Do you have any ideas about what you might do if you can't continue some of the personalized, special activities you've told me about?

12. This is the last question: HOW MUCH TIME AND ENERGY DO YOU SEE YOURSELF AS HAVING?
[May be woven into the script at earlier questions–or asked now]

13. Is there anything you would like to ask me?

OVER THE COMING DAYS AND WEEKS, YOU MAY THINK ABOUT THINGS FROM OUR DISCUSSION. I WOULD GREATLY APPRECIATE YOUR SHARING ANY IDEAS THAT COME TO MIND, ABOUT HOW THE CAREGIVING IS **MADE SPECIAL**. IF YOU THINK OF ANYTHING, WOULD YOU BE WILLING TO MAIL ME A NOTE, OR GIVE ME A CALL?

PROJECT TITLE: ENRICHMENT IN FAMILY CAREGIVING TO OLDER PEOPLE
CAREGIVER INTERVIEW GUIDE

1A. COULD YOU START BY TELLING ME A LITTLE BIT ABOUT [CR] AS A PERSON, BOTH BEFORE S/HE NEEDED YOUR HELP AND NOW?

1B. WOULD YOU TELL ME A LITTLE BIT ABOUT <u>YOUR</u> RELATIONSHIP WITH CR, BOTH BEFORE S/HE NEEDED YOUR HELP, AND NOW?

WHILE A LOT OF RESEARCH HAS LOOKED AT THE TASKS THAT CAREGIVERS PERFORM, WE KNOW VERY LITTLE ABOUT HOW FAMILIES MAKE SPECIAL THESE ACTIVITIES FOR THEIR SITUATION. I'M INTERESTED IN LEARNING ABOUT WAYS THAT THE CAREGIVING DAY AND ACTIVITIES ARE MADE SPECIAL OR PLEASURABLE FOR BOTH OF YOU.

2. I AM INTERESTED IN HOW YOUR DAY GOES IN CARING FOR [CR].

Imagine that I am coming to take care of CR and you want to make sure that I understand how to do things your way.
I'd like to hear as much as possible about the beginning of the day, when you wake up--to the end of the day, when you fall asleep, for both of you.

Can you describe to me what a typical day (perhaps yesterday) is like in providing care to [CR]?

IS THERE ANYONE THAT CR COUNTS ON AND LOOKS FORWARD TO SEEING OR BEING WITH?

3. I'D LIKE TO KNOW MORE ABOUT HOW YOU <u>MAKE SPECIAL</u> THE CAREGIVING FOR BOTH [CR] AND YOUR SELF. (Probes reflecting back to specific details of situation described in #2. Key situations may be meals, morning care, outings, evening time.)

ARE THERE ANY THINGS YOU DO BECAUSE THEY ARE SPECIAL OR YOU BOTH ENJOY THEM?

4. CAN YOU TELL ME ABOUT SOME TIMES THAT IT MATTERS THAT IT IS YOU GIVING THE CARE RATHER THAN ANOTHER PERSON? SOME THINGS THAT IT IS REALLY IMPORTANT THAT YOU DO, THAT YOU DON'T WANT ANYBODY ELSE TO DO?

Could you describe this activity in detail for me?

How did you come to start doing this?

How do you feel when you do this? How do you think CR feels?

IF I WERE IN YOUR SHOES, HOW WOULD I HAVE A SENSE THAT CR IS ENJOYING THIS ACTIVITY? *(actual statement by CR/behavioral indicators, etc.)*

HAVE YOU HAD TO CHANGE OR MODIFY HOW YOU DO THIS OVER TIME?

5. ARE THERE TIMES OF THE DAY THAT YOU SPEND WITH [CR] THAT YOU BOTH LOOK FORWARD TO?

Could you tell me about what happens during these times? How is this special for both of you?

6. ARE THERE ANY ACTIVITIES YOU AND [CR] DID ONCE, BUT CAN'T DO NOW?

How do you feel about this?

COULD YOU TELL ME ABOUT WHY THIS ISN'T HAPPENING ANY MORE?

HOW DID YOU COME TO BE DOING THIS ACTIVITY?
HOW DO YOU FEEL WHEN YOU DO THIS?
HOW DO YOU THINK [CR] FEELS? *IF I WERE IN YOUR SHOES, HOW WOULD I HAVE A SENSE THAT [CR] IS ENJOYING THIS ACTIVITY?*

7. ARE THERE THINGS YOU DO FOR [CR] JUST BECAUSE YOU THINK THAT S/HE LIKES OR ENJOYS IT? Could you tell me about what happens during these times?

8. DOES [CR] EVER INITIATE OR REQUEST ACTIVITIES THAT YOU BOTH ENJOY? WOULD YOU TELL ME A LITTLE ABOUT WHAT HAPPENS IN THESE SITUATIONS?

9. ARE THERE ANY OTHER ASPECTS IN THE CAREGIVING THAT YOU AND/OR [CR] ESPECIALLY LOOK FORWARD TO OR ENJOY?

PROBE: These activities could be things that you do every day, or only occasionally–maybe at special times of the week or year.

PROBE: Sometimes families may not even realize how they are personalizing the care, but they do certain things because that's the way they've always done them in their family. For example, one person mentioned that he always give the CR their morning coffee in a special mug--a mug that is only used by CR, and only at breakfast time because it has a special memory to them.

Could you tell me about these times or events?

INNOVATION PROBE:
HOW DID YOU
HAPPEN TO THINK ABOUT
THAT?

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HOW DID YOU COME TO DO START
    DOING THESE THINGS?
HOW DO YOU FEEL WHEN YOU DO
    THIS?
HOW DO YOU THINK CR FEELS?
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10. OVER THE TIME YOU HAVE BEEN CARING FOR CR, HAS CR'S CONDITION CHANGED IN WAYS THAT HAVE CHANGED YOUR CAREGIVING? COULD YOU TELL ME ABOUT CHANGES IN THE WAY YOU MANAGE THE SITUATION? WHAT ABOUT CHANGES IN THE WAY YOU MAKE SPECIAL THE CAREGIVING?

Probe by specific tasks mentioned earlier--how have you changed the way of personalizing these activities?

Have you had to modify or stop certain activities that were once enjoyable?

How do you feel about these changes?

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(STORY STRATEGY:  tell me a story about the personalized
task--how it started, over time, and now)
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11. LOOKING DOWN THE ROAD A PIECE, WHAT DO YOU ANTICIPATE WITH MANAGING THE CARE SITUATION? Do you have any ideas about what you might do if you can't continue some of the personalized, special activities you've told me about?

12. This is the last question: HOW MUCH TIME AND ENERGY DO YOU SEE YOURSELF AS HAVING?
[May be woven into the script at earlier questions--or asked now]

13. Is there anything you would like to ask me?

OVER THE COMING DAYS AND WEEKS, YOU MAY THINK ABOUT THINGS FROM OUR DISCUSSION. I WOULD GREATLY APPRECIATE YOUR SHARING ANY IDEAS THAT COME TO MIND, ABOUT HOW THE CAREGIVING IS MADE SPECIAL. IF YOU THINK OF ANYTHING, WOULD YOU BE WILLING TO MAIL ME A NOTE, OR GIVE ME A CALL?

CARE RECEIVER INTERVIEW GUIDE

1. Could you start by telling me a little bit about yourself and your current situation with caregiver [CG]?

2. I'm interested in how your day goes with CG. Could you describe to me what a typical day (perhaps yesterday) is like together?

I'd like to know some of the things that are special in your day with caregiver [CG].

1. Can you think of any things you and CG do that make you feel especially good?

2. Are there things you and CG do that you look forward to?
    - Can you tell me how you came to do this together?
    - How do you feel when you and CR are doing this?
    - How do you think CG feels?

3. Are there things you like to do for CG because you think that s/he enjoys them?
    - Can you tell me how you started doing this?
    - Can you tell me how doing this makes you feel?

[PROBES BY TASKS: meals, outings, evening time, bedtime]

4. Are there any other things that you look forward to, or that make you feel good? These may not happen every day–maybe only once a week, or occasionally–like special family celebrations.
    - Can you tell me about what happens at these times?
    - How did you come to start doing this?
    - How do you feel during this occasion?

December, 1991

CARE RECIPIENT INTERVIEW GUIDE

I am studying how families [couples] specialize or personalize their lives, especially in situations where different generations live together [where one person has a chronic condition]. I would like to hear about how this goes for you.

1. I'm interested in how your day goes with CG. Could you describe to me what a typical day (perhaps yesterday) is like together?

2. I'd like to know some of the things that are special in your day with caregiver [CG].
PROBE: (By activity) Could you tell me a little bit about why that is special?

3. Can you think of any things you and CG do together that make you feel especially good?

4. Are there things you and CG do that you look forward to?
    Can you tell me how you came to do this together?
    How do you feel when you and CR are doing this?
    How do you think CG feels?

5. Are there things you like to do for CG because you think that s/he enjoys them?
    Can you tell me how you started doing this?
    Can you tell me how doing this makes you feel?

[PROBES BY TASKS: meals, outings, evening time, bedtime]
[POSSIBLE PROBE: If I were in your shoes and doing these things for CG, how would I know that s/he enjoys them?]

6. Are there any other things that you look forward to, or that make you feel good? These may not happen every day–maybe only once a week, or occasionally–like special family celebrations.

Can you tell me about what happens at these times?
How did you and CG come to start doing this?
How do you feel during this occasion?

7. Is there anything you would like to ask me?

interview. cr

2/22/9263

CARE RECIPIENT INTERVIEW GUIDE

I am studying how families [couples] make special or personalize their lives, especially in situations where different generations live together [where one person has a chronic condition]. I would like to hear about how this goes for you.

1. I'm interested in how your day goes with CG. Could you describe to me what a typical day (perhaps yesterday) is like together?

2. I'D LIKE TO KNOW SOME OF THE THINGS THAT ARE SPECIAL IN YOUR DAY WITH CAREGIVER [CG].
PROBE: (By activity) Could you tell me a little bit about why that is special?

3. Can you think of any things you and CG do together that make you feel especially good?

4. Are there things you and CG do that you look forward to?

CAN YOU TELL ME HOW YOU CAME TO DO THIS TOGETHER?
HOW DO YOU FEEL WHEN YOU AND CG ARE DOING THIS?
HOW DO YOU THINK CR FEELS?

5. Are there things you like to do for CG because you think that s/he enjoys them?

Can you tell me how you started doing this?
Can you tell me how doing this makes you feel?
[PROBES BY TASKS: meals, outings, evening time, bedtime]
[POSSIBLE PROBE: If I were in your shoes and doing these things for CG, how would I know that s/he enjoys them?]

6. Are there any other things that you look forward to, or that make you feel good? These may not happen every day–maybe only once a week, or occasionally–like special family celebrations.
Can you tell me about what happens at these times?
How did you and CG come to start doing this?
How do you feel during this occasion?

7. Is there anything you would like to ask me?

7/ 6/92

Appendix I

Evidence for Trustworthiness of the Grounded Theory Study

Appendix I

Evidence for Trustworthiness of the Grounded Theory Study

Criterion	Design Strategies	Evidence
Credibility	Interviews & observations will occur over a series of visits with the participants to achieve prolonged engagement in data collection.	▸ Twelve of the 20 dyads were visited on two or more occasions and telephoned for additional information or to verify the analysis.
	Extended visits combining informal interviewing and observations will facilitate persistent observation.	▸ Visits ranged in length from 1 hour (care recipient) to six hours. Most interviews with caregivers lasted 2 to 3 hours. This included time spent in the interview, touring the home, meeting with the care recipient, and chatting as we "renegotiated" the relationship post-interview. Participants frequently showed me special family mementos such as photo albums and poetry books.

Criterion	Design Strategies	Evidence
	Triangulation will be achieved using multiple data collection sources and methods.	▸ Completed scales were obtained for 18 of the 20 caregivers and 3 of the 4 care recipients. One caregiver returned the scales untouched with a lengthy note explaining why she felt she could not answer the questions. The note and a memo were added to the field notes as data. One caregiver, whose care recipient died the week after our visit, did not return the questionnaire. In another case the caregiver indicated that participating in an additional interview to complete the questionnaire would be too tiring for the care recipient. (For 2 of the 3 care recipients who completed the questionnaire, the questions were read to them per their request.) ▸ Documents complemented the interviews and observations. Examples include: ● Periodic newsletters mailed to family members. I continue to receive copies a year later. ● Notes made by a caregiver in preparation for our interview. ● Articles from regional newspapers and organizational newsletters regarding one dyad. ● Two video tape features for national and regional television regarding one dyad. ● A letter from an author responding to my inquiry regarding interpretation of his writings which have influenced the analysis. ▸ Participant observations were originally proposed to occur around specific activities identified in the preliminary interview as enriching. Generally, this did not occur.

Criterion	Design Strategies	Evidence
Credibility (cont'd)	Triangulation (cont'd)	Most of the observations arose spontaneously with the caregiver or care recipient inviting me to participate in an activity before, during, or after the scheduled interview. Examples of spontaneous observations included sharing a birthday cake, participating in meals or snacks, assisting with morning care, an afternoon of singing, looking at photo albums, and reminiscence related to family mementoes. ▸ Planned observations related specifically to care activities did not happen for several reasons: ● The spontaneous observations provided rich data related to enrichment. ● Few enriching activities related specifically to care of the body were identified in the interviews. This finding deviated from what had been originally proposed regarding the incidence of enriching activities. In speculating on this unanticipated finding, it can be hypothesized that ● for these participants, enrichment did not occur during care activities. Rather, enrichment was most likely to occur around activities reflecting the customary relationship between caregiver and care recipient. ● participants may engage in enrichment during care activities but not articulate the experience during interviews, ● these care recipients, with one exception, were not bedridden, and may not have required extensive body care by the caregiver. Thus, the opportunity for enrichment specifically around care of the body may not have arisen for these individuals.

Criterion	Design Strategies	Evidence
Credibility (cont'd)	Peer debriefing will be achieved through ongoing discussions with advisory faculty.	▸ Peer debriefing occurred at regular meetings of the research committee. Transcripts, field notes, and theoretical memos were discussed in terms of underlying assumptions, and the clarity, cohesiveness, and reasonableness of the developing ideas. Analyses were scrutinized and sometimes challenged for their logical derivation from the data. ▸ Transcripts and emergent analyses were shared with members from three separate doctoral level seminars. Again, the clarity, cohesiveness, and reasonableness of the developing ideas, particularly as they were demonstrated in the data, were reviewed and challenged. Both the committee and seminar discussions provided constructive feedback for the emergent theory.
	Negative case analysis will be achieved by accounting for all known data, without exceptions.	▸ Negative cases expanded the density and variation in the emergent theory. The analysis was constantly compared with the data, and revised to accommodate findings in the transcripts and field notes.

Criterion	Design Strategies	Evidence
Credibility (cont'd)	Member checking will be used to assess adequacy of representation of the situation from the participants' perspectives.	▸ Member checking of the findings occurred on an intermittent basis both during interviews and in follow-up conversations. This strategy was helpful in minimizing investigator misinterpretation of participants' behaviors, feelings, and thought processes. ▸ Upon completion of the analysis, 6 caregivers and 3 care recipients were invited to review portions of the conceptual model and give their feedback. Overall, the participants agreed with the analysis. They offered additional anecdotes to illustrate several concepts, including caregiver frailty trajectory, use of personal history in making special the care, fine tuning, and acquiring symbolic meaning.
Transferability	Thick descriptions will be achieved through detailed field notes and memos regarding the analysis process.	▸ Thick descriptions were achieved through detailed field notes and field memos as well as verbatim transcription of all taped interviews. Quotations were included in the field notes whenever possible. All contacts with participants, including brief telephone calls and letters, were described in field notes or field memos. Several of the transcriptions included reporting of pauses, emotional tone, and concurrent nonverbal behavior in an effort to capture the participant's voice.

Criterion	Design Strategies	Evidence
Dependability	An inquiry audit will be conducted by an outside faculty investigator with expertise in the grounded theory method.	▸ A formal inquiry audit was not conducted as had been originally planned. Instead, the dissertation committee performed this function through selective but extensive review of transcripts, field notes, and memos. The committee met with the principal investigator approximately every three weeks, thus providing feedback at regular intervals throughout the data collection and analysis phases.
Confirmability	An audit trail will be established by maintaining detailed written recordings of raw data, field notes, theoretical memos, coding processes, interviewing strategies and schedules, and related materials.	▸ Computerized sub-directories contain all transcripts, field notes, theoretical and reflective memos, minutes from dissertation committee meetings, code lists, and methodological strategies and schedules. Additionally, hard copies of these materials are maintained in a locked file box in the investigator's possession.
	The investigator will maintain a reflective journal which documents ideas and thinking processes as they evolve.	▸ The investigator maintained a handwritten, reflexive journal during the pilot study. This journal was continued during the final phases of the study using a laptop computer.

Appendix J

Informed Consents

Appendix J

Enrichment in Family Caregiving to Frail Elders: Informed Consents

1. Three types of informed consents were developed for the study:

    - Caregiver informed consent
    - Care recipient informed consent
    - Ongoing informed consent

The Ongoing Informed Consent was developed in anticipation of intense, long term relationships between participants and investigator; and in the event that the focus of the grounded theory study changed as the analysis evolved. While several informants were visited two or more times, the focus of the study, including the nature of the interview questions did not change substantially. Follow-up visits to participants were primarily of a member checking nature rather than to elicit information regarding new topics. Therefore use of the Ongoing Informed Consent was never deemed necessary. All follow up visits were prefaced by the investigator reminding the informants that they could refuse to answer any questions or withdraw from the study at any time.

2. Differences in requirements for informed consents, Oregon Health Sciences University (OHSU) versus University of California San Francisco (UCSF).

- OHSU: Specifically required inclusion of a statement regarding mandatory reporting of elder abuse in the event it was suspected by the interviewer.

- UCSF: Specifically required inclusion of a statement that participation in the research may result in a loss of privacy.

No potential informants refused to participate in the study after reading the informed consent form. Three potential informants refused to participate after learning that a signed informed consent was required for the research. One informant commented positively regarding the clause on elder abuse reporting as "a good thing".

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CAREGIVER CONSENT TO PARTICIPATE IN A RESEARCH STUDY

PROJECT TITLE: ENRICHMENT IN FAMILY CAREGIVING TO OLDER PEOPLE

Investigators: Virginia Olesen, PhD, of the School of Nursing, University of California, San Francisco, and Juliana Cartwright, RN, MN, doctoral student, School of Nursing, Oregon Health Sciences University.

Study Purpose: The purpose of this study is to learn about how persons involved in family caregiving to older people find meaning or pleasure in the caregiving situation. To learn about these areas, I will be interviewing and observing caregivers and care recipients regarding their caregiving experiences.

Procedures: If you agree to participate, you will be interviewed, at least once, in private, in your home or some other agreeable place. The interview will last approximately 1 to 2 hours. I will be asking you questions about your caregiving day, the kinds of things you do that add meaning or pleasure to the caregiving experience, and your feelings regarding these activities. I will ask you to complete a written questionnaire regarding the caregiving experience.

I may ask to return for an additional interview and/or observation of some caregiving activities at your convenience.

Confidentiality: Participation in research may result in a loss of privacy. The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personally identifying information deleted in the transcription process. The audio-tapes will be destroyed after transcription is complete. Personally identifying information will be deleted from the written notes and the questionnaire. Only the principle investigator and co-investigator will have access to your responses.

Risks and Benefits: Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable to you. You will receive no direct benefit from participating in this study. However, some caregivers report that talking to someone about their situation is helpful.

Costs of Participation: There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Your Rights as a Participant: Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you receive at Mount Zion Medical Center or the University of California, San Francisco.

___ I have read what is written above and agree to be in this study.

___ I have had read to me what is written above and agree to be in the study.

_________________________ _________________________

Signature Date Witness Signature Date

If you have questions about this research, or your rights and responsibilities as a research participant, you may contact either of us at:

Researcher: Juliana Cartwright, RN, MN, doctoral student
Department of Sociology and Behavioral Sciences
School of Nursing
UCSF, San Francisco, CA 94143-0606
Telephone: (415) 476-2453

Supervisor/Researcher:
Virginia Olesen, PhD, Professor
Department of Social and Behavioral Sciences
N 631-Y
UCSF, San Francisco, CA, 94143-0612
Telephone: (415) 476-2453

If you have any comments or concerns about participation in this study, you should first talk with the investigators. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814.

2/4/92

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CARE RECIPIENT CONSENT TO PARTICIPATE IN A RESEARCH STUDY

PROJECT TITLE: ENRICHMENT IN FAMILY CAREGIVING TO OLDER PEOPLE

Investigators: Virginia Olesen, PhD, of the School of Nursing, University of California, San Francisco, and Juliana Cartwright, RN, MN, doctoral student, School of Nursing, Oregon Health Sciences University.

Study Purpose: The purpose of this study is to learn about how persons involved in family caregiving to older people find meaning or pleasure in the caregiving situation. To learn about these areas, I will be interviewing and observing caregivers and care recipients regarding their caregiving experiences.

Procedures: If you agree to participate, you will be interviewed, at least once, in private, in your home or some other agreeable place. The interview will last approximately 1 to 2 hours. I will be asking you questions about your day, the kinds of things you do that add meaning or pleasure to the care experience, and your feelings regarding these activities. I will ask you to complete a written questionnaire regarding the care experience.

I may ask to return for an additional interview and/or observation of some caregiving activities at your convenience.

Confidentiality: Participation in research may result in a loss of privacy. The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personally identifying information deleted in the transcription process. The audio-tapes will be destroyed after transcription is complete. Personally identifying information will be deleted from the written notes and the questionnaire. Only the principle investigator and co-investigator will have access to your responses.

Risks and Benefits: Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable to you. You will receive no direct benefit from participating in this study. However, some care receivers report that talking to someone about their situation is helpful.

Costs of Participation: There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your

Your Rights as a Participant: Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you receive at Mount Zion Medical Center or the University of California, San Francisco.

___ I have read what is written above and agree to be in this study.

___ I have had read to me what is written above and agree to be in the study.

________________________ ________________________

Signature Date Witness Signature Date

If you have questions about this research, or your rights and responsibilities as a research participant, you may contact either of us at:

Researcher: Juliana Cartwright, RN, MN, doctoral student
Department of Sociology and Behavioral Sciences
School of Nursing
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Supervisor/Researcher:
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OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: FAMILY CAREGIVERS

ENRICHMENT IN FAMILY CAREGIVING TO FRAIL ELDERS

PRINCIPAL INVESTIGATOR:	Juliana Cartwright, RN, MN, doctoral student, School of Nursing, Oregon Health Sciences University.
CONSENT FORM:	To be used with caregivers and care recipients who are involved in ongoing caregiving situations.

Study Purpose

The purpose of this study is to learn about how persons involved in family caregiving to older people find meaning or pleasure in the caregiving situation. To learn about these areas, Ms. Cartwright will be interviewing and observing caregivers and care recipients regarding their caregiving experiences.

Procedures

If you agree to participate you will be interviewed, at least once, in your home. The interview will last approximately 1 to 2 hours although sometimes caregivers wish to discuss the issues at greater length. You will be asked questions about your caregiving day, the kinds of things you do that add meaning or pleasure to the caregiving experience, and your feelings regarding these activities. You will be asked to complete a written questionnaire regarding the caregiving experience.

Ms. Cartwright may ask to return for additional interviews and/or observations of some caregiving activities.

Confidentiality

The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. Personally identifying information will be deleted from the written notes and the questionnaire. The information you share with Ms. Cartwright will be handled in a manner to ensure confidentiality. Only Ms. Cartwright and faculty dissertation advisors will have access to your responses. Any publications, including the dissertation report, will include necessary precautions to protect your identity. These include deletion of personally identifying information, and the opportunity for you to review materials in the report which directly describe your situation. In the unlikely event that Ms. Cartwright should discover elder abuse, she is required by law to report it.

Risks and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable to you. Participating in this interview may provide some benefits for you. For example, some caregivers report that talking to someone about their situation is helpful.

Costs of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability

The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Rights as a Participant

Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you receive at the Oregon Health Sciences University.

___ I have read what is written above and agree to be in this study.

___ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Juliana Cartwright at (503) 899-8141. If you have further questions you may contact Dr. Patricia Archbold, RN, DNSc, Professor of Nursing, (503) 494-3840.

_______________________ _______________________

Signature Date Witness Signature Date

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: CARE RECIPIENTS

ENRICHMENT IN FAMILY CAREGIVING TO FRAIL ELDERS

PRINCIPAL INVESTIGATOR: Juliana Cartwright, RN, MN, doctoral student, School of Nursing, Oregon Health Sciences University

CONSENT FORM: To be used with caregivers and care recipients who are involved in ongoing caregiving situations.

Study Purpose

The purpose of this study is to learn about how persons involved in family caregiving to older people find meaning or pleasure in the caregiving situation. To learn about these areas, Ms. Cartwright will be interviewing and observing caregivers and care recipients regarding their caregiving experiences.

Procedures

If you agree to participate you will be interviewed, at least once, in your home. The interview will last approximately one hour. You will be asked questions about your day, the kinds of things that occur that are meaningful or pleasant, and your feelings regarding these activities. You will be asked to complete a written questionnaire regarding the caregiving experience.

Ms. Cartwright may ask to return for additional interviews and/or observations of some caregiving activities.

Confidentiality

The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. Personally identifying information will be deleted from the written notes and the questionnaire. The information you share with Ms. Cartwright will be handled in a manner to ensure confidentiality. Only Ms. Cartwright and faculty dissertation advisors will have access to your responses. Any publications, including the dissertation report, will include necessary precautions to protect your identity. These include report, will include necessary precautions to protect your identity. These include deletion of personally identifying information, and the opportunity for you to review materials in the report which directly describe your situation. In the unlikely event that Ms. Cartwright should discover elder abuse, she is required by law to report it.

Risks and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable to you. Participating in this interview may provide some benefits for you. For example, some caregivers report that talking to someone about their situation is helpful.

Costs of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability

The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Rights as a Participant

Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you receive at the Oregon Health Sciences University.

___ I have read what is written above and agree to be in this study.

___ I have had read to me what is written above and agree to be in this study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Juliana Cartwright at (503) 899-8141. If you have further questions you may contact Dr. Patricia Archbold, RN, DNSc, Professor of Nursing, (503) 494-3840.

______________________ ______________________

Signature Date Witness Signature Date

6/29/92

OREGON HEALTH SCIENCES UNIVERSITY
ONGOING INFORMED CONSENT
ENRICHMENT IN FAMILY CAREGIVING TO FRAIL ELDERS

PRINCIPAL INVESTIGATOR: Juliana Cartwright, RN, MN, doctoral student, School of Nursing, Oregon Health Sciences University

CONSENT FORM

This consent is for use with multiple interviews, participant observation, and as unexpected changes occur in the focus of the data collection. This consent supplements and does not replace the standard informed consent form.

Purpose

The purpose of this consent is to identify areas for review and agreement between you (the participant) and the investigator (Ms. Cartwright) as collaborators. Areas which may be covered with this consent form include but are not limited to:

Data collection

1. Frequency and duration of interviews and/or observations will be agreed upon by us.
2. Any change in the focus of the study by Ms. Cartwright will be shared with you.
3. Unanticipated findings will be shared with you.

Data management

1. Protection of your anonymity and confidentiality will be achieved by deleting personally identifying information from all audio tape transcriptions, written notes, and the questionnaire.
2. All data obtained through interviews, observations, and questionnaire are considered part of the study. You are discouraged from disclosing information that you do not wish to be considered as part of the study.
3. You will be invited to review materials which directly describe your situation to insure accuracy in portrayal of information.

Distribution of findings

1. Ms. Cartwright will send you copies of abstracts from any publications related to this study.

COMMENTS BY THE PARTICIPANT:

COMMENTS BY THE INVESTIGATOR:

DATES REVIEWED:

Appendix K

References

Appendix K

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