

FAMILY CAREGIVERS' PERCEPTIONS OF ASSISTING COGNITIVELY
IMPAIRED ELDERS DURING BATHING: INSTRUMENT DEVELOPMENT

By

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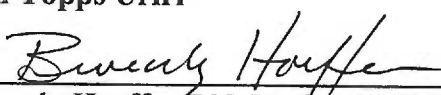
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ABSTRACT

**TITLE: FAMILY CAREGIVERS' PERCEPTIONS OF ASSISTING
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Caring for a cognitively impaired (CI) family elder can be a difficult challenge for caregivers in general. The symptoms of cognitive impairment include cognitive decline, ADLs impairments, and behavioral symptoms which often occur while the family caregiver is assisting the CI elder during bathing. Little is known about the experiences of family caregivers who assist a CI family member during bathing in the home setting. Developing valid and reliable questionnaires is an important preliminary step before the tool is used to survey family caregivers who assist CI elders during bathing. The purposes of this study were to develop and evaluate new instruments that measure concepts relevant for family CGs who are assisting CI elders with bathing in the home.

The study was conducted in two phases in Oregon and Arkansas. First, questions were developed and evaluated by experts ($n = 11$) in the field and family CGs ($n = 8$) who assist CI elders during bathing. The sample in Phase 2 of the study consisted of family CGs ($n = 62$) in the home setting. This measurement development study employed a nonexperimental, correlational design and survey methods. Data were analyzed using

item analysis, exploratory factor analysis, Cronbach's Alpha, and Pearson's correlations. Ten bathing scales were developed, and the conceptual model for the study was refined including concept labels and definitions. Cronbach's Alpha values exceeding .70 were estimated in 65% of the scales. The findings of this study overall are consistent with what has been reported in the literature in studies that address related phenomena. The Perceptions of Family Caregivers' Assisting a Cognitively Impaired Elder During Bathing Instrument, consists of the measures developed in this study for which there is evidence supportive of reliability and construct validity.

A factor limiting generalization of the results was the relatively small convenience sample. A strength of the study, however, is the inclusion of minority family caregivers. In practice, these measures can be used in a variety of health care settings that provide services to community dwelling CI elders. This will provide clinicians from various disciplines a tool to use to explore bathing problems in depth experienced by family CI and their family CGs and to develop more appropriate interventions to assist them.

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CHAPTER 1

INTRODUCTION

Caring for cognitively impaired (CI) elders can be a difficult challenge for their family caregivers (CGs). Major factors contributing to the difficulties that many family CGs experience are the elderly care receiver's (CR's) symptoms of dementia: memory decline, functional losses associated with activities of daily living (ADL), and personality changes, including behavioral symptoms (Emory & Oxman, 1994). Behavioral symptoms often occur when the CG is assisting the CI elder with personal care such as bathing. CI elders' experience of discomfort or feeling overwhelmed by personal care activities or daily events that are normally managed by cognitively intact elders may be precursors of behavioral symptoms during bathing. Whatever the cause, bathing difficulties appear to be a common concern among family CGs of CI elders. However, little is known about the experiences of family CGs who assist CI elders during bathing in the home setting. Most research on caregiving during bathing has been conducted with paid CGs in nursing homes (Aronson, Post, & Gustasiesegni, 1993; Hoeffler, Rader, McKenzie, Lavelle, & Stewart, 1997; Maxfield, Lewis, & Cannon, 1996; R. I. Miller, 1994; M. F. Miller, 1997; Rader, Lavelle, Hoeffler, & McKenzie, 1996; Rossby, Beck, & Heacock, 1992; Sloane Honn, et al., 1995). Although the practice implications of nursing home studies may be applicable to caregiving at home, their relevance is limited by differences in the two situations and settings (e.g., family versus paid CG, nature of the dyadic relationship, home versus institutional setting).

The development of reliable and valid instruments for assessing family CGs' experiences of bathing CI elders in the home is an important preliminary step for future studies of family assistance with bathing and other ADLs. Descriptive and correlational results are needed to provide the foundation for developing and testing interventions aimed at improving the bathing environment and experiences for both the CI elder and family CG in the home setting.

Background

As the aging population increases in America, dementia is becoming a common disorder among older adults (U.S. Printing Office, 1996). Dementia is manifested in behavioral symptoms that result from degenerative cognitive and emotional deficits (Beck et al., 1991). Currently, the annual number of new cases of Alzheimer's disease is 360,000; it is predicted that the prevalence will nearly quadruple in the next 50 years when approximately 1 in 45 Americans will have the disease (Brookmeyer, Gras, & Kawas, 1998). Alzheimer's disease eventually erodes all cognitive and functional abilities leading to total dependence on CGs. It is estimated that at least half of all older adults with dementia reside in the community and receive care from family members (Collins, Given, & Given, 1994; Ryden, 1988; Ryden & Feldt, 1992). The degenerative nature of the disease can place large physical, financial and emotional demands on family CGs, sometimes resulting in institutionalization of the CI elder (Dunkin & Hanley, 1998). However, a far greater number of CI elders are cared for by family members in the home than by paid CGs in nursing homes (Laird, 1993 Ryden, 1988).

Assisting with personal care and ADLs, such as bathing becomes the responsibility of the family CG as the CI elder's abilities decline. In the past 10 years, about 10 million elders reported difficulties with bathing or showering and 6 million received help with bathing or showering; 73% of those receiving help lived with others (U.S. Government Printing Office, 1996). The literature suggests that bathing can be problematic for CGs of CI elders residing in the community especially when CGs encounter behavioral symptoms during caregiving activities (Kuhlman et al., 1991; Mort, Gasper, Pulscher, & Laird, 1993; Ryden, 1988). Preliminary studies suggest that 25 to 50% of family CGs who are assisting CI elders with bathing find it difficult to do so (Archbold, Stewart, Greenlick, Harvath, 1990, 1997). Thus, a more in depth study of family CGs' experiences of, and perceptions about, assisting CI elders with bathing in the home is timely.

Bathing can be a major source of discomfort for CI elders (Freels et al., 1992; Aronson, Post, & Gustasiesegni, 1993). Many CI elders lose the cognitive ability to verbally communicate feelings of discomfort, and consequently they often communicate nonverbally through behavioral symptoms. Behavioral symptoms also communicate feelings of frustration, violation of privacy and personal space, and low self esteem related to dependence on the CG when verbal abilities are impaired (Kovach & Meyer-Arnold, 1996; McShane, 1996; Rader et al., 1996; Sloane, Rader, et al., 1995). Since the CI elder wants to feel safe and comfortable, the CG must be alert to signs that bathing may be perceived as a frightening, upsetting or painful experience (Ryden, 1988; Ryden & Feldt, 1992; Sloane, Rader, et al., 1995). Although behavioral symptoms are a form of

communication, research in nursing homes has documented that behavioral symptoms of CI elders during bathing are distressing to paid CGs (Hoeffler et al., 1997; Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992; Kovack, & Meyer-Arnold, 1996). Similarly, family CGs may experience hassles (e.g., minor irritations) associated with bathing because of the CI elder's self-care deficits, discomfort and behavioral symptoms. Also, they may not feel confident in managing these behaviors, and hence become dissatisfied with the caregiving experience.

Understanding the impact on family CGs who are providing assistance with personal care to CI elders at home, and finding ways to support them in their caregiving role are essential if the needs of both CI elders and their family CGs are to be addressed (Wuest, Ericson, & Stern, 1994). As the numbers of CI elders cared for by family CGs in the home increase, more dyads will need the assistance of health care professionals to prevent CG burnout and unnecessary institutionalization of CI elders.

Specific Aims

Various innovative strategies for the prevention and management of behavioral symptoms during personal care activities such as bathing have been suggested (Namazi & Johnson, 1996) and some have been tested (Hoeffler et al., 1997; Maxfield et al., 1996; Miller, 1994, 1997; Rader et al., 1996; Rossby et al., 1992; Ryden & Feldt, 1992; Sloane et al., 1995). However, most of the studies have been conducted in nursing homes with paid staff. No reports of studies have addressed the efficacy of interventions to reduce CI elder behavioral symptoms during bathing in the home setting by family CGs. Before developing interventions to reduce behavioral symptoms and enhance self-care behaviors

during bathing CI elders in the home, it is important to develop reliable and valid instruments that capture the experience of family CGs when assisting CI elders with bathing in the home setting.

The purposes of this study, therefore, were to develop and evaluate new instruments that measure concepts relevant for family CGs who are assisting CI elders with bathing in the home. The new instruments came from three sources: (a) they were adapted from instruments previously used in a nursing home setting; (b) they were adapted from instruments used in a home setting; and (c) they contained new items generated from the investigator's research and clinical experience in bathing CI elders (See Table 1). The specific aims for this study are:

- Aim 1. To evaluate the content validity of the new bathing instruments for use with family CGs in the home setting.
- Aim 2. To derive new bathing scales from the new instruments using item analysis and exploratory factor analysis, and to refine the conceptual model including concept labels and definitions.
- Aim 3. To estimate the internal consistency reliability of the new bathing scales.
- Aim 4. To obtain preliminary evidence about the construct validity of the new bathing scales by testing hypothesized relationships between concepts measured by the new scales and concepts measured by established scales, including the CR's memory problems, and the family CG's health, physical function, pain, depressive symptoms, mutuality, and global strain.

Aim 5. To obtain further preliminary evidence about the construct validity of the new scales by examining their intercorrelations and determining whether these intercorrelations correspond to hypothesized relationships derived from the literature and revised conceptual model.

Table 1

Initial Bathing Concepts Measured, Original Instruments, and New Instruments for Use With Family CGs

Bathing Concept	Original Instrument	New Instrument
Bathing Situation		
1. CR Self-Care During Bathing	ADL Scale: Bathing Performance Scale (Beck et al., 1988)	Bathing Tasks Scale
2. Bath Features <ul style="list-style-type: none"> • Function • Form and Frequency 	None	<ul style="list-style-type: none"> • Reasons for Bathing Scale • Form and Frequency of Bathing Scale
3. CR Bath Time Preference	None	Bath Time Scale
4. CG Attitudes About Bathing	My View of Bathing Scale (Rasin et al., 1999).	Family CG's View of Bathing Scale
5. CG Communication During Bathing	Caregiver Bathing Behavior Rating Scale (Sloane et al., 1995).	Family CG Bathing Behavior Rating Scale
6. CG Self-Reported Behaviors During Bathing	Giving a Bath Scale (Rasin et al., 1999).	Family CGs Giving a Bath Scale

Table 1(cont)

Initial Bathing Concepts Measured, Original Instruments, and New Instruments for Use With Family CGs

Bathing Concept	Original Instrument	New Instrument
7. Bathing Assistance Provided by the CG	Amount of Direct Care Scale (Archbold & Stewart, 1990).	CG Help with Bathing Scale <ul style="list-style-type: none"> • Frequency of CG Help • Amount of CG Help • Duration of CG Help
8. Help From Others With Bathing	Help From Others in Family Care Scale (Stewart & Archbold, 1994).	Help From Others With Bathing Tasks Scale
CR Responses		
9. Positive Behaviors	None	CR's Reaction to Bathing Scale <ul style="list-style-type: none"> • CR Positive Behaviors Subscale
10. Discomfort	Discomfort Scale (Hurley et al., 1992).	<ul style="list-style-type: none"> • CR Discomfort Subscale
11. Behavioral Symptoms	Disruptive Behavior Scale (Beck et al., 1997).	<ul style="list-style-type: none"> • CR Behavioral Symptom Subscale
CG Responses		
12. Satisfaction	Your Experience During Bathing (Rasin et al., 1999).	Family CG's Experience During Bathing Scale
13. Preparedness		
14. Hassles Experienced During Bathing	CG Hassles Scale (Kinney & Stephens, 1989).	Caregiving Hassles During Bathing Scale

CHAPTER 2

REVIEW OF THE LITERATURE

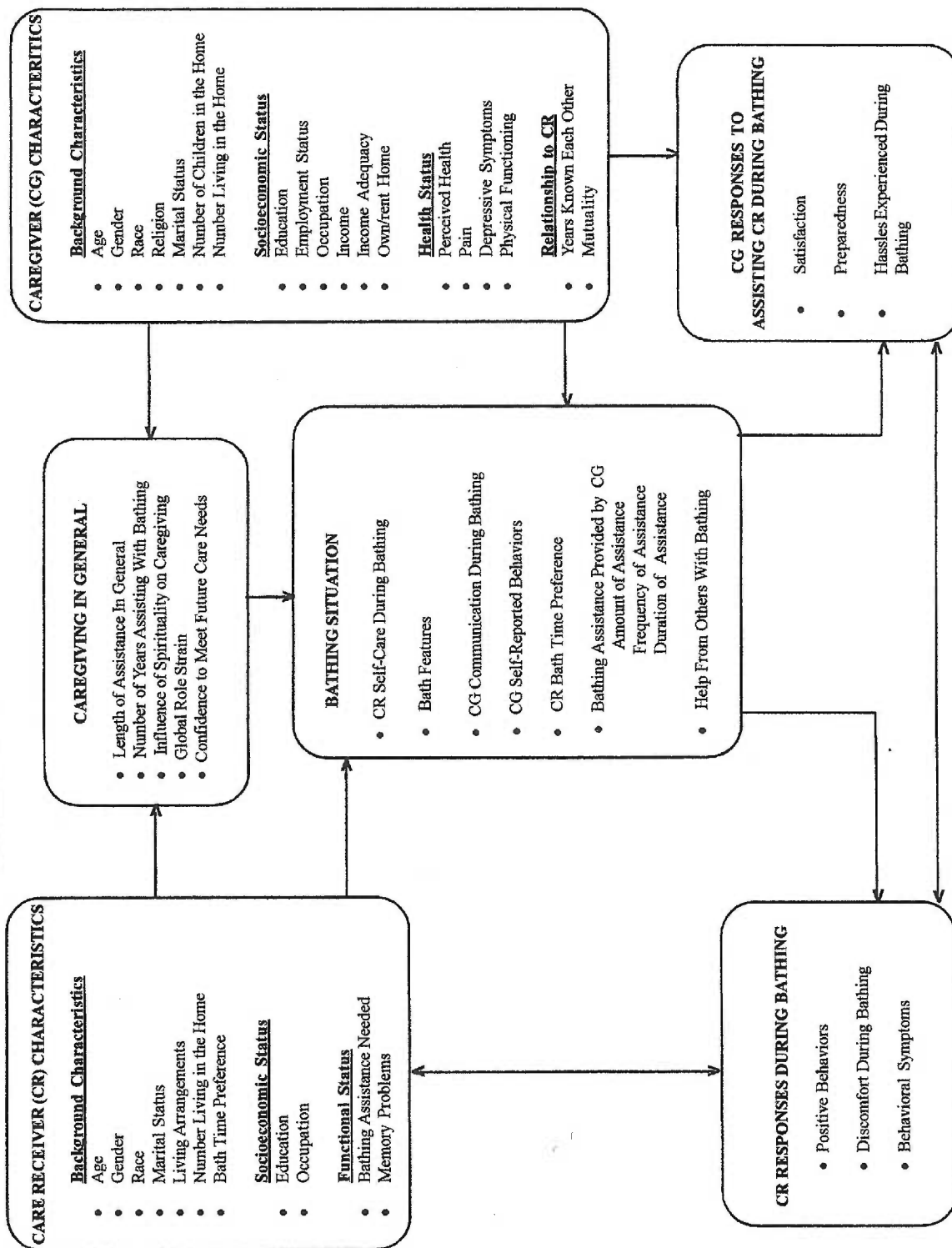
Assisting a CI elder during bathing can be a pleasant or negative experience for both the family CG and the CI elder. Bathing difficulties appear to be a common complaint among family CGs of CI elders in primary care clinics (Teri, Larson, & Reifler, 1988). However, more information is needed about the experiences of family CGs who assist a CI elder during bathing in the home setting.

In order to determine what concepts should be measured in the new bathing instruments, studies were reviewed to identify concepts relevant to assisting CI elders with bathing. Fourteen bathing-specific concepts were identified and they were organized in three conceptual areas: (a) the bathing situation; (b) CR responses during bathing; and (c) CG responses to assisting a CI elder during bathing. The first section of the literature review focuses on the 14 bathing-specific concepts. (See Appendix A for Review of Literature tables.)

The second section of the literature review summarizes the initial conceptual model, which guided the development and construct validity testing of the new instruments. The initial conceptual model of the 14 bathing concepts and other factors related to them is shown in Figure 1. The three sets of factors related to the bathing concepts include CR characteristics, CG characteristics, and caregiving in general.

The third section of the literature review presents hypotheses to be tested in order to obtain preliminary evidence about construct validity of the new instruments.

Figure 1: INITIAL CONCEPTUAL MODEL: FACTORS INFLUENCING FAMILY CAREGIVERS' PERCEPTIONS OF ASSISTING A COGNITIVELY IMPAIRED ELDER DURING BATHING



Concepts Relevant to Assisting CI Elders with Bathing

Bathing Situation

Eight concepts have been identified to describe the activities that occur, and the overall context that exists, when family CGs assist CI elders during bathing. The concepts that represent the bathing situation include: (a) CR self-care during bathing, (b) bath features, (c) CG attitudes about bathing, (d) CG communication during bathing, (e) CG self-reported behaviors during bathing, (f) CR bath time preference, (g) bathing assistance provided by the CG, and (h) help from others with bathing.

CR self-care during bathing is defined as the ability to bathe oneself or body parts using at least one object (e.g., wash cloth, soap) and switching independently from one activity to another (e.g., soaping the wash cloth then washing an arm). In other words, self-care behaviors occur when the CR prepares for the bath, washes his or her hair, or washes and dries body parts independently. The more the elder demonstrates self-care behaviors, the less assistance is required of the family CG. Self-care behaviors are reflected in the degree of independence the CI elder demonstrates in bathing.

CR self-care during bathing occurs when the CG allows the CR to bathe independently according to the CR's ability. While assisting with bathing and other ADLs, the CG focuses on the strengths of the CR instead of the CR's weaknesses. Some CI elders in the community may be dependent during ADLs. For example, Freels and colleagues (1992) studied 240 community dwelling elders diagnosed with Alzheimer's

disease and found 80 were functionally impaired during bathing; of these 80, 12% were moderately to severely impaired during bathing.

Studies conducted in the community and in nursing homes suggest that CGs tend to equate cognitive deficits with self-care deficits, so they provide total assistance with ADLs (Beck et al., 1997; Haley & Pardo, 1989; Quayhagen & Quayhagen, 1989). In response, CI elders interpret the actions of the CG as a means to deprive them of independence in self-care, resulting in CR feelings of discomfort, anxiety, and agitation (Tappen, 1994). Consequently, CI elders may be unable to attend to completing self-care activities independently (Taft & Cronin-Strubbs, 1995). Therefore, family CGs may be assisting more than needed during bathing and may contribute to increased self-care deficits of CI elders during bathing and subsequent behavioral symptoms.

In the early stages of Alzheimer's disease, memory deficits that occur have minimal if any effect on the ability to do ADLs. Early memory deficits in dementia occur in declarative memory (i.e., fact memory) involving conceptual knowledge or the things we know. Therefore, CI elders usually have difficulties with recall and recognition. However, the non-declarative part of memory (e.g., motor procedures, cognitive procedures and habits) stays intact until the later stages of the disease (Squire & Zola-Morgan, 1991). The habit portions of non-declarative memory or procedural memory (Tappen, 1996; Zanetti, Binetti, Rozzini, Bianchetti, & Trabucchi, 1999) are those things that we do every day, such as ADLs, which are over-learned motor behaviors. Self-care bathing habits are learned during early childhood, are reinforced and can be maintained throughout life. Even if an individual is cognitively impaired, self-care can be maintained

into the late stages of the disease (Namazi & Johnson, 1996). Comstock, Mayers, and Folsom (1969) stress the importance of prompting elders to maintain self-care behaviors during ADLs, since they have learned ADLs previously as a child and have executed them automatically as adults. CGs can be instrumental in reactivating self-care behaviors, which may have been lost when CGs implemented ADLs for CI elders and which CI elders had the capacity to do independently.

Several researchers have described the phenomenon of excess disability in self-care, where CGs provide unneeded assistance resulting in a loss of the CI elder's existing self-care abilities (Beck, 1988; Beck, Heacock, Mercer, Walton, & Shook, 1991; Comstock, Mayers, & Folsom, 1969; Dawson, Wells & Kline, 1993; Tappen, 1994). Rinke and colleagues (1978) tested an intervention with 6 CI elderly nursing home residents to reinstate self-bathing, enhance their personal dignity and autonomy, and save time for nursing staff for other patient care activities. The intervention included prompting and positive reinforcement strategies implemented by nursing staff during bathing. There was a 100% improvement in rinsing, soaping, and drying. Beck and colleagues (1991) used a similar technique in a small pilot study in which behavioral strategies were used to promote dressing independence in 5 community dwelling CI elders. Four of the 5 CI elders dressed more independently after the family CG used behavioral strategies to promote independence in dressing. Beck and colleagues concluded that promoting independence during ADLs can be more individualized in the home setting, and family CGs may be more motivated to encourage independence than paid CGs who are not related to the CI elder. Their study suggests that family CGs may

be assisting more than needed with dressing, and that some CI elders are able to be more independent than the family CG allows. This may also be the case with bathing. If the CI elder is more independent during bathing, it may decrease some of the time that the CG spends assisting during bathing.

Another study conducted by occupational therapists in the community resulted in contradictory findings. Gitlin, Corcoran, Winter, Boyce, and Hauck (2001) conducted a study with family CGs, in which occupational therapists assisted 171 family CGs with modifying the environment to address the outcomes of daily caregiving tasks for CI elders and their family CGs. The intervention entailed educating family CGs about the impact of the environment on the behavior of CI elders, breaking down or simplifying ADL tasks (e.g., using one- or two-step commands), and finding ways to involve other members or formal support in daily caregiving tasks. There were no significant differences in self-care improvements and ADLs between the control and experimental groups from baseline to three months following the study.

Studies have addressed improving self-care behaviors in relationship to reducing behavioral symptoms during ADLs. Wells, Dawson, Sidani, Craig, and Pringle (2001) tested a "home environment" intervention during morning care activities with 40 CI nursing home residents and their 44 formal CGs. The researchers tested the effect of the intervention on CI elders' behaviors during ADLs. The intervention included an educational program to help formal CGs deliver abilities-focused care. CI residents who received the abilities-focused care intervention displayed more interaction behaviors and socially appropriate behaviors, decreased agitation, and increased self-care behaviors.

When CI elders do not have control during bathing, they may cope with the bathing situation by exhibiting behavioral symptoms. For instance, Kovach & Meyer-Arnold (1996) concluded that CI elders cope with loss of control by asking questions, expressing confusion, or exhibiting fear. To attain control, they make verbal complaints, attempt to leave the bathing situation, and become aggressive towards the CG. Additional interpretations are that CGs' assistance may be interpreted by CI elders as an interference with privacy and independence, and that all behaviors are attempts to cope with the bathing situation.

On the basis of the literature review, I decided that the measure of self-care during bathing should include the specific bathing tasks that older adults do. The Bathing Performance Scale of the Beck ADL Scale (Beck et al., 1988), originally developed for the observation of formal CGs assisting CI elders during bathing in the nursing home, was modified for use in this study.

Bath Features are the function, form, and frequency of the bath. The function of the bath is defined as maintaining skin integrity, preventing infection, promoting social acceptability, and giving pleasure. The form of the bath is defined as the type of bath or the physical bath environment where the bath occurs (e.g., tub, shower, bedbath). The frequency of the bath is defined as how often the CR is bathed (Rader, 1994; Sloane et al., 1995; Rader, Lavelle, Hoeffler & McKenzie, 1996). Rader and colleagues (1996) suggest that nursing home CGs who consider the function, form and frequency of the bathing will make bathing a more thoughtful process. These features of the bath may have an impact on the positive or negative responses of both the family CG and CI elder.

Bathing has many therapeutic functions. In addition to cleansing the body of pathogenic organisms, other functions of bathing include stimulation, massage, and relaxation of muscles plus maintenance of the elder's well-being (Barsevick & Llewellyn, 1982; Rader et al., 1995). In addition to these therapeutic functions, family CGs have identified pleasure (e.g., warmth, relaxation and sensory stimulation) as a reason for bathing (Sloane, Honn, et al., 1995; Sloane, Rader, et al., 1995).

The most common forms of bathing in nursing homes are bed baths, partial bed baths, tub baths, and showers. To make the bath go easier, ideally CGs should be aware of the pre-dementia-onset favored form of the bath, the function the bath served, and frequency of the bath. Therefore, when a CI elder is less able to articulate bath choices, the nursing home CG can help the CI elder maintain routines practiced prior to dementia. Furthermore, CGs need to remain flexible and open to changing the function, form, and frequency of the bath, so that CI elders' wishes are respected and more positive responses to the bathing experience are elicited.

Family CGs are in a better position than paid CGs to predict the CI elder's wishes during bathing, because most have known the elder intimately for a number of years prior to caregiving (Rader, 1999; Rader & Barrick, 2000). CGs should think of the most preferred, comfortable and least frightening bath form for CI elders (Rader & Barrick, 2000).

Namazi and Johnson (1996) interviewed 22 family members of CI nursing home residents who displayed behavioral symptoms during bathing, to determine whether the form and frequency of the bath matched CI elders' preference and what behavioral

symptoms occurred during bathing. As reported by the family members, the most common form of bath preferred by CI elders was occasional sponge baths. The frequency of baths preferred by the majority of elders was twice a week (54%); weekly baths were preferred by 36% and bathing five times a week was preferred by only 10% of CI elders participating in the study.

Hoeffler and colleagues (1997) piloted an intervention in which Certified Nursing Assistants (CNAs) learned strategies designed to reduce aggressive behaviors of CI elderly nursing home residents ($n = 10$) who required assistance with bathing. The purpose of the pilot study was to test the effectiveness of the intervention in reducing the number of aggressive behaviors during bathing and improving both residents' and CNAs' experience with the bath. The intervention consisted of bedside consultation by a geropsychiatric clinical nurse specialist with CNAs to develop an individualized bathing plan for each resident. The nurse consultant assisted the CNA in determining the functions of the bath (e.g., cleansing, comfort, etc.), the frequency with which the bath was needed to achieve the identified functions (e.g., weekly), and the form the bath could take (e.g., shower or towel). The emphasis was on changing CNAs' perception of bathing from a task to a therapeutic time for CI nursing home residents. Significant changes were found between pre and post-intervention baths for both physically and verbally aggressive behaviors of the CI elders. In a comparison of bath forms (shower vs. towel bath) for one resident, resistive, physically aggressive behaviors decreased from an average of seven behaviors during two showers to one behavior during two towel baths, showing the positive effects of the alternative bath form. These findings suggest that an

individualized approach, which emphasizes a person-centered focus, skillful communication and flexibility in the function, frequency, and form of bathing, is effective in making the bathing experience more positive and less distressing for CI elders and CGs. On the basis of the literature review, I decided to develop items that ask family CGs about their perceptions of the function, form, and frequency of the bath.

Consideration of CR bath time preference is one way that CGs can individualize the bath to provide for comfort and reduce behavioral symptoms during bathing (Rader et. al., 1996; Kitwood, 1993). Bath time matches CR preference is defined as providing the bath when the CI elder prefers. CI elders may not always want to bathe according to family CGs' scheduled routine or convenience. Oftentimes CI elders are not bathed according to their premorbid bathing habits. CI elders may remember enough of their previous bathing habits to resist bathing during an "off scheduled" bath time.

When a CI elders refuses to bathe and the CG continues with the bath, the CI elder may feel that he or she has lost control or is being attacked (Rader, 1999; Rader & Barrick, 2000). Determining the bath preferences of the CI elder may make bathing go smoother for both the CG and CR. By knowing the pre-disease personality, interests, activities, and cultural identity of CI elders, CGs can better understand the CRs' care preferences, coping mechanisms, and personal care needs. When CGs have such understanding, CI elders are more apt to participate in meeting their own ADLs (Hall & Buckwalter, 1999). This principle applies to every aspect of caregiving including bathing.

In their study of premorbid bathing time preferences of 22 CI nursing home residents, Namazi and Johnson (1996) found that residents were not usually bathed at

their preferred premorbid bathing times. Most CI elders preferred to bathe in the morning (8 a.m. to noon) and late afternoon between (4 to 8 p.m.), although 2 CI elders preferred late night baths. Knowledge of the personal history of the CI elder may assist in addressing behavioral symptoms during bathing, for example assisting the CI elder during bathing in a manner consistent with the way previously enjoyed. For instance, family CGs' attempts at matching previous bath schedules and routines may make bathing less stressful and more likely to go well for the CI elder. On the basis of the literature review, I developed a new scale to ask family CGs about the CI elder's premorbid bathing time preference and current bathing time.

CG attitudes about bathing, communication during bathing and self-reported behaviors during bathing are interrelated concepts that may affect how well the bath goes. The family CGs' attitudes about bathing, communication skills and behaviors influence how the CR responds to the bathing situation. CG behaviors include patience/impatience, relaxed/tense, persuasive/coercive behaviors, and verbal/non-verbal communication skills. These behaviors affect whether or not the CG creates a bathing regimen that promotes congruence between the capabilities of CI elders with the demands of bathing. During the bath, family CGs' attitudes about bathing, communication skills and behaviors can influence the amount of environmental stimuli the CI elder receives (Frank, 1997).

Family CGs' ability to communicate and interact effectively with CI elders, while assisting during bathing, is important in individualizing CI elders' care and lessening negative responses from the CI elder during bathing. Wells and colleagues (2001) found

that their abilities-focused care intervention resulted in the formal CGs' behaviors becoming more social and flexible when interacting with CI elders during morning care.

During the early and middle stages of Alzheimer's disease, CI elders are able to verbalize fluently but may be unable to comprehend what their CGs say. As the disease progresses, CI elders lose both verbal and non-verbal abilities. Such losses in the CI elder's comprehension may be challenging for CGs during caregiving activities (e.g., bathing). Furthermore, a lack of understanding between the family CGs and CI elders while communicating may result in negative reactions from the CI elders, such as acting-out to express their needs (Richter, Roberto, & Bottenberg, 1995).

These researchers and others have concluded that many behavioral symptoms displayed by CI elders during bathing were precipitated by CGs who used approaches which resulted in defensive responses from CI elders (Bridges-Partlet, Knopman, & Thompson, 1994; Kovach & Meyer-Arnold, 1996; Namazi & Johnson, 1996). On the other hand, negative responses of CI elders during caregiving activities may result in negative responses by the family CG. Ryden (1998) found a positive association between aggressive behaviors of CI elders and family members feeling upset and acting aggressively towards the CI elder.

Family CGs using effective communication skills and appropriate interaction styles may decrease negative responses from CI elders during caregiving activities. For instance, Richter, Roberto, & Bottenberg (1995) compared the communication processes used by family CGs ($n = 23$) and nursing staff ($n = 23$) to manage commonly occurring behavioral symptoms of CI elders. Family CGs used verbal reassurance, stayed calm,

helped the CI focus on one thing at a time, accepted hostility as part of the disease process, did not argue, and did not use reality orientation techniques. The nursing staff modified the environment (e.g., clocks, calendars), and used conversation strategies (e.g., short verbal cues, continual verbal reassurance, break activities into one task at a time). In her observation of 14 CI nursing home residents, Frank (1997, p. 25) described a communicative setting as: CI elders receive affectionate attention; distress is acknowledged and skillfully responded to; physical care is a social event; information is communicated courteously during caregiving activities; CI elders' views and wishes are considered; their privacy is respected; breaches of etiquette are tolerated; CGs respond to non-verbal communication; and CGs share the CI elders' reality. Miller (1997) suggested 10 approaches to improve the bathing situation: (1) obtaining a bathing history, (2) allowing the CR to decide when to bathe, (3) individualizing the bath, (4) showing empathy, (5) observing for escalating behaviors, (6) talking to the resident, (7) helping CI elders understand instructions, (8) sharing in their fantasy world, (9) preserving CI elders' dignity, and (10) protecting the CI elder. Although these approaches are suggested for nursing home residents, they may apply to family caregiving during bathing as well since the strategies used by informal and formal CGs in the previous study were similar.

On the basis of the literature review, I decided to modify two self-report scales previously used with nursing home staff, My View of Bathing and Giving a Bath (Rasin et al., 1999), to measure the concepts of CG attitudes about bathing and CG self reported behaviors during bathing. The Caregiver Bathing Behavior Rating Scale, an observational tool to rate CNAs who are assisting CI elders during bathing (Sloane et al., 1995) was

modified into a self-report form to measure the concept of CG communication during bathing.

Bathing assistance provided by family CGs of CI elders living in the community occurs, but little is known about how much family CGs are assisting during bathing. Ory and colleagues (1999) found that 39% of family CGs of CI elders spend time assisting during bathing or showering compared to 23% of family CGs of cognitively intact elders. In their study of 20 male family CGs, Mathew, Mattocks, and Slatt (1990) found that 33% assisted a CI elder during bathing and reported the amount of hours providing care as problematic.

In their Caregiver Relief Study, Archbold and Stewart (1988) used a sample of 122 family CGs of elders who had been discharged from the hospital six weeks before the first interview ($n = 103$) or who had received extensive long-term care in-home ($n = 19$). About a quarter of the elders in this sample had dementia. Sixty-eight CGs (56%) reported assisting the elder with bathing or washing. In another study by Archbold and colleagues (1997), 41% of 64 family CGs of persons with dementia reported assisting the elder with bathing, washing, or taking a shower.

In summary, the findings suggest that one-quarter to one-half of family CGs of CI elders are assisting during bathing in the home. The more frequently the CI elder is bathed and the extent to which bathing assistance is needed increase the amount and frequency of bathing assistance and its duration (amount of time spent assisting the CI elder). Items were added to the questionnaire that elicited information regarding the amount, frequency and duration of bathing assistance from family CGs.

Help from others with bathing is defined as assistance from family, friends, and formal CGs with bathing. Help from others with bathing a CI elder in the home has received limited study. In Archbold and Stewart's (1988) Caregiver Relief Study, 12% of 122 CGs reported receiving help from another relative with bathing and 26% reported receiving help from someone whose job it is.

Help with caregiving tasks in general occurs more frequently when CG themselves are doing more physical caregiving tasks and experiencing CG distress (Harper & Lund, 1990; McCarty, 1996; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Wykle & Segal, 1991). Ory and colleagues (1999), in their survey of 1500 family CGs, found that family CGs of CI elders were more likely to report that other family members were not doing their fair share (74%) than nondementia family CGs (59%). This often resulted in conflict with other family members. Harris' (1998) study of caregiving sons suggests that the sharing of caregiving responsibilities among family members is important (e.g., actively teaming up with a spouse or other family members to plan and provide care). However, caregiving sons reported experiencing tension in sibling relationships when siblings refuse to share responsibility in their parent's care.

The literature suggests that females appear to need the most help with their caregiving role, mainly because they provide more care than males on average (Dunkin & Anderson-Hanley, 1998; Haley et al., 1995; Harper & Lund, 1990; Vernooou-Dassen, Felling, & Persoon, 1996). Female CGs providing care to a CI elder without assistance from others is associated with role strain. McCarty (1996) reported that 16 daughter CGs appeared to experience role strain because the implementation of all caregiving

responsibilities of a CI family member alone often conflicted with their roles as wives and mothers.

Wykle and Segal (1991) reported that the most difficult problem encountered by black family CGs was the lack of assistance from home health aides or paid CGs to relieve them from duties of care giving. On the other hand, some family CGs of CI elders refuse to seek the help of formal CGs due to cultural beliefs. For example, family CGs who are Asian American and Pacific Islander American tend to maintain cultural traditions which include providing care in the home setting and seeking help from family members instead of health care professionals or paid CGs (Braun & Browne, 1998).

When family caregiving of CI elders becomes too stressful, the outcome may be undesirable for the CI elder. Male family CGs tend to institutionalize the CI elder sooner than female family CGs who often receive less outside help. For example, men who continue the caregiving role are more likely to receive help from wives, daughters, visiting nurses, and housekeeper services. The absence of help from others along with the family CG's poor mental and physical health were factors that contributed to male CGs' decision to institutionalize their CI family member in one study (Mathew, Mattocks, & Slatt, 1990). Overall, when family CGs do not receive help from others with caregiving tasks, the CI elder is placed at risk for institutionalization. For instance, Vernooij-Dassen, and colleagues' (1996) study of 138 family CGs of non-institutionalized CI elders found that family CGs receiving additional home help is one factor in preventing institutionalization.

There appears to be no difference in the amount of help received by family CGs of CI elders with behavioral symptoms and the amount of help received by family CGs of CI elders who do not display behavioral symptoms during caregiving activities. Ryden's (1988) study of 183 community dwelling CI elders found that there were no significant differences in the amount of help with caregiving received from family and friends between those caring for aggressive and non-aggressive groups of CI elders. Aggressive behaviors of CI elders during bathing may be very stressful for family CGs and may result in CG distress, depressive symptoms, and poor physical health. Robinson (1989) found that family CGs have a desire for help with caregiving activities, but may have a negative attitude related to asking for help with caregiving activities.

The Help From Others in Family Care Scale (Stewart & Archbold, 1994) was modified to measure the amount of help with bathing tasks that CGs receive from relatives, friends and neighbors, and paid CGs. In addition, the scale measures help not received from a person whom the CG thought would help.

CR Responses During Bathing

CR responses during bathing are their reactions during the time that their family CG is assisting them with bathing and can be thought of as the coping behaviors of CI elders during bathing. Assessing how CI elders perceive the bathing experience may be difficult, because of changes in their ability to verbally communicate likes, dislikes, or needs as the disease progresses. Clinicians oftentimes are dependent on the reports from family CGs (Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). Some CI elders may attempt to communicate with family CGs using incoherent verbal and non-verbal

responses during bathing. How family CGs perceive these responses may have an impact on how they respond to the CI elder and view their role of assisting during bathing (Phillips & Rempuseski, 1986). For example, a challenge for many family CGs is that CI elders are unable to thank them for the care provided, and family CGs have difficulty knowing whether the CI elder is pleased with caregiving decisions made by the family CG (Cohen, Pringle & LeDuc, 2001). The components of CR responses during bathing include: (a) positive behaviors, (b) discomfort, and (c) behavioral symptoms.

Positive behaviors displayed by CI elders may occur during bathing. Positive CR responses during bathing include contentment and appreciative and affectionate behaviors. Contentment is defined as verbal or non-verbal gestures that display CI elders' comfort and satisfaction during bathing. Appreciative and affectionate behaviors are defined as verbal or non-verbal expressions of love and gratitude during bathing.

In their nursing home study, Burgener and Shimer (1993) found the number of smiles from CI elder to CG was moderately related to the amount of CGs' experience in caring for CI elders. Family CGs of CI elders often find that the CI elder's apathy is disturbing, because the CI elder does not provide positive reinforcement regarding how well the family CGs are doing (Thomas, Clement, Hazif-Thomas, & Leger, 2001).

Kinney and Stephens (1989) compared 60 family CGs to 74 non-CGs to investigate the role of daily caregiving stressors or hassles, and the potential effects of small satisfactions (uplifts) in caregiving on the well-being of CGs to persons with dementia. Family CGs reported it was uplifting to see CI elders being calm (68%), being responsive (67%), showing affection (61%), being cooperative (53%), smiling/winking

(50%), and just being with CI elder (50%). In the development of their discomfort measure for use in the nursing home setting, Hurley, Volicer, Hanrahan, and Houde (1992) describe contentment behaviors as: pleasant calm looking face, tranquil, at ease or serene, relaxed facial expression, overall look is one of peace, and relaxed body language. These behaviors represent positive responses that CI elders displayed to CGs during caregiving activities.

On the basis of the literature review and my own research and clinical experience related to bathing CI elders, I generated a list of positive CR behaviors to be included in the CR's Reactions to Bathing Scale. Contentment items from Hurley and colleagues' 1992 Discomfort Scale were added to my list of CR positive behaviors. The findings of the above studies suggest that positive behaviors of CI elders during bathing may be associated with reduced CG hassles or distress.

Discomfort during bathing experienced by the CI elder may occur while the family CG is assisting during bathing. Discomfort is defined as a negative emotional (i.e., affective) and/or physical state of the CI elder in response to environmental demands. Some CI elders are unable to verbally express to CGs, in a meaningful way, the discomfort they are experiencing during bathing activities. Discomfort may be communicated to CGs through body language, behavioral symptoms, or both.

Because of difficulties with verbal communication, self-report may not be the best way to assess discomfort in CI elders (Miller, Neelon, Dalton, Ng'andu, & Layman, 1996). Studies do suggest that discomfort can be assessed by non-verbal indicators; for example, the communication of discomfort can be assessed from non-verbal cues such as

facial expressions, behaviors, and body language. In a summary of several studies on pain in preverbal children (National Institute of Nursing Research, 2000), numerous verbal and nonverbal indicators of pain were identified: crying, whining, pointing, resistance, flexion reflex, movement of extremities, negative behaviors and negative facial expressions (e.g., frown, cry face without crying, brow contractions, eye squeeze, open mouth, tongue protrusion). Other pain indicators were body movements indicative of discomfort, such as rigidity, thrashing and a return to normal posturing movements after the discomfort is resolved. Similar indicators of pain may occur in CI elders.

Hadjistavropoulos, LaChapelle, MacLeod, Snider, and Craig (2000) examined the utility of three approaches to assess pain in 58 CI elders in a rehabilitation hospital for low back pain. The three approaches were self-report ratings, coding body movements, and a facial action coding system. Each patient was asked to sit, stand, walk, and recline for a set period of time. The self-report approach was found not to be related to facial expressions, but nonverbal measures effectively identified pain during physical activity. The findings indicate that guarded behaviors and facial grimaces during physical activities, such as bathing, reflect the actual experience of pain. This study suggests that moderately and severely CI elders are unable to complete self-reports related to discomfort, and provides support for assessing discomfort using observable non-verbal indicators.

Hurley and colleagues (1992) also believe that discomfort in CI elders is communicated in their non-verbal behaviors. Her team of researchers developed an observational measure that included the following indicators of discomfort displayed by

CI elders: noisy breathing, negative vocalization, sad facial expression, frightened facial expression, frown, tense body language, and fidgeting. The Discomfort Scale also includes items from the literature on pain in infants and non-verbal expressions of pain.

Discomfort experienced by CI elders during bathing may be one reason that CI elders are resistant to bathing or display behavioral symptoms. Feldt, Warne, and Ryden (1998) examined pain in CI nursing home residents to determine the relationship between pain and aggressive behaviors. The sample consisted of 38 CI elders who displayed one or more forms of aggression while receiving assistance during ADLs. Aggression scores were higher in CI residents with pain-related diagnoses. For example, CI residents with a diagnosis of cancer averaged more than 19 aggressive behaviors a day. CI residents diagnosed with arthritis had significantly higher non-aggressive and aggressive behaviors than residents with other types of pain diagnosis. Those individuals with two or more pain related diagnoses had significantly higher non-aggressive behaviors and significantly higher physical aggressive behaviors.

According to Namazi & Johnson (1996), CI elders experience discomfort during tub baths and a sense of helplessness due to not being allowed to participate in the bathing process, for example holding the washcloth. Individualizing care may promote feelings of comfort in CI elders during bathing. Based on the literature review, the Discomfort Scale (Hurley et al., 1992) was selected and modified to measure the family CG's view of CR discomfort during bathing in the home.

Behavioral symptoms are another set of CR responses that may occur when a CG assists a CI elder during bathing. Behavioral symptoms are defined as verbal or physical

agitated and aggressive behaviors that interfere with caregiving, or have negative consequences for the CI elder or family CG. However, according to the Need-Driven Dementia-Compromised Behavior Model (Algase et al., 1996), all behavior is viewed as meaningful and as a means of communicating unmet needs. These responses may interfere with the caregiving situation or have negative consequences for the CG or CR.

Studies in nursing homes with paid CGs who assist during bathing have suggested that CI elders may become overwhelmed with the demands of bathing and cope by displaying behavioral symptoms, such as resistive, agitated, and aggressive behaviors (Hoeffer et al., 1997; Namazi & Johnson, 1996; Newsom & Schulz, 1998; Ryden, 1988; Sloane, Honn, et al., 1995).

Several studies conducted in nursing homes have identified common behavioral symptoms displayed by CI elders during caregiving activities. Namazi and Johnson (1996) identified verbal aggression (91%), making strange noises (77%), talking to self (73%), complaining or whining (73%), threatening (59%), physical aggression (45%), rage reaction (32%), and throwing objects (5%) as negative outcomes of the bath for CI elders in nursing homes. Bridges-Partlet, Knopman, & Thompson (1994) identified physical aggressive behaviors, such as hitting, kicking, and threatening behaviors less than 1 minute up to 20 minutes. Eighty-two percent of the behaviors were directed towards the nursing staff and 54% occurred during personal care activities (e.g., toileting, bathing, grooming, and dressing). Seven of 28 episodes of physical aggressive behaviors were preceded by verbal aggression.

Hoeffler and colleagues (1997) identified behaviors displayed by 86 nursing home CI residents during bathing. Findings from the survey showed that 41% of these residents were aggressive during at least one bath, and that 16% were aggressive during three of the four baths. Of those aggressive during at least one bath, 60% had a diagnosis of dementia; of those aggressive during three of the four baths, 72% had a diagnosis of dementia. Nursing assistants reported hitting, punching, slapping, pinching, and shoving as the most frequent physical aggressive behaviors encountered. Name calling and cursing were the most frequent verbal aggressive behaviors encountered.

Kovach & Meyer-Arnold (1996) examined the experiences during bathing of 15 CI nursing home residents and 18 CI elders living in the community. The baths were given by nursing assistants in both settings. The investigators observed behavioral symptoms, such as hitting, kicking, and threatening gestures that ranged from a single occurrence (lasting 1 minute or less) to multiple behaviors occurring continuously, in 73% of the CI elders during bathing.

Similar to studies in nursing homes, research conducted in the community suggest that CI elders display behavioral symptoms during caregiving activities implemented by family CGs. Miller and associates (1995) conducted a study of 215 spousal family CGs of CI elders. They found that behaviors which family CGs find upsetting include: emotional lability, irritability, outbursts, wandering, destroying property, hoarding, and aggressive behaviors. In Ryden's (1988) study of aggressive behaviors of 183 CI elders who live in the community, family CGs reported the following behavioral symptoms: verbal aggression (50%), physical aggression (46%), and inappropriate sexual aggressive

behaviors (18%). Family CGs reported that an average of 10 out of 48 possible behaviors occurred in their situation; on average 7 behaviors occurred more than twice per week. Males exhibited more behavioral problems than female CI elders. However, Ryden did not examine the occurrence of behavioral symptoms specifically during bathing.

Freels and colleagues (1992) studied 240 community dwelling individuals diagnosed with Alzheimer's disease. The most prevalent symptoms of CI elders were agitation (30%), depressive symptoms (27%), and behavioral symptoms (22%). CI elders with behavioral symptoms were three times more likely to have moderate to severe difficulty with bathing than CI elders without behavioral symptoms. In their study of 140 family CGs of CI elders, Farran and colleagues (1993) examined bathing specifically. They found that the following behaviors occurred: restlessness, irritability, uncooperativeness, evidence of rapid emotional shifts, verbal and physical threats, physical abuse, and threats to harm self. They also found significantly greater CG burden in family CGs who were meeting greater ADL needs of the CI elder. On the basis of the literature review, I decided to modify Beck's Disruptive Behavior Scale (Beck et. al., 1997) to measure the CG's view of CR behavioral symptoms during bathing.

CG Responses During Bathing

CG responses during bathing include CG satisfaction and preparedness and CG hassles experienced during bathing.

CG satisfaction and preparedness are the perceived positive feelings and sense of confidence that CGs experience regarding their ability to successfully bathe CI elders. CG satisfaction and preparedness may be related both to the response of the CR and to

how stressful it is for the CG to assist a CI elder during bathing. Some family CGs find managing behavioral problems and functional deficits as stressful and view themselves less confident to implement caregiving tasks, so they may feel less prepared for the caregiving role (Haley, Levine & Brown, 1987). When bathing goes well for family CGs who assist a CI elder during bathing, they may feel confident in their abilities and satisfaction with the bathing experience. For example, Chang (1999) studied 65 female CGs of CI elders living in the community. The group who received an intervention designed to teach the CG skills to improve self-care of CI elders in eating and dressing reported less CG burden, anxiety and increased satisfaction with caregiving over time.

Hoeffler and colleagues (1997) tested interventions designed to reduce behavioral symptoms of 10 CI nursing home residents during bathing and to make the bathing experience more positive for residents and their paid CGs. The CGs rated their experience assisting CI elders during bathing more positively post-intervention, suggestive of greater CG satisfaction. Family CGs often feel confident when they begin in their caregiving role, but as CI elders become more disruptive, dependent and difficult to assist during ADLs, family CGs' confidence in providing care may decrease. For example, in their study of change and continuity in home care for 138 CI elders, Vernooij-Dassen and colleagues (1996) found that family CGs' sense of competence or preparedness decreased over time.

On the basis of the literature review, I selected Your Experience During Bathing Scale, developed by Rasin and colleagues (1999), to measure CNA satisfaction and

preparedness for bathing CI nursing home residents, and modified the scale for family CGs.

Hassles experienced during bathing include the stress and minor irritations perceived by CGs when assisting a CI elder during bathing. Assisting a CI elder during bathing can be a difficult task and may add to caregiving hassles. Kinney and Stephens' (1989) investigated the role of daily caregiving stressors or hassles of family CGs caring for CI elders. They reported an average of 27.5 daily hassles and 19 uplifts. Bathing was one of the most common hassles reported, along with physical decline and disruptive behaviors. Harris' (1998) study of caregiving sons found over half reported bathing as the most difficult for them.

In Archbold and Stewart's (1988) CG Relief Study, previously described in this chapter, 56% of 122 family CGs reported assisting the elder with bathing or washing. Of CGs who assisted during bathing, 28% reported that helping with bathing was difficult, 31% said it was tiring, and 16% indicated it was upsetting. Additionally, a quarter (26%) of the family CGs who assisted their elder with bathing or washing found this activity to be very hard or pretty hard. In a study of 64 family CGs, of the 26 who assisted with bathing, half found it pretty hard or somewhat hard to do, 30% found it not too hard to do, and the remaining 20% found it easy to do (Archbold et al., 1997). None of the 26 found it very hard.

In their study of 76 black and 86 Hispanic family CGs, Cox and Monk (1996) reported that Hispanic and younger CGs reported more stressors associated with assisting CI elders with ADLs, such as bathing. Wykle and Segal (1991) studied 40 black and

white family CGs to identify similarities and differences in problem solving and coping strategies, stressors, and the use of informal and formal resources. White family CGs reported feelings of guilt and isolation associated with caregiving as most problematic and the management of behavioral symptoms as the second most problematic stressor for them. Black family CGs experienced significantly more CG distress. They reported the most difficult problem encountered was the lack of assistance from home health aides to relieve them of their caregiving duties. Hassles were reported by 50% of both groups related to assisting during bathing and managing behavioral symptoms.

On the basis of the literature review, I decided to modify and use Hoeffler and colleagues (1999) adaptation of Kinney and Stephen's (1989) CG Hassles Scale to measure CG stress associated with assisting a CI elder during bathing.

Initial Conceptual Model

Overview of the Conceptual Model

As shown in Figure 1, the bathing situation is influenced by the characteristics of the CR and CG, and caregiving in general. During the bathing situation both the CR and CG, who is assisting during bathing, interact to complete the task of bathing. How well the bath goes as a result of the bathing situation is reflected in the CG's responses and how the CG interprets the CR's responses. Moreover, the characteristics and experiences that CI elders and family CGs bring to the bathing situation affect how both respond to the bathing situation.

Algase and colleagues' (1996) conceptual framework of need-driven dementia-compromised behavior, and Kahana and Kinney's (1995) general stress model are integrated to form the conceptual framework for this study. Algase and colleague's (1996) conceptual framework of need-driven dementia-compromised behavior is particularly useful in understanding behavioral symptoms of CI elders during bathing. Behavioral symptoms displayed by CI elders may be meaningful and may be an expression of an unmet need. Because dementia affects brain function in many areas, CI elders may be unable to verbally communicate their needs to others. Vocalizations become a primary mechanism that many CI elders use to make their needs known to others. If CI elders' needs are not met over time, vocal or verbal attempts to express these needs may become increasingly agitated.

CGs who "over do" for their CI elderly family member may contribute to excess disability. Excess disability (i.e., greater self-care deficits than actual functional ability) limits CI elders' ability to meet their personal care needs or goals. As CI elders become more dependent and more frustrated with needing assistance, behavioral symptoms such as physical non aggressive and aggressive behaviors may emerge.

Family CGs become distressed when assisting CI elders with bathing and begin to view this task as a "hassle" when personal care leads to conflict. Lazarus and Folkman (1984) conceptualize stress as "hassles" defined as minor irritations of daily living. Kahana and Kinney's (1995) model extends the dynamic elements of a general stress model to the specific dimensions of distress most salient to caregiving. The model identifies three major sources of stress: (a) the CI elder's illness (e.g., degree of

functional impairment, cognitive impairment, and behavioral problems); (b) objective demands on the CG (e.g., amount, duration and frequency of caregiving, and demands on mental and physical resources); and (c) dyadic interactions between the family CG and CI elder that become conflictual. Family CGs may experience distress when assisting CI elders with bathing and begin to view this task as a “hassle” when personal care leads to negative outcomes (e.g., behavioral symptoms, CR discomfort, lack of appreciative and affectionate CR behaviors). In contrast, when things “go well” during assisting CI elders with bathing, and positive outcomes occur (signs of comfort, appreciative and affectionate CR behaviors), family CGs may experience assisting with bathing as rewarding.

Precursors to the Bathing Situation

The characteristics that family CGs and CI CRs bring to the bathing situation affect the nature of the bathing situation and ultimately the CG and CR outcomes.

CR characteristics influence the bathing situation directly as well as the family CGs’ experience of caregiving in general. Further, these characteristics also affect the CRs’ response to the bathing situation. CI elder characteristics include age; gender; a diminished cognitive status resulting in memory, motor, sensory, and/ or perceptual deficits; self-care and coping behaviors during bathing; levels of competence, in these functional areas, and tolerance of assistance with bathing. These characteristics influence how CI elders interact and respond to family CGs during the bathing situation, and ultimately impact the CG’s perceptions of assisting with bathing.

CG characteristics are defined as background characteristics (e.g., age gender, race etc.), socioeconomic status (e.g., education, employment, income etc.), health status (e.g., perceived health, pain, depressive symptoms etc.), and relationship to the CR (e.g., mutuality and years known each other). Mutuality is defined as the positive quality of the CR and CG relationship and includes love, shared pleasurable activities, common values, and reciprocity (Archbold et al., 1990).

In addition to affecting the bathing situation, CG characteristics may influence how the CG perceives caregiving in general, the bathing situation, and how they respond to the CR's behavior. CG characteristics play an important role in how the CG assists the CR during the bathing situation. Background characteristics and health status may influence what caregiving activities are implemented during bathing and the CG's responses to assisting the CR during bathing. Some family CGs may feel overwhelmed, by many events in their lives resulting in deterioration in mental health (e.g., depression), lack of confidence in bathing ability, and decreased satisfaction when assisting the CI elder during bathing. CGs experiencing pain may find assisting during bathing difficult, adding to the stress or hassle that may be experienced by CGs in general and their perception of the bathing experience.

Caregiving in general has several features including the duration of the caregiving role in general as well as the length of time assisting the CR during bathing. CG characteristics influence how family CGs perceive caregiving in general, which in turn influences the bathing situation. Global Role Strain is the overall felt difficulty in fulfilling the caregiving role. Spirituality is one way CGs adapt to the stressors related to

caregiving. The CG's confidence to meet future needs is determined by how well they adapt to the CG role in general and may influence the bathing situation specifically: The duration of providing care and bathing assistance, global role strain, and how the CG copes with stressors influence confidence in general and how they respond to assisting CI elders during bathing.

Hypotheses to Be Tested in Evaluating Preliminary Construct Validity

Concepts Measured by Established Instruments

To obtain preliminary evidence about construct validity of the new bathing scales, hypothesized relationships between concepts measured by the new scales and seven concepts measured by established instruments were tested. The seven concepts include CR memory problems, and CG health, CG physical functioning, CG pain, CG depressive symptoms, CG mutuality, and CG global strain. Following is a review of selected literature about these seven concepts and their relationship to the concepts measured by the new bathing scales. Research findings about these seven concepts were used to generate hypotheses about how each concept is related to the bathing concepts measured by the new instruments. These hypothesized relationships are summarized in Table 2 and are designated as a positive relationship (+), a negative relationship (-), a near-zero relationship (0), or as no hypothesis made (?). Sometimes, no hypothesis was made when the findings from the literature were contradictory or when conceptually an argument could be made for various relationships (e.g., negative correlation versus near-zero correlation between CG physical function and CR self-care during bathing).

Table 2

Hypothesized Relationships Between Concepts Measured by the New Scales and Concepts Measured by Established Scales (Aim 4)

Bathing Concepts	Concepts Measured by Established Scales						
	CR Memory Problems	CG Health	CG Phys Function	CG Pain	CG Depressive Symptoms	CG Mutuality	CG Global Strain
Bathing Situation							
1. CR Self-Care Behaviors	-	?	?	?	?	?	-
2. Bath Features	?	?	?	?	?	?	?
3. Bath time match Preference	-	+	0	-	-	+	-
4. CG Attitudes About Bathing	+	+	0	-	-	+	-
5. CG Communication	-	+	0	-	-	+	-
6. CG Self-Rep Behavior	-	+	0	-	-	+	-
7. CG Bathing Assistance	+	?	?	-	-	?	+
8. Help From Others	+	-	-	+	+	-	+
Care Receiver Responses during Bathing							
9. CR Positive Behaviors	-	+	?	-	-	+	-
10. CR Discomfort	+	?	?	?	?	?	+
11. CR Behavioral Symptoms	+	0	0	+	+	-	+
Caregiver Responses during Bathing							
12. CG Satisfaction	-	+	+	-	-	+	-
13. CG Preparedness	-	+	+	-	-	+	-
14. CG Hassles	+	-	-	+	+	-	+

Note: + = Positive relationship hypothesized. - = Negative relationship hypothesized. 0 = Near-zero relationship hypothesized. ? = No hypothesis made.

CR memory problems of CI may or may not affect family CG reactions while assisting during bathing. In Gonzales' (1997) study of 50 family CGs of CI elders, CI elders memory problems were not associated with CG stress or hassles. Furthermore, Robinson, Adkisson, and Weinrich (1989) found that the CR memory problems caused the least negative reaction from family CGs. However, Aronson, Post and Gustasiesegni (1993) studied 338 residents of 6 nursing homes to examine the care required by CI elders residing in nursing homes in relation to behavioral and functional problems associated with agitation. The higher the level of cognitive impairment may be associated with the greater incidence of agitation on both the day and evening shifts. Highest incidence of agitation was seen during transfers. The second highest ADL with behavioral problems was bathing. However, Brashares, Dodge and Catazaro's (1994) study of 73 family CGs of CI elders suggests that memory problems may have an indirect effect on hassles reported by family CGs. Family CGs reported that CR memory problems and behavioral symptoms were the problems most often encountered during caregiving. Also, the daily hassles associated with these problems were positively correlated with CG depressive symptoms.

The health status, experience of pain, and physical function of family CGs caring for a CI elder may be related to caregiving activities. Implementing bathing to a CI family member may affect the well being of family CGs. Kinney and Stephens' (1989) study examined CG well-being. The results suggested that family CGs of persons with dementia reported significantly more hostility, anxiety, depressive symptoms, and somatization than non-CGs. Cohen and colleagues' (1993) longitudinal study of 196 CG

and CR dyads was undertaken to determine the variables predictive of CG decision to institutionalize a CR with dementia. CG health and burden, use of services, CR cognitive function and troublesome behaviors, and CG reaction to behaviors predicted actual institutionalization. Other studies have measured the rate of hospitalizations of family CGs of CI elders and found women are hospitalized more than men (Moritz et al., 1992), no changes over time in hospitalization rates (Vitaliano et al., 1990) and spouses hospitalized more than other types of family CGs (Cohen et al., 1990). In general, CGs rate their health significantly worse than non-CGs (Schulz et al., 1995) and they use more pain relievers (Baumgarten et al., 1992; Schulz et al., 1995). The literature does not address CG physical functioning directly, but physical functioning can be indirectly affected by poor health and pain.

Depressive symptoms displayed by family CGs of CI elders may be associated with caring for a CI elder. Wright, Hickey, Buckwalter, Hendrix, & Kelechi's (1999) exploratory study was conducted with 42 couples, equally divided among early phase AD, ischemic stroke after hospital discharge, and well controls. Couples were evaluated at baseline (Time 1), 6 months (Time 2) and 1 year (Time 3). Depression scores of AD CGs were significantly higher than for controls at all three times ($p < .02$), but there was no significant change over time. In studies comparing family CGs of CI elders to non-CGs, CGs were more likely to experience stress and depressive symptoms than non-CGs (Gilleard et al., 1984; Toner, 1987). Meshefjian and colleagues' (1998) study of 395 family CGs, found the CR's ADL deficits had a significant relationship with CG depression. Mohide and colleagues (1990) study of 60 family CGs of CI elders, found

that family CGs of moderately and severely CI elders experience more depressive symptoms than the general public.

Mutuality, the positive relationship between the family CG and CR, and its effect on the caregiving situation have been studied (Archbold et al., 1990; Hirschfeld, 1981). Archbold and colleagues (1990) studied 78 community dwelling CGs and CRs after the CR's hospital discharge to examine the extent to which CG mutuality and preparedness for caregiving explain the variance in CG role strain from direct care (including help with bathing). After controlling for five other predictors which explained 17% of the variance in CG role strain from direct care, mutuality accounted for an additional 10% of the variance in strain from direct care and preparedness for caregiving explained another 10% of the variance, for a total of 37% explained. Further, mutuality and preparedness for caregiving were positively correlated ($r = .50$). CI elders' deterioration (e.g. increased dependence and behavioral symptoms) associated with completing the tasks of bathing may result in the family CG experiencing decreased mutuality and preparedness during bathing. These studies indicate there may be a relationship between bathing assistance and caregiving satisfaction, preparedness, and hassles during bathing.

Global strain may be another negative outcome of caregiving for family CGs assisting a CI elder with ADLs, such as bathing. For example, Fisher and Lieberman (1994) studied 97 family CGs of CI elders, of whom 87% assisted with ADLs. They found CG strain was significantly associated with poor CG health, depressive symptoms and decreased CG well-being. Also, Gilleard et al.'s (1982) study suggested that family CGs reports of the CR's functional deficits and behavioral symptoms as highly stressful,

along with their perception of being unprepared to manage these problems, may be related to CG depressive symptoms, and contribute to CG strain

Archbold and colleagues (1990) identified strain from direct care as one of nine aspects of CG role strain. They identified mutuality and preparedness as two variables that influence CG role strain. For example, higher levels of mutuality may be associated with decreased strain associated with providing direct care, making it easier for family CGs to implement caregiving activities, such as bathing. Also, high levels of preparedness may be related to low levels of strain.

Hypotheses of Relationships Bathing Among Concepts

Overall, of the 14 bathing concepts, 8 are associated with the bath going well. These include CR self-care, bath time matching CR preference, CG attitudes, CG communication, CG self reported behaviors during bathing, CR positive behaviors, CG satisfaction, and CG preparedness. Of the 14 bathing concepts, 3 of them -- CR discomfort, CR behavioral symptoms, and CG hassles -- are associated with the bath not going well. The roles of the remaining 3 concepts -- bath features, CG bathing assistance, and help from others-- are less clear, in terms of how well the bath goes. Results of the current study provide beginning evidence about these concepts and how they relate to one another.

It is unclear how bath features would be related to CR self-care but there may be a relationship between self-care and CR bath time preference. If CR actual bath time matches the CR preference, self-care may increase. Assisting a CI during bathing may go

better if the CR bathes at a preferred bath time, because the CR may be more likely to participate in the bathing process when he or she is more willing to bathe and needed CG assistance may decrease. It is likely that CGs who allow for CR bath time preferences may have more positive attitudes, communication, and self-reported behaviors.

One might hypothesize positive correlations among CG attitudes, communication, and behaviors during bathing. For example, CGs who have positive attitudes are likely to use effective communication techniques and display behaviors that promote meaningful interactions (i.e., individualizing care and encouraging self-care behaviors) with CI elders during bathing. CGs who have positive attitudes may promote individualized care during the bath by considering the bath features that are meaningful specifically for the CR. It is suggested in the literature that CGs should consider the therapeutic function of the bath (e.g. stimulation, massage and relaxations of muscles). CG who think that the bath has a comfort function may select the most comfortable and less frightening bath form and consider limiting the frequency of the bath to support positive CR responses to bathing. Some forms of the bath may require less time to implement and may be more comfortable for the CI elder, thereby decreasing the amount of assistance (e.g., in the tub bath the CR may need more assistance getting in and out of the tub versus a sink or shower bath). When the CG focuses on the needs of the person being bathed, the CR may display more positive behaviors and less discomfort and behavioral symptoms. Such CG approaches to bathing may be associated with decreased help from others, CR discomfort, CR behavioral symptoms, and CG hassles as well as increased CR self-care, CR positive behaviors, CG satisfaction and preparedness during bathing. It is unclear

how CG attitudes, communication, and self-reported behaviors are associated with CG assistance and help from others in bathing.

The more bathing assistance provided by CGs, the less CR self-care will occur. CI elders who participate in the bath by washing and drying body parts or hair independently may require less CG assistance, resulting in lowered CG assistance during bathing. It is unclear how CG bathing assistance is associated with bath features, CR bath time matching CR preference, CG attitudes, and CG communication.

According to the literature CGs may not always ask for help from others unless caregiving becomes overwhelming for them. Help from others may be associated with decreased CR self-care, and decreased CG preparedness during bathing. Consequently, the more the CRs exhibit self-care behaviors during bathing, the less the amount of help the CG needs from others. CGs who need help may perceive themselves as less prepared for assisting CRs during bathing. It is possible that helpers will not encourage CR self-care because of lack of training or patience, or because of time constraints. CGs' communication with the CR is likely to lessen because the CG may be communicating with the helper and not the CR, especially when the CR has problems with communication skills. However, help from others may actually increase CG hassles and CR behavioral symptoms, because CI elders can be easily over stimulated with too many people involved in caregiving activities. It appears that negative or positive outcomes of help from others may be dependent on a number of other factors (e.g., number of helpers, CR and CG relationship with helpers, caregiving skills of helpers). Therefore it is unclear

how help from others would be associated with CR bath time matching CR preference, CG attitudes about bathing, and CG self-reported behaviors.

CRs who are able to do more self-care during bathing may exhibit fewer behavioral symptoms by replacing behavioral symptoms with positive behaviors associated with carrying out meaningful activities, such as bathing. Allowing the CR to participate in bathing may decrease feelings of CR discomfort associated with having someone else implement bathing tasks that the CR is able to complete independently. Family CGs who choose the most preferred, comfortable, and least frightening form of the bath and are flexible in determining the CI elder's bathing schedule may see lower levels of behavioral symptoms (resistance, agitation, aggression) displayed by CI elders during bathing.

As CG hassles increase, the CG may rush the bath to get it over quickly without allowing the CR to participate in the bath, consequently decreasing CR self-care behaviors. Forcing CI elders to bathe at a non-preferred time may result in increased behavioral symptoms, such as verbal and non-verbal resistive, agitated and aggressive behaviors, and discomfort during bathing. Therefore, considering the CR bath time preference may decrease behavioral symptoms and discomfort and increase CR positive behaviors, because the CR experiences autonomy by participating in the decision of when to bathe and bathing at the preferred time. CGs who display more positive attitudes during bathing may be more satisfied and prepared and experience less CG hassles when assisting a CI elder during bathing. CGs who apply good communication skills, including behaviors and attitudes while assisting a CR during bathing, may decrease CR behavioral

symptoms and discomfort, may increase CG satisfaction and preparedness, and decrease CG hassles. CG satisfaction and preparedness may be higher when CR self-care is higher. As a result of the literature review I generated hypothesized relationships between the concepts measured by the new bathing scales (See table 3).

Table 3
Hypothesized Relationships Between Concepts Measured by the New Bathing Scales (Aim 5)

Bathing Concepts	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. CR Self-Care Behaviors														
2. Bath Features	?													
3. Bath time Match Preference	+	?												
4. CG Attitudes About Bathing	+	?	+											
5. CG Communication	+	?	+	+										
6. CG Self-Reported Behaviors	+	?	+	+	+									
7. CG Bathing Assistance	-	?	0	?	?	?								
8. Help From Others	-	?	?	?	-	?	?							
9. CR Positive Behaviors	+	?	+	+	+	+	-	-						
10. CR Discomfort	-	?	-	-	-	-	+	+	-					
11. CR Behavioral Symptoms	-	?	-	-	-	-	+	+	-	+				
12. CG Satisfaction	0	?	+	+	+	+	-	-	+	-	-			
13. CG Preparedness	0	?	+	+	+	+	-	-	+	-	-	+		
14. CG Hassles	-	?	-	-	-	-	+	+	-	+	+	-	-	

Note: + = Positive relationship hypothesized. - = Negative relationship hypothesized.
0 = Near-zero relationship hypothesized. ? = No hypothesis made.

CHAPTER 3

RESEARCH DESIGN AND METHODS

Overall Design

This measurement development study employed a nonexperimental, correlational design and survey methods including mailed questionnaires and interviews. The nonexperimental design was an appropriate design to explore and develop measures to describe the experiences of family CGs assisting CI elders during bathing in the home setting. The design was used to make inferences about the relationships of variables as they occur in natural settings without manipulating the variables (Pedhauzer, 1991). The design is strengthened when a researcher uses a conceptual framework that makes explicit the expected relationships between variables.

The study was conducted in two phases. Phase 1 focused on evaluating content validity of the new instruments. Phase 2 focused on obtaining preliminary reliability and validity evidence for the new instruments with a sample of 62 family CGs. Self-administered questionnaires were mailed to experts (Phase 1 only) and family CGs (Phase 1 & 2) living in Oregon and Arkansas. This chapter includes the method and results for Phase 1, as well as the method for Phase 2.

Human Subjects

Before collecting data, the proposal for this study was reviewed and approved by the Institutional Review Boards (IRBs) of the Oregon Health & Science University (September 28, 1999) and University of Arkansas for Medical Sciences (November 16, 1999). Consent forms were not required for Phase 1 of the study by Oregon Health &

Science University's IRB, but were required by University of Arkansas for Medical Sciences' IRB. Consent forms were required for Phase 2 at both universities. (See Appendix B for Consent Forms.)

Phase 1 Method

Content validity is a systematic examination of items in a questionnaire to see whether they represent the conceptual domain to be measured (Carmines & Zeller, 1979). The purpose of Phase 1 was to address Aim 1, to evaluate the content validity of the new bathing instruments for use with family CGs in the home setting.

New Bathing Instruments for Phase 1 Content Validity Evaluation

The new bathing instruments are described below. They came from three sources. First, some were adapted from instruments previously used in nursing homes with CNAs who bathe CI nursing home residents. For the purposes of this study, the nursing home scales were adapted for use with family CGs. For example, items that were inappropriate to the home setting were eliminated; the words CNA and resident were replaced with family CG and CR, respectively. Second, some new instruments were adapted from instruments previously used with family CGs in the home setting. Third, on the basis of my research and clinical experience in bathing CI elders, I developed new instruments and added new items to existing scales. The new instruments and the concepts they measure are presented in Chapter 1, Table 1. Copies of the new instruments used in Phase I can be found in Appendix C (Phase 1 Instruments for Content Validity Rating Forms).

Concept 1: CR Self-Care During Bathing. The new instrument, Bathing Tasks Scale, was adapted from the ADL: Bathing Performance Scale (Beck et al., 1988). Beck's original 23-item tool is completed either by observers or by nursing home CNAs, who rate self-care behaviors of CI elders during bathing. Beck's ADL: Bathing Performance Scale was a modified version of the Katz Index of ADL scale (Katz et al., 1963), which was developed to measure the amount and type of assistance that was required by CI elders. Compared to Beck's scale, the new instrument, Bathing Tasks Scale, contains more items (34 versus 23) and revised response options. The new items include the rating of additional body parts that are washed and dried (e.g., underneath arms, stomach, between toes). In Beck's scale, observers or CNAs rate amount of CG involvement using response options ranging from no assistance (0) to complete assistance (7). In the new instrument, family CGs rate what bathing tasks they do and what bathing tasks the CR does (See Appendix D for the ADL: Bathing Performance Scale).

Concept 2: Bath Features. One new instrument, Reasons for Bathing Scale, is a 9-item instrument developed to assess the function of the bath. Family CGs respond to each item using a yes (1) or no (0) response format. Another new instrument, Form and Frequency of Bathing Scale, was developed to measure the form and frequency of the bath. It is a 4-item scale which asks family CGs to indicate where (e.g., bathroom sink, tub, shower, bedbath) and how often the CR bathes or washes up. Family CGs answer each item using a 5-point response format ranging from doesn't use (0) to everyday (5). An optional fifth item allows family CGs to write a form or place of the bath that is not listed as one of the choices in Items 1-4.

Concept 3: CR Bath Time Preference. In Phase 1, no measure was developed for this concept.

Concept 4: CG Attitudes About Bathing. The new instrument, Family CG's View of Bathing Scale, was adapted from its nursing home counterpart, My View of Bathing Scale (Rasin et al., 1999). Rasin's 12-item instrument measures nursing home CNAs' attitudes about bathing CI elders and has two subscales, Taking the Resident's Perspective and Holding to Traditional Views. CNAs respond to each item using a 4-point response format, including strongly disagree (1), disagree somewhat (2), agree somewhat (3), and strongly agree (4). CNAs scoring high on this scale report attitudes that are supportive of CI elders' feelings and autonomy. Cronbach's alpha reliability for the subscales were .80 (Taking the Resident's Perspective) and .53 (Holding to Traditional Views). Subscales were computed by averaging responses to the items. Three items inappropriate for the home setting were eliminated and the wording of items was changed for use with family CGs of CI elders (See Appendix E My View of Bathing Scale)

Concept 5. CG Communication During Bathing. The new instrument, Family CG Bathing Behavior Rating Scale, was adapted from the Caregiver Bathing Behavior Rating Scale (CBBRS) (Sloane et al., 1995). The CBBRS was developed specifically for rating caregiving behaviors during bathing in the nursing home setting. It is a 14-item scale that measures the verbal and nonverbal interaction style of the CG behaviors during bathing. Each item is rated on a 6-point scale ranging from often (1) to never (6). Interrater reliability studies of the CBBRS yielded percentage of agreement on scale items ranging

from 64% to 100% with an average of 90% across all items. Internal consistency was high with Cronbach's alpha values of .91 to .93 on the original scale. The items were changed from observer ratings to self-report and three non-verbal items were deleted. (See Appendix F for Caregiver Bathing Behavior Rating Scale).

Concept 6: CG Self-Reported Behaviors During Bathing. The new instrument, Family CGs Giving a Bath Scale, was adapted from its nursing home counterpart, Giving a Bath Scale (Rasin et al., 1999). Rasin's original instrument is a self-report scale measuring behaviors related to making sure the bath goes well. The scale was designed for nursing home CNAs, and it measures the extent to which the CNA individualizes the bath process and is responsive to the CI elder's feelings. The scale measures the frequency of self-reported behaviors of CGs related to making the bath go well and has two subscales, Reading the Resident and Attending Thoughtfully. CNAs use a 4-point response format, including the options of never or rarely (1), sometimes (2), often (3), and almost always (4) to answer the 13-item scale. A score is computed by averaging the responses to the items. Cronbach's alpha as a measure of internal consistency was .77 (Reading the Resident) and .66 (Attending Thoughtfully). Two of the original 13 items were eliminated because they were inappropriate for the home setting and the wording of items was changed for use with family CGs of CI elders (See Appendix G for Giving a Bath Scale).

Concept 7: Bathing Assistance Provided by the CG. At Phase 1, the new instrument, CG Help with Bathing Scale, included a single item to measure the frequency of assistance the family CG provides during bathing. The Frequency of CG Assistance

Scale includes five response categories: once or twice a month (1), once a week (2), 2 or 3 times a week (3), every other day (4), and every day (5).

Concept 8: Help From Others With Bathing. The new instrument, Help From Others With Bathing Tasks Scale, is a 3-item instrument modified from the Help From Others in Family Care Scale on the Family Care Inventory: The Caregiver's View (Stewart & Archbold, 1994). The new instrument measures how much help in bathing came from each of three sources: (a) people whose job it is, (b) relatives, and (c) friends and neighbors. The response options are none at all (0), a little (1), some (2), quite a bit (3), and a great deal (4) (See Appendix H for Help from Other in Caring For Your Family Member).

Concept 9: CR Positive Behaviors is measured by a 12-item subscale of the new instrument, CR's Reactions to Bathing Scale. The scale asks CGs to indicate which of seven reactions (e.g. smiles at you, hugs you, jokes with you, thanks you) they observed in the CR during bathing. The family CGs respond to each item using a yes (1) or no (0) response format. The items were generated from the literature and my research and clinical experience with bathing CI elders.

Concept 10: CR Discomfort is measured by an 8-item subscale of the new instrument, CR's Reactions to Bathing Scale. The subscale items were adapted from the Discomfort Scale for Advanced Dementia of the Alzheimer's type (DS-DAT) (Hurley et al., 1992), which is an observational tool used to rate the level of discomfort evidenced in persons with dementia. A quantitative scheme yields scores ranging from 0 (no observed discomfort) to 27 (high level of observed discomfort). The scale was developed to assess

discomfort in persons with advanced dementia who were hindered in their verbal communication abilities. It can be used to rate discomfort during typical ADLs such as bathing in naturalistic settings. Interrater reliability was $r = .67$ and $r = .64$. The items related to non-verbal communication and the technical terms were changed to lay person's terms. The scale asks CGs to use a yes (1) or no (0) response format to indicate which of CR reactions (e.g., has frightened facial expression, makes sounds like a moan or a groan, has a pleasant peaceful expression [reverse coded]) they observed in the CR during bathing (See Appendix I for Discomfort Scale for Advanced Dementia of the Alzheimer's Type).

Concept 11: CR Behavioral Symptoms is measured by a 30-item subscale of the new instrument, CR's Reactions to Bathing Scale. The subscale items were adapted from the Disruptive Behavior Scale (DBS) (Beck et al., 1997), which is a 45-item scale that measures the frequency of physically, verbally, and sexually disruptive behaviors of the CI elder. The intra-class correlation coefficient for the DBS was $r = .80$. For the current study, items that were inappropriate to family CGs were eliminated and the item wording was changed for the use with family CGs of CI elders. The scale asks CGs to use a yes (1) or no (0) response format to indicate which of CR reactions (e.g., hits you, spits at you, uses obscene or profane language) they observed in the CR during bathing. The CI elder receives a total score for the frequency of disruptive behaviors displayed during bathing (See Appendix J for Disruptive Behavior Scale).

Concepts 12 and 13: CG Satisfaction and CG Preparedness. The new instrument, Family CG's Experience During Bathing Scale, was adapted from the Caregiver's

Experience During Bathing Scale (Rasin, et, al., 1999), which is a self-report scale that measures nursing home CNAs' satisfaction and preparedness with assisting CI elders with bathing. The scale consists of two dimensions: CG enjoyment and CG perceived competence. The 24-item scale contains 20 items adapted from the 41-item Care Effectiveness Scale (Archbold & Stewart, 1995) and 4 items from the revised Experience of Caring Scale (Feldt & Ryden, 1992). CGs are asked to check the response that best describes their experience when assisting a specific CI elder with bathing. The response format include five options of not at all (1), a little (2), some (3), quite a bit (4), and a great deal (5). A score is computed by averaging the responses to the items. A high score is interpreted as high levels of perceived satisfaction and competence in bathing a specific CI elder. Cronbach's alpha as a measure of internal consistency was .94 for Rasin's original scale. Items inappropriate for the home setting were eliminated and the language was changed for use with family CGs of CI elders (see Appendix K for Caregiver's Experience During Bathing Scale (Rasin, et, al., 1999).

Concept 14: CG Hassles Experienced During Bathing. The new instrument, Caregiving Hassles During Bathing Scale, was adapted from the nursing home counterpart, Caregiving Hassles During Bathing Scale (Hoeffler et al., 1996). The nursing home scale is a 9-item self-report scale that measures CGs' hassles associated with their experience of caregiving distress during bathing CI elders, and was adapted from the 12-item Behavioral Hassles Subscale of Kinney and Stephens (1989). The Caregiving Hassles Scale includes 7-items of the 12-items modified specifically to the bathing situation; 2 other items were added. CGs indicate whether each item occurred during the

past month and, if it occurred, they rate how much of a hassle it was on a 4-point scale. The response format includes options of not a hassle (1), a small hassle (2), a medium hassle (3), and a big hassle (4). The scale was constructed by averaging the scores on the 9-items. CGs scoring high on the scale reported more events during bathing that were a big hassle. Cronbach's alpha as a measure of internal consistency was .88. Items inappropriate for the home setting were eliminated and the language was changed for the use with family CGs of CI elders (see Appendix L for The Caregiving Hassles Scale).

Phase 1 Sample of Professional Experts

Purposive sampling of professional experts from Oregon and Arkansas was used in Phase 1 of the study. The professional experts ($n = 11$) were recruited from a group of participants in the gerontological nursing seminar at Oregon Health & Science University School of Nursing ($n = 9$) and gerontological nursing experts at the University of Arkansas for Medical Sciences College of Nursing ($n = 2$). A diverse group of experts was obtained to prevent bias related to using exclusively experts in the area of dementia. There was a 100% response rate from the experts. The final sample of experts were nurses and one psychometrician with expertise in the area of gerontological nursing ($n = 6$), geropsychiatric nursing ($n = 2$), family caregiving ($n = 2$), and instrument development ($n = 1$). The race of the experts were white ($n = 8$), black ($n = 2$), and Asian ($n = 1$). Of the 11 experts, 7 held a doctoral degree and 4 held a master's degree in nursing science.

Phase 1 Sample of Family CGs

Because nursing faculty and clinicians may not be aware of the subtle nuances experienced by family CGs when assisting a CI elder during bathing, family CGs can provide helpful insights that may be overlooked by professional experts (Litwin, 1995). Moreover, using a diverse group to assist in the development of scales is important, so that the scales are culturally relevant and easily understood by family CGs who will be completing the scales.

Recruitment Procedures for Family CGs. Family members who were known to provide care for their CI relative were invited into the study. Two recruitment strategies were employed. First, an advertisement was placed in the Oregon Trail and Arkansas Alzheimer's Association Newsletters; then family CGs contacted the directors and their names and phone numbers were forwarded to the researcher. Second, family members were targeted from people in the community by word of mouth; these family CGs were also contacted by the researcher. Family CGs were contacted by phone and an overview of the study was presented by the researcher. Furthermore, the researcher questioned the family CG to determine whether or not they met the selection criteria.

Eligibility Criteria for Family CGs. To be eligible for the study, all family CGs had to meet the following criteria. Family CGs had to be able to speak, read, and write English. The CI elder being cared for needed to:

- (a) be 55 years of age or older,
- (b) have a diagnosis of possible Alzheimer's Disease or vascular dementia (defined by the DSM-IV) obtained from staff or family CG report,

- (c) reside in the community, and
- (d) receive help from the CG during bathing as reported by family CGs on the questionnaire.

CGs were excluded from the study if the CI elder: (a) had a diagnosis of Huntington's Disease, or alcohol-related or AIDS-related dementia; or (b) had severe persistent mental illnesses other than dementia. Cognitive impairment of elders was determined by family CGs' reports that the elder had at least a little difficulty with one or more of the eight items on the Memory Problems Scale (see Appendix M for Memory Problems Scale).

Response Rate for Family CGs. A purposive sample of 14 family CGs of community-dwelling CI elders in Arkansas ($n = 7$) and Oregon ($n = 7$) was recruited for Phase 1 of the study. Due to low return rates of mail questionnaires (Woods & Catanzaro, 1988), the goal was to over sample to achieve the recommended sample size of 10 (Dillman, 1978). Therefore questionnaires were mailed to 14 family CGs in Oregon and Arkansas.

Of 7 questionnaire booklets mailed to family CGs living in Oregon, 5 were returned resulting in a response rate of 71%. Two family CGs in Oregon did not return the questionnaire booklet. One was a white male family CG who was the son of the CI elder. The other family CG who did not return the booklet was an African American family CG who was the CI elder's daughter. Two family CGs contacted gave the questionnaires to their live-in paid CGs who usually assisted CI elders during bathing.

Consequently, these 2 respondents were excluded because they were live-in paid CGs instead of family CGs. Thus, 3 CGs from Oregon were in the final family CG sample.

Of 7 booklets mailed in Arkansas, 5 were returned, resulting in a response rate of 71%. Two white family CGs did not return the booklets, and their relation to the CI elder is unknown.

The final sample size was $n = 8$ family CGs. Of the 8 family CGs, 4 also agreed to participate in a face-to-face interview, but only 3 actually participated in the interview because 1 family CG could not be contacted.

Description of Phase 1 Sample of Family CGs. The final sample of family CGs consisted of family CGs who lived in Oregon ($n = 3$) and Arkansas ($n = 5$). The family CGs' ages ranged from 30 to 76 years of age and the average age was 52; five family CGs were female and 3 were male. The racial composition of the family CGs was 4 African American/black, 1 Asian/Pacific Islander, and 3 white family CGs. Half of the family CGs were daughters of the CI elder and the remaining family CGs included a husband, a son, a son-in-law, and a granddaughter. Most of the family CGs and the CI elders lived together in the same household (88%) and had lived together from 2 years to 53 years. The family CG and CI had known one another between 29 to 54 years. The typical family CG was widowed and had completed high school; 75% were not employed outside of the home. All 8 family CGs assisted with bathing (See table 4 for Description of Family CGs).

Most of the family CGs assist a CI during bathing two or more times during the week (57%). The most common reasons reported by most family CGs for bathing the CI

elder were personal hygiene (88%), urinary incontinence (75%), food on the skin (75%), odor (63%), perspiration (63%) and bowel movements (71%). Most family CGs (63%) found caregiving in general difficult much of the time.

Family CGs reported that the CI elders' ages ranged from 77 to 93 years of age. The average age was 83 years of age. All of the CI elders were female, and are the same racial composition as the family CG. Most of the CI elders were widowed (62%), lived with their children (63%), and had completed high school.

Table 4
Description of Phase 1 Sample of Family CGs

Gender		Race		Marital Status		Relation to CR		Assist with Bathing	
Females	63%	White	50%	Single	0%	Daughters	50%	Once a week	43%
Males	38%	Black	38%	Married	75%	Wives	13%	Every other day	29%
		Asian	13%	Divorced	25%	Sons	13%	2-3 times a week	14%
						Son-in-Laws	13%	Every day	14%
						Granddaughters	13%		

Table 5
Description of Phase 1 Sample of CI Elders Cared for by Family CGs

Gender		Race		Marital Status		Living Arrangements	
Females	100%	White	50%	Married	25%	Spouse	25%
Males	0%	Black	38%	Widowed	62%	Children	63%
		Asian	12%	Never Married	13%		

Phase 1 Data Collection Procedures for Experts

The content validity form was developed using the guidelines and recommendations of Imle and Atwood (1988). First a questionnaire booklet containing the new bathing instruments was distributed to professional experts in Oregon during a

gerontological nursing seminar and sent through interdepartmental mail to experts in Arkansas. Those who decided to participate returned the questionnaires to the researcher by interdepartmental mail. Additionally, the University of Arkansas for Medical Sciences' experts returned the questionnaire and a signed consent form.

The experts were asked to determine the degree of content validity of the scales by completing a booklet of content validity rating forms to rate items of the new bathing instruments. A definition of the bathing concept was provided, and the expert panel was asked to determine whether the items generally belonged together in relation to the concept being measured. Experts were asked to evaluate the concept being measured, the directions of each instrument, and items of the new instruments.

The experts were asked to read each item of the new instruments and respond to the following four content validity questions: A. Are the items clear or unclear? B. In terms of consistency, do the items belong together? C. Should any items be deleted? D. Should any items be added? Space was allotted for comments, for example, to make suggestions to improve the wording. The results of the rating sheets were summarized and a similar content validity rating form was developed for family CGs.

Phase 1 Data Collection Procedures for Family CGs

The family CGs were contacted by phone, and the study was described and CGs were invited to participate. Family CGs who agreed to participate were sent a packet including a cover letter, the questionnaire with an accompanying content validity form, and two consent forms. The packet included a cover letter introducing the questionnaire, which included a statement of the purpose of the study, directions, and a telephone

number so family CGs could call the researcher if they had questions. The letter suggested a time frame to return the forms, and a note of appreciation for their time and effort in completing the booklet of questionnaires (See Appendix N for Phase 1 cover letter). As a token of appreciation, a \$10 bill was included for the CG's time and effort spent in completing the booklet of rating forms and to motivate the CG to complete the content validity rating forms (Dillman, 1978). Also contained in the packet were two consent forms explaining the study, including the risk and benefits of participation. Further, the consent form included a question that asked whether or not the family CG would participate in a face-to-face or telephone interview.

The content validity rating forms contained the new bathing instruments and, on the opposite page, questions related to content validity. The content validity rating forms are located in Appendix C. For the content validity testing, family CGs were asked to read each item of the new instruments and respond to the following three questions: A. Are the questions clear or confusing? B. Which question is confusing? C. Do you have suggestions to improve wording? Space was allotted for comments.

Additionally, family CGs were asked to answer all questions contained in the booklet with respect to their own caregiving situation and their experiences in assisting the CI elder with bathing. By obtaining the family CGs' answers to all questions, I could obtain information about variation in their responses to the items. Further, CGs were asked to rate how interesting or boring, clear or confusing, and upsetting the items were.

Phase 1 Interviews with Family CGs

After the content validity ratings by experts and family caregivers were analyzed, interviews with 3 family CGs were conducted at a location selected by the family CGs. Areas of congruence and disagreement among expert clinicians and family CGs were identified and used to develop interview questions (see Appendix O for Interview Questions). Family CGs were contacted to set up a location and time for the face-to face or telephone interview. The locations were at the participant's home, by telephone, and in the researcher's office. Two interviews were face-to-face interviews (one in Oregon and one in Arkansas) and one was a telephone interview in Oregon. The interviews lasted 1 to 1.5 hours and were audio taped. Questions were asked in relation to: a) the clarity of the questions; b) written comments; c) several answers for the same question; d) questions that were consistently left unanswered; and e) questions generating unexpected answers or patterns of responses (Finke & Kosecoff, 1985).

Phase 1 Results

Aim 1. To evaluate the content validity of a new set of bathing instruments for use with family CGs.

The Phase 1 results were derived from quantitative ratings and qualitative comments from 11 gerontological nursing experts and 8 family CGs. Quantitative ratings of clarity and consistency were obtained from content validity forms. Descriptive statistics were employed to obtain a summary of clarity, homogeneity, completeness, variation, appealing, and the structure of the measures. Qualitative comments were

obtained from written responses on the content validity forms and face-to-face interviews with family CGs who assist a CI elder during bathing. When 60% of the experts and family CGs found a certain item undesirable, the item was deleted.

Clarity and Consistency

Expert and family CG ratings of clarity are summarized in the second column of Table 6. The experts rated each item as clear (C) or unclear (U). The family CGs rated the set of items on each instrument using response categories ranging from very clear (1) to very confusing (4), and then listed items that were unclear. Of the 8 family CGs and 11 experts who completed the content validity ratings, some had missing data for the content validity ratings. Therefore in Table 6, there are not ratings from all family CGs and experts for all scales.

Expert ratings of consistency are summarized in the third column of Table 6. Gerontological nursing experts were asked to rate the new instruments to determine if the items belonged together. They also indicated which items needed to be deleted to make the scale more internally consistent and any items that should be added to improve content coverage. The experts and family CGs agreed that items were clear on instruments measuring Concepts 4, 5, 6, 9, 10, and 11. The experts agreed that items generally belonged together for instruments measuring Concepts 1, 2, 6, 9, 10, 12, and 13 (See Table 6).

Descriptive statistics were employed to obtain a summary of clarity, homogeneity, completeness, variation, the extent to which the questions were interesting or upsetting, and readability. Evaluating the homogeneity or logical consistency of the items is

important to determine if the items in a scale belong together. The assessment of variation is important in the evaluation of the measure to distinguish whether or not the measure discriminated among the respondents. Finally, the measures should be interesting to the respondent to engage their attention to complete the questionnaire and provide meaningful responses without being too upsetting to respondents. Readability or the level of reading ability was assessed to determine the applicability of the measure to assess whether the respondents understand the directions and questions of the measure (McLaughlin, 1969).

Revisions in the New Bathing Instruments Based on Phase 1 Results

When 60% of the experts found a certain item unclear or undesirable the item was deleted. In order to make the time frame for answering each instrument clearer, the phrase "during the last month" was added to the directions when appropriate.

Concept 1. CR Self-Care During Bathing. The Bathing Tasks Scale measures how much of the bath the CI elder implements independently. Two experts rated the items, "bottom" and "private areas," as unclear. It was noted that the two terms might mean the same thing to family CGs, so these two items were combined. The Bathing Tasks Scale included homogenous items, but one expert commented that holding and wetting the washcloth, and applying soap to the washcloth did not belong under bath preparation because this occurs throughout the bath. The heading "Bath Preparation" was moved so it was above these items. Also it was suggested adding "shampoo" as one of the supplies obtained, since hair washing is included on the scale.

Table 6
Summary of Expert and Family CG Ratings of Clarity and Consistency.

Bathing Concept <i>New Instrument</i>	Clarity of Items on Scale (Rated by Experts and Family CGs)	Internal Consistency (Rated only by Experts)
Bathing Situation		
1. CR Self-Care During Bathing <i>Bathing Tasks Scale</i>	<p>Experts: 9 of 11 experts rated all items as clear. 2 experts rated 2 items as unclear. See text.</p> <p>Family CGs: 7 of 8 CGs rated the set of items as clear. 1 family CG of 8 rated the set of items as somewhat confusing.</p>	<p>Experts: 9 of 11 experts rated all items as generally belonging together. 1 of 11 experts rated 4 items on bath preparation as not belonging together. See text. 1 of 11 experts suggested that 2 items be deleted.</p>
2. Bath Features <i>Reasons for Bathing Scale</i>	<p><u>Function of the Bath.</u> Experts: Except for 1 item, all experts rated items as clear. See text.</p> <p>Family CGs: 3 of 6 family caregivers rated 1 item unclear. The remaining items were rated clear by family caregivers.</p>	<p><u>Function of the Bath.</u> Experts: 9 of 10 experts rated all items as generally belonging together. 1 of 10 experts suggested that 1 item be deleted. See text.</p>
<i>Form and Frequency of Bathing Scale</i>	<p><u>Form and Frequency of the Bath.</u> Experts: Except for 1 item, all experts rated items as clear. See text. Family CGs: All items rated very clear by all family CGs.</p>	<p><u>Form and Frequency of the Bath.</u> 11 of 11 experts rated all items as generally belonging together.</p>
3. CR Bath Time Preferences Bath Time Scale	Experts or family CGs did not rate these items, because they have not been developed until after the CG interviews.	N/A

Table 6 (cont)

Summary of Expert and Family CG Ratings of Clarity and Consistency

Bathing Concept New Instrument	Clarity of Items on Scale (Rated by Experts and Family CGs)	Internal Consistency (Rated only by Experts)
4. CG Attitudes About Bathing Family CG's View of Bathing Scale	Experts: All items rated clear by all experts. Family CGs: All items rated clear by all CGs.	Experts: 9 of 11 experts rated all 12 items as generally belonging together. 2 of 11 experts rated 2 items not belonging to the other items. Experts suggested that 5 items be deleted from the instrument.
5. CG Communication During Bathing Family CG Bathing Behavior Rating Scale	Experts: 11 experts rated 10 items as unclear. Family CGs: All items rated clear by all CGs.	Experts: All 11 experts rated all 11 items as generally belonging together.
6. CG Self-Reported Behaviors Family CGs Giving a Bath Scale	Experts: All items rated clear by all experts. Family CGs: All items rated clear by all CGs.	Experts: All 11 experts rated all items as generally belonging together.
7. Bathing Assistance Provided by the CG <i>CG Help with Bathing Scale</i> 1. <i>Frequency of CG Help</i> 2. <i>Amount of CG Help</i> 3. <i>Duration of CG Help</i>	Experts: 7 of 9 experts rated the Frequency of CG Help as very clear and 2 of 9 experts rated it as mostly clear. Family CGs: Frequency of Assistance was rated clear by all experts. The Amount and Duration of CG Help were not rated by experts or family CGs because the items had not been developed.	Internal consistency of these items were not rated by experts because the items had not been developed.
8. Help From Others With Bathing <i>Help From Others With Bathing Tasks Scale</i>	Experts and CGs were not asked to rate the Help From Others With Bathing Tasks Scale because the items had not been developed.	Experts and CGs were not asked to rate the Help From Others With Bathing Tasks Scale because the items had not been developed.

Table 6 (cont)
Summary of Expert and Family CG Ratings of Clarity and Consistency.

Bathing Concept <i>New Instrument</i>	Clarity of Items on Scale (Rated by Experts and Family CGs)	Internal Consistency (Rated only by Experts)
Care Receiver Responses		
9. CR Positive Behaviors 10. CR Discomfort 11. CR Behavioral Symptoms <i>CR's Reaction to Bathing Scale</i>	Experts: 10 of 11 experts rated 47 of 52 items clear. 1 of 11 experts rated 5 items rated unclear. Family CGs: 6 of 8 CGs rated the items very clear, 1 mostly clear and 1 somewhat confusing.	Experts: 8 of 8 experts reported that all items belong together. Experts suggested deleting 24 items.
Caregiver Responses		
12. CG Satisfaction 13. CG Preparedness <i>Family CG's Experience During Bathing Scale</i>	Experts: 8 of 11 experts rated the set of items clear. 1 of 11 experts rated 8 items unclear Family CGs: 5 of 8 CGs rated the set of items as very clear and 2 CGs rated the set of items as mostly.	Experts: all experts rated the set of items as belonging together. Experts suggested deleting 11 items.
14. CG Hassles Experienced During Bathing <i>Caregiving Hassles During Bathing Scale</i>	Experts: 6 of 11 experts rated the set of items clear. 5 of 11 experts rated the 2 of the items unclear. See text. Family CGs: 5 of 8 CGs rated the set of items as very clear, 1 mostly clear and 1 somewhat confusing.	Experts: 3 of 11 experts rated 3 items as not belonging together. Experts suggested deleting 5 items.

The scale was revised and shown to family CGs during the interview. Based on input from the family CGs and after consultation with committee members, the format was further revised. Formatting changes were made so that the response choices would be easier to select. In the revised scale, family CGs rate who does each bathing task, using four response options: you (0 = least CR self-care), your family member (2 = most CR

self-care), both (1 = shared self-care) or not done (scored as missing). Similar to the scoring of Beck's scale, scoring of the new instrument involved calculating a total score and dividing by the number of bathing tasks performed, resulting in an average score with a potential range from 0.0 (the lowest CR self-care during bathing) to 2.0 (the highest CR self-care).

Concept 2: Bath Features. Function of the bath was initially measured by the CG's view of eight possible reasons that the CR bathes or washes up. Experts identified items related to the function of the bath that did not belong and reported additional items were needed to complete the measure. Nine percent of the experts reported that "to get warm" and "to get cool" did not belong with Items 7-15, because they did not appear to be a function of the bath. Most of the family CGs (83.3%) answered no to both items. The following additional reasons for bathing were suggested by 40% of the experts: (a) diversion activity, (b) to feel good or better, (c) to soothe, (d) to help wake up, and (e) to get through the day. However, during the interview, family CGs suggested that the researcher change "diversion activity" to "distract" instead. The above changes were made and diversion activity was changed to "to distract." Also, experts suggested that personal hygiene be deleted from the instrument, because the term is too global and it includes all other items in the scale. Also, half of the family CGs rated personal hygiene as unclear. Experts made suggestions to clarify the items related to the function of the bath. After discussing the suggestions with family CGs during the interview the following suggestions were incorporated into the measure.

1. The wording "personal hygiene" was changed to "get clean."

2. The wording "bladder or urine accident" was changed to "remove urine from the skin."
3. The wording bowel moment or diarrhea was changed to "clean skin after a bowel movement."
4. The wording "bad odor or smelling" was changed to "reduce bad odors or smells".
5. The wording "sweaty skin or perspiration" was changed to "remove sweat or perspiration."
6. The wording "food spilled on skin" was changed to "remove food spilled on skin."

All experts found the remaining items clear and consistent with the label concept. One expert provided suggestions to make the items more parallel. The items were revised to make them more parallel.

The form and frequency of the bath were measured by Form and Frequency of Bathing Scale. There were suggestions in making items that target the form of the bath clearer. The term "bedbath" was viewed as unclear by one expert, because it was considered a nursing term and therefore may not be a familiar term for family CGs. However, all experts agreed that the item belongs together with other items and did not recommend the item be deleted. During the interviews, family CGs reported that they understood the meaning of bedbath. Most of the experts (56%) suggested that other questions be added and recommended minor formatting changes and changes to the directions. For example, experts suggested using the term "bathtub" instead of "tub."

Concept 3: CR Bath Time Matches Preferences. The new instrument, CR Bath Time Scale was not developed until after the CG interviews. It consists of 2 items that assess what time of day the family CG usually bathes the CR and the time of day the CR preferred to bathe before he or she had memory problems. The six response categories are in 4-hour item time segments and include 12:00 midnight – 3:59 AM (1), 4:00 AM – 7:59 AM (2), 8:00 AM – 11:59 AM (3), 12:00 Noon – 3:59 PM (4), 4:00 PM – 7:59 PM (5), and 8 PM – 11:59 PM (6).

Concept 4: CG Attitudes about Bathing. On the new instrument Family CG's View of Bathing Scale, all of the experts found some items unclear and one expert rated three items as unclear (e.g., "taking a shower can frighten my family member", "bed baths don't clean very well"; and "my family member may think getting bathed is an invasion of privacy"). One CG rated one item as somewhat confusing without giving an explanation. The items remained in the instrument.

Concept 5: CG Communication During Bathing. On the new instrument Family CG Bathing Behavior Rating Scale, 1 expert rated four items as unclear (e.g., "CG speaks disrespectfully", "not paying attention", "tells what is about to happen; and "gives a bath in a hurry"). Two experts rated two items as unclear (e.g., "During bathing how often do you praise your family member"? "During bathing how often do you act as if you care about you him or her"?). However, all of the experts agreed that the items belonged together and one expert suggested that caring be deleted from the instrument. These items remained in the instrument.

Concept 6: CG Self-reported Behaviors During Bathing. On the new instrument, Family CGs Giving A Bath, 2 experts rated three items as unclear (e.g., “I feel ready to deal with difficult problems bathing my family member”, “When talking to my family member during the bath, I make sure that we are face to face so he or she can see me”; and “I take the time to make things really calm for my family member at bath time”) Two experts rated two items as not belonging together with other items on the scale (e.g., “I make sure that we are face to face so he or she can see me” and “I make eye contact before saying what I’m going to do to him or her during the bath”). Each of the remaining items 1 expert rated the items as unclear and not belonging together with other items. One expert recommended the following items be deleted from the scale: “I feel ready to deal with difficult problems bathing my family member”, “When talking to my family member during the bath I make sure that we are face to face so he or she can see me”, and “I use ways to make bathing my family member go smoothly without taking too much time”.

Concept 7: Bathing Assistance Provided by the CG. The new instrument CG Help with Bathing Scale, 30% of the experts suggested improvements in item wording Scale. For Item 6 frequency of CG assistance, the wording was changed from “How often did you assist your family member during bathing the past month?” to “How often do you assist your family member with a total body bath (e.g., bathtub, shower, or bedbath)?” The family CGs interviewed thought the terms were appropriate. Some of the terms were reworded for example the term “tub” was used instead of “bathtub”.

After Phase 1, two items were added to the new instrument, CG Help with Bathing Scale. The version of the scale for Phase 2 included 3 single-item subscales: the

Frequency of Assistance subscale used in Phase 1 and the new items, Amount of CG Help and Duration of CG Help (e.g., hours and minutes spent on a day when the CG helps with bathing). The Duration of Help item was modified from the Extent of Help items from Archbold and Stewart's (1994) Family Care Inventory.

Concept 8: Help From Others With Bathing. Experts and family CGs were not asked to rate the Help From Others With Bathing Tasks Scale.

Concept 9: CR Positive Behaviors are included in the CR's Reaction to Bathing. In general, family CGs and experts found the items clear. The item "Thanks you" was rated unclear by one expert.

Concept 10: CR Discomfort is included on the CR's Reaction to Bathing Family CGs rated the items clear and expert rated those behaviors that represent discomfort clear. One expert rated "sounds that may suggest discomfort" as unclear.

Concept 11: CR Behavioral Symptoms are included on the CR's Reaction to Bathing. One expert rated "displays inappropriate sexual behavior" as unclear and not belonging together with items in the scale because this behavior may not be seen inappropriate if the CG is a spouse. Experts also suggested items related to sexual behaviors and aggressive behaviors be deleted, because they may not occur in the home setting in contrast to the nursing home setting. All items related to concepts 9, 10, and 11 were left in the instrument so that I can get a idea of whether family CGs observe these behaviors while assisting the CR during bathing in the home setting.

Concepts 12 and 13: CG Preparedness and CG Satisfaction During Bathing. On the Family CG's Experience During Bathing Scale, the experts suggested that the phrase

"during bathing" should be added to items when appropriate in order for the scale to focus more explicitly on the bathing situation. For example, the item "I was able to manage specific problems" was changed to "I was able to manage specific problems that occur during bathing."

The experts also found some items too similar in that they seemed to be asking the same question. The item, "I was confident in my ability to assist with bathing," was very similar to "I felt self-assured" and "I felt confident in my ability to care for him or her." The last two items were deleted from the questionnaire. The experts suggested the deletion of the following items: "I felt comfortable in the things I did to help my family member," "Caring for him or her was pleasurable," "I was confident in finding solutions for difficult situations during bathing," and "I got frustrated when assisting with bathing." Family CGs did not suggest deleting the above items, therefore all items remained but some were reworded.

Concept 14: Caregiving Hassles Experienced During Bathing. The Caregiving Hassles During Bathing Scale measures distress and minor irritations experienced by family CGs while assisting a CI elder during bathing. Only one expert rated the "CR being verbally inconsiderate" as unclear. Only one expert rated "yelling" or "swearing" and "verbally inconsiderate" as not belonging with the other items. However, 64% of the experts stated that Item 6, "Just being with my family member during bathing," was unclear, but only one expert said it did not belong with the other items. The experts suggested that these items be deleted from the instrument.

All items remained on the scale to determine how family CGs would evaluate the clarity, especially of Item 6. Family CGs found Item 6 clear, and 5 of the 8 family CGs surveyed answered "just being with my family" as "not a hassle" and 3 reported that it "was a hassle." Consequently, Item 6 was left on the instrument for Phase 2. One family CGs requested that Item 7 "Family member leaving tasks related to bathing uncompleted" be more specific. Another family CGs commented that answers may vary because CG minor irritations tend to fluctuate depending on whether the CI elder is having "bad or smooth times".

Variation

The items were tested for an acceptable initial level of variation in responses from family CGs to ascertain whether measure discriminated among the respondents. Table 7 displays the variation results. The results may be misleading due to the small sample size and a closer examination of variation of the items occurred during Phase 2 of the study.

Table 7
Variation of Family CG Responses in Phase 1 to Scale Items

New Bathing Instruments	Number of items with <u>no variation</u> in responses	Number of items <u>with variation</u> (2 or more options were used as responses)
1. Bathing Tasks Scale	0	24
2. Reasons for Bathing Scale	1	7
3. Form and Frequency of Bathing Scale	0	4
4. Family CG's View of Bathing Scale	0	12
5. Family CG Bathing Behavior Rating Scale	0	11
6. Family CGs Giving a Bath Scale	0	11
7. CG Help with Bathing Scale: Frequency of CG Help	0	3
8. Help From Others With Bathing Tasks Scale	0	3
9. CR's Reaction to Bathing Scale	10	42
10. Family CG's Experience During Bathing Scale	0	23
11. Caregiving Hassles During Bathing Scale	0	9

Readability

To determine the applicability of the measure one must predict the level of reading ability the respondents must have to understand the directions and questions of the measure. This procedure is a crucial step in determining the appropriateness and accuracy of data collection. The SMOG Readability Method was used to assess the reading level of the measures (McLaughlin, 1969). After the changes were made based on experts suggestions, the reading level was assessed on the Phase 2 questionnaire.

A sample of the measures were obtained from a selection of measures in the survey booklet that had at least 30 sentences. The section titled "You and Your Family Member," which includes seven scales (Relationship to the CR Scale, Years Known CR Scale, Living Arrangements Scale, Amount of CG Assistance Scale, Difficulty of Bathing Assistance Scale, Frequency of Bathing CG Assistance Scale, Bath Time Match Bath Preference Scale, and Reasons for Bathing Scale), initially scored at a 7th grade reading level. After the word family, which was repeated nine times, was deleted, the reading level decreased to a 6th grade reading level. Family CG's Experience During Bathing Scale and CR's Reaction During Bathing Scale are at a 7th grade reading level. Lastly, Bathing Tasks Scale is at a 6th grade reading level. The measures appeared appropriate for the educational level of this sample of family CGs given that they all attended high school.

Interest

The measures should be interesting to the respondent to engage their attention to complete the questionnaire and provide meaningful responses. The family CGs found the

measures very interesting ($n = 4$ or 50%), pretty interesting (33.3%), and somewhat interesting and somewhat boring (16.7%). The family CGs reported that the questions were not emotionally upsetting (71.4%) and a little upsetting (14.3%). The average length of time to complete the questionnaire was 1 hour and 30 minutes.

Generally, the items on the measures are clear and homogenous. Overall it appears that the questionnaires were interesting enough to generate appropriate responses from this group of family CGs. After addressing the responses of experts, family CGs, and interview data, the scales were generated into a final booklet form for Phase 2 of the study. This was established to be at a 7th grade reading level at the most which may be appropriate for most CGs to understand. Although, the length of the entire booklet is long, family CGs completed the questionnaires in a timely manner. Difference in the designs of the various questionnaires appeared to have made it seem less monotonous to complete.

After addressing the responses of experts, family CGs, interview data, and discussions with committee members, the following new instruments were generated into a final booklet form for Phase 2 of the study.

1. What You and Your Family Member Do During Bathing Scale
2. Frequency and Form of the Bath
3. Function of the Bath
4. Your View of Bathing Scale: Family CG Version
5. Family CG Bathing Behavior Rating Scale
6. Giving a Bath Scale: Family CG Version
7. Amount, Frequency, and Duration of CG Assistance During Bathing.
8. CR Bath Time Preference Matches Bath Time
9. Help From Others With Bathing Tasks Scale

10. CR's Reaction to Bathing
11. Family CG's Experience During Bathing
12. Caregiving Hassles During Bathing

Phase 2 Method

The purpose of Phase 2 was first to address Aim 2: To derive new bathing scales from the new and adapted bathing instruments using item analysis and exploratory factor analysis, and to refine the conceptual model including concept labels and definitions. Secondly, address Aim 3: To estimate the internal consistency reliability of the new bathing scales. Cronbach's alpha was calculated on all of the measures during Phase 2 to estimate the internal consistency or reliability of the measures (Cronbach & Meehl, 1967). Internal consistency is how well a group of items measure the same concept (Litwin, 1995). Furthermore, reliability is the degree of consistency and accuracy with which an instrument measures the characteristics it is supposed to measure (Carmines & Zeller, 1979). Construct validity is the theoretical rationale for score interpretation involving score meaning and expected performance differences over time and across groups and settings (Messick, 1995).

Thirdly, to address Aims 4 and 5. Aim 4: To obtain preliminary evidence about the construct validity of the new bathing scales by testing hypothesized relationships between concepts measured by the new scales and concepts measured by established scales of the family CGs' health, physical functioning, pain, depressive symptoms, mutuality, and global strain. The Pearson's Product Moment Correlation statistic was used to test associations. Aim 5: To obtain further preliminary evidence about the

construct validity of the new scales by examining their intercorrelations and determining whether these intercorrelations correspond to hypothesized correlations derived from the literature and revised conceptual model. Construct validity was assessed by using the Pearson's Product Moment for continuous data to test hypotheses for relationships between variables predicted by the theoretical model (See Tables 2 & 3 in chapter 2).

Phase 2 Sampling Procedure

The same inclusion criteria was used as in Phase 1 of the study. Subjects were recruited in Little Rock, AR and in Portland, OR at four sites. Subject recruitment was handled differently within each health care facility, but according to IRB rules and regulations. All of the sites required the submission of an application and proposal to gain permission by the directors to conduct research in their facilities. First, subjects were recruited from the Pennebaker Adult Day Care Center in North Little Rock, AR; most of the clients were black CI elders. The administrator was contacted by phone and arrangements were made to recruit subjects. Thirty-eight packets were hand delivered to the director of nurses. The packets were assigned subject numbers to protect the confidentiality of the participants. The director of nurses maintained a list of subject numbers and client name. She gave the packets to all family members who picked up their elder from the center and mailed the remainder to family CGs to protect subjects' confidentiality. A post card was sent to the center three weeks after the mail out so that staff can remind family CGs to return the questionnaire and consent form (See Appendix P for Post Cards). The researcher covered the cost of the mail out.

The manager of the Reynolds Center on Aging Dementia Clinic generated lists of 100 potential subjects. The list consisted of the names and addresses of those clients with a diagnosis of Dementia. Initially, every other name on the list was selected to receive a mailed questionnaire. Fifty packets were addressed to the family CG of the named of the CI elder. Each packet was assigned a subject number, and the researcher maintained a subject list. After the Oregon data were collected, packets of fifty were sent to the remaining 50 names on the list.

The data manager of the Dementia Core Center at the Oregon Health Science University's Aging and Alzheimer's Clinic was contacted and given the inclusion and exclusion criteria. The data manager matched individuals with the inclusion criteria on clinic's database. The potential subjects were assigned ID numbers, but the names of the subjects were maintained by the data manager to maintain subject confidentiality. Seventy-three questionnaires were mailed to potential subjects. The clinic provided a research assistant to assist with the mail out. Those individuals who did not assist with bathing were not mailed the questionnaire. The clinic director also included a letter, since all of the selected family CGs had previously agreed to participate in studies that occurred in the clinic. The letter served as a way to introduce the researcher, institution and funding agency to potential subjects.

An advertisement was posted in the Alzheimer's Disease Association monthly newsletters to recruit potential family CGs (See Appendix Q for Advertisement). The researcher contacted the three family CGs who responded to the advertisement to explain the study and to ascertain that they met the inclusion criteria. One family CG was not

asked to participate because she was a former CG who remained active in the support group after the death of her family member.

Phase 2 Sample

The 62 family CGs in the final sample lived in Oregon ($n = 25$) and Arkansas ($n = 37$) and were CGs of CI elders who were clients of the Pennebaker Center ($n = 9$), University of Arkansas for Medical Sciences Reynold's Center on Aging Dementia Clinic ($n = 26$), Arkansas Alzheimer's Association ($n = 2$) and Oregon Health and Sciences University Center on Alzheimer's and Aging Clinic ($n = 25$). The family CGs' ages ranged from 39 to 86 years; 46 family CGs were female and 16 were male. The racial composition of the family CGs was 49 white, 10 African American/black, 1 Asian/Pacific Islander, 1 Hispanic and 1 Native American. Most of the family CGs were wives of the CI elder (34%); the remainder of family CGs were daughters (30%), husbands (21%), other relatives (5%), sons (3%), daughter-in-laws (3%), son-in-laws (2%), and significant others (2%). Most of the family CGs were Baptist and most (73%) considered themselves as religious or spiritual. The majority of CGs attended college (74%). The majority of family CGs were married (82%). Family CGs reported knowing the CI elder on average 48 years and most family CGs and CI elders live in the same household (93%). The household size reported was usually 2 (66.1%) and 23% of the family CGs reported a household size of 3 people. Only 4 family CGs reported children under the age of 18 living in their household. The average yearly income of the family CGs ranged from \$25,000 - \$34,999 and 57% of the family CGs own their homes. Most (87%) are able to get along on their income and have enough with a little extra sometimes

or always have money left over after expenses. Most (55%) of the family CGs were retired and 13% of family CGs had to quit work to care for their family member; 29% both cared for their family member and worked outside the home.

Family CGs report being involved in caregiving for an average of 4 years. On average family CGs reported assisting a CI elder during bathing every other day ($SD = 1$). Most family CGs assisted the CI elder during bathing everyday (34%), every other day (19%), 2 to 3 times a week or once a week (15%). The remainder of family CGs assisting bathing once or twice a month (3%). Half of the family CGs reported that assisting during bathing is somewhat hard to very hard. Most family CGs reported that they receive no outside help with bathing tasks from paid CGs (71%), friends and neighbors (95%) or relatives (67%).

Most of the CI elders were moderately to severely cognitively impaired (76%). The CI elders' ages ranged from 58 to 93 years of age; 37 CI elders were female and 25 were male. The racial composition was 49 white, 10 African American/black, 1 Asian/Pacific Islander, 1 Hispanic and 1 Native American. Most received a high school education or less (57%). Most of the CI elders were married ($n = 38$) and the remainder were either widowed ($n = 14$), divorced ($n = 6$), separated ($n = 1$), or never married ($n = 3$). Most of the CI elders lived with a spouse (61%) or live with a child or children (31%). (See Table 8 for Demographic Characteristics of Phase 2 sample)

Phase 2 Instruments

In addition to the new instruments, a few instruments were added to complete the survey for future use in research. These included: instruments that measure demographic

characteristics of the CG and CR, familial relationship of the CG and CR, difficulty assisting during bathing, living arrangements, and a measurement of an indicator of CG decision for future nursing home placement of the CG.

Table 8
Phase 2 Sample: Demographic Characteristics of Family CGs and CRs

Demographic Characteristics		Family CGs $n = 62$	CRs $n = 62$
Age		$\bar{X} = 65, SD = 12$ (range, 40 – 87)	$\bar{X} = 77, SD = 8$ (range, 58 – 93)
Gender	Male	26%	60%
	Female	74%	40%
Race	White	79%	82%
	Black	16%	15%
	Native American	2%	0%
	Asian	2%	2%
	Hispanic	2%	2%
Marital Status	Married	82%	61%
	Widowed	3%	23%
	Divorced	8%	10%
	Separated	2%	2%
	Never Married	5%	3%
Education	6 th Grade or less	2%	7%
	Junior High	3%	15%
	Partial High School	2%	8%
	High School Graduate	19%	28%
	Partial College Training	24%	20%
	Completed College	29%	8%
	Graduate Professional Training	21%	15%

Measurement of CG Characteristics and Caregiving in General

Measurement of background characteristics addressed the demographic characteristics of both the family CG and CI elder. Included were the age, ethnicity, gender, and familial relationship. Descriptive information also included information related to the socioeconomic status of the CG, caregiving experience, and the amount of help the CG receives by others. Geographical location was coded within the subjects' ID

located on the booklet after it was returned to the researcher. Also included in the booklet were questions regarding the family CG's physical health (including pain), mental health (depression), physical functioning, mutuality, and perceptions of strain related to total caregiving activities.

Mutuality Scale (Archbold et al., 1992) measures how the family CG and CR currently feel about each other. The 12-item self-report scale uses a 5-point response format, including the options of not at all (0), a little (1), some (2), quite a bit (3), and a great deal (4). The family CG was asked to check the response that best describes their degree of agreement. A score was computed by averaging the response to the items. Family CGs who have high scores on the Mutuality scale report their relationship with the CR as characterized by a great deal of love, shared pleasurable activities, common values, and reciprocity. Cronbach's alpha as a measure of internal consistency was 0.91 (See Appendix R for Mutuality Scale).

The Center for Epidemiological Studies of Depression Scale (CES-D) (Radloff, 1977) measures depressive symptoms (See Appendix S for the CES-D). The instrument was developed as an inexpensive measure of depressive symptoms used for community surveys. The 20 item self-report scale uses a 4-point response format. The total scores range from 0-60 and the higher the score the more impairment. Cronbach's alpha as a measure of internal consistency was .85 (Radloff, 1977) and .74 (Andrews et al., 1993).

The RAND Corporation Medical Outcomes Study Short-Form 36 Health Status Questionnaire (MOS SF-36). The 36 item self-report survey was a multi-item scale measuring eight general health concepts: 1) physical functioning; 2) role limitations due

to physical health problems; 3) bodily pain; 4) general health perceptions; 5) vitality; 6) social functioning; 7) role limitations due to emotional problems; 7) social functioning; and 8) mental health. The concepts of general health perceptions, physical functioning and bodily pain, were measured in the proposed study. Likert's method for summated rating scales was used to score the items. Higher scores indicate better health. Cronbach's alpha for physical functioning across multiple groups, general health, and bodily pain were .94, .80 and .87 respectively (McHorney et al., 1994). (See Appendix T for the MOS SF-36.)

Global Role Strain (Archbold et al., 1986) measures the overall felt difficulty in fulfilling their caregiving responsibilities. Initially the measure consisted of one item and a Cronbach's alpha was not reported. Currently, the instrument consists of a 4-item self-report scale uses a 5-point response format. The family CG was asked to check the response that best describes their degree of agreement. Three items assess the stress associated with caregiving. The remaining item addresses the CGs perception of the positive and negative aspects of caregiving. Global strain was found to be significantly related to direct care, such as protection and financial, legal, and health both ($r = .46$, $p < 0.01$). The concept of global role strain was expected to correlate with the new bathing measures formerly used with nursing home staff (See Appendix U for Global Role Strain).

Descriptive Information About Bathing

The questionnaire contained a screening question that asked "do you assist your family member during bathing?" If the answer was no, the family CG was asked to stop

and return the booklet of questionnaires to the researcher. Space was provided throughout the booklet for comments. At the end of the booklet of questionnaires, questions included related data collection techniques that were used in nursing home research and asked about their appropriateness in the home setting.

Response Rate

The overall response rate is one guide to the representativeness of the sample. Achieving a high response rate minimizes the chance of response bias. However, it is not clear how high a response rate should be in order to be acceptable. According to Babbie (1990) “a response rate of 50 percent is generally considered adequate for data analysis and reporting” (p.182). The suggested response rate for a mailed questionnaire is 70% for the general public and 77% for a specialized group (Dillman, 1978). Many of the procedures recommended by Dillman (1978) were employed to increase the response rate (e.g., reminder post cards, replacement questionnaires). These strategies were not used at the sites where the addresses of were unknown to the researcher.

A total of 220 questionnaires were sent to family CGs of CI elders. The first page of the booklet contained a screening question which asked the family CG whether or not they assisted their CI family member during bathing. When the answer was no, the family CG was instructed to stop at that point and return the questionnaire booklet, so that the researcher could track the number of participants who do not assist a CI elder during bathing. Participating family CGs who assist during bathing completed the questionnaire and returned the questionnaire. Of the 220 questionnaires sent to family CGS, 128 were returned by respondents. Of these, 66 were not included in the study because 61 family

CGs did not assist the CI elder during bathing, 1 CG was a former family CG of a CI elder, 3 family CGs reported the CI elder living in an long-term care facilities (2 in nursing homes and 1 in an assisted living center), and 1 family CG assisted only during the preparation of the bath in one case, so many of the questions was not applicable. Five packets were returned by the post office because of an invalid address and 87 family CGs did not respond. Thus the overall response rate was 60%, and the usable response rate was 47%. To be part of the study, family CGs were screened to determine whether they actually assisted a CI elder during bathing. Most of the respondents did not assist during bathing. This may be due to the mild cognitive impairment of many CI elders who live in the community whereas CI elders living in nursing homes usually experience more severe cognitive impairment and may need more assistance during bathing. The final sample consisted of 62 family CGs who reported assisting a CI elder during bathing at home.

Procedure for Data Collection

A total of 220 packets containing two consent forms, a questionnaire, and \$10 were mailed to family CGs of CI elders. The money was included as a token of appreciation for the CGs' time and efforts spent to complete the booklet of questionnaires (Woods & Catanzaro, 1988). A return addressed stamped envelope was included in the packet to enhance the ease for CGs in returning the booklet. A cover letter (See Appendix V for Phase 2 Cover Letters) was included in the packet to introduce the study and to motivate family CGs to complete the booklet of questionnaires (Dillman, 1978). The cover letter consisted of a statement of the purpose of the study, directions, explanation of the procedure, the risk and benefits of participation, the approximate amount of time it

takes one to complete the booklet of questionnaires, a telephone number so family CGs can call the researcher if they have questions, when the booklet of questionnaires should be returned, and a note of appreciation for their time and efforts in completing the booklet of questionnaires (See Appendix W for Phase 2 Questionnaire Booklet). The participants were instructed to complete the booklet of questionnaires, over a 3 week period. During the 4th week reminder post cards were sent to family caregivers who had not returned the questionnaire. During the 6th week a booklet and reminder post cards were sent to the remainder of participants who had not returned the questionnaire.

Data Management

During the study, a mailbox was maintained at both universities. The packets were mailed from each state; family CGs who live in Oregon received packets mailed from OHSU and return envelopes addressed to the researcher at OHSU. The same procedure occurred at UAMS. The questionnaires received at OHSU were sent by Federal Express mail on a weekly basis to the researcher at UAMS for data entry. The questionnaires containing the raw data are kept in locked secured files; and the researcher will destroy the raw data two years after the study. Data were entered into the computer (assessed by a password) using a SPSS statistical software. The data output was kept in notebooks filed in a locked file cabinet to ensure subject confidentiality. Analysis of the data occurred at OHSU in consultation with co-research advisor of the study.

Data Processing and Analysis

Data Processing

The researcher conducted data processing and analysis. The questionnaires were coded, and a computerized SPSS and statistical files were developed. The data were cleaned and entered into the SPSS files. The data were verified by the researcher and two research assistants. The output of each data run was labeled with an identification code and the date. A log of the data runs were generated including the identification code, and dates of the data run.

Phase 1 Data Analysis

Aim 1: To evaluate the content validity of a new set of bathing instruments for use with family CGs. Seven bathing instruments adapted from other measures, their original source, and the bathing concepts they were intended to measure are listed in Table 1.

The responses received from experts on the content validity forms and the responses of family CGs during the interviews of Phase 1 was summarized to ascertain any items that need to be added to or deleted from the scales. The results of the rating sheets were summarized and areas of congruence and disagreement among raters identified and used to develop interview questions.

Phase 2 Data Analysis

Aim 2: To derive new bathing scales from the new and adapted bathing instruments using item analysis and exploratory factor analysis, and to refine the conceptual model including concept labels and definitions. A sample size of 80- to 100 is

needed to report the results of factor analysis. However, the purpose of using factor analysis for this proposed study is to obtain preliminary evidence of the dimensions.

Aim 3: To estimate the internal consistency reliability of the new bathing scales. The Cronbach's alpha was calculated on all of the measures during Phase 2, to estimate the internal consistency or reliability of the measures (Cronbach & Meehl, 1967). Internal consistency is how well a group of items measure the same issue (Litwin, 1995).

Aim 4: To obtain preliminary evidence about the construct validity of the new bathing scales by testing hypothesized relationships between concepts measured by the new scales and concepts measured by established scales of the family CGs' health, physical functioning, pain, depressive symptoms, mutuality, and global strain. The Pearson's Product Moment statistic was used to test associations.

Aim 5: To obtain further preliminary evidence about the construct validity of the new scales by examining their intercorrelations and determining whether these intercorrelations correspond to hypothesized correlations derived from the literature and revised conceptual model. Construct validity was assessed by using the Pearson's Product Moment for continuous data to test the following hypotheses for relationships between variables predicted by the theoretical model (See Tables 2 & 3).

CHAPTER 4

RESULTS

Phase 2 Results

Measurement development proceeded in four stages: 1) exploratory factor analysis, 2) examination of internal consistency reliability, 3) scale construction review of frequency distribution and descriptive statistics, and 4) examination of construct validity. Data were analyzed using the Statistical Package for Social Science (SPSS) for Windows. After reviewing the frequency distribution and descriptive statistics for each item, Cronbach's alpha and item analysis of each new bathing scale was calculated to determine the internal consistency reliability and to see how well the items fit together.

Phase 2 results address the following specific aims:

Aim 2. To derive new bathing scales from the new and adapted bathing instruments using item analysis and exploratory factor analysis, and to refine the conceptual model including concept labels and definitions.

Aim 3. To estimate the internal consistency reliability of the new bathing scales.

Aim 4. To obtain preliminary evidence about the construct validity of the new bathing scales by testing hypothesized relationships between concepts measured by the new scales and concepts measured by established scales of the family CGs' health, physical functioning, pain, depressive symptoms, mutuality, and global strain.

Aim 5. To obtain further preliminary evidence about the construct validity of the new scales by examining their intercorrelations and determining whether these

intercorrelations correspond to hypothesized relationships derived from the literature and revised conceptual model.

Exploratory Factor Analysis

Aim 2. To derive new bathing scales from the new and adapted bathing instruments using item analysis and exploratory factor analysis, and to refine the conceptual model including concept labels and definitions. If items on the scale did not appear to belong together based on corrected item-total correlations, exploratory factor analysis was also used to see if there were alternative subscales in which the items fit together. Those items that had factor loadings equal or greater than .40 were viewed as fitting together. Because of the exploratory nature of the study, the remaining items with loadings less than .40 were analyzed together in one factor analysis to determine if there were additional concepts they could measure. Using this overall inductive approach, decisions were made to group items that had theoretical coherence and statistical support. The items that were not compatible with any scale were deleted from the final analysis.

Most items in the Family CG Bathing Behaviors Rating Scale were not retained after the factor analysis. The original CBBRS was an observational tool and may not be useful for self-report.

Internal Consistency Reliability

Aim 3. To estimate the internal consistency reliability of the revised bathing scales. Cronbach's alpha was estimated based on the pairwise correlation matrix among items on the measures. After exploratory factor analysis and the internal consistency

reliability results were examined, revised bathing instruments were derived from the new and adapted bathing instruments. Eleven scales and 18 subscales were generated and some instruments contain subscales. (See Table 9 for concepts and definitions, new instruments and subscales and see Table 10 for summary of reliability results).

Eleven of 17 scales and subscales tested have Cronbach's Alpha values exceeding .70 recommended by Nunnally (1978) for scales to be used for research purposes. For 6 of 17 scales and subscales, the reliability is marginal (.50-.69), due to the small number of items on the scale or dichotomous response format or both.

It is important that the percentages of missing data on scales are at acceptable levels. All of the instruments had acceptable levels of percentages of missing data except two. The subscales "Self-Care Preparing for the Bath" and "What you and Your Family CG Do During Bathing Scale" had 10% missing data; "Self-care Wash and Dry Hair" had 18% missing data (See Table 7). The high percentage of missing data is a concern in the instance of "Self-Care Preparing for the Bath". The format was the same as the other self-care subscales, but family CGs may have found the items in this particular subscale as confusing. On the other hand, unanswered "Self-care Wash and Dry Hair" items may be due to some family CGs writing "beauty shop" in "other" instead of selecting "not done" (See Table 9 for definitions of new scales and subscales).

Table 9

Concept and Definitions, Revised Scales and Sample Items

Concept Name Revised Instrument	Definition of Concept	Sample Item
1. CR Self-Care During Bathing	CRs' ability to gather supplies and prepare the bath. Including the ability to bathe and dry oneself or body parts using at least one object (e.g., wash cloth, soap) and switching independently from one activity to another (e.g., soaping the wash cloth then washing an arm).	
<i>Bathing Tasks Scale</i> <ul style="list-style-type: none"> • <i>Self-Care Prepare for The Bath</i> • <i>Self-care Wash Body Parts</i> • <i>Self Care Dry Body Parts</i> • <i>Self-Care Wash and Dry Hair</i> 		Turn on the cold water Wash face Dry face Wash Hair
2. Bath Features	The function, form and frequency of the bath.	
<i>Reasons For Bathing Scale</i> <ul style="list-style-type: none"> • <i>Cleansing Function of the Bath</i> • <i>Comfort Function of the Bath</i> <i>Form and Frequency of the Bath Scale</i>	Maintaining skin integrity and preventing infection, and promoting social acceptability and gives pleasure. Type of bath or the physical bath environment where the bath occurs (e.g., tub, shower, bedbath) including how often the bath occurs in a particular form.	To remove urine from the skin. To feel good or better. Bathroom sink every day

Table 9 (cont)

Concept and Definitions, Revised Scales and Sample Items

Concept Name Revised Instrument	Definition of Concept	Sample Item
3. CR Bath Time Matches CR Preference	Assisting a CI elder during bathing when the CI elder prefers to bathe.	
<i>Bath Time Scale</i>		What time of day did your family member prefer to bathe before he or she had memory problems?
4. CG Communication.	Strategies CGs used to individualize the bath according to what the CI elder request.	
<i>Considering the CR's Wishes Scale</i>	Family Caregiving Behaviors Rating Scale and Giving A Bath	When he or she complains of pain or discomfort I apologize and change what I do.
5. Bathing Assistance Provided by CG	The frequency, amount, and duration of CG bathing assistance to CRs during bathing.	
<i>CG Help With Bathing Scale</i>		How often do you assist your family member with a total body bath (bathtub, shower, or bedbath)?
• <i>Frequency of CG Help</i>		How much help does your family member need during bathing?
• <i>Amount of CG Help</i>		On the days you help your family member with bathing, about how long do you spend helping him or her during bathing?
• <i>Duration of CG Help</i>		

Table 9 (cont)

Concept and Definitions, Revised Scales and Sample Items

Concept Name Revised Instrument	Definition of Concept	Sample Item
6. Help From Others With Bathing <i>Help From Others With Bathing Tasks Scale</i>	CG assistance from family, friends, and/or formal CGs with bathing.	How much have relatives helped with bathing him or her?
7. Positive CR Behaviors <i>CR Reactions During Bathing Scale</i> <ul style="list-style-type: none"> Contentment During Bathing Affectionate or Appreciative Behaviors During Bathing 	Verbal or non-verbal gestures that display CI elders' comfort and satisfaction during bathing.	Smiles at you?
8. Behavioral Symptoms <ul style="list-style-type: none"> CR Reactions During Bathing Scale CR Discomfort CR Vocal or Verbal Agitated Behaviors CR Non-Aggressive Behaviors CR Aggressive Behaviors 	Vocal/ verbal agitated, non-aggressive, and physically aggressive behaviors of the CI elder that reflect discomfort or efforts to cope with stressors during bathing.	Makes repetitious noises?

Table 9 (cont)

Concept and Definitions, Revised Scales and Sample Items

Concept Name Revised Instrument	Definition of Concept	Sample Item
9. Satisfaction From Bathing And Confidence in Bathing Ability <i>Family CG's Experience During Bathing Scale</i> <ul style="list-style-type: none"> • <i>CG Satisfaction</i> • <i>CG Confidence in Bathing Ability</i> 	Family feelings of contentment, pleasure, and confidence associated with assisting the care receiver during bathing.	I felt relaxed while assisting with bathing.
10. Hassles Experienced During Bathing <i>Caregiving Hassles During Bathing Scale</i>	Minor irritations perceived by CGs when assisting CI elders with bathing.	Your family member criticizing or complaining during bathing.
11. CG Strain During Bathing <i>CG Strain From Bathing Scale</i>	CGs perceive assisting during bathing complicated and difficult. CGs' perceptions are often influenced by the CI elder's behaviors during bathing and the conflict or discord that occurs between the dyad during bathing.	I got frustrated when assisting my family member.

Table 10

Summary of Missing Data and Reliability of the New Bathing Scales

Scale Name	New Subscale	Number of Items	Response Options	Missing Data (%)	Internal Consistency (Cronbach's α)	Range Item-Total r s	Median Item-Total r
Bathing Situation							
Bathing Tasks Scale	Self-Care Preparing for the Bath	3	You Your Family Member Both Not Done	10%	.80	.36 - .86	.86
	Self-Care Washing Body Parts	11	You Your Family Member Both Not Done	1.6%	.95	.53 - .87	.79
	Self-Care Drying Body Parts	11	You Your Family Member Both Not Done	0%	.96	.64 - .92	.83
	Self-Care Wash and Dry Hair	2	You Your Family Member Both Not Done	18%	.77	.62	.62

Note: Did not assess Bathing Assistance Scale and Help from Others with Bathing Tasks Scale, because they are currently valid and reliable when used in studies with family CGs

Table 10 (cont)

Summary of Missing Data and Reliability of the New Bathing Scales

Scale Name	New Subscale	Number of Items	Response Options	Missing Data (%)	Internal Consistency (Cronbach's α)	Range Item-Total r_s	Median Item-Total r
Bathing Situation (cont)							
Reason for Bathing Scale	Cleansing Function of the Bath	5	Yes No	0 %	.53	.05 - .46	.32
	Comfort Function of the Bath	4	Yes No	2%	.57	.31 - .41	.36
Bath Time Scale		2	12:00 Midnight - 3:59 AM 4:00 AM - 7:59 AM 8:00 AM - 11:59 AM 12:00 Noon - 3:59 PM 4:00 PM - 7:59 PM 8:00 PM - 11:59 PM	2%	.15	None	.08
Considering The CR Wishes Scale		9	Strongly Disagree Disagree Somewhat Agree Somewhat Strongly Agree	2%	.69	.27 - .54	.37

Note: Did not assess Bathing Assistance Scale and Help from Others with Bathing Tasks Scale, because they are currently valid and reliable when used in studies with family CGs

Table 10 (cont)

Summary of Missing Data and Reliability of the New Bathing Scales

Scale Name	New Subscale	Number of Items	Response Options	Missing Data (%)	Internal Consistency (Cronbach's α)	Range Item-Total r s	Median Item-Total r
CR Responses to Bathing							
Your Family Member's Reaction During Bathing	Appreciative/Affectionate Behaviors	7	Yes No	2%	.65	.23 - .46	.39
	Contentment	4	Yes No	0	.89	.70 - .82	.75
	Discomfort	8	Yes No	2%	.86	.44 - .68	.62
	Vocal or Verbal Agitated Behaviors	9	Yes No	2%	.75	.12 - .73	.46
	Physical Non-Aggressive Behaviors	7	Yes No	0	.50	.08 - .74	.27
	Physical Aggressive Behaviors	10	Yes No	0	.89	.42 - .84	.66

Note: Did not assess Bathing Assistance Scale and Help from Others with Bathing Tasks Scale, because they are currently valid and reliable when used in studies with family CGs

Table 10 (cont)

Summary of Missing Data and Reliability of the New Bathing Scales

Scale Name	New Subscale	Number of Items	Response Options	Missing Data (%)	Internal Consistency (Cronbach's α)	Range Item-Total r_s	Median Item-Total r
CG Responses to Bathing							
Family CG's Experience During Bathing Scale	Satisfaction With Bathing	9	Not At All A Little Some Quite a bit A Great Deal	3%	.88	.45 - .72	.64
	Confidence During Bathing	11	Not At All A Little Some Quite a bit A Great Deal	2%	.94	.65 - .89	.69
CG Strain of Bathing Scale		4	Not At All A Little Some Quite a bit A Great Deal	3%	.64	.32 - .53	.43
Caregiving Hassles During Bathing Scale	Hassles Experienced During Bathing	7	Not a Hassle A Small Hassles A Medium Hassle A Big Hassle	2%	.89	.60 - .80	.68

Note: Did not assess Bathing Assistance Scale and Help from Others with Bathing Tasks Scale, because they are currently valid and reliable when used in studies with family CGs

Frequency Distributions and Descriptive Statistics for the New Bathing Scales

Family CGs reported assisting a CI elder during on average 6 days a week.

Family CGs reported that, on average, CRs assist CGs a little in preparing for the bath ($M = 0.39$; $SD = 0.59$) on a 0.00-2.0 scale, but some CRs are dependent on CGs to wash (33%) and dry (37%) their body parts, and wash and dry their hair (67%). Most family CGs reason given for bathing the CR is for cleansing purposes (63%). Most family CGs did not use the tub bath as the usual form of the bath (64%), however, those family CGs who did mainly bathed CRs in the bathtub 2-3 times a week. Many CGs reported using both the bathroom sink (55%) 2 or 3 times a week to every day (53%) and shower (50%) once a week or 2 to 3 times a week (34%) when bathing the CR. CGs usually matched the CR bath time to their premorbid bath times (58%); and on average the CRs' wishes were sometimes considered during bathing ($M = 3$, $SD = 0.63$). Family CGs reported on average that CRs need some assistance during the bath, for instance, both the CG and CR performed bathing tasks ($M = 2$, $SD = 2.5$). Family CGs reported assisting CRs every other day ($M = 4$, $SD = 1.19$) and most family CGs (65%) took 45 - 60 minutes to complete the bath. Over half of family CGs (52%) did not receive help from others when assisting the CR during bathing.

Most family CGs reported quite of bit to a great deal of CG satisfaction (62%) and CG confidence during bathing (87%). On average CGs reported a little CG strain during bathing ($M = 2$; $SD = .78$), although 35% of the CGs reported experiencing some to quite a bit of CG strain during bathing. Only 39% of the CGs reported assisting the

CR during bathing as a small hassle; and most CGs did not view assisting the CR during bathing as a hassle (61%).

Family CGs reported that 84% of the CRs have moderate memory problems. Family CGs reported that 68% of the CRs were content during bathing, and some showed appreciative and affectionate behaviors (26%) during bathing. Also, 39% of CRs displayed discomfort during bathing. Family CGs reported only a small percent of CR behavioral symptoms during bathing, such as vocal-verbal agitated behaviors (8%), and physically aggressive behaviors (5%). Family CGs reported no physically non-aggressive behaviors.

Family CGs reported their health as good to excellent (84%) and good physical function ($M = 70$; $SD = 24$), however, 25% of CGs assisting CRs during bathing reported poor physical function. Depressive symptoms were reported by 44% of the CGs, however, 56% of the CG scores were below 16 indicating that most of the CGs were not experiencing significant depressive symptoms. Over half of CGs reported a quite a bit to a great deal of mutuality (56%) between the CG and CR. On average CGs report some global strain associated with caregiving in general ($M = 2$; $SD = .61$).

Although family CGs reported their health as good to excellent (86%), they report that their health limits them in vigorous activities (82%), lifting or carrying groceries (58%), bending kneeling or stooping (72%), and walking more than a mile (53%). Seventy-four percent of the CGs report a little pain to extreme pain interfering with normal work activities. The average depression score of the family CGs was 34.

Scores were computed on each scale when subjects answered 75% or more of the items. For each scale, the possible range of scores, the actual range of scores, the mean, standard deviation, skewness, and kurtosis are presented in Table 11. The actual range of the scores for CR Bath Time Scale, CG Help with Bathing Scale, and Help From Others with Bathing Tasks Scale was the same or nearly the same as the possible range of scores (See Appendix X Computation of Scores).

For the scales or subscales in the “bathing situation,” the skewness ranged from -0.33 - +1.6. However only three subscales were significantly skewed; self-care wash and dry hair ($z = \pm 4$), duration of CG assistance during bathing ($z = \pm 5$) and help from others with bathing ($z = \pm 4$). For the scales or subscales in the “CR’s Responses,” the skewness ranged from -0.41-3.12. All of the behavioral symptoms were significantly skewed: vocal or verbal agitated behaviors ($z = \pm 5.86$), physical non-aggressive behaviors ($z = \pm 5.67$), and physically aggressive behaviors ($z = \pm 10.25$). The skewness of CG responses ranged from -0.30 – 1.16, and CG hassles experienced during bathing was significantly skewed ($z = \pm 3.79$). The summary of the descriptive statistics of the new bathing measures can be found in Table 11.

Analysis of Construct Validity

Aim 4. To obtain preliminary evidence about the construct validity of the new bathing scales by testing hypothesized relationships between concepts measured by the new scales and concepts measured by established scales of the family CRs’ Memory Problems and CGs’ Health, Physical Functioning, Pain, Depressive Symptoms, Mutuality, and Global Strain.

According to Messick (1980) construct validity can be obtained using several methods. The most common method of obtaining evidence of construct validity is testing hypothesized relationships between variables (Stewart & Petersen, 1982). To obtain evidence for construct validity, correlation statistical procedures were used to examine the magnitude and direction of the relationships between the new scales and established scales. This section includes an examination of the revised scales' intercorrelations with established measures. Significant results of the hypothesized relationship are reported at the $p < .01$ and $.05$ level of significance (See Table 12 for revised hypothesized relationships).

Correlations Coefficients to Test Hypothesized Relationships of the New Bathing Scales with Established Measures

CR Memory Problems had a positive moderate correlation with the amount of CG assistance ($r = .50, p < .001$) and negative moderate correlations with self-care wash body parts ($r = -.44, p < .001$), dry body parts ($r = -.40, p = .001$) and CR discomfort ($r = .41, p = .001$). CR memory problems had weak positive correlations with cleansing function of the bath ($r = .28, p = .015$), CR vocal-verbal agitated behaviors ($r = .24, p = .028$), physically non-aggressive behaviors ($r = .23, p = .035$), physically aggressive behaviors ($r = .24, p = .028$), and CG hassles experienced during bathing ($r = .24, p = .032$), and negative correlations with self-care prepare for the bath ($r = -.23, p = .047$), CR wishes considered ($r = -.36, p = .003$), CR contentment ($r = -.28, p = .012$), and appreciative/affectionate behaviors ($r = -.25, p = .027$).

Table 11

Summary of the Descriptive Statistics of the New Bathing Scales

Scale Name or Subscale	Possible Range of Score	Actual Range of Score	Mean	SD	Skew	Kurt
Bathing Tasks Scale	0.00 – 2.00	0.00 – 2.00	0.78	0.73	0.32	-1.59
CR Self-Care Prepare for Bath	0.00 – 2.00	0.00 – 2.00	0.39	0.59	1.29	0.78
CR Self-Care Washing Body Parts	0.00 – 2.00	0.00 – 2.00	0.89	0.81	0.22	-1.70
CR Self-Care Drying Body parts	0.00 – 2.00	0.00 – 2.00	0.84	0.83	0.28	-1.68
CR Self-Care Wash and Dry Hair	0.00 – 2.00	0.00 – 2.00	.44	0.70	1.33	0.36
Cleansing Function of the Bath	0.00 – 5.00	0.00 – 5.00	3.31	1.26	-0.80	0.61
Comfort Function of the Bath	0.00 – 4.00	0.00 – 4.00	1.50	1.45	0.49	-0.39
CR Wishes Considered	1.78 – 5.00	1.89 – 4.50	3.09	0.63	0.29	-0.77
Amount of CG Assistance	1.00 – 4.00	2.00 – 4.00	3.19	0.87	-0.39	-1.57
Duration of CG Assistance	0.13 – 2.50	0.13 – 2.50	0.72	0.47	0.23	3.01
Frequency of CG Assistance	1.00 – 5.00	1.00 – 5.00	3.66	1.19	-0.34	-0.96
Match CR Preferences	1.00 – 3.00	1.00 – 3.00	1.87	0.83	0.26	-1.52
Amount of CG Assistance	1.00 – 5.00	1.00 – 5.00	5.00	1.19	-0.34	-0.96

Table 11 (cont)
Summary of the Descriptive Statistics of the New Bathing Scales

Scale Name	Possible Range of Score	Actual Range of Score	Mean	SD	Skew	Kurt
Help From Others with Bathing Scale	1.00 - 4.00	2.00 - 4.00	3.19	0.87	-0.39	-1.57
CR Contentment During Bathing	0.00 - 1.00	0.00 - 1.00	0.59	0.43	-0.41	-1.57
CR Appreciative/ Affectionate Behaviors	0.00 - 1.00	0.00 - 1.00	0.37	0.25	0.53	-0.22
CR Discomfort	0.00 - 1.00	0.00 - 1.00	0.22	0.29	1.41	0.09
CR Vocal or Verbal Agitated Behaviors	0.00 - 1.00	0.00 - 0.89	0.16	0.20	1.78	2.92
CR Physical Non-Aggressive Behaviors	0.00 - 1.00	0.00 - 0.43	0.01	0.13	1.73	2.08
CR Physical Aggressive Behaviors	0.00 - 1.00	0.00 - 0.90	0.01	0.20	3.12	9.98
CG Satisfaction With Bathing	1.78 - 5.00	1.78 - 5.00	3.72	0.81	-304	-625
CG Confidence in Bathing Ability	2.36 - 5.00	2.36 - 5.00	4.23	0.70	0.49	0.69
CG Hassles Experienced Bathing	0.00 - 1.71	0.00 - 1.71	0.48	0.45	1.16	1.04
CG Strain During Bathing	1.00 - 4.25	1.00 - 4.25	2.06	0.78	0.74	0.24

Table 12

Aim 4 Revised Hypothesis of Established Instruments and the New Scales

Bathing Concepts	Concepts Measured by Established Scales					
	CR Memory	CG Health	CG Function	CG Pain	CG Depressive Symptoms	CG Global Strain
Bathing Situation						
1. CR Self-Care Behaviors	-	0	0	0	0	-
CR Prepare for Bath	-	0	0	0	0	-
CR Wash Body Parts	-	0	0	0	0	-
CR Dry Body Parts	-	0	0	0	0	-
CR Wash and Dry Hair	0	0	0	0	0	0
2. Bath Features						
Comfort Function	?	?	?	?	?	?
Cleansing Function	+	-	?	+	?	+

Note: + = Positive relationship hypothesized, — = Negative relationship hypothesized, 0 = Near-zero relationship hypothesized, ? = No hypothesis made.

Table 12 (cont)

Aim 4: Revised Hypothesis of Established Instruments and the New Scales

Bathing Concepts	Concepts Measured by Established Scales						
	CR Memory	CG Health	CG Function	CG Pain	CG Depressive Symptoms	CG Global Strain	CG Mutuality
From and Frequency	?	?	?	?	?	?	?
3. Bath Time CR Match Preference	-	?	0	?	?	-	+
4. CR Wishes Considered	-	+	0	-	0	-	+
5. CG Bathing Assistance							
Amount	+	0	0	0	0	+	-
Frequency	?	?	?	?	?	?	?
Duration	+	?	?	-	-	?	?
6. Help From Others	0	-	-	+	+	+	0

Note: + = Positive relationship hypothesized, - = Negative relationship hypothesized, 0 = Near-zero relationship hypothesized, ? = No hypothesis made.

Table 12 (Cont)

Aim 4 Revised Hypothesis of Established Instruments and the New Scales

Bathing Concepts	Concepts Measured by Established Scales						
	CR Memory	CG Health	CG Function	CG Pain	CG Depressive Symptoms	CG Global Strain	CG Mutuality
CR Responses During Bathing							
7 CR Reactions CR Appreciative and Affectionate	-	0	+	-	-	-	+
CR Contentment	-	+	+	-	0	-	+
CR Discomfort	+	0	0	0	0	+	-
CR Vocal and Verbal Agitated Behaviors	+	-	0	0	0	0	-
CR Physically Non-Aggressive Behaviors	+	-	0	+	+	+	-
CR Physically Aggressive Behaviors	+	-	0	+	+	+	-

Note: + = Positive relationship hypothesized. - = Negative relationship hypothesized. 0 = Near-zero relationship hypothesized. ? = No hypothesis made.

Table 12 (Cont)

Aim 4: Revised Hypothesis of Established Instruments and the New Scales

Bathing Concepts	Concepts Measured by Established Scales						
	CR Memory	CG Health	CG Function	CG Pain	CG Depressive Symptoms	CG Global Strain	CG Mutuality
CG Responses During Bathing							
8. CG Satisfaction	-	+	+	-	-	-	+
9. CG Confidence in Bathing Ability	0	+	0	-	-	-	0
10 CG Hassles Experienced During Bathing	+	-	0	+	+	+	-
11. CG Strain From Bathing	+	-	-	+	+	+	-

Note: + = Positive relationship hypothesized. - = Negative relationship hypothesized. 0 = Near-zero relationship hypothesized. ? = No hypothesis made.

CG Health had a moderate negative correlation with CG strain during bathing ($r = -.42, p = .000$). CG health had a weak negative correlations with the cleansing function of the bath ($r = -.23, p = .038$), and CR contentment ($r = -.24, p = .03$), and weak positive correlations with CG satisfaction ($r = .28, p = .016$) and CG confidence in bathing ability ($r = .28, p = .013$).

CG Physical Functioning had a weak negative correlation with CR physical non-aggressive behaviors $r = -.33, p = .005$), and a moderate positive correlation with CR contentment ($r = .40, p = .001$).

CG Pain had weak positive correlations with the cleansing function of the bath ($r = .28, p = .013$), CG strain from bathing ($r = .34, p = .004$), and physical non-aggressive behaviors ($r = .25, p = .028$). CG Pain had a weak negative correlation with CG confidence with bathing ($r = -.26, p = .02$).

CG Depressive Symptoms had weak negative correlations with self-care dry body parts ($r = -.27, p = .017$), self-care wash and dry hair ($r = -.34, p = .008$), CG confidence in bathing abilities ($r = -.33, p = .006$) and a weak positive correlation with CG strain from bathing ($r = .37, p = .002$).

Global Strain had moderate positive correlations with CG strain from bathing ($r = .40, p = .001$) and CG hassles experienced during bathing ($r = .40, p = .001$). Also, global strain had weak positive correlation with amount of CG assistance ($r = .24, p = .029$), the cleansing function of the bath ($r = .37, p = .002$), and CR discomfort ($r = .30, p = .009$); and weak negative correlations with self-care dry body parts ($r = -.27, p = .008$), CG wishes considered ($r = -.39, p = .001$), CR contentment ($r = -.29, p = .012$),

CG satisfaction with bathing ($r = -.38, p = .001$), and CG confidence in bathing abilities ($r = -.24, p = .032$).

Mutuality had a moderate positive correlations with self-care prepare for bath ($r = .41, p = .001$). Mutuality had weak positive correlations with overall CR self-care ($r = .32, p = .019$), self-care wash body parts ($r = .31, p = .008$), dry body parts ($r = .34, p = .004$), CR wishes considered ($r = .37, p = .002$), CR appreciative or affectionate behaviors ($r = .32, p = .006$), and CG satisfaction with bathing ($r = .31, p = .009$). Weak negative correlations were found with cleansing function of the bath ($r = -.32, p = .006$), vocal or verbal agitated behaviors ($r = -.34, p = .004$), and physical and aggressive behaviors ($r = -.25, p = .026$). Also, Mutuality had a moderate negative correlation with the amount of CG assistance ($r = -.50, p = .000$), CG hassles ($r = -.41, p = .001$), CR discomfort ($r = -.46, p = .000$), and a moderate positive correlation with CR contentment ($r = .41, p = .001$). (See Table 13 for Correlations)

Correlations Coefficients to Test Hypothesized Relationships Among the New bathing Scales

Aim 5. To obtain further preliminary evidence about the construct validity of the new scales by examining their intercorrelations and determining whether these intercorrelations correspond to hypothesized relationships derived from the literature and revised conceptual model. The conceptual model was revised to address the new concepts derived from the reliability results, then preliminary evidence of construct validity was examined. Significant results of the hypothesized relationship are reported at the $p < .01$ and $.05$ level of significance (See Table 14 for revised hypotheses).

Relationships among measures within the same group and hypothesized relationships among the scales were examined; the correlations are in Table 15. A summary of the number of correlations per hypothesized relationship between and among scales is in Table 16.

Correlations Coefficients to Test Hypothesized Relationships Among the New bathing Scales: Bathing Situation

CR self-care was strongly positively correlated with the four subscales (wash body parts, dry body parts, and wash and dry hair) and the subscales were moderately or strongly positively correlated with one another (range = .48 -.91). Self-care was strongly correlated with self-care prepare for the bath ($r = .84, p < .001$), wash body parts ($r = .91, p < .001$), dry body parts ($r = .89, p < .001$), wash and dry hair ($r = .77, p < .001$). Self care prepare for the bath was strongly correlated with self-care wash body parts ($r = .68, p < .001$), dry body parts ($r = .61, p < .001$) and moderately correlated with wash and dry hair ($r = .60, p < .001$). Self-care wash body parts was strongly correlated with dry body parts ($r = .83, p < .001$), and moderately correlated with wash and dry hair ($r = .55, p < .001$). Dry body parts was moderately correlated with wash and dry hair ($r = .48, p < .001$).

Self-care was strongly negatively correlated with amount of assistance ($r = -.75, p = -.74$). Weak positive correlations were found for self-care with comfort function of the bath ($r = .26, p = .046$), CR contentment ($r = .29, p = .026$), and CG hassles experienced during bathing ($r = -.32, p = .017$). Weak negative correlations with CR vocal or verbal agitated ($r = -.25, p = .046$), CR physical aggressive behaviors ($r = -.27, p = .036$), and

CG's confidence in bathing abilities ($r = -.26, p = .046$) were found. Self-care prepare for bath was strongly negatively correlated with the amount of assistance provided by the CG during bathing ($r = -.64, p < .001$), and moderately negatively correlated with CG hassles during bathing ($r = -.44, p < .001$). Weak positive correlations were found for self-care prepare for the bath with CR wishes considered ($r = .31, p = .011$), and CR contentment ($r = .32, p = .008$), while weak negative correlations were found with discomfort ($r = -.25, p = .03$), physical non-aggressive behaviors ($r = -.28, p = .02$), physical aggressive behaviors ($r = -.33, p = .006$), and CG strain during bathing ($r = -.25, p = .03$).

Self-care wash body parts was strongly negatively correlated with amount of CR assistance ($r = -.70, p < .001$). Self-care had a weak negative correlation with comfort function of the bath ($r = -.28, p = .016$), help from others ($r = -.25, p = .032$), contentment ($r = -.21, p = .049$), discomfort ($r = -.27, p = .02$), and physical aggressive behaviors ($r = -.30, p = .009$), and weak positive correlations with CR wishes considered ($r = .22, p = .045$) and CG hassles during bathing ($r = .24, p = .04$). Self-care dry body parts was strongly negatively correlated with amount of CR assistance ($r = -.74, p < .001$). Self-care dry body parts had a weak negative correlation with the frequency of assistance ($r = -.32, p = .006$) and weak positive correlations with frequency and form of the bath ($r = .31, p = .007$) and CR appreciative/affectionate behaviors ($r = .28, p = .01$). Wash and dry hair was moderately negatively correlated with the amount of CG assistance ($r = -.41, p < .001$), and weakly negatively correlated

with the CG's confidence in bathing ability ($r = -.36, p = .01$) and had a weak positive correlation with comfort function of the bath ($r = .26, p = .036$).

Bath features include the function and frequency and form of the bath. The function of the bath included the comfort and cleansing functions of the bath. The comfort function of the bath had a weak positive correlation with the frequency of assistance ($r = .32, p = .006$), and negative correlations with the form and frequency of the bath ($r = -.32, p = .006$) and CG satisfaction with bathing ($r = -.26, p = .025$). The cleansing function of the bath had a weak positive correlation with CR discomfort ($r = .26, p = .02$), vocal or verbal agitated behaviors ($r = .34, p = .003$), and strain during bathing ($r = .26, p = .02$) and a weak negative correlation with CG satisfaction with bathing ($r = -.22, p = .048$). The frequency and form of the bath had a moderate negative correlation with the frequency of CG assistance during bathing ($r = -.428, p = .01$) and a weak negative correlation with CG satisfaction with bathing ($r = -.32, p = .007$).

CR's wishes considered had a moderate positive correlation with CR appreciative/affectionate behaviors ($r = .36, p = .003$), and a weak negative correlation with vocal or verbal agitated behaviors ($r = -.24, p = .04$), physical non-aggressive behaviors ($r = -.37, p = .002$), and physical aggressive behaviors ($r = -.31, p = .008$). Also, CR wishes considered had a weak positive correlation with CG satisfaction with assisting during bathing ($r = .33, p = .006$), and weak negative correlation with CG hassles during bathing ($r = -.34, p = .004$) and strain during bathing ($r = -.32, p = .008$). CR bath time matches CR preference had a weak positive correlation with appreciative and affectionate behaviors ($r = .26, p = .021$).

Bathing assistance provided by CG during bathing consisted of three subscales (amount, frequency and duration of CG assistance). The amount of CG assistance during bathing had a strong negative correlations with CR self-care prepare for the bath ($r = -.65, p < .001$), wash body parts ($r = -.68, p < .001$), dry body parts ($r = -.71, p < .001$) and moderate positive correlation with wash and dry hair ($r = -.41, p = .001$). Also, overall CR self-care had a high negative correlation with the amount of CG assistance during bathing ($r = -.74, p < .001$). The amount of CG assistance during bathing had weak positive correlations with CR appreciative/affectionate behaviors ($r = .33, p = .005$), discomfort ($r = .32, p = .006$), vocal or verbal agitated behaviors ($r = .33, p = .005$), physical non-aggressive behaviors ($r = .28, p = .02$), physical aggressive behaviors ($r = .30, p = .009$) and weak negative correlation with contentment ($r = -.31, p = .008$). The amount of CG assistance had a weak positive correlation with CG responses, such as CG satisfaction ($r = .30, p = .01$). Duration of CG assistance was not significantly correlated with any of the measures or sub-scales. The frequency of bathing assistance had a moderate negative correlation with the form and frequency of the bath ($r = -.414, p = < .001$). On the other hand, the frequency of bathing assistance had weak negative correlations with CR self-care wash body parts ($r = -.23, p = .04$) and dry body parts ($r = -.32, p = .006$). The frequency of CG bathing assistance did not correlate significantly with overall CR self-care behaviors during bathing. The frequency of CG bathing assistance had weak positive correlations with the comfort function of the bath ($r = .32, p = .006$), CR bath time matches CR preferred bath time ($r = .26, p = .02$) and CG satisfaction ($r = .30, p = .01$).

Help from others had a weak positive correlation with CR physical non-aggressive behaviors ($r = .35, p = .003$) and weak negative correlation with physical aggressive behaviors ($r = -.32, p = .007$).

CR Responses

CR contentment was strongly negatively correlated with CR discomfort ($r = -.64, p = .000$), vocal or verbal agitated behaviors ($r = -.60, p < .001$) and CG hassles experienced during bathing ($r = -.67, p < .001$). CR contentment was moderately positively correlated with CG satisfaction with bathing ($r = .56, p < .001$). Also, CR contentment had a moderate negative correlation with physical aggressive behaviors ($r = -.40, p = .001$), CG confidence in bathing ability ($r = -.40, p = .001$), strain during bathing ($r = -.43, p < .001$); and a weak negative correlation with CR non-aggressive behaviors ($r = -.32, p = .006$). Furthermore, CR contentment behaviors had a weak positive correlation with CR affectionate/appreciative behaviors ($r = .39, p = .001$), and weak negative correlations with CG discomfort ($r = -.30, p = .009$), and physical aggressive behaviors ($r = -.23, p = .04$).

CR discomfort had a moderate positive correlation with vocal or verbal agitated behaviors ($r = .43, p < .001$), and CG hassles experienced during bathing ($r = .48, p < .001$). Also, a weak positive correlation was found among discomfort and CR physical non-aggressive behaviors ($r = .22, p = .04$), physical aggressive behaviors ($r = .39, p = .001$), and strain during bathing ($r = .29, p = .012$). Discomfort had a weak negative correlation with CG satisfaction with bathing ($r = -.35, p = .003$), and confidence in bathing ability ($r = -.29, p = .011$). Vocal or verbal agitated behaviors were strongly

positively correlated with CG hassles experienced during bathing ($r = .71, p < .001$), and moderately correlated with physical non-aggressive behaviors ($r = .45, p < .001$), and physical aggressive behaviors ($r = .55, p < .001$). These agitated behaviors had a moderate negative correlation with CG satisfaction with bathing ($r = -.46, p < .001$). Lastly, vocal or verbal agitated behaviors had a weak positive correlation with CG strain during bathing ($r = .37, p = .002$).

CR physical non-aggressive behaviors had a strong negative correlation with physical aggressive behaviors ($r = -.60, p < .001$) and moderate positive correlation with CG hassles experienced during bathing ($r = .50, p < .001$). Physical non-aggressive behaviors had a weak negative correlation with CG satisfaction with bathing ($r = -.24, p = .03$) and a weak positive correlation with strain during bathing ($r = .26, p = .02$).

CR physical aggressive behaviors had a strong positive correlation with CG with hassles experienced during bathing ($r = .64, p < .001$). Physical aggressive behaviors also had a weak negative correlation with CG satisfaction with bathing ($r = -.25, p = .03$) and weak positive correlation with strain during bathing ($r = .29, p = .011$).

CG Responses

CG satisfaction with bathing had a strong positive correlation with CG confidence in bathing ability ($r = .71, p < .001$) and strong negative correlation with hassles experienced during bathing ($r = -.73, p < .001$). CG satisfaction was moderately correlated with CG strain during bathing ($r = -.54, p < .001$). CG confidence in bathing ability had a moderate negative correlation with CG hassles experienced during bathing ($r = -.52, p < .001$) and weak positive correlation with strain during bathing ($r = -.39, p =$

.001). CG hassles experienced during bathing had a moderate positive correlation with CG assistance during bathing ($r = .57, p < .001$).

Table 13

Aim 4: Summary of Correlations Coefficients To Test Hypothesized Relationships of the New CG Responses Scales with CR's Memory Problems, CG's Health, CG's Physical Functioning, CG's Pain, CG's Depressive Symptoms, CG's Mutuality, and CG's Global Strain

	CR Memory Problems	CG Health	CG Physical Functioning	CG Pain	CG Depressive Symptoms	CG Global Strain	CG Mutuality
CR Self-Care	-.263*	-.008	.129	-.016	.022	-.203	.338*
CR Self-Care Prepare for Bath	-.226*	-.127	.026	.045	.119	-.143	.406**
CR Self-Care Wash Body Parts	-.441**	.015	.160	-.133	-.013	-.140	.311**
CR Self-Care Dry Body Parts	-.403**	.045	-.134	-.127	.181	-.269*	.336**
CR Self-Care Wash and Dry Hair	.040	-.176	-.156	.133	.341**	.020	.138
Comfort Function of the Bath	-.008	.065	.014	-.125	.138	.026	.121
Cleansing Function of the Bath	.275*	-.232*	-.108	.283*	-.003	.370**	-.320**
Form and Frequency of the Bath	-.099	-.099	.040	-.044	-.136	-.051	-.077
CR Wishes Considered	-.355**	.130	.134	-.102	-.184	-.386**	.371*
Bath time Matches CR Preference	-.102	-.068	-.037	.028	.001	.171	.104
Amount of Assistance	.269*	-.104	-.168	.089	.050	.243*	-.495**
Frequency of Assistance	.195	.122	-.054	.058	-.013	-.052	-.052
Duration of Assistance	.168	.030	.077	-.031	-.092	-.146	.005
Help From Others	.068	-.112	.067	.187	.044	.060	-.086

Note: * $p < .05$. ** $p < .01$

Table 13 (cont.)

Aim 4. Summary of Correlations Coefficients To Test Hypothesized Relationships of the New CG Responses Scales with CR's Memory Problems, CG's Health, CG's Physical Functioning, CG's Pain, CG's Depressive Symptoms, CG's Mutuality, and CG's Global Strain

	CR Memory Problems	CG Health	CG Physical Function	CG Pain	CG Depressive Symptoms	CG Global Strain	CG Mutuality
Contentment	-.287*	.239*	.401**	-.195	-.185	-.367**	.410**
Appreciative/ Affectionate Behaviors	-.247*	-.066	.100	.063	-.008	-.198	.323**
Discomfort	.406**	.000	-.203	.169	.105	.299**	-.459**
Vocal or Verbal Agitated Behaviors	.243*	-.127	-.147	.101	-.040	.194	-.335**
Physical Non-Aggressive Behaviors	.231*	-.168	-.331**	.245*	.001	.153	-.091
Physical Aggressive Behaviors	.244*	-.051	-.187	.097	-.120	.186	-.252*

Note: * $p < .05$. ** $p < .01$

Table 13 (cont)

Aim 4: Summary of Correlations Coefficients To Test Hypothesized Relationships of the New CG Responses Scales with CR's Memory Problems, CG's Health, CG's Physical Functioning, CG's Pain, CG's Depressive Symptoms, CG's Mutuality, and CG's Global Strain

	CR Memory Problems	CG Health	CG Physical Function	CG Pain	CG Depressive Symptoms	CG Global Strain	CG Mutuality
CG Satisfaction With Bathing	-.097	.281*	.188	-.199	-.194	-.380**	.310**
CG Confidence in Bathing Ability	-.126	.286*	.165	-.263*	-.327**	-.238*	.210
CG Hassles Experienced Bathing	.238*	-.211*	-.201	.178*	.211	.395**	-.412**
CG Strain From Bathing	.191	-.419**	-.210	.343**	.373**	.403**	-.198

Note: *p < .05. ** p < .01.

Table 14

Aim 5 Revised Hypothesized Relationships Between Concepts Measured by the New Bathing Scales and Subscales

Bathing Concepts	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
1. CR Self-Care Behaviors																								
2. Prepare for Bath	+																							
3. Wash Body Parts	+	+																						
4. Dry Body Parts	+	+	+																					
5. Wash and Dry Hair	+	+	+	+																				
6. Comfort Function of Bath	+	0	0	0	+																			
7. Cleansing Function of Bath	0	0	0	0	0	-																		
8. Form and Frequency of Bath	?	?	?	?	?	?	?																	
9. CR Wishes Considered	+	?	+	+	+	+	0	?																
10. Bath Time Match Preference	0	0	0	0	0	+	0	?	+															
11. Amount of Bathing Assistance	-	-	-	-	-	0	0	?	-	-														
12. Frequency of Bathing Assistance	-	0	-	-	0	+	0	?	0	0	0													
13. Duration of Assistance	?	?	?	?	?	+	0	?	0	0	0	0												
14. Help From Others	-	-	-	-	-	0	+	?	0	0	-	0	-											
15. CR Appreciative/Affectionate Behaviors	0	0	0	0	0	0	?	?	+	+	0	0	0	-										
16. CR Contentment During Bathing	+	+	+	+	?	+	?	?	+	+	-	0	0	-	+									
17. CR Discomfort	-	0	-	-	-	-	+	?	0	0	0	0	0	-	-									
18. CR Vocal/Verbal Agitated Behaviors	-	0	-	-	-	-	+	?	-	-	+	?	0	0	-	-								
19. CR Non-Aggressive Behaviors	-	0	-	-	-	-	+	?	-	-	+	?	0	-	-	-	+							
20. CR Aggressive Behaviors	?	?	?	?	?	-	+	?	-	-	+	?	0	-	-	-	0	+						
21. CG Satisfaction From Bathing	+	0	+	+	?	+	+	?	+	+	-	-	0	-	+	+	-	-	-	-	-	-	-	-
22. CG Confidence in Bathing Ability	+	0	+	+	0	0	+	?	+	0	0	0	0	-	+	+	-	-	-	-	+	+	+	+
23. CG Hassles During Bathing	-	-	-	-	-	-	-	?	-	?	+	-	0	+	-	-	+	+	+	+	-	-	-	-
24. CG Strain From Bathing	-	-	-	-	0	-	+	?	-	?	+	-	0	+	-	-	+	+	+	+	+	+	+	+

Note: + = Positive relationship hypothesized. - = Negative relationship hypothesized. 0 = Near zero relationship hypothesized. ? = No hypothesis made.

Table 15

Aim 5: Summary of Correlations Coefficients To Test Hypothesized Relationships Among The New Bathing Scales

	Self-Care	Self-Care Prepare for Bath	Self-Care Wash Body Parts	Dry Body Parts	Wash and Dry Hair	Comfort Function of the Bath	Cleansing Function of the Bath
Self Care							
Self-care Prepare for Bath	.844**						
Self-care Wash Body Parts	.908**	.676**					
Dry Body Parts	.892**	.605**	.834**				
Wash and Dry Hair	.770**	.595**	.548**	.484**			
Comfort Function of the Bath	.257*	.023	.135	.115	.257*		
Cleansing Function of the Bath	-.007	.059	-.099	-.132	-.044	-.318**	
Frequency and Form of Bath	.117	.120	.201	.312**	.032	.103	-.125

Note: *p < .05. **p < .01

Table 15 (Cont)

Aim 5: Summary of Correlations Coefficients To Test Hypothesized Relationships Among The New Bathing Scales

	Self-Care	Self-Care Prepare for Bath	Self-Care Wash Body Parts	Dry Body Parts	Wash and Dry Hair	Comfort Function of the Bath	Cleansing Function of the Bath
CR Wishes Considered	.213	.310*	.220*	.156	.169	.054	-.150
CR Preference Match Bath Time	.167	-.016	.241*	.168	.089	.082	.081
Amount of Assistance	-.752**	-.643**	-.702**	-.737**	-.411**	-.094	.166
Frequency of Assistance	-.208	-.140	-.213*	-.316**	.017	.320**	.124
Duration of Assistance	-.181	.011	-.202	-.105	-.203	.014	-.031
Help From Others	-.117	-.153	-.207	-.042	-.146	-.311**	-.031
Contentment	.291*	.322**	.214*	.139	.154	.159	-.190
Appreciative/ Affectionate Behaviors	.219	.220	.207	.279*	.047	.157	-.040

Note * $p < .05$. ** $p < .01$

Table 15 (cont)

Aim 5: Summary of Correlations Coefficients To Test Hypothesized Relationships Among The New Bathing Scales

	Self-Care	Self-Care Prepare for Bath	Self-Care Wash Body Parts	Dry Body Parts	Wash and Dry Hair	Comfort Function of the Bath	Cleansing Function of the Bath
Discomfort	-.234	-.246*	-.268*	-.192	-.076	-.130	.260*
Vocal or Verbal Agitated Behaviors	-.254*	-.214	-.199	-.088	-.190	-.158	.341**
Physical Non-Aggressive Behaviors	-.171	-.280*	-.211	-.065	-.007	-.075	.090
Physical Aggressive Behaviors	-.270*	-.334**	-.302**	-.081	-.155	-.099	.121
CG Satisfaction With Bathing	.067	.163	-.040	-.041	-.113	-.256*	-.216*
CG Confidence in Bathing Ability	-.258 *	-.071	-.099	-.157	-.357**	.026	-.204
CG Hassles Experienced Bathing	-.320	-.439**	-.236*	-.193	-.075	-.152	.163
CG Strain During Bathing	-.162	-.253*	-.055	-.105	.034	-.140	.257*

Note * $p < .05$. ** $p < .01$

Table 15 (cont)

Aim 5. Summary of Correlations Coefficients To Test Hypothesized Relationships Among The New Bathing Scales

	Frequency and Form	CR Wishes Considered	Preference Match Bath Time	Amount of Assistance	Frequency of Assistance	Duration of Assistance	Help From Others
Discomfort	.123	-.175	-.152	.320**	.023	-.024	.088
Vocal or Verbal Agitated Behaviors	.101	-.235	-.044	.329**	-.112	.196	.120
Physical Non-Aggressive Behaviors	-.191	-.374**	-.020	.275*	.091	.099	.348**
Physical Aggressive Behaviors	.078	-.308**	-.074	.302**	-.048	-.083	.317*
CG Satisfaction With Bathing	-.318*	.329**	-.093	-.178	.295*	-.102	-.067
CG Confidence in Bathing Ability	-.100	.139	-.096	.004	.199	-.112	-.153
CG Hassles Experienced Bathing	.078	-.343**	-.002	.382**	-.153	.081	.184
CG Strain During Bathing	-.086	-.317**	.020	.193	-.178	-.176	.082

Note * $p < .05$. ** $p < .01$.

Table 15 (cont)

Aim 5: Summary of Correlations Coefficients To Test Hypothesized Relationships Among The New Bathing Scales

	Contentment	Appreciative Behaviors	Discomfort	Vocal or Verbal Agitated Behaviors	Physical Non-Aggressive Behaviors	Physical Aggressive Behaviors
Contentment						
Appreciative Behaviors	.393**					
Discomfort	-.637**	-.298**				
Vocal or Verbal Agitated Behaviors	-.599**	-.106	.427**			
Physical Non-Aggressive Behaviors	-.319**	-.162	.223*	.448**		
Physical Aggressive Behaviors	-.401**	-.229*	.392**	.547**	.596**	
CG Satisfaction With Bathing	.561**	.045	-.351**	-.458**	-.243*	-.252*
CG Confidence in Bathing Ability	.396**	-.106	-.292*	-.205	-.198	-.047
CG Hassles Experienced Bathing	-.671**	.161	.481**	.714**	.497**	.636**
CG Strain from Bathing	-.426**	-.120	.292*	.367**	.262*	.293*

Table 15 (cont)
 Aim 5: Summary of Correlations Coefficients To Test Hypothesized Relationships Among The New Bathing Scales

	CG Satisfaction With Bathing	CG Confidence in Bathing Ability	CG Hassles Experienced Bathing	CG Strain from Bathing
CG Satisfaction With Bathing				
CG Confidence in Bathing Ability	.714**			
CG Hassles Experienced Bathing	-.725**	-.515**		
CG Strain During Bathing	-.542**	-.393**	.568**	

Note * $p < .05$. ** $p < .01$.

Table 16

Summary of Number of Significant Correlations per Hypothesized Correlations with Established Scales

	# of Significant Correlations/ # Hypothesized Correlations	# of Non Significant Relationships/ # of Zero Hypothesized Correlations	# of significant Correlation/ # of Correlations with no Hypothesis Made
Bathing Situation			
Self-Care	2/3 Range = .26 - .34 Median = 0.30	5/4 Range = .008 - .0.20 Median = 0.22	0/0
CR Self-Care Prepare for Bath	2/3 Range = .23 - .41 Median = .32	5/4 Range = .03 - .14 Median = .11	0/0
CR Self-Care Wash Body Parts	2/3 Range = .21 - .31 Median = .38	5/4 Range = .05 - .18 Median = .38	0/0
CR Dry Body Parts	3/3 Range = .27 - .40 Median = .33	4/4 Range = .04 - .19 Median = .11	0/0
CR Wash and Dry Hair	1/0	6/7 Range = .02 - .18 Median = .14	0/0
Bath Features			
Comfort Function of the Bath	0/0	0/0	0/7 Range = .008 - .14 Median = .07
Cleansing Function of the Bath	5/5 Range = .23 - .37 Median = .28	2/2 Range = .003 - .011 Median = .05	0/0
Form and Frequency of the Bath	0/0	0/0	0/7 Range = .03 - .20 Median = .08

Table 16 (cont)

Summary of Number of Significant Correlations per Hypothesized Correlations with Established Scales

CG Communication			
	# of Significant Correlations/ # Hypothesized Correlations	# of Non Significant Relationships/ # of Zero Hypothesized Correlations	# of significant Correlation/ # of Correlations with no Hypothesis Made
CR Wishes Considered	3/5 Range = .22 - .35 Median = .32	4/2 Range = .08 - .20 Median = .13	3/0
CG Assistance			
Amount of CG Assistance	3/3 Range = .24 - .50 Median = .24	4/4 Range = .05 - .17 Median = .10	0/0
Frequency of CG Assistance	0/0	7/0 Range = .13 - .20 Median = .05	0/7
Duration of CG Assistance	0/3	7/0 Range = .01 - .17 Median = .10	0/0
Help From Others	0/5	7/2 Range = .44 - .19 Median = .07	0/0
Care Receiver Responses			
CR Positive Behaviors			
Contentment	5/6 Range = .24 - .41 Median = .37	2/3 Range = .19 - .20 Median = .20	1/0
Appreciative/ Affectionate behaviors	2/5 Range = .25 - .32 Median = .29	5/1 Range = .008 - .20 Median = .07	0/0

Table 16 (cont)

Summary of Number of Significant Correlations per Hypothesized Correlations with Established Scales

	# of Significant Correlations/ # Hypothesized Correlations	# of Non Significant Relationships/ # of Zero Hypothesized Correlations	# of significant Correlation/ # of Correlations with no Hypothesis Made
CR Behavioral Symptoms			
CR Discomfort	3/3 Range = .41 - .46 Median = .43	4/4 Range = .000 - .20 Median = .14	0/0
CR Vocal or verbal- agitated behaviors	2/3 Range = .23 - .71 Median = .43	5/4 Range = .04 - .19 Median = .13	0/0
CR Physical non- aggressive behaviors	3/6 Range = .22 - .60 Median = .28	4/1 Range = .001 - .17 Median = .12	0/0
Physical aggressive behaviors	2/5 Range = .24 - .25 Median = .25	5/1 Range = .05 - .19 Median = .12	0/0
CG Satisfaction and Preparedness			
CG Satisfaction With Bathing	3/7 Range = .28 - .38 Median = .31	4/3 Range = .09 - .20 Median = .19	0/0
CG Confidence in Bathing Ability	3/4 Range = .24 - .37 Median = .26	4/3 Range = .00 - .21 Median n = .11	0/0
CG Hassles	5/6 Range = .21 - .40 Median = .24	2/1 Range = .20 - .21 Median = .21	0/0
CG Strain From Bathing	4/7 Range = .34 - .42 Median = .39	3/0 Range = .19 - .21 Median = .20	0/0

CHAPTER 5

Discussion

Introduction

Caring for CI elders can be a difficult challenge for their CGs. Major factors contributing to the difficulties that many family CGs experience are CRs' symptoms of dementia: memory decline, functional losses associated with ADLs, and personality changes, including behavioral symptoms (Emory & Oxman, 1994). Behavioral symptoms often occur when the CG is assisting the CI elder with personal care such as bathing. CI elders' experience of discomfort or feeling overwhelmed by personal care activities or daily events that are normally managed by cognitively intact elders may be precursors of behavioral symptoms during bathing. Whatever the cause, bathing difficulties appear to be a common concern among family CGs of CI elders. However, little is known about the experiences of family CGs who assist CI elders during bathing in the home setting. Most research on caregiving during bathing has been conducted with paid CGs in nursing homes (Aronson, Post, & Gustasiesegni, 1993; Hoeffler, Rader, McKenzie, Lavelle, & Stewart, 1997; Maxfield, Lewis, & Cannon, 1996; R. I. Miller, 1994; M. F. Miller, 1997; Rader, Lavelle, Hoeffler, & McKenzie, 1996; Rossby, Beck, & Heacock, 1992; Sloane Honn, et al., 1995). The development of reliable and valid instruments for assessing family CGs' experiences of bathing CI elders in the home is an important preliminary step for future studies of family assistance with bathing and other ADLs.

This chapter is a discussion of the interpretation of the results, theoretical and practical implications of the findings of this study. The relationships between the findings

from this study, findings from previous research, and the conceptual model for the study are discussed as are the limitations of the study. Implications of the study for nursing practice and future research in the field are described.

Interpretation of Results

Aim 1. To evaluate the content validity of the new bathing instruments for use with family CGs in the home setting.

The new bathing instruments were developed from nursing home scales and adapted for use with family CGs are described in Chapter 1, Table 1. Content validity was evaluated by experts in the field of gerontological nursing, geropsychiatric nursing and instrument development. Also, family CGs who assisted a CI elder during bathing participated in the initial development of the scales. The family CGs represented a range of age, racial, and socioeconomic groups consistent with potential family CGs with whom the new bathing scales would be used. Both groups evaluated the clarity, consistency, and variation of the items. Furthermore, they evaluated the readability and interest levels of the scales to enhance the scales' usability. Generally, the items on the measures are clear, homogenous, and readable. Overall it appears that the questionnaires were interesting enough to generate appropriate responses from this group of family CGs. After addressing the responses of experts, family CGs, interview data, and consultation with my dissertation committee the scales were generated into a final booklet form for Phase 2 of the study.

Phase 2 Characteristics of the Sample

The characteristics of family CGs ($n = 62$) who assisted with bathing in this study were similar to family CGs in the United States (U. S. Bureau of Census, Current Population Reports, Special Studies 1996). For instance, most (59%) of the family CGs' were age 65 and older (mean age 65 years). The usual length of time spent caregiving ranged from 1- 5 or more years (64%), and 50% spend 1- 4 hours per day caregiving seven days a week (80%). Many of the family CGs were not working (71%), were low to middle income (58%), and reported their health as being fair or poor (42%). The majority of the family CGs were married (78%) and living with the disabled elder (91%), female (73%), and either a spouse (36%) or child (37%) of the CI elder. A strength of this study was the inclusion of minority family CGs (21%) and male CGs (26%). The extent to which the family CGs who participated in this study resemble family CGs in general is important in determining how typical were their experiences and reflective of those in the US population.

Aim 2. To Derive New Bathing Scales From the New Instruments Using Item Analysis and Exploratory Factor Analysis, and to Refine The Conceptual Model Including Concept Labels and Definitions.

Ten bathing scales were developed from the instruments using item analysis and exploratory factor analysis. The process also helped to refine the conceptual model for the study including concept label and definitions. Exploratory factor analysis provided guidance, however, due to the small sample size exploratory factor analysis could not be

relied on totally to develop the new scales. Internal consistency was evaluated on the following new bathing scales.

New Bathing Scale	Concept
1. Bathing Task Scale	1. CR Self-Care During Bathing
2. Reasons for Bathing Scale	2. Bath Features
3. Bath Time Scale	3. CR Bath Time Matches CR preference
4. Considering the CR's Wishes Scale	4. CG Communication
5. CG Help with Bathing Scale	5. Bathing Assistance Provided by CG
6. Help From Others with Bathing Scale	6. Help form Others with Bathing
7. CR Reactions During Bathing Scale	7. Positive CR Behaviors and CR Behavioral Symptoms
8. Family CG's Experience During Bathing Scale	8. CG Satisfaction and confidence with bathing ability
9. Caregiving Hassles During Bathing Scale	9. Hassles Experienced During Bathing
10. CG Strain From Bathing Scale	10. CG Strain From Bathing

See Table 6 for concept definitions and sample scale items.

Aim 3. To Estimate The Internal Consistency Reliability of The New Bathing Scales.

Internal consistency reliability was estimated for the new and revised bathing scales developed in this study. Cronbach's alphas for 11 of the 17 scales or subscales (65%) tested have Cronbach's Alpha values exceeding .70, a criterion for use for research purposes recommended by Nunnally (1978). The reliability was marginal for 6 subscales [cleansing function of the bath, instruments ($\alpha = .53$), comfort function of the bath ($\alpha = .57$), strain of bathing ($\alpha = .64$), considering the CI elder's wishes ($\alpha = .69$), appreciative or affectionate behaviors ($\alpha = .65$), and physical non-aggressive behaviors ($\alpha = .50$)]. Table 7 provides detailed information about these subscales. These scales may not be homogenous because of the small sample size of those responding to the items. Moreover, Cronbach's alpha is related to the number of items in the scale and range of response options. Thus, lower internal consistency could have been suspected

for 5 of the above 6 sub-scales. The items in cleansing function of the bath (5 items), comfort function of the bath (4 items), appreciative or affectionate behaviors (7 items), and physical non-aggressive behaviors (7 items) are dichotomous variables (i.e., yes and no response options). Moreover, the number of family CGs who responded “yes” were minimal. Although Strain of Bathing has a wider range of response options, the number of items (4 items) within the subscale were low. Since Cronbach’s alpha was very close to Nunnally’s recommended criterion for the scale “Considering the CG’s Wishes”, further reliability testing of this scale is suggested with a larger sample size.

All of the scales had acceptable levels of missing data except two. The subscales “self-care preparing for the bath” of the “What you and Your Family CG Do During Bathing Scale” had 10% missing data and “self-care wash and dry hair” had 18% missing data (See table 7). The high percentage of missing data is a concern in the instance of “self-care preparing for the bath”. The format was the same as the other self-care subscales, but family CGs may have found the items in this particular subscale confusing. On the other hand, when self-care wash and dry hair items were left unanswered it may be due to some family CGs who wrote beauty shop in “other” instead of selecting not done.

Aim 4. To Obtain Preliminary Evidence About The Construct Validity of The New Bathing Scales by Testing Hypothesized Relationships Between Concepts Measured by the New Scales and Concepts Measured by Established Scales

According to the results of this study the final concepts and new measures were developed. The most common method of obtaining evidence of construct validity is

testing hypothesized relationships between variables (Stewart & Petersen, 1982). To obtain evidence for construct validity, correlation statistical procedures were used to examine the magnitude and direction of the relationship between the new measures and established scales. Established scales included CR's Memory Problems, and CG's Health, Physical Function, Pain, Depressive Symptoms, Mutuality, and Global Strain.

The new measures intercorrelations with established measures are examined in this section. Significant results of the hypothesized relationship are reported at the $p < .01$ and $.05$ level of significance (See Tables 12 and 13 for relationships among the measures for hypothesized relationships). For this study, the most important validity issue is whether or not the construct validity of the instruments and its subscales are supported by the findings. Although some of the correlations were not significant most of the hypothesized relationships were supported.

Concept 1: CR Self-Care During Bathing. The new measure, Bathing Tasks Scale, measures CR self-care behaviors. It consists of 27 items and has four subscales: prepare for the bath, wash body parts, dry body parts, and wash and dry hair. Three of 4 subscales (self-care prepare for the bath, self-care wash and dry body parts) were significantly related to CR Memory Problems and CG Mutuality. As predicted, the self-care behaviors decrease as CR memory problems increased. However, there was not a significant relationship among wash and dry hair and CR Memory Problems in part because these activities are not always done by the CG during bathing in the home setting.

As predicted, CR self-care behaviors, CR prepare for the bath, CR wash body parts, CR dry body parts, and CR wash and dry hair did not have a significant relationship with CG Health, Physical Functioning, and Pain. It was predicted that CR wash and dry hair was not correlated with CG Depressive Symptoms. However, CR wash and dry hair was correlated with CG Depressive Symptoms. As CR self-care wash and dry hair behaviors decrease, the more depressive symptoms are reported by family CGs. This may be due to the difficulties family CGs experience who assist a CI elder with washing and drying their hair. This finding does support clinical observations made in the nursing home setting. CNAs appear to have a lot of difficulty when washing a CI elder's hair. Oftentimes in the nursing home, hair washing occurs in the shower and during rinsing the CI elder yells and attempts to strike the CG to end hair washing. Family CGs may be experiencing the same problems during hair washing.

It was predicted that CR self-care behaviors, CR prepare for the bath, CR wash body parts, CR dry body parts, CR wash and dry hair would be negatively correlated with CG Global Strain. CR self-care dry body parts behaviors was the only self-care behavior significantly related to Global Strain in that when the CR can dry body parts, less strain was reported by family CGs. It is unclear from the results why the other self-care behaviors did not produce the same results. Conceptually, CRs' participation in the bath lessens the workload of the CG, thereby reducing CG strain. One explanation may be that when CGs are assisting during bathing, drying is usually the last task to complete. At this point CGs may be feeling tired or strained, so when the CR dries their body parts or assists the CG with this activity, workload during bathing is decreased.

All self-care behaviors were significantly correlated with Mutuality, except self-care wash and dry hair. The more functionally independent CRs are during bathing the more feelings of mutuality were reported by family CGs. Similarly, Archbold and colleagues (1990) found that mutuality was negatively correlated with CI elders' deterioration (e.g. increased dependence and behavioral symptoms). As predicted, CR Self-Care Behaviors did not have a significant relationship with CG Health, Physical Functioning, and Pain. Also, no relationship between CR wash and dry hair and CG depression was predicted because in the home setting CR may go to beauty or barber shops. However, in this study it appears that as the CR is more able to wash and dry their hair independently, the more CGs report depressive symptoms. This may occur as CGs observe the CR washing and drying their hair and they may observe the deterioration in the CRs' functional abilities during hair washing and drying behaviors, indicating the elder may becoming progressively cognitively impaired. Meshefejian and colleagues (1998) study of family CGs found that CR ADL deficits had a significant relationship with CG depression. However, in this study other self-care behaviors were not significantly correlated with Depressive Symptoms.

Concept 2: Bath Features. Reasons for Bathing Scale, (a 9-items scale) which has two subscales: comfort and cleansing function of the bath. The response format consists of yes and no response options. Form and Frequency of the Bath consists of 4 items; the forms of the bath are listed vertically and the frequency of each form of the bath is listed horizontally. The Cleansing Function of the Bath was significantly correlated with CR Memory Problems, CG Health, Pain, Global Strain and Mutuality. As the CR memory

problems increase, the more the CG will bathe primarily for cleansing reasons. CGs who assist a CI elder during bathing for the purpose of cleansing more frequently report more Pain and Global Strain, poorer Health, and less Mutuality. No predictions were made about the cleansing function of the bath and CG Physical Functioning, and the results suggested no significant correlation.

Little was known about how the comfort function and the Form and Frequency of the Bath are related to the established measures, therefore no predictions were made regarding these scales. The findings in this study confirm that the comfort function and the Form and Frequency of the Bath had no significant relationship with any of the established scales. In this study family CGs used the comfort function of the bath (used 46% of the time) less frequently than the cleansing function of the bath (used 79% of the time), therefore it may be a less familiar concept to family CGs. A weakness of this study was in the development of the Form and Frequency of the Bath Scale, which made it difficult to interpret the results. The concepts are combined, thus it is difficult to distinguish statistically which concept (form or frequency) is related to the established scales.

Concept 3: CR Bath Time Preference. Bath Time Scale is a 2-item scale on which family CGs are asked to select the CR's usual bath time and the CR premonitory bath time; preference is honored when the two matched. It was predicted that bath time matches CR preference would have no relationship with CG Physical Function and the findings confirmed no relationship. Predictions were not made regarding CG Health, CG Pain and CG Depressive Symptoms and the findings suggest that there are no correlations. The CR

bath time matches bath preference was not significantly correlated with CR Memory Problems, Global Strain and Mutuality. However, the correlation was in the predicted directions. For example, honoring the CR bath time preference decreases as memory problems increase, and CGs report more strain and CG mutuality.

Concept 4. CRs' Wishes Considered. The new instrument, Considering the CRs' Wishes Scale is a 9-item Likert scale. As predicted CRs' wishes were significantly correlated with CR memory problems, CG global strain and mutuality. The findings confirm that CRs' wishes are considered more when the CR has less memory problems. Most likely as the CRs experience more memory impairments, family CGs assumed more responsibility for determining when bathing would occur in their schedule. Also, when the CR wishes are considered, family CGs reported greater feelings of mutuality and less CG strain. For instance, the more CGs report shared pleasurable activities, common values, and reciprocity, the more likely the CR wishes will be considered during bathing. When considering the CRs wishes during bathing the bath should go well and decrease CG strain. According to researchers, by knowing the pre-disease personality, interests, activities, and cultural identity of CI elders, CGs can better understand the CRs' care preferences, coping mechanisms, and personal care needs. Knowledge of the personal history of the CI elder may assist in addressing behavioral symptoms during bathing, for example, assisting the CI elder during bathing in a manner consistent with the way previously enjoyed. When CGs have such understanding, CI elders are more apt to participate in meeting their own ADLs (Hall & Buckwalter, 1999; Namazi & Johnson 1996).

Concept 5: Bathing Assistance Provided by CG. The new instrument, CG Help with Bathing Scale, the 3-item scale has three subscales: amount, frequency, and duration of assistance during bathing provided by the family CG. Only one subscale “amount of CG assistance” was correlated with the established measures, CR Memory Problems, CG Global Strain and Mutuality when increased assistance was required by family CGs. As predicted the amount of CG assistance during bathing increased with increased CR Memory Problems. The more CG memory problems, the more assistance is required by family CGs. Also, as the amount of CG assistance increases, CGs report more strain. Lastly, the more family CGs reported less shared pleasurable activities, common values, and reciprocity the more likely these CGs are assisting more during bathing. As predicted, there was not a correlation with CG Health, CG Function, CG Pain, and CG Depressive Symptoms. Mattocks, and Slatt (1990) found that CGs of elders during bathing reported the amount of hours providing care as problematic.

Concept 6: Help From Others with Bathing. The new instrument, Help From Others With Bathing Tasks Scale is a 3-item scale that measures the help received from relatives, friends and neighbors, and formal caregivers. Help from others was not significantly correlated with any of the established measures. It was predicted that help from other would be correlated with CG Health, CG Function, CG Pain, CG Depressive Symptoms, and CG Global Strain. For example, family CGs would seek help from others when they were sick, in poor physical shape, experiencing pain, feeling depressed or strained. However, help from others was correlated in the predicted directions only with CG Health and Pain. It appears that seeking help from others may be somewhat related to

CG health, pain and physical status but not related to psychological reasons. Researchers agree that family CGs tend to seek help with caregiving tasks in general when CG themselves are doing more physical caregiving tasks and experiencing CG distress (Harper & Lund, 1990; McCarty, 1996; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Wykle & Segal, 1991). However, this finding was not confirmed in this study. Although Global Strain was not significantly associated with help from others, it was correlated in the predicted direction. This prediction is consistent with previous findings, and a larger sample size is needed to further test this hypothesis.

Concept 7: Positive CR Behaviors and Behavioral Symptoms. The new instrument, Care Receiver's Reaction to Bathing is a 45-item measure consisting of yes and no response options. This measure has two subscales: contentment (4-items), and appreciative or affectionate (7-items) behaviors during bathing.

Appreciative and affectionate behaviors were significantly correlated with CR Memory Problems and CG Mutuality. CR appreciative and affectionate behaviors decrease as the CR memory problems increase, as predicted. However, more CR appreciative or affectionate behaviors were perceived as occurring during assistance with bathing, and the more appreciative or affectionate behaviors displayed by CRs, the more family CGs reported greater feelings of mutuality. As predicted there was no correlation among CR appreciative or affectionate behaviors and CG Health. CR appreciative or affectionate behaviors were not correlated with the remaining established measures as predicted. It was hypothesized that when family CGS are more healthy, physically fit and experiencing less pain, depressive symptoms and strain, the bath will go better. Thus,

CRs displayed more appreciative or affectionate behaviors during bathing. This hypothesis was not confirmed in this study.

CR contentment during bathing was significantly correlated with established measures, including CR memory problems, CGs being healthy and physically fit, CG strain and CG perceptions of mutuality. CRs with less memory problems experienced more contentment during bathing. Secondly, as CR contentment during bathing increased the CGs' perception of strain decreased. Lastly, the more contentment behaviors displayed by CRs during bathing, the more feelings of mutuality were reported by family CGs who assist a CI elder during bathing. It was predicted that CG Pain and CG Depressive symptoms were correlated with CR contentment, but not with CR health. These predicted relationships are consistent with previous findings about caregiving reported in the literature and clinical experience. The findings of this study further expand the findings of Cohen, Pringle & LeDuc, 2001. According to the researchers, a challenge for many family CGs is that CI elders are unable to thank them for the care provided. Family CGs have difficulty knowing whether the CI elder is pleased with caregiving decisions made by the family CG and find CRs' behavioral symptoms and lack of positive reinforcement regarding how well family CGs are doing as disturbing (Thomas, Clement, Hazif-Thomas, & Leger, 2001).

CR Behavioral Symptoms (from the new instrument, Your Family Member's Reactions During Bathing Instrument). The measurement of this concept consists of the remaining three subscales, CR discomfort (8-items), vocal or verbal agitated (9-items), physically non-aggressive behaviors (7-items), and physical aggressive behaviors (10-

items). CR discomfort was significantly correlated with CR memory problems, CG global strain, and mutuality. As predicted, the more memory problems the CR had, the more discomfort was displayed by CRs during bathing, and the more family CGs reported global strain. The more discomfort displayed by CR during bathing, the less feelings of mutuality were reported by family CGs. The results confirm the predictions that there is not a correlation among CR discomfort and CG pain, CGs being healthy and physically fit.

As predicted, the greater the CRs' memory problems, the more the CR displayed vocal or verbal agitated behaviors during bathing and family CGs reported less feelings of mutuality. As predicted, no correlations among vocal or verbal agitated behaviors and CG Function, Pain, and depressive symptoms were found. However, it was predicted that vocal or verbal agitated behaviors would have a negative correlation with CR Health. Although the results did not confirm this prediction, the correlations were in the predicted direction.

CR physical non-aggressive behaviors during Bathing were significantly correlated with CR Memory Problems, CG Physical Function and Pain. The results confirmed the following predictions: as CR memory problems increase the more CRs displayed physical non-aggressive behaviors during bathing. As CRs displayed physical non-aggressive behaviors, the more family CGs reported poor physical functioning and pain. Although the predictions were not confirmed related to CR physical non-aggressive behaviors and CG Health and Global Strain, the correlations were in the predicted direction. Also, CG Depressive Symptoms appears to have no association with physical

non-aggressive behaviors. These behaviors displayed exclusively may not affect the above CG responses.

As predicted, CR physical aggressive behaviors during bathing were significantly correlated with CR Memory Problems and Mutuality. More physical aggressive behaviors displayed by the CR during bathing were associated with increased CR memory problems and less perceived CG mutuality. Although the predictions were not confirmed relating CR physical behaviors and CG Health, Physical Functioning, Pain, Depressive Symptoms and Global Strain, the correlations were in the predicted direction. The predicted hypothesis regarding aggression and pain are supported by the results of a study in which Feldt, Warne, and Ryden (1998) examined pain in CI nursing home residents to determine the relationship between pain and aggressive behaviors during ADLs. Aggression scores were higher in CI residents with pain-related diagnoses.

The CGs in this study did not report many CR behavioral symptoms. This restricted range may have affected the results and strength of associations found with established measures. However, according to the literature it appears that all CR behavioral symptoms occur concurrently and may result in negative CG responses. Wortley, McDonald, & Wargon (1993) found that CR cognitive function and troublesome behaviors, and CG reaction to behaviors, predicted actual institutionalization of the CI elder.

Concept 8: CG Satisfaction from bathing and CG confidence in bathing ability (from the new instrument, Family CG's Experience During Bathing Scale) is a 20-item Likert scale which includes two subscales: CG satisfaction with bathing (9 items) and CG

confidence in bathing ability (11 items). CG satisfaction with bathing was significantly correlated with CG Health, Global Strain and Mutuality. The healthier the family CGs, the more satisfied they were with the bathing assistance they provided during bathing and the less strain they reported. Also, family CGs who reported feeling satisfied with assisting CRs during bathing reported experiencing more feelings of mutuality, as predicted. Archbold and colleagues' (1990) findings lend support to this methodological study, in that they found mutuality was also positively correlated, suggesting a relationship between CGs' perception of shared pleasurable activities, common values, and reciprocity with the CR. Moreover, the more family CGs feel satisfied while providing care to the CR in general, the more positively they feel about the experience. The remaining established measures were not correlated with CG Satisfaction From bathing as predicted, however, the correlations are in the predicted direction.

As predicted, CG confidence in bathing ability was significantly associated with CG Health, Pain, Depressive Symptoms and Global Strain. The better family CGs health, the less CG pain and depressive symptoms and global strain, the more confident the family CGs is in their ability to assist a CI elder during bathing. The results of the study confirmed the prediction of no significant relationship among CG confidence in bathing ability and CR Memory and CG function.

Concept 9: CG Hassles Experienced During Bathing. The new instrument, Caregiving Hassles During Bathing Scale, is a 7-item Likert Scale. Contrary to what was predicted, there appears to be no association between CG reporting more depressive symptoms and CG distress. Family CGs report of CG Hassles Experienced During

Bathing was not related to CG Depressive Symptoms. Furthermore, there was no relationship between CG hassles and CG Physical Function as predicted. As predicted, CG hassles during bathing are significantly correlated with CR Memory Problems, CG Health, CG Pain, CG Global Strain and CG Mutuality. CG reported increased poor health, pain, strain, and decreased feelings of mutuality when they experienced hassles associated with assisting a CI elder during bathing. The findings in this study contradict those of Gonzales (1997) and Adkisson, and Weinrich (1989) studies which indicated that family CGs did not associate CI elders' memory problems with CG stress or hassles. However, Brashares, Dodge and Catazaro's (1994) suggests that memory problems may have an indirect effect on family CGs perception and experiences of difficulties encountered during caregiving. Also, the daily hassles associated with these problems were positively correlated with CG depressive symptoms.

Concept 10: CG Strain from Bathing. The new instrument, CG Strain From Bathing Scale, is a 4-item Likert Scale. CG strain from bathing was significantly correlated with CG Health, Pain, Depressive Symptoms and Global Strain as predicted. The poorer the CG health and the more reported CG pain, depressive symptoms, and overall strain, the greater the strain from bathing experienced by CGs. Archbold and colleagues (1990) identified strain from direct care as one of nine aspects of CG role strain. They identified mutuality and preparedness as two variables that influence CG role strain. For example, higher levels of mutuality may be related to decreased strain associated with providing direct care, making it easier for family CGs to implement

caregiving activities such as bathing. Also, high levels of preparedness may be related to low levels of strain.

Other studies, such as Fisher and Lieberman (1994), also found a relationship between CG strain of family CGs of CI elders and CG poor health, depressive symptoms and decreased well-being. Furthermore, Gilleard et al.'s (1982) study also suggested that family CG's reports of CR's functional deficits and behavioral symptoms is highly stressful, and that their perception of being unprepared to manage these problems may be related to CG depressive symptoms, and CG strain. Results from Kinney and Stephens' (1989) study suggested that family CGs of persons with dementia reported significantly more hostility, anxiety, depressive symptoms, and somatization than non-CGs. CG strain was not correlated with CR Memory Problems, CG Function and Mutuality.

In summary, the findings of this study support the predicted relationships between the new bathing scale and existing measures with known validity and are similar to research finding reported in the literature. However, some of the relationships have not been previously examined by researchers, therefore, warranting further study. Confirmation of a significant number of predicted relationships based on previous research, the conceptual model and clinical experience provides evidence of at least preliminary validity of the new bathing scales.

However, in some cases the hypothesized relationships were not supported. For example, due to the structure of the items combined to measure the frequency and form of the bath, hypotheses could not be made among these variables and other variables in the study or to interpret results related to them. Moreover, CR behavioral symptoms were

not associated as predicted with other measures. Most likely this occurred because the frequency distributions indicated that few CRs displayed behavioral symptoms during bathing. Thus distributions of behavioral symptoms were significantly skewed.

Aim 5. To Obtain Further Preliminary Evidence About The Construct Validity of The New Scales

To obtain further preliminary evidence of the construct validity for the new scales, an examination of intercorrelations between scales and subscales was conducted to determine whether hypothesized relationships derived from the literature and the revised conceptual model were supported.

Concept 1: CR Self-Care During Bathing subscales were significantly correlated among one another indicating they are measuring the same concept. CR self-care including wash and dry hair is significantly positively associated with the comfort function of the bath. These findings suggest that the more CRs are able to bathe independently and wash and dry their hair, the more likely family CGs perceive the bath as providing comfort or being done for comfort reasons. Self Care was positively correlated with CR wishes considered and CR contentment. These findings suggest that when CRs participate in bathing activities, family CGs perceive that they are considering CRs' wishes during bathing and that CRs are more content. Moreover, self-care during bathing is negatively associated with the occurrence of behavioral symptoms (e.g., vocal and verbal agitation, physical aggression) and with CG hassles experienced when assisting with bathing. Thus, family CGs perceive that the more assistant they provide, the less likely they are honoring the wishes of the CI elder during bathing and more likely

behavioral symptoms will occur. Similarly they perceive that the more the CR participates in bathing through self-care, the less likely behavioral symptoms will occur and the less likely assistance with bathing will be experienced as a stressful event.

Wells, Dawson, Sidani, Craig and Pringle (2001) explains that when CI elders do not have control during bathing, such as participating in the bathing tasks they may cope with the bathing situation by exhibiting behavioral symptoms and discomfort. CI elders who receive the abilities-focused care in the study to enhance self-care behaviors during ADLs displayed more interactive and socially appropriate behaviors and less agitation. Freels and colleagues (1992) found that CI elders with behavioral symptoms were three times more likely to have moderate to severe difficulty with bathing than CI elders with out behavioral symptoms. Thus the findings in this study are consistent with those reported in the literature.

Concept 2: Bath Features. The comfort function of the bath was significantly negatively correlated with the cleansing function of the bath, help from others, and CG satisfaction with bathing, and significantly positively correlated with frequency of CG assistance. The comfort function of the bath is inversely correlated with the cleansing function the bath, suggesting that family CGs do not see these two purposes of bathing as occurring simultaneously. Moreover, the comfort function is perceived as associated with CI elder' ability to participate in bathing and less need of the CG to obtain help from others. It is less clear why the comfort function of the bath is positively associated with frequency of CG assistance and negatively associated with CG satisfaction with the assistance they provide during bathing.

The cleansing function of the bath was positively correlated with CR discomfort, vocal or verbal agitated behaviors, and CG strain during bathing, and negatively correlated with CG satisfaction during bathing. It appears that the cleansing function becomes the focus of bathing as the CR participates less in bathing. As noted under concept 1 discussion, family CGs also perceive that the more assistance provided during bathing the less they are honoring the CRs' wishes and the more behavioral symptoms and discomfort are exhibited by the CR. Thus, the cleansing function may serve as "proxy" variable for this interrelated set of events. Additionally, having to cope with CR behavioral symptoms may contribute to family CGs experiencing less satisfaction during bathing and reporting more CG strain during bathing. Rader (1994) suggests that nursing home CGs make bathing a more thoughtful process when they consider the function, form and frequency of the bath. These features of the bath may have an impact on the positive or negative responses of both the family CG and CI elder as seen in this study. Hoeffler and colleagues (1997) emphasize changing CNAs' perception of bathing from a task to a therapeutic time for CI nursing residents by providing an individualized approach. This approach emphasizing a person-centered focus, skillful communication and flexibility in the function, form and frequency of the bath can be effective in making the bathing experience a more positive and less distressing experience for CI elders and CGs. It may be that family CGs could benefit from a similar approach as they struggle with how to provide assistance with bathing to CI elders whose functional and cognitive abilities have declined.

Concept 3: CR Bath Time Matches CR Bath Time Preference was positively correlated with CR affectionate and appreciative behaviors indicating that CRs respond positively to bathing during their premorbid bathing times. Namazi and Johnson (1996) found that nursing home residents were not usually bathed at their preferred premorbid bathing times potentially contributing to difficult bathing situations. Family CGs' attempts at matching previous bath schedules and routines may make bathing a more positive experience and more likely to go well for the CI elder.

Concept 4: CRS' wishes considered was negatively correlated with the amount of CG assistance, physical non-aggressive behaviors, physical aggressive behaviors and CG hassles experienced during bathing. Also, CRs' wishes considered was positively correlated with CR affectionate and appreciative behaviors, and CG satisfaction with bathing. According to the findings of this study, the CR whose wishes are considered during bathing may not require as much assistance during bathing. Considering the CRs' wishes may result in more appreciative or affectionate behaviors expressed towards the CG and feelings of CR contentment during bathing. Similarly, CRs whose wishes are considered may display fewer behavior symptoms (e.g., physical non-aggressive and aggressive behaviors). These factors combined, (i.e., more positive CR expressions of behavior and fewer negative behaviors; less assistance required) may promote CG satisfaction with bathing and mitigate CG hassles and strain associated with assisting a CI elder during bathing.

By knowing the premorbid bathing preferences of CI elders, CGs can better address CI elders' personal care needs during bathing. Moreover, honoring and being

sensitive to the wishes of CI elders during bathing is critical to a person-focused individualized approach to caregiving. Findings from studies conducted in nursing homes consistently support that approaches which incorporate a focus on the wishes of the person being bathed ameliorate or prevent behavioral symptoms, increase positive CR behaviors and decrease CG stress, thus making bathing a more positive experience for both CGs and CRs (Sloane et, al., 1995, Rader et, al., 1996; Hoeffler et, al., 1997; Rader & Barrick 2000).

Concept 5 Bathing Assistance provided by CGs was negatively correlated with CR self-care, appreciative behaviors, CR contentment, and positively correlated with CR discomfort, vocal or verbal agitated, physical non-aggressive and aggressive behaviors. A direct relationship exists between the amount of assistance that CGs provide during bathing and the amount of self-care behaviors during bathing undertaken by the CR. Although cause and effect cannot be determined from this analysis, the result seems clear. An increase in CG assistance and decrease in the CR self-care behaviors results in a decrease in affectionate or appreciative and contentment behaviors. Conversely, CRs may display greater discomfort, vocal or verbal agitated behaviors, and physical non-aggressive and aggressive behaviors during bathing. However, the frequency and duration of assistance provided does not seem to affect CR behaviors. Although the amount of assistance provided appears to increase the hassles family CGs experience during bathing. Ory and colleagues (1999) found that CGs of CI elders spend more time assisting during bathing or showering compared to family CGs of cognitively intact elders. Mattocks and Slatt (1990) found that CGs of CI elders during bathing reported the

amount of hours providing care as problematic. Thus, previous research lends some support to this interesting finding. Clearly family CGs perceive more negative CR and CG outcomes with the more assistance they provide during bathing. The strong negative association between the amount of assistance they provide and CR self-care behaviors (especially washing and drying hair during bathing) indicates that they see these activities as inextricably linked.

Concept 6: Help From Others with Bathing was positively correlated with CR physical non-aggressive and aggressive behaviors. It appears that the more difficult the CR becomes during bathing, the more help from others is required. Or it may be that help from others during bathing has a negative affect on CR responses to bathing. Of interest is that help from others in this study was not associated with CG strain, satisfaction with assistance they provide during bathing or hassles. Little is reported in the literature related to help from others and its affects on CR behavioral symptoms and CG responses during bathing in the home setting. However, family CGs tend to seek help with caregiving tasks in general when CGs themselves are doing more physical caregiving tasks, such as bathing, and experiencing CG distress (Harper & Lund, 1990; McCarty, 1996; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Wykle & Segal, 1991).

Concept 7: Positive CR Behaviors. CR appreciated or affectionate behaviors during bathing were significantly positively correlated with CR wishes considered, preference matched bath time, self-care (dry body parts) and contentment. CR appreciative or affectionate behaviors are negatively associated with the amount of CG assistance, CR discomfort and physically aggressive behaviors. Similarly, CR

contentment was positively associated with CG satisfaction with assistance provided during bathing and CR appreciative or affectionate behaviors. CR contentment was significantly associated with CR discomfort and behavioral symptoms (vocal or verbal agitated behaviors, physically non-aggressive and aggressive behavior) and CG confidence during bathing, hassles and strain. CR positive reactions to the assistance of family CGs during bathing were correlated in the predicted directions. According to the findings of this study CRs display affectionate or appreciative behaviors when their wishes and preferences related to bathing were observed and when experiencing feelings of contentment during bathing. However, CRs feelings of contentment lessen when CRs experience discomfort during bathing. Fewer affectionate or appreciative behaviors occur as more verbal, vocal and physical behavioral symptoms occur and more assistance with bathing is required from the CG. But, when CRs show contentment during bathing, family CGs report more satisfaction with bathing, confidence in bathing ability, and less hassles and strain during bathing.

These findings lend support to Cohen, Pringle & LeDuc (2001) who found that a challenge for many family CGs is that CI elders are unable to thank them for the care provided. Family CGs have difficulty knowing whether the CI elder is pleased with caregiving decisions made by the family CG, and find CRs' behavioral symptoms and lack of positive reinforcement regarding how well Family CGs are doing as disturbing (Thomas, Clement, Hazif-Thomas, & Ledger, 2001). Family CGs who perceive CR contentment, affectionate or appreciative behaviors during bathing experience that they are doing a good job and that the CR is pleased with the assistance they provide. In

Burgener and Shimer's (1993) nursing home study, the number of smiles from CI elders to CGs was moderately related to the amount of CGs' experience in caring for CI elders. Family CGs in this study felt more satisfied with assisting with bathing and confident in their abilities to do so when CRS displayed positive behaviors during bathing.

CR behavioral symptoms were significantly positively correlated with CR discomfort, and CG hassles and strain. Behavioral symptoms were negatively correlated with CG satisfaction. CRs tend to become vocal or verbally agitated, or display physically non-aggressive or aggressive behaviors when CRs are experiencing discomfort during bathing. CR behavioral symptoms and CR discomfort affects family CGs' responses, resulting in a decrease in CG satisfaction with assistance provided during bathing. Furthermore, family CGs may experience more hassles and strain associated with assisting a CI elder during bathing as a result of behavioral symptoms and discomfort experienced by the CR. The findings of this research suggest discomfort experienced by CI elders during bathing may be one reason that CI elders are resistant to bathing and respond with behavioral symptoms, such as vocal or verbal agitation or physical aggression.

The results of this study are very consistent with findings from other studies conducted in nursing homes and home settings. For example, Bridges-Parlet, Knopman, & Thompson (1994) identified that 54% of physical aggressive behaviors directed towards nursing staff occurred during personal care activities such as bathing. Hoeffler and colleagues (1997) reported that CI elderly residents were more likely than non-CI residents to respond with verbal or physically aggressive behavior in 3 of 4 baths during

one month. In their study of 140 family CGs of CI elders, Farran and colleagues (1993) found that the following behaviors occurred among CI elders in home settings: restlessness, irritability, uncooperativeness, evidence of rapid emotional shifts, verbal and physical threats, physical abuse, and threats to harm self. These behaviors often occurred during personal care activities such as bathing. Resulting in greater CG burden in family CGs who were meeting greater ADL needs of the CI elder. Although behavioral symptoms were reported infrequently during bathing by family CGs in this study, their impact was clearly felt by family CGs when they did occur.

Concept 8: CG Satisfaction From Bathing and CG Confidence in Bathing Ability.

CG satisfaction and CG confidence in bathing abilities were positively correlated with one another and negatively correlated with hassles experienced and strain during bathing. According to the results of this study the more satisfied family CGs are with the assistance they provided bathing, the more confident they are in their bathing abilities. Also, it appears that the more satisfied and confident family CGs are with the assistance they give, the less CG hassles and strain they experience when assisting a CI elder during bathing.

The literature suggests family CGs appear to respond positively with satisfaction and confidence in bathing abilities when CRs display positive responses during bathing. For example, Kinney and Stephen's (1989) found that family CGs reported it was uplifting to see CI elders being calm, being responsive, showing affection, being cooperative, smiling/winking during caregiving activities. On the other hand, some family CGs may find managing behavioral problems and functional deficits as stressful

and view themselves as less confident to implement caregiving tasks, and less prepared for the caregiving role (Haley, Levine & Brown, 1987). Family CGs often feel confident when they begin in their caregiving role, but as CI elders respond with behavioral symptoms and become dependent and difficult to assist during ADLs, family CGs' sense of competence or preparedness decreases over time.

Concept 9: CG Hassles Experienced During Bathing. CG hassles during bathing were negatively correlated with CR self-care behaviors during bathing (prepare for bath, wash body parts) and contentment, and positively associated with CR discomfort and behavioral symptoms and the amount of CG assistance provided during bathing. CG hassles during bathing were significantly negatively correlated with CG satisfaction with the assistance they provided during bathing and confidence in their abilities, and positively correlated with the strain they experienced from assisting with bathing. Thus, the less the CR is able to participate in bathing the more assistance is required of the CG, resulting in a stressful experience especially when the CR responds with behavioral symptoms, discomfort and less contentment. Ryden (1988) argues that negative responses of CI elders during caregiving activities may result in negative responses by the family CG. Ryden found a positive association between aggressive behaviors of CI elders and family members feeling upset and acting aggressively towards the CI elder.

These experiences seem to accumulate into a sense of dissatisfaction with the assistance provided during bathing and confidence in their abilities and contribute to an overall perception of strain or burden associated with this caregiving activity. Kenney & Stephens' (1989) study of family CGs of CI elders found that bathing assistance was

strongly associated with hassles experienced as were behavioral symptoms. In these studies, family CGs reported that helping with bathing was difficult and found this activity to range from somewhat hard to very hard.

Concept 10: CG Strain from Bathing.

CG Strain from Bathing was negatively correlated with CR self-care behaviors during bathing (prepare for bath), CR wishes considered, CR contentment, CG satisfaction with bathing and confidence in bathing ability, and positively associated with cleansing function of the bath, CR discomfort and behavioral symptoms and CG hassles experience during bathing. The relationship between CG strain during bathing and other existing concepts previously discussed is supported by the findings of Archbold and Stewart's (1988) CG Relief Study and Archbold and colleagues' (1997) study. In both studies family CGs who assisted during bathing reported that helping with bathing was difficult, said it was tiring, and indicated it was upsetting. Additionally, family CGs who assisted their elder with bathing or washing found this activity to range from somewhat hard to very hard. Also, Harris' (1998) study of caregiving sons found over half reported bathing as the most difficult for them.

In summary, the findings of this study overall are similar to what has been reported in the literature in studies that address related phenomena. Since some of the concepts relate to bathing CI elders at home have not been previously examined by researchers, more research is needed in this area. The findings for the most part are consistent with inferences derived from the conceptual model and support from the researcher's clinical experiences.

Limitations of The Study

This study was an exploratory study using a small convenience sample, limiting generalizability of the findings. Another limitation was in the design of the Form and Frequency of Bathing Scale. The form and frequency items were combined in such a way that it was difficult to delineate the results of each concept discretely. This measure needs to be divided into two separated measures prior to further reliability and validity testing. The CR Reaction to Bathing Scale appeared to lack items related to resistive behaviors, that may be more prevalent behavioral symptoms than behavioral symptoms among CI elders living at home.

A larger sample size is needed to further assess the reliability and validity of the measures developed in this study. A subscale is needed to target resistive behaviors. The Form and Frequency of the Bath Scale needs to be divided into two separated scales prior to further reliability and validity testing. Another limitation of the study is that a correlational design appropriate for reliability and validity testing yields large numbers of correlation coefficients among multiple variables. This makes interpretation difficult even with apriori hypotheses since not all relationships can be predicted. Moreover, the tendency is to focus on the variables for which significant relationships were found in presenting the results. Lastly, although the meaning of the association between variables is often inferred, this design does not allow for distinction between predictor and outcome variables.

Implications for Research and Practice

Implications for Research

Since little is known about the experiences of family CGs who assist CI elders during bathing in the home setting, the development of reliable and valid instruments for assessing family CGs' experiences of bathing CI elders in the home is an important preliminary step for future studies. The Perceptions of Family Caregivers' Assisting a Cognitively Impaired Elder During Bathing Instrument consists of the measures developed in this study as described in Table 17. Initially, another survey study using the measures developed in this study, with a larger sample size than $n = 62$, is needed to further assess the reliability and validity of the measures. The scales should be retested using the data in this study and the new study using the larger sample size. As the measures are used in other studies, the data should be added to the data bank and the reliability and validity of the measures should be continually assessed. After the measures achieve good reliability and validity results, a large survey study should be conducted throughout the country to examine the bathing situation in the home setting with family CGs. One approach would be to collect data at the 29 Alzheimer's Disease Centers nationwide. However, the sample should include family CGs of CI elders who do not assist with bathing so that comparisons can be made. After the analysis of the data from this study, the researcher can determine the needs of family CGs assisting CI elders during bathing in the home setting.

Lastly, a quasi-experimental intervention study needs to be developed to assist in helping family CGs in making bathing go smoother. This study would include a control

group of family CGs who assist CI elders during bathing. The measures developed in this study and refined through further testing can be used for pre-and post testing purposes of the study. Ideally this study would include an interdisciplinary team of researchers, such as a geriatrician, gerontological nurses, occupational therapists, physical therapists, psychologists, social workers and a former family CG of a CI elder. Future studies are needed to develop measures for family CGs of CI elders in the home setting targeting the remaining ADLS (e.g., dressing, grooming, toileting, transferring and eating).

Implications for Practice

The measures are designed for family CGs of CI elders in the home setting, therefore, the measures can be used in outpatient healthcare settings and rehabilitation hospital settings. In outpatient clinics, the measures can be used to assess the history of CI elders and their family CGs related to bathing. For example, when the client or family member states they are having problems with bathing, clinicians could begin to explore the problem in depth and develop more appropriate interventions by using the measures developed in this study. Also, some of the scales can be used in acute care hospitals and nursing home settings to obtain objective data that can assist clinicians in developing care plans including interventions to enhance the functional status of CI elders and address behavioral symptoms during bathing. For example, the Bathing Tasks Scale may be useful in obtaining a bathing functional score; the subscales enable clinicians to determine the specific strengths and weaknesses of the CI elder during bathing (e.g., able to wash arms but not legs and feet). Furthermore, these measures can be used to measure the outcomes of interventions. Although it is not always appropriate to adapt research

tools for practice, these new bathing scales were developed to address daily care issues that are germane to CGs in institutional and home settings.

Table 17

Family Caregivers Perception of Assisting Cognitively Impaired Elders During Bathing Instrument.

Concept Name	Scale Item	Page. Item #
	Family Caregiver Characteristics	
Background Characteristics	Age	16.1
	Gender	16.2
	Race	16.3
	Marital Status	16.4
	People Living in the House	16.7
	Children Living in the House	16.8
Socioeconomic Status	Religion	17.13 & 14
	Education	16.4
	Type of Work	16.5
	Income Adequacy	16.9
	Own/Rent Home	16.10
	Occupation	16.11
Health Status	Income	17.12
	Pain	18.6
	Perceived Health	18.17
	Physical Activity	18.18-27
	Physical functioning	
	Depressive Symptoms	20.1-20
Relationship to Care Recipient	Relation to Care Recipient	1.1
	Years Known Each Other	1.2
	Years Living Together	1.4
	Mutuality	1.5
		14.1-15
Caregiving to Care Recipient	Duration of Caregiving In General	1.3, 19.1
	Duration of Bathing Assistance	19.3
	Influence of Spirituality	17.15
	Global Role Strain	21.1-4

Table 17 (cont)

Family Caregivers Perception of Assisting Cognitively Impaired Elders During Bathing Instrument

Concept Name	Scale Item	Page, Item #
CR Characteristics		
Background Characteristics	Age	15.1
	Gender	15.2
	Race	15.3
	Marital Status	15.6
	Living Arrangements	15.7
	Number Living in Household	15.8
	Bath Preference	2.9
Socioeconomic Status	Education	15.4
	Occupation	15.5
Functional Status	Bathing Assistance Needed	1.6
	Memory Problems	3.6-13
Bathing Situation		
Bathing Assistance Received	Frequency of Assistance	1.5
	Duration	19.2
	Scheduled Bath match Bath Time Preferred by Care Recipient	2.8, 9
	Help From Others With Bathing	
Care Recipient Self-Care During Bathing	Caregiver Behaviors During Bathing	19.4-6
	Prepare for Bath	4.4, 6-8
	Wash Body Parts	4.9-19
	Dry Body Parts	5.22-32
Bath Features	Wash/Dry Hair	4.20, 5.33
	Function	
	Cleansing	2.10-13
	Comfort	2.16-18
	Form	3.1-5
	Frequency	3.1-5

Table 17 (cont)

Family Caregivers Perception of Assisting Cognitively Impaired Elders During Bathing Instrument

Concept Name	Scale Item	Page, Item #
Role Strain in Bathing	Caregiver Response to Assisting With Bath	
	How Hard Confidence in Bathing Negative Aspects of Bathing Appraisal of Behavior Hassles Confidence in Providing Future Care	1.7 6.4, 5, 7-9; 7.13, 19, 20 7.14, 21, 22 6.1-3, 6, 11; 7.12, 15-17, 23, 24 8.1-8 21.5
	Care Receiver's Response Perceived by Caregiver During Bathing	
Occurrence of Behavior Hassles	Criticizing or complaining Yelling or swearing Not cooperating Frowning or scowling Verbally inconsiderate; not respecting your feelings Leaving tasks related to bathing uncompleted Hitting or pinching	8.1-8
Appreciative or Affectionate Behaviors	Hugs Jokes Kisses Pats you on the back Prices and compliments you. Thanks you Smiles	12.2,3,14,20,13,29,47
Contentment During Bathing	Has a pleasant peaceful expression Looks tranquil, at ease or serene Has relaxed body language Has frightened facial expression Makes "flushed low sounds" like constant muttering	12.1,17,18,13,40
Discomfort	Has frowning facial expression Fidgeting body language Make sounds like a moan or groan	12.19,13,38,39,41,42, 48,50

Table 17 (cont)

Family Caregivers Perception of Assisting Cognitively Impaired Elders During Bathing Instrument

Concept Name	Scale Item	Page, Item #
Vocal or Verbal Agitation	<p>Makes threats or attempts to physically harm self</p> <p>Makes repetitious noises</p> <p>Uses hostile accusatory language</p> <p>Talks constantly</p> <p>Repeat words</p> <p>Gives orders</p> <p>Makes threats implying physical harm to you</p> <p>Screams or yells</p>	12, 9, 21, 23, 25; 13, 26, 27, 35, 36, 37
Physical Non-Aggressive Behavior	<p>Bangs objects</p> <p>Making insulting but not obscene gestures</p> <p>Has excessive motor activity</p>	12, 16, 22, 24
Physical Aggressive Behavior	<p>Hits you with an object</p> <p>Scratches you</p> <p>Elbows you</p> <p>Hits you with hand</p> <p>Kicks</p> <p>Physically takes objects from you</p> <p>Pinches/Squeezes</p> <p>Pushes or shoves</p> <p>Bites</p> <p>Spits on you</p>	12, 4, 5, 7, 10, 11, 13; 13, 30, 32, 44, 45

Conceptual Implications of the Findings

The results of this study do not confirm all relationships among the concepts as predicted, hence, further testing is needed to assess the relationships among the scales and concepts or variables within them. As a result of this study new variables were developed. The conceptual framework and model were revised to account for the newly developed variables (see Figure 2 for revised conceptual model). The following variables were added to the conceptual model: 1) the subscales of the Bathing Tasks Scale are included in the model, 2) cleansing function and comfort function of the bath were listed as reasons for bathing, 3) CR bath time preference, 4) considering the CR wishes, 5) frequency, amount, and duration of CG help with bathing, 6) CR contentment, 7) CR appreciative and affectionate behaviors, 8) CR verbal or vocal agitated behaviors, 9) CG Confidence in bathing ability, and 10) CG Strain during bathing. The initial conceptual framework was revised to include the newly developed concepts. The revised conceptual framework is described below.

Algase, Beck, Kolanoskwi, Whall, Bernent, Richard and Beattie's (1996) and Kolanowski's, (1999) conceptual framework of need-driven dementia-compromised behavior and Kahana and Kinney's (1995) general stress model are integrated to form the conceptual framework for this study. Algase and colleague's (1996) conceptual framework of need-driven dementia-compromised behavior is particularly useful in understanding behavioral symptoms of CI elders during bathing. Behavioral symptoms displayed by CI elders may be meaningful and may be an expression on an unmet need. Communications involve one's awareness of a need. Due to dementia the CI elder may

be unable to communicate verbally his or her needs to others, hence; vocalizations is the mechanism that many CI elders use to make their needs known to others. If the CI elder's needs are not met over time, the CI elder begins to display vocal or verbal agitated behaviors. CGs who "over do" contribute to excess disability. When the CI elder's self-care behaviors are less than the CI elder's functional abilities, the CI elder's ability to meet their personal needs or goals are limited. The more functional CI elders are, the more able they are to meet their needs. As the CI elder becomes more dependent and their wishes are less often considered in providing bathing assistance, more behavioral symptoms may occur, such as physical non aggressive and aggressive behaviors. It is critical to not only support the functional abilities of CI elders during bathing, but also to individualize bathing care focused on the CI elder's wishes. This shift away from a task approach to a person centered approach is at the heart of the model.

Family CGs may become distressed when assisting CI elders with bathing and begin to view this task as a "hassle" when personal care leads to conflict. Lazarus and Folkman (1984) conceptualize stress as hassles that are defined as minor irritations of daily living. Kahana and Kinney's (1995) model extends the dynamic elements of a general stress model to the specific dimensions of distress most salient to caregiving. The model identifies three major sources of stress: 1) the CI elder's illness (e.g., degree of functional impairment, cognitive impairment, and behavioral problems), 2) objective demands on the CG (amount duration and frequency of caregiving, and mental and physical resources); and 3) dyadic interactions between the family CG and CI elder that become conflictual. Family CGs may become distressed when assisting CI elders with

bathing and begin to view this task as a “hassle” when personal care leads to negative outcomes (e.g., behavioral symptoms, CR discomfort and a lack of appreciative and affectionate CR behaviors).

The factors that influence family CGs’ perceptions of assisting a cognitive impaired elder during bathing are: 1) the bathing situation; 2) caregiving in general; 3) the CR characteristics; 4) the CG’s characteristics; 5) The CRs’ response; and 6) the CG’s response. These factors influence their perception of the outcomes of assisting the CI elders during bathing.

The bathing situation occurs when the CG assists the CI elder with bathing. The bathing situation includes: CR self-care during bathing, features of the bath, considering the CR’s wishes; CR bath time matches CR preference and the amount, frequency and duration of bathing assistance provided by the CG; and help from others with bathing. The characteristics and behaviors that CI elders and family CG bring to the bathing situation affect the bathing regimen and congruence between the capabilities of CI elders with the demands of bathing. The more the elder wants to and demonstrates self-care behaviors the less assistance is required of the family CG, which lessens the demands of caregiving during bathing. Self-care behaviors are defined as the ability to prepare the bath, wash and dry oneself or body parts using at least one object (e.g., soap, wash cloth, towel) and switching independently from one activity to another (e.g., soaping the wash cloth then washing an arm). In other words, self-care behaviors occur when the CR prepares the bath, wash his or her hair, or wash and dry body parts independently. These

behaviors are reflected in the degree of independence/ dependence the CI elder demonstrates in bathing.

The bath features include the three Fs: function, form, and frequency (Rader, 1994; Sloane et, al. 1995; Rader et, al. 1996). The function of the bath is defined as maintaining skin integrity, preventing infection, promoting social acceptability (cleansing reasons), and giving pleasure (comfort reasons). The form of the bath is defined as the type of bath or the physical bath environment where the bath occurs (e.g., tub, shower, bedbath). The frequency of the bath is defined as how often the CR is bathed. These features of the bath may have an impact on the positive or negative responses from both the family CG and CI elder. The more frequent the CI elder is bathed and the more frequent bathing assistance is needed from the CG, bathing assistance and the duration of assistance (amount of time spent assisting CI elder) increases.

Decisions related to the bathing situation should be made with the input of the CI elder. For example CGs should consider the CR wishes which includes bath time preference and attending to their responses and needs during bathing. Considering the elder's wishes is defined as individualizing the bath according to what the CI elder requests and demonstrates through their verbal and nonverbal communication. For instance, family CGs interact positively with the CR by being patience, relaxed, and using appropriate verbal/non-verbal communication skills during bathing activities. Considering the elder's wishes may lessen the demands of bathing and negative responses from CI elders during bathing. Part of considering the CR wishes is that family CGs assist CRs during bathing at the bath time most preferred by the CR. Bath time

matches CR preference is defined as assisting during bathing when the CI elder prefers.

CI elders may not always want to bathe according to family CGs scheduled routine.

Oftentimes CI elders are not bathed according to their premorbid bathing habits. If they remember these habits at bath time, they may resist being bathed. This problem may occur because the CGs are maintaining a routine schedule of caregiving activities. The family CGs' attitudes about bathing, communication skills and behaviors often influence the amount of environmental stimuli the CI elder receives during bathing. Bathing

Assistance Provided by the CG is defined as the frequency, amount, and duration of CG bathing assistance to CRs during bathing. CR self-care behaviors may impact the amount of assistance CGs are providing CI elders during bathing. For instance the more dependent CRs are, the more assistance must be provided by CGs. As the memory and functional status of CI elders deteriorate, family CGs may have to assist with bathing more often (e.g., due to incontinence). Behavioral symptoms and bathing for comfort reasons may increase the duration of the bath. However, it is unclear whether promoting self-care behaviors makes bathing go faster.

Caregiving in general is defined as the duration of caregiving which includes the length of time assisting the CR during bathing. How CGs perceive caregiving in general has an impact on the outcomes of the bathing situation. Help the CG receives from others is defined as assistance from family, friends, or formal CGs with bathing. Help from others can make bathing go smoothly and lessen the amount of overall caregiving activities, but strangers present during bathing may negatively affect CI elders. Also included are basic stressors and how the CG handles those stressors. For example, global

role strain is a common stressor associated with caregiving. Global role strain is associated with the caregiving role and other roles that may cause conflict for CGs in implementing the CG role. Also, spirituality is a common way CGs adapt to the stressors related to caregiving. The CG's confidence to meet future needs is determined by how well they adapt to the CG role in general. Caregiving in general is influenced by both characteristics of the CG and care receiver. The duration of providing care and bathing assistance, global role strain, and how CGs cope may have an impact on CGs' confidence about remaining in the caregiving role.

CR Characteristics include age, gender, a diminished cognitive status (resulting in memory, motor, sensory, and/ or perceptual deficits), CI elders' existing self-care and coping behaviors during bathing, levels of competence in these functional areas, and stress tolerance level. The characteristics and behaviors that CI elders bring to the bathing situation affect the bathing regimen, and congruence with the demands of bathing.

Also, these characteristics influence how CI elders will interact and respond to family CGs during the bathing situation and have an impact on how the CG perceives the care receiver's responses.

CG characteristics are factors that influence caregiving and the family CGs' perceptions of the outcomes of assisting a CI elder during bathing. CG characteristics are defined as the combination of background characteristics (e.g. age gender, race etc.); socioeconomic status (education, employment, income etc.); health status (e.g. perceived health, pain depressive symptoms etc.); and relationship to the CR (e.g., mutuality and years known each other). Mutuality is defined as a great deal of love, shared pleasurable

activities, common values, and reciprocity (Archbold et, al. 1990). CG characteristics may have an impact on how the CG perceives caregiving in general, and the bathing situation, CG response. Also, CG characteristics play an important role in how the CG responds to assisting the CR during bathing. CG characteristics and CG health, pain, depressive symptoms or global strain may have an impact on how caregiving activities are implemented during the bathing situation,

CR Repones During Bathing are the coping behaviors of CI elders during bathing. The positive CR responses during bathing are contentment and appreciative/affectionate behaviors. Contentment is defined as verbal or non-verbal gestures that displayed CI elders' comfort and satisfaction during bathing. Appreciative and affectionate behaviors are defined as verbal or non-verbal expressions of love and gratitude during bathing. CRs also displayed negative responses to the bathing situation, such as discomfort and behavioral symptoms. Discomfort occurs when the CRs experience physical or mental pain during bathing. Discomfort is defined as a negative emotional (i.e., affective) and/or physical state of the CI elder in response to environmental demands. Behavioral symptoms include vocal/verbal agitated, non-aggressive, and physical aggressive behaviors of the CI elder that reflect discomfort or efforts to cope with stressors during bathing. These responses may interfere with the caregiving situation or have negative consequences for the CG or CR. These behaviors can be offensive, hostile, injurious, or destructive and range from verbal agitation to striking CGs. Physical Aggressive behaviors are defined as physically assaulting the CG by pinching, scratching, elbowing, biting, kicking, pushing, and spitting on someone.

Physical non-aggressive behaviors are defined as making obscene gestures, banging objects nondestructively, does not follow directions, places inappropriate substances in mouth, spits, paces, refuses to bathe and excessive motor activity. Verbal or Vocal agitated behaviors are defined as talks constantly, repeats words or phrases, makes repetitious noises, uses obscene or profane language, and screams. Also, the CR may experience discomfort during bathing. The responses of CRs during bathing may determine how the family CGs respond to the bathing situation. These responses can also be negative or positive depending on the CG's perception of negative or positive responses from the CR.

CGs' responses to assisting during bathing include CG satisfaction with the assistance they provide during bathing, confidence in bathing abilities, hassles experienced during bathing and strain from bathing. How the CGs respond to CR responses and influence how they interact with the CI elder during bathing. CG satisfaction from bathing is defined as the family feelings of contentment and pleasure associated with assisting the CR during bathing. Confidence in assisting during bathing is defined as the CG's ability to meet the CI elder's needs during bathing and manage problems that may occur during bathing. Negative CG responses are CG hassles and strain from bathing. CG hassles are minor irritations perceived by CGs when assisting CI elders with bathing. Furthermore, assisting CI elders during bathing may cause CGs to experience strain. Strain from bathing is defined, as family CGs perceiving assisting during bathing as complicated and difficult.

CGs' perceptions are often influenced by the CI elder's behavioral symptoms, an expression of unmet needs during bathing, which may cause conflict or discord between the dyad during bathing. These responses may affect whether or not the CG creates a bathing regime that promotes congruence between the capabilities of CI elders and the demands of bathing. When congruence is obtained, the CG feels satisfied with assisting the CI elder during bathing. Also, the CG may feel more confident to assist with bathing, which may result in positive responses from the CR and positive outcomes of the bathing situation. On the other hand, CGs may perceive assisting with bathing as a hassle because of CI elders' behavioral symptoms behaviors, cognitive and self-care deficits, and increased caregiving demands. The CGs responses are influenced by the outcomes of the bathing situation and the CI elder's response to the bathing situation. Both CG and CR responses are influenced by their characteristics and the bathing situation. CGs' responses are dependent on the bathing situation and the CR's responses during bathing. Also, the CG characteristics influence their perceptions and responses to the bathing situation.

During the bathing situation, both the CR and CG who is assisting during bathing interact to complete the task of bathing. How both parties respond during the bathing situation determines whether the outcome of the bathing situation is a positive or negative experience. Furthermore, when the bath goes well, the CI elders express less discomfort, and demonstrate a decrease in behavioral symptoms and an increase in self-care behaviors through participation in the bath. The CG's perception of bathing being a hassle will decrease, and the sense of satisfaction with bathing and confidence in bathing abilities when assisting a CI elder during bathing will increase. It is within this situation

that CGs adequately meet the needs of the CRs during bathing; the CI elder is more responsive to the CG, may participate more with the tasks of bathing, experience less discomfort, and demonstrates a decrease incidence of behavioral symptoms during bathing. Consequently, the bathing routine is less demanding for the CG and CI elder and more positive for both.

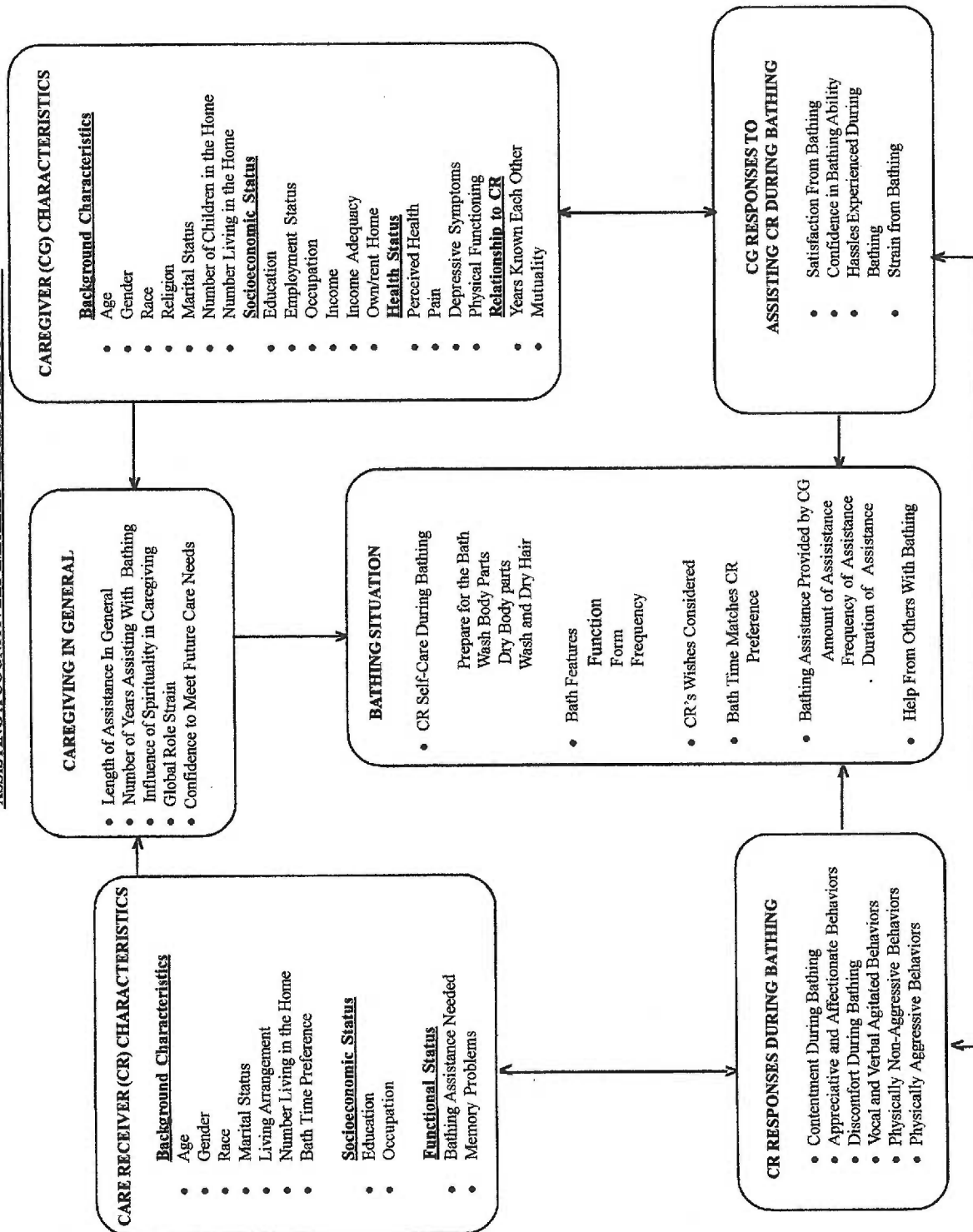
In summary, the bathing situation is influenced by the characteristics of the CG and care receiver, and caregiving in general. How well the bath goes is determined by the care receiver's and care giver's response and how the CG interprets the care receiver's response. The characteristics and behaviors that CI elders and family CG bring to the bathing situation affect how both will respond to the bathing situation. During the bathing situation both the CR and CG, who is assisting during bathing, interact to complete the task of bathing. How both parties respond during the bathing situation determines whether the outcome of the bathing situation is a positive or negative experience.

Family CG's resources include mental resources or coping strategies and physical resources that include the physical health of the family CG. Caregiving activities may cause global strain when stress exceeds the family CG's resources. Consequently, the family CG may feel burdened, resulting in a deterioration in the family CG's mental health (distress, depression) and physical health, decreased satisfaction, and lack of confidence in their ability to assist the CI elder with bathing

The CI elder's capabilities and/or the CG's abilities, resources, and assistance need to be congruent with the demands of bathing; such congruence results in the bathing routine becoming less demanding for the CGs and CI elders and a more positive

experience for both. In a congruent situation, the CI elders express less discomfort, and demonstrate a decrease in disruptive behaviors and an increase in self-care behaviors through participation in the bath. The CG's perception of bathing being a hassle will decrease, and the sense of preparedness and satisfaction when assisting their demented family member with bathing will increase. If congruence is not obtained, the opposite relationship between these factors will be found.

Figure 2:
REVISED CONCEPTUAL MODEL: FACTORS INFLUENCING FAMILY CAREGIVERS' PERCEPTIONS OF ASSISTING A COGNITIVELY IMPAIRED ELDER DURING BATHING



Summary of Study

Caring for a cognitively impaired (CI) family elder can be a difficult challenge for caregivers in general. The symptoms of cognitive impairment include cognitive decline, ADLs impairments, and behavioral symptoms which often occur while the family caregiver is assisting the CI elder during bathing. Little is known about the experiences of family caregivers who assist a CI family member during bathing in the home setting. Developing valid and reliable questionnaires is an important preliminary step before the tool is used to survey family caregivers who assist CI elders during bathing. The purposes of this study were to develop and evaluate new instruments that measure concepts relevant for family CGs who are assisting CI elders with bathing in the home.

The study was conducted in two phases in Oregon and Arkansas. First, questions were developed and evaluated by experts ($n = 11$) in the field and family CGs ($n = 8$) who assist CI elders during bathing. The sample in Phase 2 of the study consisted of family ($n = 62$) in the home setting. This measurement development study employed a nonexperimental, correlational design and survey methods. Data were analyzed using item analysis, exploratory factor analysis, Cronbach's Alpha, and Pearson's correlations. Ten bathing scales were developed, and the conceptual model for the study was refined including concept labels and definitions. Cronbach's Alpha values exceeding .70 were estimated in 65% of the scales. The findings of this study overall are consistent with what has been reported in the literature in studies that address related phenomena. The Perceptions of Family Caregivers' Assisting a Cognitively Impaired Elder During

Bathing Instrument, consists of the measures developed in this study for which there is evidence supportive of reliability and construct validity.

A factor limiting generalization of the results was the relatively small convenience sample. A strength of the study, however, is the inclusion of minority family caregivers. In practice, these measures can be used in a variety of health care settings that provide services to community dwelling CI elders. This will provide clinicians from various disciplines a tool to use to explore bathing problems in depth experienced by family CI and their family CGs and to develop more appropriate interventions to assist them.

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APPENDIX A
REVIEW OF LITERATURE TABLES

Author	Sample	Description	Results	Comments
Archbold and colleagues (1990).	78 caregivers and care receivers. Care receivers ranged in age from 65-93 (M=63). 70% of them were female and 42% were married. Caregivers' ages ranged from 21-82. 97% of them were female and 81% married. Caregivers included in the study were wives (19%), husbands (26%), daughters (21%), sons (6%), daughters-in-law (13%) other relatives (10%) and friends (5%).	<p>Purpose: to explain how mutuality and preparedness for care giving explain the variance in aspects of role strain.</p> <p>The design was explanatory qualitative. Two interviewers, in separate rooms in the care receivers' homes, conducted interviews of the care receiver and caregiver simultaneously.</p> <p>Descriptive and psychometric statistics were used for measures of predictor and outcome variables. Hierarchical multiple regression analysis was used to test the hypothesis.</p>	<p>Mutuality and preparedness were significant in predicting 37% of the explained variance in role strain r/t direct care. Mutuality and preparedness r/t increased tension predicted 49% of the explained variance in role strain.</p> <p>These findings suggest that mutuality and preparedness for care giving have an impact on providing direct care and the tensions r/t care giving.</p>	Generalizability is limited due to small sample size. Only 25% of the total sample were caregivers of CI elders. CI elder's deterioration results in decreased mutuality and preparedness. Also, disruptive behaviors that may be encountered during bathing may affect the caregiver's sense of preparedness with care giving.

Aronson, M.K., Post, D.C., Gustasiesegni, P. (1993). Dementia, agitation, and care in the nursing home. *Journal of American Geriatric Society* 41 (5) 507-512.

Author	Sample	Description	Results	Comments
Aronson, Post & Gustasiesegni (1993)	338 residents of 6 nursing homes aged 70-103 (mean 85.3) and 236 nursing assistants on day and evening shifts aged 23-68 (mean 44.4) with experience ranging from 1-32 years.	<p>Purpose: To examine the care required by CI elders residing in nursing homes in relation to behavioral and functional problems associated with agitation</p> <p>Design: An exploratory study using chart review, RUG classification, patient cognitive and functional abilities assessments, caregiver interviews and observations of CI elders and caregivers. The research team observed the interactions of caregivers and every fourth resident for 1 hour between 7 am. and 7 p.m., excluding meals. The interactions were coded into five categories: physical care (e.g., dressing, toileting); record keeping (e.g., recording intake and output); environmental tasks (e.g., bedmaking); behavioral interventions (e.g., directing and encouraging the patient); and related tasks (e.g., transport).</p> <p>Several methods were used for data analysis.</p>	<p>The higher the level of cognitive impairment the greater the incidence of agitation on both the day and evening shifts. Highest incidence of agitation was seen during transfers. The second highest ADL with behavioral problems was bathing. Cognitive impairment had a significant main effect on agitation scores as rated by both the day [F (3,334) = 19.10, $p < 0.001$] and evening shifts [F (3,334) = 23.33, $p < 0.001$]. Post hoc analyses indicated that subjects with moderate and severe cognitive impairment had significantly higher agitation scores than normal or mildly impaired subjects. The most frequently reported behaviors on both day and evening shifts occurred in residents with more cognitive impairment. These behaviors were inability to sit or stand still, pacing, and resistance to bathing, grooming and dressing. Moderately and severely impaired subjects required more staff supervision, monitoring, and interventions on both shifts. Moderately and severely CI elders had more behavioral symptoms during transfers [F (3,334) = 52.84, $P < 0.001$] on the day shift and [F (3,334) = 57.47, $P < 0.001$] on the evening shift than in any other ADL. Bathing was the second most common ADL in which moderately and severely CI elders displayed behavioral symptoms. The problem behaviors associated with bathing increased as cognitive impairment increased, during both the day shift [F (3,334) = 14.15, $p < 0.001$] and evening shift [F (3,334) = 124.06, $p < 0.001$]. Subjects diagnosed with dementia were significantly more dependent in their ADLs than non-demented subjects on both shifts. For subjects diagnosed with dementia, cognitive impairment accounted for almost half (49%) of the variance in ADL performance on the day shift and approximately the same variance (47%) on the evening shift. Cognitive impairment had a significant main effect on physical care and behavioral interventions. For instance, the Scheffe test indicated that physical care was greater and more behavioral interventions were needed for severely impaired CI elders.</p>	<p>A limitation of the study is that the baths were given at the usual scheduled times. The results of the study may have been different had an assessment of the CI elders' preferred bath time been obtained; some CI elders may have shown fewer disruptive behaviors and more self-care behaviors had the baths been given in the morning instead of during the evening (or vice versa). More information could have been obtained to substantiate that the schedule of the bath may have an impact on disruptive behaviors and the ability of the CI elder to exhibit self-care behaviors during bathing. It is of interest to note that Findings of relationship between cognitive impairment and disruptive behaviors were opposite those findings of Bridges-Parlett, et al (1994). Moderately and severely CI elders nursing home residents displayed more behavioral symptoms and were more dependent in self-care behaviors during bathing; therefore, they required more staff supervision and monitoring.</p>

Beck, C., Heacock, P., Mercer, S., & Walton, C. (1992). Decreasing caregiver assistance with older adults with dementia. *Key Aspects of Elder Care Managing Falls, Incontinence and Cognitive Impairment*. Funk, S.G., Tornquist, E.M., Champagne, M.T., Wiese, R.A. Ed. pp 309-319.

Author	Sample	Description	Results	Comments
Beck, Heacock, Mercer & Walton (1992).	Convenience sample of 15 subjects with dementia in a nursing home. Mean age 71.56 and mean MMSE score was 10.06. Caregivers included four nursing assistants, 6 LPNs and 2 RNs.	<p>Purpose - to examine amount of dressing assistance CI elders required before and after receiving interactional behavioral strategies. Videotaping during dressing was used to obtain baseline data and analyzed to determine level of assistance provided.</p> <p>Subjects took Neurobehavioral Cognitive Status Exam, Cognitive Skills for Dressing Assessment and MMSE.</p> <p>Eight 1-hour sessions of "Strategies for Promoting Independence in Dressing" was taught to caregivers. Treatments were implemented for 6 weeks and were individualized. During intervention period dressing was videotaped twice a week and reviewed by researchers to ensure protocol adherence. Feedback and encouragement was provided to caregivers. There were 2 follow-up observations during the week following intervention.</p>	<p>Paired t-test used to assess change in mean scores of dressing performance. Wilcoxon sign rank test also used to confirm significance of decreased dependence. Level of caregiver assistance decreased significantly from 6.26 to 4.93 after intervention. This decreased significantly again during follow-up to 4.71.</p>	<p>Suggests CI does not interfere with regaining dressing independence. Behavioral strategies and environmental adaptations aid in increased independence. Strategies included repeated verbal prompts, modeling, physical prompts and physical guidance. Results suggest similar gains can be made in other ADLs, such as bathing.</p>

Bridges-Partlet, S., Knopman, D., Thompson, T. (1994). The study was a descriptive study of physically aggressive behavior in dementia by direct observation. *Journal of the American Geriatrics Society* 42 (2) 192-197.

Author	Sample	Description	Results	Comments
Bridges-Partlet, Knopman, and Thompson (1994).	20 CI elders residing in nursing homes to describe the occurrence of these behaviors in CI elders. The average age of the sample was 77 years old (range 65-77).	<p>Purpose: to describe the occurrence of these behaviors in CI elders.</p> <p>Design: Non-experimental observational study. The researchers observed residents directly and recorded their behaviors using an event recorder. Timewand, which coded aggressive behaviors (e.g., screaming, yelling, swearing, hitting, biting, and kicking, physical threatening) were coded and the observed behaviors were scanned on the desired code. The codes included the room the individual was in, ongoing activity, other individuals present (e.g., staff and residents), type of interaction (e.g., verbal or physical) and behaviors occurring during each minute of the observation period. The Ryden Aggression by nursing assistants who retrospectively completed a checklist of verbal and physical aggressive behaviors observed on each shift.</p>	<p>The physical aggressive behaviors identified were hitting, kicking, and threatening gestures. These behaviors ranged from a single occurrence to multiple behaviors occurring continuously. Twenty-five percent of physical aggressive behaviors were single occurrences lasting 1 minute or less. In 12 (43%) cases, the duration of aggressive behaviors were 1-5 minutes, and in nine cases (32%) they lasted 5-20 minutes. Multiple physical aggressive behaviors were recorded in the same 1-minute time period. Eighty-two percent of the behaviors were directed towards the nursing staff and 54% occurred during personal care activities (e.g., toileting, bathing, grooming, and dressing). Seven of 28 episodes of physical aggressive behaviors were preceded by verbal aggression.</p>	<p>Although the number of physical aggressive behaviors was low ($n = 28$ episodes), the study suggests that CI elders display behavioral symptoms during assistance with personal care, such as bathing. These behaviors are directed at the caregivers. Many of the behaviors observed were precipitated by caregivers using approaches that resulted in defensive responses (e.g., hitting, kicking etc.) by the CI elder to a perceived threat</p>

Brody, E.M., Kleban, M.H., Lawton, M.P., & Moss, M. (1974). A longitudinal look at excess disabilities in the mentally impaired aged. The Journal of Gerontology, 29, 1, 79-84.

Author	Sample	Description	Results	Comments
Brody, Kleban, Lawton & Moss (1974).	47 subjects who participated in 1972 research by same authors. 21 were in the previous treatment group and 26 were in the control group.	Longitudinal study to determine long-term effects of treatment to reduce excess disability 9 months post termination of experimental conditions. Outside raters reviewed documentation and did not observe subjects' behaviors directly. Nursing staff rated physical interaction with subjects.	Paired t-tests were used for comparison of two groups. Residual variances both immediately after treatment and 9 months after were significantly positively correlated on overall ratings. According to staff there were no strong significant differences in excess disabilities between the two groups during 9 months post treatment period. Outside raters revealed decline in self-care behaviors but no significant difference in excess disabilities or overall change in both groups.	Treatment was not maintained so self-care behaviors were not maintained. Indicates that focus should be on continuous treatment vs. cure (i.e. include continued consultation in a study to increase self-care and decrease disruptive behaviors). Also indicates that use of outside raters for direct observation of subjects may provide more accurate data than staff.

Brody, E.M., Kleban, M.H., Lawton, M.P., & Silverman, H.A. (1972). Excess disabilities of mentally impaired aged: Impact of individualized treatment. The Gerontologist, 11, (No. 2 Pt. 1) 124-132.

Author	Sample	Description	Results	Comments
Brody, Kleban, Lawton & Silverman (1972)	32 pairs of women placed into experimental and control groups. Ages ranged from 77-99 (M=82.2) in experimental group. Ages ranged from 66-94 (M=81.1) in control group.	Two group pre-test/post-test quasi-experimental designed exploratory study. Conducted in a nursing home to determine methods of treatments to prevent excess disability. Subjects phased into the project at rate of one pair per week over one year. Baseline data was obtained, an interdisciplinary team conference was held and an individualized treatment plan was developed for every subject in the treatment group. Those in experimental group received intense treatment over 1 year period and the health care team met every 6 months. Control group received usual services provided by nursing home.	Significant improvement in excess disability in both experimental group (33%) and control group (17%). Difference in improvement in both groups was non-significant.	Setting of busy nursing home may have affected outcome because it was difficult for staff to implement care plan consistently in the experimental group. Data on self-care behaviors not observed directly was dependent on memory of already overworked nursing staff. Even though no significant improvement was seen in self-care behaviors, there were improvements in excess disabilities in social and recreational activities.

Burgener, S.C., Shimer, R. (1993) Variables related to caregiver behaviors with cognitively impaired elders in institutional settings. *Research in Nursing and Health* 16, 193-202.

Author	Sample	Description	Results	Comments
Burgener, & Shimer (1993).	58 CI elders ranging in age from 69-97 (M=85). Average MMSE score was 6.9 - severe dementia. They were severely functionally impaired and exhibited behavioral problems.	<p>Purpose: To identify variables that influence behaviors of institutional caregivers when they interact with CI elders. Three research questions were asked, two addressing caregiver characteristics and behaviors and the other characteristics of CI elders and caregiver behaviors.</p> <p>Non-experimental one-group two-test design using observation methods. Same caregiver and CI elder were observed in 3 different care giving situations. Conducted in nursing home with 38 CNAs, 14 LPNs and 6 RNs as caregivers.</p> <p>Disruptive behaviors, calm & relaxed behaviors, self-care and cognitive status of elders were measured. Caregiver behaviors and their knowledge of dementia also measured. Observation occurred over 5 months with 2 observers rating same procedure simultaneously. Descriptive statistics were used. Correlational analysis was used to assess relationships of caregiver characteristics and behaviors as well as relationships of CI elder characteristics to care giving behaviors. MANOVA used to assess level of education and caregiver behaviors.</p>	<p>Caregiver knowledge of dementia was moderately r/t caregiver's 1) being more social and flexible during dressing and bathing and 2) providing praise during bathing. Number of smiles during bathing was moderately r/t caregiver experience with CI elders. More educated caregivers tended more to comfort of CI during dressing and gave less feedback during bathing. RNs rated highest in socially oriented and flexible behaviors during bathing. LPNs offered more praise. There was a negative association between elders with increased self-care behaviors and social touching behaviors. The more educated the elder, the more personal attending during bathing. Disruptive behaviors of CI were non-significant.</p>	<p>RNs and LPNs provided more positive care giving behaviors toward elders. Family caregivers may not have nursing background and experience but they may have some knowledge of the disease process. Non-significant findings associated with caregiver behaviors and disruptive behaviors of CI during bathing were surprising. Frequency and type of disruptive behaviors during bathing were not reported so it is hard to determine if few subjects exhibited disruptive behaviors or if the staff had become immune to the behaviors over time.</p>

Author	Sample	Description	Results	Comments
Colenda & Hamer (1991)	410 patients in bed long-term care geropsychiatric state hospital to describe aggressive behaviors and staff interventions. Hospitalized patients were diagnosed with dementia (42.1%) and other mental health illnesses, such as schizophrenia (22.2%), major affective disorder (11.8%), organic psychosis (10.8%), and alcohol related disorders (4.4%).	<p>Purpose: to obtain descriptive data on the prevalence of aggression by diagnosis, and on the types of aggression and the antecedents of aggression.</p> <p>Design: Exploratory Non-experimental study.</p> <p>Two surveys were administered to staff before and after training. The survey instrument listed five kinds of aggressive events: 1) patient to patient exchange (hitting, pushing or biting); 2) patient-staff exchange (hitting, pushing or biting); 3) yelling or threatening behavior (cursing, verbal threats); 4) physical and vocal behavior (both physical and vocal aggression towards staff or patients); and 5) property damage. It also contained four types of triggering events: not observed, patient-patient exchange, patient-staff, and group activity.</p>	48 patients committed 199 aggressive events. Dementia patients had a higher rate of aggression (.90) than non-dementia patients (.50). After training 40 patients exhibited 119 aggressive events, and again dementia patients showed a higher rate of aggression (.85) than non-dementia patients (.51). In both surveys, most aggressive events occurred during the day shift (52.9% on the first survey and 80.7% on the second survey). Patients diagnosed with dementia accounted for 66.8% and 65.7% respectively, of the three forms of physical violence. The most common antecedents to aggression reported by staff were "unknown". The second most frequently reported triggering event (especially with dementia patients) was patient-staff exchange. Usually physical aggression occurred between staff and patients.	This study suggests that, behavioral symptoms occur during the morning shift when most of the ADL activities occur during that time. Also CI elders were the most disruptive. Although the staff did not know why the behavioral symptoms occurred but they were most often displayed during staff and CI exchange Staff.

Cox, C., Monk, A. (1996). Strain among caregivers: Comparing the experiences of African American and Hispanic caregivers of Alzheimer's relatives. *International Journal of Aging and Human Development* 43, (2) 93-105.

Author	Sample	Description	Results	Comments
Cox, C., Monk, A. (1996).	A convenience sample of 76 Black American and 86 Hispanic caregivers of CI elders living in the community were selected for the study. The sample consisted of Black American (77%) and Hispanic (76%) family caregivers that were mainly female. Hispanic caregivers were significantly younger ($M = 54$, $p < .01$).	<p>Purpose: to compare Black American and Hispanic caregivers of demented relatives to determine the factors most associated with stress in the two groups and the effects which ethnicity itself may have on the outcomes of care giving.</p> <p>Design: survey design with interview techniques. All interviews were conducted in either English or Spanish. Caregiver demographics, health, social support, personal role strain (e. g., care giving placed restrictions on activities and demands on their time), and role strain (stress caused by role conflict and role strain) were measured.</p> <p>The CI elder's need for assistance with ADLs, and behavioral symptoms and the effects of the behavioral symptoms on the family caregiver were also measured.</p>	<p>Hispanics reported significantly more stressors associated with behavioral symptoms ($b = 80.3$, $p < .001$) and care giving assisting the CI elder during ADLs ($b = 15.5$, $p < .001$). They also reported significantly more personal strain ($b = 18.1$, $p < .001$) and role strain ($b = 9.1$, $p < .001$) than Black Americans. The caregivers' age was significantly negatively associated with caregiver role strain ($b = -.44$, $p < .001$). Younger caregivers experience more role strain. ADL problems were significantly associated with personal strain ($b = .22$, $p < .01$) and role strain ($b = .13$, $p < .05$). Hispanics experienced significantly more personal strain ($b = .33$, $p < .01$) and role strain ($b = .59$, $p < .001$).</p>	<p>This study suggests that both groups experience stress when assisting CI elders with ADLs (e.g., bathing, dressing, toileting etc.) than managing disruptive behaviors. Younger caregivers in this study seemed to experience more role strain. For instance, younger caregivers reported experiencing more stress related to behavioral symptoms and ADL problems. Generally, Hispanic family caregivers experienced more personal and role strain than Black American family caregivers.</p> <p>The researchers make two good points that one can not generalized the results to all Hispanics and Black Americans because they are a diverse groups within their own groups. Also, although these African-Americans seem to be less disturbed by disruptive behaviors than whites, this does not imply that they are immune to stress associated to care giving demands</p>

Farran, C.J., Keane-Hagerty, E., Tatarowicz, L. & Scorza, E. (1993) Dementia care-receiver needs and their impact on caregiver. *Clinical Nursing Research*, 2, 1, 86-97.

Author	Sample	Description	Results	Comments
Farran and colleagues (1993)	<p>Convenience sample of 140 caregivers and CI elders diagnosed with Alzheimer's or multi-infarct dementia. They lived in the community. Mean age of caregivers was 61 and mean age of elders was 73. Caregivers were wives, daughters, husbands, other family, sons and non-family. 82% were white, 13% black and 2% other races.</p>	<p>Descriptive study to identify perceptions r/t providing assistance with ADLs and IADLs, managing cognitive impairment and disruptive behaviors, and to describe how distressing it is for family caregivers to meet those needs. 2 hour interviews were conducted with primary caregiver. Caregiver self-maintenance, level of distress, and burden were measured. CI elders' IADLs, ADLs and behavioral problems were measured. Descriptive statistics were used and correlations were obtained to look at relationships between caregiver burden and 1) level of CI ADL impairment and caregiver distress, 2) frequency of elders' cognitive impairment or disruptive behavior, and 3) caregiver distress.</p>	<p>No significant relationships between caregiver burden and level of elders' ADL impairment. Significant association occurred with meeting elders' needs and caregiver burden. Positive relationship between dyad conflict and caregiver distress during attempts to meet ADL needs as well as the occurrence of behavior problems and their frequency. A negative relationship existed between caregiver satisfaction and caregiver distress associated with meeting IADLs.</p>	<p>Findings indicate that caregivers experience negative feelings associated with care giving tasks. Sampling procedure may prevent generalizability to all community dwelling caregivers. Study does suggest agitation and aggression contribute to caregiver distress. Study is limited because it addresses ADLs in general.</p>

Freels, S., Cohen, D., Eisdorfer, C., Paveza, G., Gorelick, P., Luchins, D.J., Hirschman, R., Ashford, J.W., Levy, P., Semla, T., & Shaw, H. (1992). Functional status and clinical findings in patients with Alzheimer's disease. *Journal of Gerontology: Medical Sciences* 47, 6, M177-M182.

Author	Sample	Description	Results	Comments
Freels and colleagues (1992).	240 subjects from Alzheimer's Disease Patient Registry from four sites. Average age was 74.5. Average MMSE score was 15.5.	<p>Exploratory study. Variables examined were demographics and MMSE scores, functional status ratings on 6 ADLs (including bathing), presence and absence of specific physical conditions, and signs and symptoms observed during evaluation (including behavioral disorders).</p> <p>Multiple logistic regression was used to test association of clinical symptoms and conditions to ADL impairment. Forward stepwise selection procedure was used to predict best combination of symptoms and conditions associated with functional status. Proportional Odds Model Logistic Regression Equation to control for age, sex, race and MMSE score. Nonproportional Odds Ratio Model was used for ordered outcomes.</p>	<p>80 subjects were functionally impaired during bathing. 11.7% of these were moderately to severely impaired during bathing. Prevalent psychiatric symptoms were agitation (30%), depressive symptoms (27.1%) and behavioral disorders (22%). CI elder with behavioral disorder was 4.5 times more likely to have one or more ADL impairments and 5.9 times more likely to have moderate to severe difficulty with ADLs. Analysis predicted those with behavioral disorders were 3 times more likely to have moderate to severe difficulty with bathing. Prevalent neurologic symptoms included apraxia (23%) and dysphoria (21%). Prevalent physical conditions included HTN (32%) and cardiovascular disease (20%). HTN most prevalent associated with predicting ADL impairment. History of HTN, behavioral disorder and apathy 1.97 times more likely to be functionally impaired in 1-6 ADLs. CI elder with HTN 5.5 times more likely to be functionally impaired in all 6 ADLs.</p>	<p>Suggests those with disruptive behavior during ADLs may require more assistance because self-care behaviors are interfered with. Strategies to decrease disruptive behaviors may increase self-care behaviors during bathing. Limited study because conditions were chronic and under control. Acute illnesses, falls, fractures, etc were not included.</p>

Greiner, P. A., Snowdon, D. A., & Schmitt, F. A. (1995). The loss of independence in activities of daily living: The role of low normal cognitive function in elderly nuns. *American Journal of Public Health*, 86, 1, 62-66.

Author	Sample	Description	Results	Comments
Greiner, Snowdon & Schmitt (1995).	678 Catholic nuns ranging in age from 75-102 (M=83.3) with 575 of these completing the study.	Examined relationships of cognitive function to loss of ADL in a group with similar lifestyle. Cognitive and functional assessments completed twice within 2 year period. Performance assessed on 6 ADLs (including bathing). Independence defined as requiring no human or mechanical assistance. MMSE used to test cognition. Cox Proportional Hazards Regression used to compute risk of loss of independence in ADLs.	12 subjects were at risk for loss of independence in bathing with cognitive impairment during 1 st assessment - 5 of those demonstrated a loss of independence. Cognitive impairment increased the risk of losing independence with bathing 2.4 times. During 2 nd assessment number of cognitively impaired subjects increased to 39 and those with loss of independence in bathing increased to 21. Relative risk of losing independence during bathing increased from 2.7 to 4.4 times with cognitive impairment.	As cognitive status deteriorates the risk for loss of self-care during bathing increases. Limitation of study was lack of generalizability because all subjects had high education level, history of healthy lifestyle, and equal access to health care. Co-morbid conditions are not addressed. Indicates CI elders are at risk for self-care deficits during bathing. Caregivers can provide support during bathing and encourage use of all remaining abilities.

Haley, W.E., West, C.A.C., Wadley, V.G., Ford, G.R., White, F.A., Barrett, J.J., Harrell, L.E., & Roth, D.L. (1995). Psychological, social, and health impact of care giving: A comparison of black and white dementia family caregivers and non-caregivers. *Psychology and Aging* 10, 4, 540-552.

Author	Sample	Description	Results	Comments
Haley and colleagues (1995)	Four groups: black CGs, black non-CGs, white CGs and white non-CGs. Final sample consisted of 175 CGs and 175 non-CGs. Racial mix was 70 blacks and 105 whites. Average CI elder in both groups was severely cognitively impaired.	<p>Purpose: to compare the social and health consequences of care giving among black and white CGs.</p> <p>Non-experimental design using survey and interview techniques. A structured interview and a series of questionnaires were completed and all participants were paid \$10.00. Variables measured were psychological distress, life satisfaction, mental health, physical health, and social support and social activities. Descriptive stats were used to describe the sample. MANOVA was used to analyze the multiple dependent variables of the subscales of the measures. ANOVA was used to follow-up on significant multivariate effects. ANCOVA was used to follow-up on significant ANOVAs to verify the effects of race with and without covariate adjustments. Socioeconomic income and age were used as covariates with female CGs instead of education and income because of problems with using these indices in older women.</p>	<p>Indication that white CGs were significantly more clinically depressed and had higher percentages of elevations of depression than other groups. Black CGs had lower levels of obsessive-compulsive symptoms and anxiety but higher levels of paranoid ideation than white CGs and non-CGs. White CGs had the highest level of life satisfaction than other groups. Whites significantly reported more types of illness. Blacks reported a higher frequency of illness and tend to rate their health worse than whites. Women and spousal CGs report significantly more physiological problems. Black CGs receive significantly more visits by relatives and friends than whites and non-CGs. CGs visit relatives less than non-CGs. Women and spouses reported more visits from relatives and friends than men and non-spousal CGs. Both groups of CGs made fewer visits to relatives. Whites were more active than blacks and non-CGs. Blacks have more people living in the household but non-CGs had highest level of social support in the household. CGs had more family outside the household</p>	<p>An examination of the responses of black and white CGs might be useful in providing more information about how they respond differently to problems that occur when assisting a CI during bathing. Spousal CGs received less support in the home but more outside support from family and friends.</p>

Harper, S., & Lund, D.A. (1990). Wives, husbands, and daughters caring for institutionalized and noninstitutionalized dementia patients: Toward a model of caregiver burden. *International Journal of Aging and Human Development* 30, 4, 241-262.

Author	Sample	Description	Results	Comments
Harper and Lund (1990)	The sample consisted of family caregivers of CI who lived in Midwestern, Northern, Southern, Southwestern and Northwestern regions of the country. The final sample consisted of 409 family caregivers and CI elders who were divided into three groups according to the resident of the CI elder: the CI elder lives at the same resident with the caregiver (66%); CI elder lives in a nursing home (22%); and the CI lives in the community without the caregiver (12%). These groups were further divided into seven sub-groups according to the caregiver's gender and relationship to the CI elder. Two groups were composed of husbands, wives, and daughters of CI elders who lived with the CI elder or of CI elders living in the nursing home. The seventh group consisted of daughters who did not live in the same home as the community dwelling CI elder.	Purpose: To identify sets of variables that best explain the different levels of burden among caregivers. (e.g., such as, kinship between the CI elder and caregiver, residential location, and characteristics of the CI elder and caregiver. Design: Exploratory, nonexperimental survey design using mail questionnaires. Life satisfaction and caregiver burden of family caregivers, and the CI elders' ADLs, memory, and behaviors were measured. Descriptive statistics were used to describe the sample and multiple regression techniques were used to examine the correlates of burden or variables that best predict burden.	The rapid decline and gender of the CI elder was associated with decreased life satisfaction, working outside the home, and others living in the home was associated with caregiver burden. The CI elders' memory loss, lack of support, and other people living in the home, were associated with caregiver burden experienced by husbands who live with the CI elder. The CI elders' behavioral symptoms, lack of support, managing behavioral symptoms, decreased income, and decreased life satisfaction, was associated with caregiver burden of wives who live with the CI. Daughters who live with the CI elder experienced the highest degree of caregiver burden. The next highest average caregiver burden score was caregivers of elders living in a nursing home. The lowest average caregiver burden score was with the family caregivers who lived elsewhere in the community.	Daughters who do not live with their CI parent seemed to experience more burdens in the areas of dealing with the loss of the person that once knew as their mother. All family caregivers living with the CI experience stress associated with others living in the home. Wives seem to need assistance with managing behavioral symptoms. Husbands also seem to need support with their care giving role. Future studies might examine other factors that affect caregiver burden. Examining the stress associated with bathing assistance would be one type of study that would examine a factor that contributes to caregiver burden.

Harris, P.B. (1998). Listening to care giving sons: Misunderstood realities. *The Gerontologist* 38, 342-352.

Author	Sample	Description	Results	Comments
Harris (1998).	Purposeful sample of 30 sons who are primary caregivers of a CI parent or assist their parents on a daily basis to care for their CI spouse. Ages ranged from 32 to 71 years (M=50). 83% were white and 17% black. Most had sisters in the area but they were the primary caregiver. More took care of their mothers.	<p>Purpose: to describe the day-to-day experiences of sons in care giving roles to extend research to include the care giving experiences of men.</p> <p>Descriptive using grounded theory methods. An interview guide was developed and each interview was scheduled four times. Categories for interviews were 1) role of caregiver, 2) stress and coping, 3) interpersonal and family relationships, and 4) meaning and motivations. Duration of study was 8 months. Interviews lasted 1.5 to 2 hours. Interviews were done outside of the caregivers' homes.</p>	<p>Content analysis was completed, the data was coded and the themes divided into two parts: common themes and common issues. These described reactions of the sons to the disease, the care giving responsibilities and thoughts and feelings as caregivers. The issue of role reversal seemed problematic. Dependence was traumatic for both the son and the CI elder.</p>	<p>Data bits r/t bathing were not published but findings suggest that sons are assisting with bathing and it appears problematic for them. A more in-depth interview might provide information specifically r/t experience of assisting with bathing. The study was limited because the sons were middle class and health service users. A more diverse sample should be sought.</p>

Harvath, T. (1994). Interpretation and management of dementia related behavior problems. *Clinical Nursing Research*, 3, (1), 7-26.

Author	Sample	Description	Results	Comments
Harvath (1994)	Ten white female community-dwelling family caregivers ranging in age from 51-80. Eight were spousal caregivers and two were daughters caring for their mothers. CI elders lived with their caregivers and ranged in age from 67-86.	Purpose: to explore nature of caregiver's perceptions and interpretations of behavioral problems related to dementia. One semi-structured interview of caregivers was conducted in their home. Data was analyzed using an interactive process to identify dominant themes r/t behavior problems, caregiver interpretation of the behaviors, management strategies used and the consequences for the caregiver.	Theme 1: care receiver behavior and context in which behavior occurs. Context of behavior appeared to influence caregiver interpretation of behaviors. Theme 2: management of behaviors and resulting consequences. Most attributed problem behavior to dementia secondary to other causes. Those who did believed that the CI elder had no control over behavior and felt that management of these behaviors was less stressful. Some believed that the CI elder could control the behavior and that these problems were deliberate. No attempts were made to manage behaviors that did not threaten the caregiver or were perceived to be a problem. Strategies to manage behaviors were tailored to the individual CI elder. Success of management of behaviors was measured according to caregiver expectations. When expectations were too high, the caregiver experienced anger, sadness and increased stress.	Small sample size and lack of diversity of participants prohibits generalizability. Useful information was obtained about attitudes of family caregivers concerning management of problem behaviors. Bathing was not specifically addressed. However, an understanding of caregiver interpretations of behaviors, management strategies used and the consequences for the caregiver is important when dealing with problem behaviors during bathing.

Hoeffer, B., Rader, J., McKenzie, D., Lavelle, M., & Stewart, B. (1997). Reducing aggressive behavior during bathing cognitively impaired nursing home residents. *Journal of Gerontological Nursing*, 25, 16-23.

Author	Sample	Description	Results	Comments
Hoeffer and colleagues (1997).	86 nursing home residents	<p>Purpose: To describe the frequency and nature of disruptive behaviors during bathing.</p> <p>Design: Preliminary survey study.</p> <p>Nursing assistants trained to use Ryden Aggression Scale with added components of standardized definitions of each behavior, checklist r/t bath and when behaviors were observed.</p>	<p>Four baths were observed. of 86 residents 41% were aggressive during at least one bath; 16% aggressive during at least 3 of 4 baths. 60% of those aggressive at least once had a diagnosis of dementia. 72% of those aggressive 3 times had a diagnosis of dementia.</p> <p>The most frequent physically aggressive behaviors were hitting, punching, slapping, pinching and shoving. Name calling and cursing were the most frequent verbally aggressive behaviors.</p>	Led to an intervention study. See next page.

Hoeffter, B., Rader, J., McKenzie, D., Lavelle, M., & Stewart, B. (1997). Reducing aggressive behavior during bathing cognitively impaired nursing home residents. *Journal of Gerontological Nursing*, 25, 16-23.

Author	Sample	Description	Results	Comments
Hoeffter and colleagues (1997)	10 CI elderly nursing home residents requiring bathing assistance. Ages were 86-98 (M=89.5).	Design: Intervention pilot study. Consisted of bedside consultation by geropsych CNS with certified nursing assistants and individualized bathing plans and strategies. Emphasis was on changing the nursing assistants' perception of bathing from task to therapeutic time for CI elderly. Pre and post intervention data was collected using revised version of Ryden Aggression Scale completed by both nurse consultant and CNA. CNAs also completed Assessment of Bathing Experience to assess perception of behavior and their experience during bathing.	Significant differences pre- and post intervention. CNA experience in caring for CI resident during bathing improved significantly. No significant difference was found in CNA description of their relationship with CI elder during bathing. Physically aggressive behaviors decreased from 7 during 2 showers to 1 during 2 towel baths, indicating positive effect of alternative bath form.	<ol style="list-style-type: none"> 1. Supports effectiveness of individualized approach emphasizing function, frequency and form of bathing and the psychosocial environment in reducing aggressive behavior and making experience more positive for patient and caregiver. 2. Researchers were successful in training CNAs in implementation of individualized approach during bathing. 3. Bathing interventions were effective in behavior changes during bathing. 4. Testing these interventions in home settings is warranted but modification will be necessary.

Lynch-Sauer, J. (1990). When a family member has Alzheimer's Disease: A Phenomenological description of care giving
Journal of Gerontological Nursing 16, (9) 8-11.

Author	Sample	Description	Results	Comments
Lynch-Sauer (1990)	Seven family caregivers who wrote books r/t providing care to a person with Alzheimer's Disease. There were 4 female and 3 male authors. Of these, two were spouses, four were children and one was a daughter-in-law. The elders whom they cared for consisted of four women and three men. Two of the spouses and the daughter-in-law were primary caregivers. The others received outside assistance.	<p>Purpose: to interpret the subjective experience of caregivers of CI elders.</p> <p>Design was a phenomenological interpretative used with a meta-analysis of published works of caregivers of persons with Alzheimer's Disease.</p> <p>Data was analyzed using phenomenological analyses. Accounts of non-care giving activities were omitted from the analysis. Theme statements were listed and categorized.</p>	A good description of how family caregivers of CI elders react emotionally and physically to the role of caregiver was provided. Eating was the only ADL discussed. Bathing may not have been written about because the authors may have viewed publicly discussing this as compromising the CI elders' dignity. Lack of mutuality was one theme that emerged.	Knowledge of the personal history of the dyad may provide important information for developing interventions that aid in managing behavioral symptoms and self-care deficits (i.e. preparing the bath the way the elder previously enjoyed the bath).

Kinney, J.M., & Stephens, M.A. (1989) Hassles and uplifts of giving care to a family member with dementia *Psychology and Aging* 4, (4), 402-408

Author	Sample	Description	Results	Comments
Kinney and Stephens (1989)	<p>60 family caregivers of CI elders. 82% were women. One-half were spouses and the remainder family caregivers were daughters or other family. Caregiver ages ranged from 24-81 (M=57.4). They spent an average of 12.4 hours/day in care giving activities. CI elders were 62% female and 90% required assistance with bathing or dressing. Ages ranged from 55-94 (M=73). Comparison group sample (n=974) consisted of non-caregivers, community dwelling, middle aged (M=46) adults. 51% were men, 85% spouses and 87% white.</p>	<p>Caregiver hassles and uplifts were measured and health status of caregiver and CI elder were compared.</p>	<p>Caregivers reported significantly more hostility, anxiety, depression and somatization than non-caregivers. Average of 27.5 daily hassles and 19 uplifts were reported by caregivers. Bathing was one of the most common hassles reported. Physical decline and disruptive behavior also reported as hassle.</p> <p>Uplifts were seeing CI elder calm, responsive, showing affection, cooperative, smiling or winking and in being with the CI elder. Those caring for less socially withdrawn and those with more disruptive behaviors reported significantly more hassles. The more physically impaired the elder, the more ADL hassles that were reported. Women reported more behavior and cognitive related hassles. Younger caregivers spending more time with elders reported significantly more uplifts.</p>	<p>Bathing is one of the most common care giving hassles experienced by caregivers during ADLs. Studies r/t disruptive behaviors can demonstrate how much of a hassle exists for caregivers with bathing. This knowledge could lead to planning interventions to decrease hassles and improve overall well-being of family caregiver.</p>

Mathew, L.J., Mattocks, K., Slatt, L.M. (1990). Exploring the roles of men: Caring for demented relatives. *Journal of Gerontological Nursing* 16, 10, 20-25.

Author	Sample	Description	Results	Comments
Mathew, Mattocks, and Slatt (1990)	<p>Convenience sample of two groups of men, totaling 20.</p> <p>Group 1: 12 male caregivers from 42-80 years old (M=59). Majority of caregivers were married and ½ were caring for a spouse.</p> <p>Group 2: 8 male caregivers from 35-74 years old. All were married. Most were caring for their spouse and 3 were caring for their mother or other relative.</p> <p>All men were white and middle to upper class. Two had less than a high school education.</p> <p>Elders they cared for ranged in age from 63-89.</p>	<p>Purpose: to describe the care giving experiences of men in terms of contribution and how they can become more involved in caring giving activities.</p> <p>Descriptive and quantitative study using survey questions and interview techniques to compare male caregivers who provided direct care to those who place CI relative in nursing homes.</p> <p>Interview questions focused on demographics, caregiver's family, CI elder, resources, dyad relationship and open-ended questions on the reasons they decided to care for their CI relative. Also surveyed the areas of burden and functional ADLs.</p> <p>Data was analyzed using descriptive statistics and paired t-test to compare the group means.</p>	<p>90% of men reported a strong obligation to provide care. Group 1 was more likely to receive help from wives and daughter, visiting nursing and housekeeper services.</p> <p>Main motivation to continue provision of care was love and no one else to care for the elder. Both groups provided more IADL assistance than ADL. Problems reported by Group 1 included loss of communication, incontinence, wandering, the time required for care and lifestyle changes affecting professional life. They reported humorous moments and stated that it was rewarding to know exactly how the elder is being treated. Main problem reported by Group 2 was not being in control of the elder's care. They institutionalized their loved one r/t their own poor physical or mental health, the elder's impairment, lack of assistance and sadness r/t progressive deterioration of the elder. Burden and feelings of closeness were very similar in both groups.</p>	<p>This sample was more financially able to access outside resources for assistance with ADLs and there was minimal report of information r/t the bathing process.</p> <p>Burden scores were lower than expected.</p> <p>Study limited due to sample size.</p>

Maxfield, M.C., Lewis, R.E., & Cannon, S. (1996). Training staff to prevent aggressive behavior of cognitively impaired elderly patients during bathing and grooming. *Journal of Gerontological Nursing*, 22, 37-43.

Author	Sample	Description	Results	Comments
Maxfield, Lewis and Cannon (1996)	Caregivers (71 NAs, 12 LPNs and 14 RNs) in a geropsychiatric hospital. Ages ranged from 22-75 (mean 41).	Intervention study consisting of 3 training groups. Trainers were 2 APNs specializing in geropsychiatric and gerontological nursing.	Unannounced caregiver observations revealed observable gain in skill application following training.	Supports effects of caregiver training to manage disruptive behaviors. Key component was availability of trainers for assistance and consultation. This availability could be replicated with family caregivers.

McCarty, E.F. (1996). Caring for a parent with Alzheimer's disease: process of daughter caregiver stress. *Journal of Advanced Nursing* 23, 4, 792-803.

Author	Sample	Description	Results	Comments
McCarty (1996)	16 daughters and 1 daughter-in-law, who provided primary care, helped a spouse or was an advocate for an institutionalized demented parent.	<p>Purpose: to discover the unknown components that enter into and shape daughter caregivers' lives during care giving experiences.</p> <p>Combination of qualitative and quantitative methods. Grounded theory method used to generate a theoretical mode to explain care giving experience of daughters caring for demented parents. Semi-structured interviews using questionnaires were also included with open-ended questions.</p> <p>Data collected over 6 months and interviews were conducted at different phases of care giving. Unit of analysis was sentences and they were open coded to identify commonalities in data.</p>	<p>A theory of the stress process in daughter caregivers of CI elders was developed. Major constructs were beliefs, perceptions, transactions and relationship patterns. Current and previous relationships with parents appeared to affect the daughters' problem solving techniques, decisions, perceived stress, coping mechanisms and providing care in a caring and compassionate way. Caring for both parent and family without assistance was stressful. Daughters initially became attached with diagnosis but as the care giving phase progressed they became detached at times and felt attached at other times. Those who coped with stress by being actively involved in the grieving process, seeking support and dealing with reality of the situation displayed less anxiety, depression, obsessive-compulsive behaviors and somatization.</p>	<p>Implementing physical tasks such as bathing associated with the progression of the disease may result in the need for detachment from the CI elder. There is a need to examine the issues of 1) problems associated with assisting in physical care, 2) beliefs about care giving, and 3) how families respond to problems that may occur when assisting with bathing. Since the past relationship between the caregiver and elder seems to be important in determining how well the care is implemented, more should be known about the relationship.</p>

Author	Sample	Description	Results	Comments
Miller and colleagues (1995)	The sample (n = 215) of spousal caregivers was composed of 22 Black males, 56 white males, 22 Black females, and 82 white females. Black caregivers were on average three years younger than white caregivers and had been married an average of seven years less. The mean age of spousal caregivers was 75.	<p>Purpose: to explore whether or not race makes a difference in predicting caregiver distress in spousal caregivers of CI elders.</p> <p>Design: The study was a quantitative study using interview techniques. In home structured interviews were performed by interviewers matched by race. The researchers measured stressors (e.g., ADL self-care deficits, disruptive behaviors, difficulties of care giving, health), psychological resources, caregiver mastery, depression, and role strain. Descriptive and regression statistics were employed to describe the sample and predict caregiver distress respectively. A count of the number of ADL deficits in seven areas (mobility, eating, dressing, grooming, bed mobility, bathing, and toileting) was obtained.</p>	<p>The average number of ADL deficits was 4 (SD 2.8). Frequency counts of problem behaviors resulting in caregivers becoming upset were obtained in the areas of emotional lability, irritability, outburst, wandering, destroying property, hoarding, and aggressive behavior. The average number of problem behaviors was 71 (SD = 57.4) out of a possible 271 behaviors. White caregivers experience more distress related to problem behaviors. The mean level of caregiver distress related to care giving was 21 (SD = 9.9) out of a total 60. The caregivers' self-report of their physical health was 2.8 (SD = .9), with 1 exemplifying poor health. The caregivers experiencing role strain averaged 8.24. White caregivers reported significantly higher levels of distress especially for depression higher levels of</p>	<p>Depression were associated with being white (b = -7.32, p < .001); in poor health (b = -2.65, p < .001); more behavior problem upset (b = .03, p < .05); CI elders with higher levels of ADL deficits (b = .43, p < .05); and more task distress (b = .38, p < .001). Higher levels of role strain were predicted by being white (b = -1.19, p < .001); behavioral upset (b = .02, p < .001); task distress (b = .08, p < .001); and less caregiver mastery (b = -.26, p < .001). For those family caregivers with low mastery, there was a positive relationship between behavioral upset and depression (b = .04, p < .01). Similarly, for caregivers with low mastery, there was a positive relationship between and ADL deficits of the CI elder (b = .82, p < .01).</p>

Author	Sample	Description	Results	Comments
Miller (1997).	27 nursing staff (RNs, LPNs and CNAs) in one nursing home	Purpose was to explore staff response to physically aggressive behaviors during bathing. Interviews were used to obtain data that was analyzed using ethnography.	<p>Physically aggressive behaviors were disturbing to staff, often unexpected and appeared unprovoked. The overall theme was "caregivers in conflict". The staff reported that those CI elders who consistently refused assistance with activities of daily living were the most challenging. The effects of aggressive behaviors on nursing staff included physical problems (e.g., scratches, wounds, pain exhaustion) and mental problems (e.g., fear, worry, anger, sadness, and frustration). Physically aggressive behaviors led to: a lessened perception of the amount and quality of nursing care, an increased risk for staff to patient abuse and neglect, and increased staff turnover. Five sub-themes describing nursing staff's conflicts emerged from the study. The theme "working through aggression to the person" led to 10 nursing approaches that staff can use to improve the care of CI elders in nursing homes. These include 1) obtaining a bathing history, 2) allowing the resident to decide when to bathe, 3) individualizing the bath, 4) showing empathy, 5) observing for escalating behaviors, 6) talking to the resident, 7) helping CI elders understand instructions, 8) becoming part of their fantasy world (e.g., allowing the CI elder to continue to fantasize and entering into it with the CI elder), 9) preserving CI elders' dignity, and 10) protecting the CI elder.</p>	<p>Study draws from nursing assistant experiences to identify common behaviors during bathing, caregiver reactions. Miller suggests that approaching the CI elder in a calm manner and smiling, providing individualized care and allowing the CI elder to perform self-care tasks are associated with decreased behavioral symptoms during bathing.</p>

McCarty, E.F. (1996). Caring for a parent with Alzheimer's disease: process of daughter caregiver stress. *Journal of Advanced Nursing* 23, 4, 792-803.

Author	Sample	Description	Results	Comments
McCarty (1996)	16 daughters and 1 daughter-in-law, who provided primary care, helped a spouse or was an advocate for an institutionalized demented parent.	<p>Purpose: to discover the unknown components shape daughter caregivers' lives during caregiving experiences.</p> <p>Combination of qualitative and quantitative methods. Grounded theory method used to generate a theoretical mode to explain caregiving experience of daughters caring for demented parents. Semi-structured interviews using questionnaires were also included with open-ended questions.</p> <p>Data collected over 6 months and interviews were conducted at different phases of caregiving. Unit of analysis was sentences and they were open coded to identify commonalities in data.</p>	<p>A theory of the stress process in daughter caregivers of CI elders was developed. Major constructs were beliefs, perceptions, transactions and relationship patterns. Current and previous relationships with parents appeared to affect the daughters' problem solving techniques, decisions, perceived stress, coping mechanisms and providing care in a caring and compassionate way. Caring for both parent and family without assistance was stressful. Daughters initially became attached with diagnosis but as the caregiving phase progressed they became detached at times and felt attached at other times. Those who coped with stress by being actively involved in the grieving process, seeking support and dealing with reality of the situation displayed less anxiety, depression, obsessive-compulsive behaviors and somatization.</p>	<p>Implementing physical tasks such as bathing associated with the progression of the disease may result in the need for detachment from the CI elder. There is a need to examine the issues of 1) problems associated with assisting in physical care, 2) beliefs about caregiving, and 3) how families respond to problems that may occur when assisting with bathing. Since the past relationship between the caregiver and elder seems to be important in determining how well the care is implemented, more should be known about the relationship.</p>

Author	Sample	Description	Results	Comments
Namazi and Johnson (1996)	22 nursing home residents in moderate and late stages of dementia; 10 were women and 12 men; their ages ranged from 72-98 years (mean age 81.5). Twelve caregivers (10 women, 2 men) employed by the nursing home participated in the study).	<p>Purpose: To document behaviors that CI elders display during bathing and to identify the antecedents of such behaviors reported by nursing staff.</p> <p>Design: An 8-week observational study.</p> <p>The caregivers completed a bathing questionnaire for each resident. The questions were in four parts: the residents' bathing habits and idiosyncrasies, condition of the physical environment, safety issues, and other related bathing problems. They also completed a checklist, immediately after the CI elder's bath of observations of aggressive or assaultive (e.g., complaining, whining, yelling, spitting, kicking) behaviors during bathing.</p> <p>Caregivers evaluated themselves and environmental factors that might influence the outcomes of bathing.</p> <p>Family members of the CI elders were interviewed to determine each resident's past bathing habits, preferences, and usual time of bathing. A bathing schedule was generated to</p>	<p>Most of the CI elders preferred to bathe in the morning (8 a.m. - noon) and late afternoon between (4 and 8 p.m.). Two subjects preferred late night baths. The most common form of bath preferred by subjects was occasional sponge baths. The frequency of baths preferred by the majority of subjects was twice a week (54%); weekly baths were preferred by 36%, and bathing five times a week were preferred only by 10% of CI elders participating in the study.</p> <p>Caregivers observed mainly verbal aggression (91%), making strange noises (77%), talking to self (73%), complaining or whining (73%), threatening (59%), physical aggression (45%), rage reaction (32%) and throwing objects (5%). CI elders recently admitted to the nursing home displayed more disruptive behaviors during bathing. Caregivers reported that assisting CI elders with bathing was the most difficult task they did.</p>	<p>Namazi and Johnson (1996) suggest that the social and physical environment of the unit influences the behaviors of cognitively patients. For example, disruptive behaviors resulted from being suddenly swept away from friends with whom the residents were interacting and being taken to a room that did not resemble a familiar bathroom. This made it difficult for the CI patient to focus on the bath, resulting in disruptive behaviors. The high rate of physical aggression (45%) may indicate physical or emotional discomfort, a negative outcome of the bathing experience.</p>

Author	Sample	Description	Results	Comments
Newsom and Shulz (1998)	288 spousal caregivers and elders. CI elders had ADL and IADL impairment and required assistance from the caregiver. Average age of elders was 77 and 52% were females. Five of the elders were severely CI impaired. Average age of caregivers was also 77 and 48% were females.	<p>Purpose: to investigate the potential causes of negative reactions to assistance and the consequences of negative reactions on the care receivers' well-being.</p> <p>Non-experimental design using interview techniques. Elder and caregiver were interviewed separately. Assistance with ADLs and IADLs and the elders' control, self-esteem and feelings of fatalism were measured.</p> <p>Data was analyzed using descriptive statistics, correlations and multiple regression statistical techniques.</p>	<p>Caregivers reported assisting with an average of 3 ADLs and IADLs. 28% of elders reported needing assistance with one or more ADL that the caregiver did not report. Elders reported distress while receiving assistance. Assistance from family caregivers increased experience of fatalism, decreased control and low self-esteem.</p> <p>Elders with low self-esteem were more likely to experience distress with high caregiver assistance vs. low caregiver assistance. Elders experiencing fatalism were more likely to experience distress with high caregiver assistance vs. low caregiver assistance. Elders with marital conflict were more likely to experience distress with high caregiver assistance vs. those with less marital conflict caregiver assistance. Elders with low internal control had more distress with under helping than those with high internal control.</p>	<p>Study suggests that assistance with ADLs and IADLs from family caregivers causes discomfort for the elders. The relationship between them may affect the level of distress. Caregivers should maintain the elder's autonomy.</p> <p>Caregiver behaviors may cause the elder to feel dependent, inferior, inadequate and unable to control the bathing situation. Feelings of discomfort may then be expressed in resistive and disruptive behaviors during bathing when they are unable to verbally communicate their discomfort.</p>

Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999) Prevalence and impact of caregiving: a detailed comparison between dementia and non-dementia caregivers. *The Gerontologist*, 39 (2), 177-185.

Author	Sample	Description	Results	Comments
Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999)	1,500 family CGs	<p>Purpose: To provide a detailed description of the differences between dementia and non-dementia CGs with regard to several areas that are relevant to CG's well being. Differences are examined in terms of whom is providing care impacts of caregiving on the CG, involvement in care giving, and the effects of caregiving on employment and service utilization.</p> <p>Design: Survey design using telephone interview techniques. The respondents were asked 44 questions regarding: 1. the amount and type of care (activities of daily living and instrumental activities of daily living); 2. Care giving impacts (employment related issues, physical, emotional, financial and role stress); Service utilization; and care giving involvement. Statistical analysis included multiple regression, Chi square, paired t test and descriptive statistics.</p>	<p>Care giving Involvement: Dementia CGs spent more hours per week providing care than non-dementia CGs, $t(1243) = 4.61, p < .001$. Dementia CGs provided 40 more hours of care and constant care than did non-dementia CGs. There were no differences between dementia CGs and non-dementia CGs in how long care had been provided to the care receiver.</p> <p>Assistance in ADLs: Dementia CGs assisted with more ADLs ($m = 7.07$) than non-dementia CGs ($M = 5.73$). Dementia CGs ($M = 2.29$) provided more aid with a higher total of ADLs than non-dementia CGs ($M = 4.78$).</p> <p>Impacts of Care giving: More dementia CGs report more problems associated with employment. Dementia CGs are more likely to report negative effects of care giving related to physical, emotional, financial and role stress.</p> <p>Dementia CGs were more inclined than non-dementia CGs to perceive that other family members were not doing their fair share (74.1% vs. 59.4%) of care giving and report a greater degree of family conflict ($M = 1.55$ vs. $M = 2.22$). All CGs reported a moderate amount of physical strain. Dementia CGs reported higher levels of emotional and physical strain ($M = 2.40$ vs. $M = 1.8$). Dementia CGs are more likely to report they suffer from mental or physical problems (22.3% vs. 12.6) as a result of care giving. Women reported more physical strain.</p>	<p>Dementia CGs are providing more care giving activities and report more negative effects of care giving than other types of family CGs. The researchers report that a limitation of this study that it was hard to determine by telephone whether the dementia CGs were taking care of an elder experiencing delirium vs. dementia.</p>

Phillips, L. R., & Rempusheski, V.R. (1986). Caring of the frail elderly at home: toward a theoretical explanation of the dynamics of poor quality family caregiving. *Advances in Nursing Science* 8, 4, 62-84.

Author	Sample	Description	Results	Comments
Phillips & Rempusheski (1986)	19 Midwestern family CGs ranging in age from 15-70 years (mean 47). The elders they cared for ranged in age from 66-92. The sample also include 20 Southwestern family CGs ranging in age from 32-85 (M=58). They cared for elders ranging in age from 66-92 years old as well.	Purpose: To explore CGs' perceptions of their care giving relationships. Exploratory study consisting of grounded theory methods to generate theoretical model.	Four stages w/ dynamics of family care giving were generated: 1) definition of situation, 2) cognitive processes, 3) expressive processes and 4) evaluation processes of social interaction. Definition of the situation: includes 2 constructs, 1) personal identity of elder (or mental image the CG has of the elder based on past associations, present observations and reconciliation of past with present) and 2) CGs image of care giving (the degree to which personal imperatives, standards and values are realized). These 2 constructs result in the CGs' role belief. Cognitive Process: based on standards and values held by the CG regarding the performance of CG role Expressive Process: persons execute role they perceive themselves in. Caregivers behavioral management strategies are methods used to manage behavioral problems and conflict. Three types of strategies: positive, negative or neutral. Evaluation Process: CGs representation of elder's response. Caregiver attaches meaning to observations of the elder during interactions and is able to positively or negatively modify their image of the elder (feedback mechanism). Role interdependence occurs and both individuals believe that termination of the relationship is prohibited.	Factors were illustrated that may shape CG attitudes that affect the way that they interact with and care for CI elders. Identifying CG attitudes regarding enhancing self-care, managing disruptive behaviors and providing comfort when assisting with bathing can assist in developing interventions to improve bathing outcomes.

Rinke, C.L., Williams, J.J., Lloyd, K.E., & Smith-Scott, W. (1978). The effects of prompting and reinforcement on self-bathing by elderly residents of a nursing home. *Behavior Therapy* 2, 873-881.

Author	Sample	Description	Results	Comments
Rinke and colleagues (1978)	6 subjects diagnosed with OBS (1 male and 5 females) who received bathing assistance but were thought capable of bathing themselves. They were selected by nursing home staff.	Two groups pretest and post test quasi-experimental design. Baseline - subjects bathed in usual manner with bathing divided into 5 categories: undressing, soaping, rinsing, drying and dressing. Categories were further divided into specific responses (i.e. soaping: applying and removing soap to 8 body parts). Treatment conditions consisted of prompting and reinforcement, separately and in combination. Two subjects acted as control by receiving usual nursing home care. Observation was used. A prompt score was given if verbal or physical prompts were used and a reinforcement score given if behavior occurred without prompts. Use of prompts and reinforcement by NA was recorded every 10 th second.	Analysis consisted of percentage of each subjects' improvement in self bathing. Control group: subject 1 showed no difference and subject 2 decreased in percentage of improvement in undressing. Prompting and Reinforcement Group: Subject 3 improved 100% in all categories. Subject 4 improved 100% in all categories except undressing. Subjects 5 and 6 received reinforcement, prompting and reinforcement and prompting. #5 improved 100% in all dressing and undressing and showed no improvement in soaping with reinforcement. #5's rinsing improved to 7 behaviors with prompting and reinforcement but decreased to 6 behaviors with prompting alone. #6 improved 100% in undressing with prompting alone but showed no improvement in dressing. Rinsing, soaping and drying improved to 6 behaviors with prompting and reinforcement. Prompting alone improved undressing and rinsing to 6 behaviors.	Sample size small. Suggests prompting and reinforcement increase self-care bathing behaviors. Improvements suggest that well-learned self-care behaviors can be reinstated.

Author	Sample	Description	Results	Comments
Ryden (1988)	183 community-dwelling individuals with dementia. Ages 45-87 (mean age 71.1). 99 females and 84 males. Living arrangements : 72% with spouse 10% with child 2% with other relatives 3.3% with non-relatives 12% alone	Survey Study Surveyed the CI diagnosis, medications, behavioral symptoms, and cognitive impairment. Data analysis consisted of frequency distributions and correlations.	Behavioral symptoms: 65% Verbal (50%), physical (46%), and sexual (18%) Aggression were reported in 119 (65%) of the CI individuals. Seventy percent of family members with a severely aggressive elder found ways to prevent aggressive behaviors. There was a positive association between aggressive behaviors and the family member feeling upset and aggressive and acting aggressively towards the elder [$F(4,102)=3.02, p=0.02$]. There were no significant difference in the amount of help received from family and friends between the aggressive and non-aggressive group.	The findings of study indicate that community dwelling family CGs of CI elders are having problems with behavioral symptoms. Families with more aggressive family members refused to participate. These family members seem to recognize that aggressive behaviors can result in negative responses on their part so they are interested in using strategies to prevent aggressive behaviors. A weakness of the study is families with more aggressive family members refused to participate.

Sandman, P.O., Norberg, A., Adolfsson, R., Axelsson, K. & Hedlly, V. (1986) Morning care of patients with Alzheimer-type dementia. A theoretical model based on direct observations. *Journal of Advanced Nursing*, 11, 369-378.

Author	Sample	Description	Results	Comments
Sandman and colleagues (1986)	3 females and 2 males from age 54 to 76. Sample represented Alzheimer's stages from ambulatory to vegetative.	Qualitative observational study in hospital setting. Four observers simultaneously observed each subject on 6 occasions. Notes were taken in unsystematic way. Grounded theory method was used to analyze and categorize notes.	Twelve categories were developed describing self-care abilities of CI elders and assistance provided by staff. Agreement between 2 independent observers was 88%. Of those subjects who could participate in care, washing was easier for them than dressing. Instructions were provided by the nurse in 55% of baths and the action was initiated by the nurse for 4% of the baths. During dressing, nurses initiated action 22% of the time and only gave instructions to the CI elder 4% of the time. None of the subjects could bathe or dress independently. 75% of all action required for these tasks was performed by nursing staff.	Suggests that independent bathing is more difficult than dressing independently for CI elders (high percentage of subjects received assistance with bathing and dressing). This study provided a way to begin assessing deficits during dressing and bathing.

Author	Sample	Description	Results	Comments
Tappen (1994)	63 CI elders. Ages ranged from 59-100 (M=84).	<p>Three group pre-test, post-test quasi-experimental design. Study conducted in 3 series of 3 concurrent groups (skills training, stimulation and control). Intervention period was 20 weeks. Skill training and stimulation groups received 2.5 hours of functional skill training that focused on regaining ADL function. Least amount of assistance needed was provided. Stimulation group also participated in adult games, group discussions, etc. Control group received regular care from nursing home staff.</p> <p>Physical Self-Maintenance Scale and Performance Test of ADLs were used to measure pre and post test functional level. Five goals r/t ADLs were set for each subject after pre-test evaluation. ANOVA was used to compare difference in goal attainment of the 3 groups. ANOVA was also used to test differences among all groups in physical self-maintenance. ANCOVA was used to control for differences in functional ability levels between groups.</p>	<p>No significant differences in Physical Self-Maintenance Scale or Performance Test of ADLs during pre-test.</p> <p>Physical Self-Maintenance Scale was significant after removal of pre-test scores effect.</p> <p>Skills training group showed significant increase compared to control group. Stimulation group showed no significant difference.</p> <p>Performance Test of ADLs showed no significant effect over time. Mean scores did increase in skill training and stimulation group and decreased in control.</p> <p>Skill training group showed highest post-test mean r/t goal attainment, followed by stimulation then control groups.</p>	<p>Study suggests skill training may be effective in preventing decline or improving self-care in CI elders. Author acknowledges limitation r/t no provisions for testing role of procedural memory in facilitation self-care.</p> <p>Shorter studies are needed to determine appropriate intervention length.</p> <p>Studies also needed to address individual training instead of group training.</p> <p>Study also needed to train CGs to perform interventions to reduce dependency during bathing.</p>

Teri, L., Borson, S.M., Kiyak, H.A., Yamagishi, M. (1989). Behavioral disturbance, cognitive dysfunction and functional skill: Prevalence and relationship in Alzheimer's Disease. *Journal of American Geriatrics Society* 37, 109-116.

Author	Sample	Description	Results	Comments
Teri and colleagues (1989)	56 community-dwelling CI elders and their caregivers. Caregivers were spouses (83%), daughters or daughters-in-law (11%) and friends (6%). Ages of CI elders ranged from 58-85 (M=71).	<p>Purpose: to clarify the nature of behavioral problems in dementia and to identify cognitive and functional factors that might be associated with the type and level of behavioral problems.</p> <p>Design: non-experimental. Caregivers were interviewed in their home re problematic behaviors and IADL and ADL self-care behaviors of elders. MMSE was administered to CI elders.</p> <p>Sample was described using descriptive statistics (frequencies, means and SDs). T-test used to compare total number of behavioral problems in CI males and females. Fisher's exact test was used to compare reports of specific behavioral problems. Correlations obtained to determine relationship of behavioral problems to level of cognitive and functional impairments.</p>	<p>Average CI elder was moderately impaired in cognitive functioning, more in the areas of memory and initiation/preservation. Avg. number of behaviors reported by caregivers was 10 out of a total of 48 behaviors with the mean occurrence being 2. Average number of behaviors occurring more than twice per week was 7. 22% of caregivers reported at least 15 behaviors. Average duration of behaviors was three. Males were reported to have significantly more behavioral problems than females. No significant difference in males and females regarding self-care behaviors. Elders with more impaired conceptual skills had more problematic behaviors and more persistent behaviors.</p>	<p>Study suggests that CI males have more behavioral problems than females. Limitation to the study was the use of a relatively new instrument to measure disruptive behaviors. Another limitation acknowledged is the potential of bias in caregivers' ratings of behaviors; however responses of caregivers and observation ratings of research assistants have found to be compatible.</p> <p>The researchers addressed the need for further examination of how gender of the caregiver may affect how sensitive or tolerant they are to certain behavioral problems.</p>

(1) 1-6.

Author	Sample	Description	Results	Comments
Teri, Larson, and Reifer (1988)	127 subjects were selected from a group of 200 community dwelling clinic patients participating in a prospective study of the evaluation of dementia. Their ages ranged from 60-94 years (mean age 77 years). The subjects were administered the Folstein Mini-Mental State Exam (MMSE), and The Blessed Dementia Rating Scale; eight additional items evaluated behaviors reported routinely in the literature as problematic and prevalent among CI elders.	<p>Purpose: to describe the nature and rates of behavioral disturbances among CI elders, with particular attention to the relationship between the level of impairment and nature of behavioral disturbances</p> <p>Design: Exploratory Non-experimental study</p> <p>The subjects were administered the Folstein Mini-Mental State Exam (MMSE), and The Blessed Dementia Rating Scale; eight additional items evaluated behaviors reported routinely in the literature as problematic and prevalent among CI elders. A trained geriatrician rated the presence or absence of behaviors from observations and/or family reports</p>	<p>Hygiene care was most problematic in severely CI elders (71%). The number of behavioral symptoms also significantly increased as cognitive impairment increased [$F(2,124) = 29.38, P < .001$]. The percentage of subjects reported to have behavioral symptoms significantly increased with the level of cognitive impairment ($\chi^2 1,125 = 13.13, p < .001$). The Blessed Dementia Rating Scale revealed the same results. The number of behavioral symptoms significantly increased as cognitive impairment increased [$t(1,123) = 2.94, p < .01$], the percentage of subjects reported to have behavioral symptoms significantly increased ($\chi^2 1,125 = 12.75, p < .01$). No correlation was found between age or gender and behavioral symptoms.</p>	<p>This study suggests that, community dwelling family caregivers of CI elders during hygiene care encounters more behavioral symptoms. Further studies are needed to examine the specific types of behaviors that occur when family caregivers assist CI elders with bathing.</p>

Author	Sample	Description	Results	Comments
Vernooij-Dassen, Felling & Persoon (1996)	138 caregivers and 138 non-institutionalized CI elders. Spouses, children and friends made up the caregivers. 68% of caregivers were female and 69% of CI elders were female. Average age of CI elders was 78 and average age of caregiver was 63.	<p>Purpose: Aim- to investigate predictors of change in caregivers' ability to care for CI elders and admission to nursing homes. 10 month intervention study conducted in the Netherlands. Design was quasi-experimental with treatment and control groups. Treatment group received outside support and care giving assistance four hours/week. Researchers interviewed both CI elder and caregiver.</p> <p>Descriptive statistics were used to describe caregivers' sense of competence. Stepwise Regression Analysis used to predict change in sense of competence. Logistic Regression Analysis used to predict nursing home admission.</p>	<p>Sense of competence by caregivers decreased from average of 18.44 to 17.4. Factors influencing change in sense of competence were initial sense of competence, females living with CI elder, agitated behaviors by CI elders during care giving. Catholic family caregiver and duration of dementia. CI elders were 2 times more likely to remain in home with family caregiver if dementia was mild to moderate, the caregiver received home help and the caregiver received the intervention. CI elders with ADL impairment were 3 times more likely to receive home care if provided by family caregiver.</p>	<p>Findings show reality of care giving decreases feeling of competence. Agitated behaviors also contribute to this. Females living with CI elders without outside assistance have more difficulty. Catholic caregivers dealt with disease progression better, supporting importance of religious beliefs in satisfaction as caregiver. Institutionalization was prevented with less severe dementia, additional home help, receipt of family support and increased ADL impairment (an unanticipated finding). Cultural differences r/t ADL assistance may have affected the results.</p>

Wykle, M., Segal, M. (1991). A comparison of black and white family caregivers experience with dementia. *Journal of the National Black Nurses Association* 5, 1, 29-41.

Author	Sample	Description	Results	Comments
Wykle and Segal (1991)	<p>Purposeful sample of 40 primary family caregivers (20 black and 20 white). Black caregivers ages ranged from 29-82 (M=57) and whites ranged from 29-87 (M=64). 85% of whites and 55% of blacks were married. Majority of caregivers were female who were daughters or daughters-in-law. Educational backgrounds were similar. White incomes were higher (\$30,000-34,999) than black incomes (\$20,000-24,999).</p>	<p>Purpose: pilot study to identify similarities and differences in problem solving and coping strategies, stressors and the use of informal and formal resources by white and black family caregivers. Reliability and validity of the quantitative measures in the study were also estimated. Variables of interest were health status, problems and stressors, and coping strategies of caregivers.</p> <p>Design: Non-experimental design using interview techniques. Qualitative and quantitative methods were used in interviews. Interviews averaged 1 1/2 hours Data was analyzed using descriptive statistics and t-test to compare the two groups.</p>	<p>Black caregivers experienced significantly more psychological distress. Blacks reported the most difficult problem encountered was the lack of assistance from home health aides to relieve them from duties of care giving. Whites reported the feelings associated with the demands of care giving (i.e. guilt and isolation) as the most difficult problem. The second most difficult problem reported by both groups was management of disruptive behaviors. Hassles reported by 50% of both groups were behaviors associated with cognitive decline. Bathing was viewed as a hassle by 50% of both groups. Blacks used prayer, faith and religion as coping strategy. Whites used acceptance of changes, help from professionals, emotional release and problem solving as coping strategies.</p>	<p>This study illustrates the specific hassles r/t care giving and the coping strategies used by black family caregivers. This is important to know that the clinical interventions and research protocols can be designed to address the needs of both black and white caregivers. The researchers suggest that programs that are more culturally sensitive should be implemented.</p>

APPENDIX B
CONSENT FORMS

Phase 1 Expert Consent Form

TITLE: Family Caregivers' Perceptions of Assisting Cognitively Impaired Elders During Bathing: Instrument Development

PRINCIPAL INVESTIGATOR: Johannah Uriri, RN, MNsc, (501) 296-1939 or 405-8132; ***After hours:*** 221-1205 or 405-8132.

PURPOSE:

You are invited to participate in this research study because you are an expert in the areas of gerontological nursing, dementia, family caregiving, and/or instrument development. The purpose of this study is to develop and test a series of questions to examine perceptions of family caregivers when assisting a family member with dementia during bathing. Results from the study will assist me in developing a better questionnaire to be used in future studies.

PROCEDURES:

You have received a booklet of questionnaires sent through the mail to you by the principal investigator (Johannah Uriri). A stamped return envelope addressed to the principal investigator is included. You are asked to comment on the clarity and consistency of the questions and directions. You will have two weeks to complete the questionnaire. A post card and another questionnaire will be sent if the booklet is not returned after week two. A total of 10 experts will participate in the study, 2 experts will be recruited from Arkansas and 8 experts will be recruited from Oregon.

RISKS AND DISCOMFORTS:

It is possible that some of the questions could make you feel mildly anxious or uncomfortable. There are no other anticipated risks for participating in this study.

BENEFITS:

You may or may not personally benefit from participating in this study. But, by participating in the research, you may contribute new information, which may benefit family caregivers of persons with dementia in the future.

ALTERNATIVES:

You may choose not to participate in this study. Your participation is voluntary.

Phase 1 Expert Consent Form

CONFIDENTIALITY:

The information that you give is confidential. Your name will not be linked in any way with your responses and data from the questionnaire. Neither your name nor your identity will be used for publication or publicity purposes. The questionnaires will have a code number that can be linked to you. However, only the principal investigator (Johannah Uriri) will have access to your name and the list that links your name and number. The questionnaires will be kept in a locked cabinet and destroyed when the project is finished. The summary of data of all questionnaires will be kept indefinitely and may be used in future research. Your signed consent form will be kept separate from the questionnaire.

COSTS:

There are no costs to you for participating in the study.

LIABILITY:

You have not waived any legal rights to which you are legally entitled to by signing this form. If you have any questions about your rights as a research subject or concerning a research-related injury, you can call the Institutional Review Board representative at phone number (501) 686-5667.

PARTICIPATION:

The principal investigator, Johannah Uriri (501) 296-1939 or 405-8132, will answer any other questions you may have about this study. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled, and you may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. The principal investigator may terminate your participation. If significant new findings are developed during the course of this research, which may relate to your willingness to continue to participate, this information will be shared with you.

I have read the above statement and have been able to ask questions and express concerns, which have been satisfactorily responded to by the principal investigator. I understand the purpose of the study as well as the potential benefit and risks that are involved. I hereby give my informed and free consent to be a participant in this study. I have been given a copy of this consent form.

Your signature below indicates that you have read the foregoing and agree to participate in this study. Enclosed are two consent forms. Please keep one copy for your records and sign and return the second in the return self-addressed stamped envelope along with the questionnaire.

Phase 1 Expert Consent Form

Do you want the results of the study sent to you? Yes_____ No _____.

Participant's Signature

Date

Investigator's Signature

Date

Phase 1 Family Caregiver Consent Form

TITLE: Family Caregivers' Perceptions of Assisting Cognitively Impaired Elders During Bathing: Instrument Development

PRINCIPAL INVESTIGATOR: Johannah Uriri, RN, MNsc, (501) 296-1939 or 405-8132; *After hours:* 221-1205 or 405-8132.

PURPOSE:

You are invited to participate in this research study because you are a caregiver of a family member who has some form of dementia. The purpose of this study is to develop and test a series of questions to examine perceptions of family caregivers when assisting a family member with dementia during bathing. Results of the study will assist me in developing a better booklet of questions to be used in future studies.

PROCEDURES:

You have received a booklet of questions sent through the mail or given to you by your support group facilitator. The booklet includes this consent form and instructions to complete the booklet. A stamped return envelope addressed to the principal investigator is also included. You are asked to complete a series of questions. Your answers will help to develop questions that will be later used with family caregivers examining their perceptions of assisting a family member with dementia during bathing. You are asked to comment on the clarity and consistency of the questions and directions. You will have two weeks to complete the questionnaire. A post card and another questionnaire will be sent if the booklet is not returned during after week two. Again, you will have two weeks to complete the booklet and a post card will be sent to remind you to complete the booklet during week three if the booklet is not returned. Also, you are asked to participate in an optional face-to-face interview with the principal investigator to examine your responses and comments. The booklets will take approximately 30-45 minutes to complete, but it is suggested that you stop at 15-minute intervals to rest. The interviews will last approximately one hour to 1 1/2 hours if you decide to participate in the interview.

A total of 10 family caregivers (18 years old and older) will participate in the study, recruited from Arkansas and Oregon (5 family caregivers from each location).

RISKS AND DISCOMFORTS:

It is possible that some of the questions could make you feel mildly anxious or uncomfortable. There are no other anticipated risks for participating in this study.

Phase 1 Family Caregiver Consent Form

BENEFITS:

You may or may not personally benefit from participating in this study. For instance, by answering the questions, you may or may not become more aware of you and your family member's actions and feelings while assisting a family member with dementia during bathing. Also, by participating in the research, you may contribute new information, which may benefit other family caregivers of persons with dementia in the future.

ALTERNATIVES:

You may choose not to participate in this study. Your participation is voluntary.

CONFIDENTIALITY:

The information that you give is confidential with the exception of the Human Research Advisory Committee which may review records to make sure I am following proper procedures. Neither your name nor your identity will be used for publication or publicity purposes. The booklets will have a code number that can be linked to you. However, only the principal investigator (Johannah Uriri) will have access to your name and the list that links your name and number. The booklet will be kept in a locked cabinet and destroyed when the project is finished. The summary of data of all booklets will be kept indefinitely and may be used in future research. Your signed consent form will be kept separated from the booklet. According to Arkansas Laws, suspected elder abuse must be reported to the appropriate authorities.

COSTS:

There are no costs to you for participating in the study. Enclosed in the return envelope for the consent form is \$10.00, a token of appreciation for the time you spent completing the booklet.

LIABILITY:

You have not waived any legal rights to which are legally entitled to by signing this form. If you have any questions about your rights as a research subject or concerning a research-related injury, you can call the Institutional Review Board representative at phone number (501) 686-5667.

PARTICIPATION:

Johannah Uriri, (501) 296-1939 or 405-8132, will answer any other questions you may have about this study. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled, and you may

Phase 1 Family Caregiver Consent Form

discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. The principal investigator may terminate your participation. If significant new findings are developed during the course of this research, which may relate to your willingness to continue to participate, this information will be shared with you. Enclosed are two consent forms. Please keep one copy for your records and sign and return the second in the stamped self-addressed envelope along with the booklet of questions.

I have read the above statement and have been able to ask questions and express concerns, which have been satisfactorily responded to by the investigator. I understand the purpose of the study as well as the potential benefit and risks that are involved. I hereby give my informed and free consent to be a participant in this study.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

Participant's Signature

Date

Do you wish to further discuss your answers (approximately 1-1 ½ hrs)?

Yes_____ No _____.

If Yes:

Participant's Signature

Date

Do you want the results of the study sent to you?

Yes_____

No _____.

Investigator's Signature

Date

Phase 2 Family Caregiver Consent Form

TITLE: Family Caregivers' Perceptions of Assisting Cognitively Impaired Elders During Bathing: Instrument Development

PRINCIPAL INVESTIGATOR: Johannah Uriri, RN, MNSc, and (501) 296-1939

PURPOSE:

You are invited to participate in this research study because you are a caregiver of a family member that has some form of dementia. The purpose of this study is to develop and test a series of questions to examine perceptions of family caregivers when assisting a family member with dementia during bathing. Results from the study will assist me in developing better questions to be used in future studies.

PROCEDURES:

You have received a booklet of questions through the mail or given to you by your support group facilitator, clinic staff or adult day care staff. The booklet includes this consent form and instructions to complete the booklet. A stamped return envelope addressed to the principal investigator is also included. You are asked to complete a series of questions. Your answers will help me to develop questions that will be later used with other family caregivers examining their perceptions of assisting a family member with dementia during bathing. You will have two weeks to complete the booklet of questions. A post card and another booklet will be sent if the booklet is not returned after week two. The questions will take approximately 30-45 minutes to answer, but it is suggested that you stop at 15-minute intervals to rest. A total of 100 family caregivers will participate in the study, recruited from Arkansas and Oregon. Approximately 50 family caregivers will be from Arkansas and 50 from Oregon.

RISKS AND DISCOMFORTS:

It is possible that some of the questions could make you feel mildly anxious or uncomfortable. There are no other anticipated risks for participating in this study.

BENEFITS:

You may or may not personally benefit from participating in this study. For instance, by answering the questions, you may or may not become aware of you and family member's actions and feelings while assisting a family with dementia during bathing. However, by participating in the research, you may contribute new information, which may benefit other family caregivers of persons with dementia in the future.

Phase 2 Family Caregiver Consent Form

ALTERNATIVES:

You may choose not to participate in this study. Your participation is voluntary.

CONFIDENTIALITY:

The information that you give is confidential with the exception of a Human Research Advisory Committee which may review records to make sure I am following proper procedure. Neither your name nor your identity will be used for publication or publicity purposes. The booklets will have a code number that can be linked to you. However, only the principal investigator (Johannah Uriri) will have access to your name and the list that links your name and number. The booklet will be kept in a locked cabinet and destroyed when the project is finished. The summary of data of all booklets will be kept indefinitely and may be used in future research. Your signed consent form will be kept separated from the booklet. According to Arkansas Laws, suspected elder abuse must be reported to the appropriate authorities

COSTS:

There are no costs to you for participating in the study. Enclosed in the return envelope for the consent form and booklet is \$10.00, a token of appreciation for the time you spent completing the questionnaire.

LIABILITY:

You have not waived any legal rights to which you are legally entitled to by signing this form. If you have further questions about your rights as a research subject or concerning a research-related injury, you can call the Institutional Review Board representative at phone number (501) 686-5667.

PARTICIPATION:

Johannah Uriri, (501) 296-1939 or 405-8132, will answer any other questions you may have about this study. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled, and you may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. The principal investigator may terminate your participation. If significant new findings are developed during the course of this research, which may relate to your willingness to continue to participate, this information will be shared with you. Enclosed are two consent forms. Please keep one copy for your records and sign and return the second in the self-addressed stamped envelope along with the booklet.

Phase 2 Family Caregiver Consent Form

I have read the above statement and have been able to ask questions and express concerns, which have been satisfactorily responded to by the principal investigator. I understand the purpose of the study as well as the potential benefit and risks that are involved. I hereby give my informed and free consent to be a participant in this study. I have been given a copy of this consent form.

Your signature below indicates that you have read the foregoing and agree to participate in this study

Participant's Signature

Date

Do you want the results of the study sent to you? Yes _____ No _____.

Investigator's Signature

Date

IRB # 5606**OREGON HEALTH SCIENCES UNIVERSITY****Phase 2 Family Caregiver Consent Form**

TITLE: Family Caregivers' Perceptions of Assisting Cognitively Impaired Elders During Bathing: Instrument Development

PRINCIPAL INVESTIGATOR: Johannah Uriri, RN, MNSc, (503) 494-1136

PURPOSE:

You are invited to participate in this research study because you are a caregiver of a family member who has some form of dementia. We need family caregivers to assist in the development of a questionnaire. The purpose of this study is to develop and test a series of questions that examine perceptions of family caregivers when assisting a family member with dementia during bathing. Results from the study will help develop better questions for future studies. You will have two weeks to complete the booklet of questions.

PROCEDURES:

You have received a package with a booklet of questions through the mail or given to you by your support group facilitator, clinic staff, or adult day care staff. The package includes two consent forms and instructions to complete the booklet. A stamped return envelope addressed to the principal investigator is also included. You are asked to complete a series of questions about you and your family member. The questions ask about your family member's preferences, participation, and reactions during bathing. Also, included in the booklet are questions about the usual bathing routine, your health, and assistance received from others. General questions will be asked regarding you and your family members (e.g., age race religion, occupation etc.). Your answers will help to develop questions that will be used later with other family caregivers. You will have two weeks to complete the booklet of questions. A post card and another booklet will be sent if the booklet is not returned after week two.

RISKS AND DISCOMFORTS:

The questions will take approximately 30-45 minutes for you to complete, however, it is suggested that you rest at 15-minute intervals. It is possible that some of the questions will make you feel mildly anxious or uncomfortable. For instance, sometimes individuals with dementia may display difficult behaviors during bathing, which may be disturbing to caregivers. Some of the questions ask about these types of

emotionally upset. If it is determined that you may benefit from counseling an appropriate referral will be made. You may refuse to answer any questions that you wish. There are no other anticipated risks for participating in this study.

BENEFITS:

You may or may not benefit personally from participating in this study. For instance, by answering the questions, you may or may not become aware of you and your family member's actions and feelings while assisting a family member with dementia during bathing. However, by participating in the research, you may contribute new information, which may benefit other family caregivers of persons with dementia in the future.

ALTERNATIVES:

You may choose not to participate in this study. Your participation is voluntary.

CONFIDENTIALITY:

The information that you give is confidential. Neither your name nor your identity will be used for publication or publicity purposes. The booklets do not have code numbers that can be linked to you. The booklet will be kept in a locked cabinet and destroyed when the project is finished. The summary of data, of all booklets, will be kept indefinitely and may be used in future research. Your signed consent form will be kept separated from the booklet. According to Oregon law, suspected elder abuse must be reported to the appropriate authorities

COSTS (For OHSU Patients):

There are no costs to you for participating in the study. Enclosed in the booklet is a \$10.00 token of appreciation for the time you spent answering the questions. The \$10.00 is yours to keep whether you participate in the study or not.

LIABILITY:

It is not the policy of the U.S. Department of Health and Human Services, or any federal agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury.

The Oregon Health Sciences University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the university, its officer or employees, you have the right to bring legal action against the university to recover the damage done to you. Subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived any legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the Oregon Health Sciences University's legal department at (503) 494-5222.

OREGON HEALTH SCIENCES UNIVERSITY**Phase 2 Family Caregiver Consent Form****PARTICIPATION:**

Johannah Uriri, (503) 494-1136, will answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at anytime without affecting your relationship with or treatment at the Oregon Health Sciences University.

Participation in the study is determined by a question, at the beginning of the booklet, that asks: "Do you assist your family member with bathing"? Those family caregivers who do not assist with bathing will not be included in this study. Enclosed are two consent forms. Please keep one copy for your records and sign and return the second in the self-addressed stamped envelope along with the booklet.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

Participant's Signature

Date

Do you want the results of the study sent to you? Yes____ No ____.

Investigator's Signature

Date

APPENDIX C

Phase 1 Instruments Content Validity Rating Forms

Purpose

These questions are designed for family members who have a relative with memory problems and who assist that relative during bathing. In these questions, we use the term **family member** to refer to your relative who has memory problems.

Your answers will help us to better understand the situation of family caregivers like you. Your view will be very helpful to nurses, doctors, and other people who work with family caregivers.

Directions

It should take about 30-40 minutes to answer these questions.

Answer the questions as honestly as you can; there are no right or wrong answers. Please do not consult with other people before you answer the questions. It is your view that we need.

If you have comments on any questions, feel free to write in the blank spaces around the questions, on the back cover, or on other sheets of paper.

Your role as a caregiver

We will be asking you many detailed questions surrounding bathing, because we would like to have a good picture of what you do to assist your family member during bathing.

In some questions, we use the term **family caregiver** to refer to you.

Although you may not think of yourself as a caregiver, we use the term caregiver very broadly as someone who assists a family member during bathing because of the family member's health or memory problems.

Questions?

If you have any questions, please contact:

Johannah Uriri at (501) 296-1939 Arkansas or (503) 494-1137 Oregon

We thank you for your thoughtful answers.

You And Your Family Member

Family member refers to your relative or friend who has health or memory problems. Please tell us about you and your family member. For all questions, fill in the blank or **CIRCLE** the answer that best describes you and your family member.

- | | |
|--|---|
| <p>1. How are you related to the family member you are helping?</p> <p><u>You</u> are his or her:</p> <p>Wife1</p> <p>Husband..... 2</p> <p>Daughter..... 3</p> <p>Son..... 4</p> <p>Daughter-in-law..... 5</p> <p>Son-in-law..... 6</p> <p>Other relative 7</p> <p>Neighbor or friend..... 8</p> <p>Other:_____</p> | <p>5. Do you assist your family member during bathing?</p> <p>Yes..... 1 No 0</p> |
| <p>2. About how many years have you and your family member known each other?</p> <p>_____ years _____ months</p> | <p>6. How often did you assist your family member during bathing the past month?</p> <p>Once or twice in the month..... 1</p> <p>Once a week..... 2</p> <p>2 or 3 times a week..... 3</p> <p>Every other day..... 4</p> <p>Everyday..... 5</p> |
| <p>3. How long have you personally been involved in caregiving for your family member because of his or her memory problems?</p> <p>_____ years _____ months</p> | <p>7-15 What are the reasons that your family member baths or washes up? CIRCLE NO or YES for each reason.</p> |
| <p>4. At this time, do you and your family member live in the same household?</p> <p>Yes..... 1</p> <p>No..... 0</p> <p>↓</p> | <p>7. Personal hygiene? Yes No</p> <p>8. Bladder or urine accident? Yes No</p> <p>9. Bowel movement or diarrhea gets on skin Yes No</p> <p>10. Bad odor or smelly? Yes No</p> <p>11. Sweaty skin or perspiration Yes No</p> <p>12. Food spilled on skin Yes No</p> <p>13. To get warm Yes No</p> <p>14. To get cool? Yes No</p> <p>15. Other reasons (please describe).</p> <p>_____</p> <p>_____</p> |
| <p>4a. If NO, how far away do you live from your family member?</p> <p>_____ miles</p> | |

YOUR OPINIONS ABOUT QUESTIONS # 6- 15 ON PAGE 2

Concepts being measured: Bathing assistance provided by the family caregiver.

- A. Is question # 6 on page 2 clear or confusing?
- 1). Very Clear
 - 2). Mostly clear; only a little confusing
 - 3). Somewhat confusing
 - 4). Very confusing
- B. Do you have any suggestions for improving the wording of Question #6? Please make your comments below or you may write directly on Question # 6.

Concepts being measured: Function of the bath.

ITEMS 7-15 ON PAGE 2

- A. Item Clarity? C (clear) or U (unclear)
Write C or U by #s 7 - 15 on page 2. Feel free to give any suggestions for revising unclear items if you wish.
- B. Consistency? Do items 7 - 15 on page 2 generally belong together?
Circle Yes or No.

Yes

No

If No, which items do not belong? _____

- C. Delete items? Should any items be deleted?

Yes

No

- D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Your Family Member And Bathing

Directions: Describe where and how often your family member bathes or washes up? **CIRCLE** one answer for each type of bathing.

	Doesn't use	Once or twice month	Once a week	2 or 3 times week	Every other day	Every day
1. Bathroom sink	0	1	2	3	4	5
2. Tub	0	1	2	3	4	5
3. Shower	0	1	2	3	4	5
4. Bedbath	0	1	2	3	4	5
5. Other (please describe) _____						

Your Family Member and Memory Problems

Now, we'd like to ask you some questions about your family member's memory and the difficulty he or she may have doing some things. (**CIRCLE** your answer.)

How difficult is it for your family member to:	Not At All Difficult	Just A Little Difficult	Fairly Difficult	Very Difficult	Can't Do At All
6. Remember recent events?	0	1	2	3	4
7. Know what day of the week it is?	0	1	2	3	4
8. Remember his or her home address?	0	1	2	3	4
9. Remember words?	0	1	2	3	4
10. Understand simple instructions?	0	1	2	3	4
11. Find his or her way around the house?	0	1	2	3	4
12. Speak sentences?	0	1	2	3	4
13. Recognize people that he or she knows?	0	1	2	3	4

YOUR OPINIONS ABOUT QUESTIONS #s 1 - 5 ON PAGE 4

Concepts being measured: Frequency of the bath.

ITEMS 1 - 5 ON PAGE 4

- A. Item Clarity? C (clear) or U (unclear)
Write C or U by #s 1 - 5 on page 4. Feel free to give any suggestions for revising unclear items if you wish.
- B. Consistency? Do items 1-5 on page 4 generally belong together?
Circle Yes or No.

Yes

No

If No, which items do not belong? _____

- C. Delete items? Should any items be deleted?

Yes

No

- D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

**Because Questions 6 - 13 were developed by another researcher, we do not need you to rate them.
(Please go to page 6)**

What You and Your Family Member Do During Bathing

Directions: Please circle yes or no if you or your family member perform any of the activities during bathing.

Bath Preparation				
Task	What Do You Do		What Does Your Family Member	
1. Obtain supplies (e.g., soap, wash cloth, towels, shampoo)	Yes	No	Yes	No
2. Remove clothing	Yes	No	Yes	No
3. Turn on the cold water	Yes	No	Yes	No
4. Turn on the hot water	Yes	No	Yes	No
5. Adjust Water Temperature	Yes	No	Yes	No
6. Hold wash cloth	Yes	No	Yes	No
7. Wet wash cloth	Yes	No	Yes	No
8. Apply soap to the wash cloth	Yes	No	Yes	No

9. Other (Please describe) _____

Please: Circle Y(Yes) or N (No) to indicate if you or your family member wash or dries each body part.

Body part	You wash		You Dry		Family member wash		Family member dry	
10. Face	Y	N	Y	N	Y	N	Y	N
11. Neck	Y	N	Y	N	Y	N	Y	N
12. Ears	Y	N	Y	N	Y	N	Y	N
13. Hands	Y	N	Y	N	Y	N	Y	N
14. Underneath Arms	Y	N	Y	N	Y	N	Y	N
15. Chest	Y	N	Y	N	Y	N	Y	N
16. Stomach	Y	N	Y	N	Y	N	Y	N
17. Back	Y	N	Y	N	Y	N	Y	N
18. Bottom	Y	N	Y	N	Y	N	Y	N
19. Private areas	Y	N	Y	N	Y	N	Y	N
20. Legs	Y	N	Y	N	Y	N	Y	N
21. Toes	Y	N	Y	N	Y	N	Y	N
22. Hair	Y	N	Y	N	Y	N	Y	N

23. Other (Please describe) _____

YOUR OPINIONS ABOUT QUESTIONS # 1 - 5 ON PAGE 6

Concepts being measured: Bath Preparation

ITEMS 1 - 9 ON PAGE 6

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by #s 1 - 9 on page 6. Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items 1-5 on page 6 generally belong together?

Circle Yes or No.

Yes

No

If No, which items do not belong?

- C. Delete items? Should any items be deleted?

Yes

No

- D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Concepts being measured: Self-care behaviors of cognitive impaired elders during bathing

ITEMS 10 - 23 ON PAGE 6

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by #s 10 - 23 on page 6. Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items 10 - 23 on page 6 generally belong together?

Circle Yes or No.

Yes

No

If No, which items do not belong? _____

- C. Delete items? Should any items be deleted?

Yes

No

- D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Your Experience During Bathing

Directions: For each statement, **CIRCLE** the one response that best describes your experience when helping your family member with bathing during the last month.

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
1. I was confident in my ability to assist with bathing	1	2	3	4	5
2. I felt comfortable in the things I did to help my family member during bathing	1	2	3	4	5
3. I felt prepared to take care of his or her physical needs during bathing	1	2	3	4	5
4. I was patient while assisting	1	2	3	4	5
5. I felt relaxed while assisting	1	2	3	4	5
6. I felt I was doing a good job	1	2	3	4	5
7. I had an easy time doing the bath	1	2	3	4	5
8. I felt safe caring for my family member during bathing	1	2	3	4	5
9. Helping him or her during bathing was pleasurable	1	2	3	4	5
10. I thought things through when bathing my family member	1	2	3	4	5
11. I was comfortable with my ability to communicate with him or her during bathing	1	2	3	4	5

Your Experience During Bathing (continued)					
	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
12. I felt confident finding solutions for difficult situations during bathing.....	1	2	3	4	5
13. Taking care of my family member during bathing was satisfying.....	1	2	3	4	5
14. I felt unsure about my ability to help him or her during bathing.....	1	2	3	4	5
15. I was able to manage specific problems that occur during bathing.....	1	2	3	4	5
16. I understood what my family member needed during bathing.....	1	2	3	4	5
17. I felt confident in my ability to care for him or her during bathing.....	1	2	3	4	5
18. There were positive aspects of caring for my family member.....	1	2	3	4	5
19. Bathing my family member was done quickly.....	1	2	3	4	5
20. Bathing him or her went smoothly.....	1	2	3	4	5
21. I got frustrated when assisting my family member with bathing.....	1	2	3	4	5
22. I got frightened when assisting my family member with bathing.....	1	2	3	4	5
23. I thought the bath got my family member clean.....	1	2	3	4	5
24. I was able to manage unexpected events that occurred during bathing.....	1	2	3	4	5

YOUR OPINIONS ABOUT QUESTIONS # 1 - 24 ON PAGE 8 & 9

Concept being measured: Satisfaction and preparedness with assisting CI elders

A. Item Clarity? C (clear) or U (unclear)

Write C or U by #s 1 - 24 on pages 8 & 9. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 24 on pages 8 & 9 generally belong together? Circle Yes or No.

Yes

No

If No, which items do not belong? _____

C. Delete items? Should any items be deleted?

Yes

No

D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Caregiving Hassles During Bathing

Directions: Sometimes when assisting your family member with bathing things can happen that annoy or bother you. These things are called hassles.

Think about the times you have bathed your family member in the past month. Some of the things may have been a hassle while others were not. For each question, **CIRCLE** NO if the event did not happen. **CIRCLE** YES if it did happen.

If you **CIRCLED** YES, indicate how much of a hassle it was for you

DID IT HAPPEN?

DID IT HAPPEN?

			NOT A HASSLE	A SMALL HASSLE	A MEDIUM HASSLE	A BIG HASSLE
1. Family member criticizing or complaining	NO	YES	1	2	3	4
2. Family member yelling or swearing	NO	YES	1	2	3	4
3. Family member not cooperating	NO	YES	1	2	3	4
4. Family member frowning or scowling	NO	YES	1	2	3	4
5. Family member verbally inconsiderate; not respecting your feelings	NO	YES	1	2	3	4
6. Just being with my family member during bathing	NO	YES	1	2	3	4
7. Family member leaving tasks related to bathing uncompleted	NO	YES	1	2	3	4
8. Family member hitting or pinching	NO	YES	1	2	3	4
9. Overall, how much of a hassles was it to bathe your family member?			1	2	3	4

Comments

YOUR OPINIONS ABOUT QUESTIONS # 1 - 9 ON PAGE 11

Concept being measured: Caregiver distress

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 9 on page 11. Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items # 1 - 9 on page 11 generally belong together? Circle Yes or No.

Yes

No.

If No, which items do not belong? _____

- C. Delete items? Should any items be deleted?

- D. Add items? Should any items be added?

Yes

No.

If yes, give suggestions. _____

Family Caregiver Bathing Rating Scale

Directions: **CIRCLE** the number that best reflects what you think you do when helping your family member during bathing.

During bathing how often do you.....	Never					Often
1. Address your family member by name or title (mom, dad, etc.) to get his or her attention?	1	2	3	4	5	6
2. Praise your family member? For example, do you say "Good job, that's right, you smell nice"?	1	2	3	4	5	6
3. Confront your family member? For example, argue with him or her?	1	2	3	4	5	6
4. Keep your voice calm and soothing?	1	2	3	4	5	6
5. Speak disrespectfully to your family member?	1	2	3	4	5	6
6. Find yourself not paying attention to your family member?	1	2	3	4	5	6
7. Carry on a conversation with your family member during the bath? (even if you do most of the talking).....	1	2	3	4	5	6
8. Allow your family member to help with bathing tasks?	1	2	3	4	5	6
9. Tell your family member what is going to happen before each part of the bath?	1	2	3	4	5	6
10. Give a bath in a hurry?	1	2	3	4	5	6
11. Act as if you don't care about him or her?.....	1	2	3	4	5	6

YOUR OPINIONS ABOUT QUESTIONS # 1 - 11 ON PAGE 13

Concept being measured: Caregivers' verbal communication and task presentation style.

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 11 on page 13. Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items # 1 - 11 on page 13 generally belong together? Circle Yes or No.

Yes

No.

If No, which items do not belong? _____

- C. Delete items? Should any items be deleted?

- D. Add items? Should any items be added?

Yes

No.

If yes, give suggestions. _____

Your View of Bathing

Directions: Please read each statement and CIRCLE the number that describes how much you agree or disagree with the following statements. Be sure to answer every question.

	STRONGLY DISAGREE	DISAGREE SOMEWHAT	AGREE SOMEWHAT	STRONGLY AGREE
1. Taking a shower can frighten my family member	1	2	3	4
2. My family member needs to take his or her bath when it is scheduled	1	2	3	4
3. When my family member complains of pain during bathing, it is best to ignore it and go on with the bath	1	2	3	4
4. The best way to get someone clean is to bathe him or her in the tub or the shower	1	2	3	4
5. It helps to praise my family member when he or she is cooperative during bathing	1	2	3	4
6. Some people may feel like they are being sexually assaulted when their private parts are being bathed	1	2	3	4
7. If I start taking off my family member's clothes and he or she hits me, it may be because I didn't explain what I was doing	1	2	3	4
8. Bed baths don't clean people really well	1	2	3	4
9. It is okay for my family member to have only one bath a week even if he or she is accustomed to taking two or three baths a week	1	2	3	4
10. Looking at my family member's point of view helps me understand why he or she is difficult during bathing	1	2	3	4
11. My family member may think getting bathed is an invasion of privacy	1	2	3	4
12. My family member should have a choice about how and when the bath is done	1	2	3	4

YOUR OPINIONS ABOUT QUESTIONS # 1 - 12 ON PAGE 15

Concept being measured: Caregiver attitudes towards assisting with bathing.

A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 12 on page 15. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 12 on page 15 generally belong together? **Circle** Yes or No.

Yes

No.

If No, which items do not belong? _____

C. Delete items? Should any items be deleted?

D. Add items? Should any items be added?

Yes

No.

If yes, give suggestions. _____

Giving a Bath

Directions: Please read each statement and **CIRCLE** the number that best describes you. Be sure to answer every question.

	NEVER OR RARELY	SOMETIMES	OFTEN	ALMOST ALWAYS
1. I feel ready to deal with difficult problems when bathing my family member.....	1	2	3	4
2. When he or she complains of pain or discomfort, I apologize and change what I do.....	1	2	3	4
3. When talking to my family member during the bath, I make sure that we are face to face so he or she can see me.....	1	2	3	4
4. If my family member looks me straight in the face and tells me "no" that he or she doesn't want a bath, then I should respect that and postpone the bath.....	1	2	3	4
5. I use ways to make bathing my family member go smoothly without taking too much time.....	1	2	3	4
6. If something about the bathing process bothers my family member, I wait and do the bath another time.....	1	2	3	4
7. During the bath, I watch for signs that my family member is upset so that I can slow down or change what I do.....	1	2	3	4
8. When telling my family member it is time for a bath, I take the time to understand his or her body language.....	1	2	3	4
9. When my family member tells me she or he doesn't want bathe, I feel like I need to go ahead and bathe him or her to keep with the planned routine for that day.....	1	2	3	4
10. I take the time to make things really calm for my family member at bath time.....	1	2	3	4
11. I make eye contact before saying what I'm going to do to him or her during the bath.....	1	2	3	4

YOUR OPINIONS ABOUT QUESTIONS # 1 - 11 ON PAGE 17

Concepts being measured: Caregiver behaviors towards assisting with bathing.

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 11 on page 17 Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items # 1 - 11 on page 17 generally belong together?
Circle Yes or No.

Yes No.

If No, which items do not belong?

- C. Delete items? Should any items be deleted?

- D. Add items? Should any items be added?

Yes No.

If yes, give suggestions.

Your Family Member's Reaction During Bathing

When you help your family member during bathing, he or she may show a wide range of reactions. Think about the last month when you helped your family member during bathing. What types of reactions did you observe during the bath? Please **CIRCLE** Y (YES) N (NO).

1. Smiles at you?	Y	N	20. Pats you on the back or other places?	Y	N
2. Hugs you?	Y	N	21. Makes repetitious noises (repeats sound over and over again)?	Y	N
3. Jokes with you?	Y	N	22. Makes insulting, but not obscene, gestures (making faces, sticking out tongue, etc.)?	Y	N
4. Hits you with an object (with towels, wash cloths etc.)?	Y	N	23. Uses hostile accusatory language towards you?	Y	N
5. Scratches you (marks digs, tears the surface of your skin)?	Y	N	24. Has excessive motor activity (a great deal of movement of any body part)?	Y	N
6. Makes sexual advances (acts in way that encourages sexual contact)?	Y	N	25. Talks constantly (continuous talking)?	Y	N
7. Elbows you (uses elbow to push or shove)?	Y	N	26. Uses obscene or profane language (curses, uses dirty language)?	Y	N
8. Makes obscene gestures (uses hands or other body parts to make improper/indecent motions)?	Y	N	27. Repeats words (uses the same words or phrases over and over again)?	Y	N
9. Makes threats or attempts to physically harm self?	Y	N	28. Causes you to smile/laugh?	Y	N
10. Hits you (uses hands to strike you)?	Y	N	29. Praises/compliments you (good job, etc.)?	Y	N
11. Kicks (uses leg/foot to strike out)?	Y	N	30. Pinches/squeezes?	Y	N
12. Places inappropriate substances in mouth soap, etc.)?	Y	N	31. Make noises that were monotone, subdued and low pitched, but a definite unpleasant sound?	Y	N
13. Physically takes objects from you?	Y	N	32. Pushes/shoves (presses against you)?	Y	N
14. Kisses you?	Y	N	33. Paces (walks back and forth during bathing)?	Y	N
15. Spits at you (spits without hitting you)?	Y	N	34. Follows directions (does what is asked of him or her)?	Y	N
16. Bangs objects nondes- tructively (bangs objects without causing harm)?	Y	N	35. Gives orders?	Y	N
17. Has a pleasant peaceful expression?	Y	N			
18. Looks tranquil, at ease or serene?	Y	N			
19. Has frightened facial expression?	Y	N			

Your Family Member's Reaction During Bathing (Continued)		
36. Makes threats implying physical harm to you? (uses words or body movements to harm you)?	Y	N
37. Screams, yells?	Y	N
38. Repeats the same words over and over in a mournful manner, expressing hurt or pain?	Y	N
39. Has a frowning facial expression?	Y	N
40. Has relaxed body language?	Y	N
41. Has tense body language? (moving a lot)?	Y	N
42. A fidgeting body language	Y	N
43. Tackles (jumps on you with force)?	Y	N
44. Bites(grabs your skin with teeth or gums)?	Y	N
45. Spits on you (saliva hits you)?	Y	N
46. Displays inappropriate sexual behavior?	Y	N
47. Thanks you?	Y	N
48. Makes noises of speech that are "hushed low sounds" like constant muttering?	Y	N
49. Does not follow directions (will not do what is asked of him or her)?	Y	N
50. Makes sounds like a moan or a groan?	Y	N
51. Other reactions during bathing		

Adapted from Beck et al., (1997) Disruptive Behavior Scale; and Hurley et al., (1992) Discomfort Scale

YOUR OPINIONS ABOUT QUESTIONS # 1 - 52 ON PAGES 19 & 20

Concept being measured: Care receiver's reactions to being assisted by the family caregiver during bathing.

A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 52 on pages 19 & 20. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 22 on pages 19 & 20 generally belong together?

Circle Yes or No.

Yes No.

If No, which items do not belong? _____

C. Delete items? Should any items be deleted? _____

D. Add items? Should any items be added? _____

Yes No.

If yes, give suggestions.

You and Your Family Member's Feelings

Now we would like you to let us know how you and your family member feel about each other at the current time. Please **CIRCLE** the answer that describes you and your family member.

	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	2	3	4	
2. How close do you feel to him or her?0	1	2	3	4	
3. How much do you enjoy sharing past experiences with him or her?0	1	2	3	4	
4. How much does he or she express feelings of.....0	1	2	3	4	
5. How attached are you to him or her?0	1	2	3	4	
6. How much does he or she help you?.....0	1	2	3	4	
7. How much do you like to sit and talk with him or her?.....0	1	2	3	4	
8. How much love do you feel for him or her?.....0	1	2	3	4	
9. To what extent do the two of you share the same values?0	1	2	3	4	
10. When you really need it, how much does he or she comfort you?0	1	2	3	4	
11. How much do the two of you laugh together?0	1	2	3	4	
12. How much do you confide in him or her?.....0	1	2	3	4	
13. How much emotional support does he or she give you?0	1	2	3	4	
14. To what extent do you enjoy the time the two of you spend together?0	1	2	3	4	
15. How often does he or she express feelings of warmth toward you?0	1	2	3	4	

Your Family Member

"Family member" refers to your relative or friend with health or memory problems. Please tell us about your family member. (Fill in the blank or **CIRCLE** the answer that describes your family member.)

1. How old is your family member?

_____ years

2. Is your family member female or male?

Female 1

Male 2

3. What is your family member's race?

African American/Black 1

Asian/Pacific Islander 2

Hispanic 3

Native American 4

White 5

Other 6

If other, write in _____

4. What is the highest grade in school that your family member completed?

Completed 6th grade or less 1

Junior high school (7th-9th grade) 2

Partial high school (10th-11th grade) 3

High school graduate 4

Partial college training 5

Completed college 6

Graduate professional training 7

5. What kind of work has your family member done most of his or her working life? _____

6. What is your family member's current marital status ?

Married 1

Widowed 2

Divorced 3

Separated 4

Never married 5

7. With whom does your family member live?

CIRCLE ALL that apply

No one, lives alone 0

With spouse 1

With child(ren) 2

With relative(s) 3

With friend(s), housemate(s) 4

In a nursing home or care facility 5

8. Altogether, counting your family member, how many people live in your family

member's household? _____ people

Tell Us About You

- | | |
|--|--|
| <p>1. In what year were you born? 19_____</p> <p>2. Are you female or male?</p> <p style="padding-left: 40px;">Female 1</p> <p style="padding-left: 40px;">Male 2</p> <p>3. What is your race?</p> <p style="padding-left: 40px;">African American/Black 1</p> <p style="padding-left: 40px;">Asian/Pacific Islander 2</p> <p style="padding-left: 40px;">Hispanic 3</p> <p style="padding-left: 40px;">Native American 4</p> <p style="padding-left: 40px;">White 5</p> <p style="padding-left: 40px;">Other 6</p> <p style="padding-left: 40px;">If other, write in _____</p> <p>4. What is the highest grade in school that you completed?</p> <p style="padding-left: 40px;">Completed 6th grade or less 7</p> <p style="padding-left: 40px;">Junior high school (7th - 9th grade) 6</p> <p style="padding-left: 40px;">Partial high school (10th - 11th grade) 5</p> <p style="padding-left: 40px;">High school graduate 4</p> <p style="padding-left: 40px;">Partial college training 3</p> <p style="padding-left: 40px;">Completed college 2</p> <p style="padding-left: 40px;">Graduate professional training 1</p> <p>5. What kind of work have you done most of your working life?</p> <p style="padding-left: 40px;">_____</p> <p style="padding-left: 40px;">_____</p> <p>6. What is your current marital status?</p> <p style="padding-left: 40px;">Married 1</p> <p style="padding-left: 40px;">Widowed 2</p> <p style="padding-left: 40px;">Divorced 3</p> <p style="padding-left: 40px;">Separated 4</p> <p style="padding-left: 40px;">Never married 5</p> | <p>7. Counting yourself, how many people live in your household?</p> <p style="padding-left: 40px;">_____ people</p> <p>8. Do you have children under age 18 living in your household or for whom you have caregiving responsibilities?</p> <p style="padding-left: 40px;">No 0</p> <p style="padding-left: 40px;">Yes 1</p> <p>9. Which of the following four statements describes your ability to get along on your income?</p> <p style="padding-left: 40px;">I can't make ends meet 1</p> <p style="padding-left: 40px;">I have just enough, no more 2</p> <p style="padding-left: 40px;">I have enough, with a little extra sometimes 3</p> <p style="padding-left: 40px;">I always have money left over 4</p> <p>10. For your own home, we are interested in whether you have to pay rent or make mortgage payments?</p> <p style="padding-left: 40px;">I pay rent 1</p> <p style="padding-left: 40px;">I make mortgage payments 2</p> <p style="padding-left: 40px;">I own my home outright and do not pay mortgage or rent 3</p> <p style="padding-left: 40px;">Other 4</p> <p style="padding-left: 40px;">If other, explain _____</p> <p style="padding-left: 40px;">_____</p> <p>11. Are you currently employed?</p> <p style="padding-left: 40px;">No, I am retired 1</p> <p style="padding-left: 40px;">No, I am looking for employment 2</p> <p style="padding-left: 40px;">No, I never have been employed 3</p> <p style="padding-left: 40px;">No, I quit work because of my family member's health condition 4</p> <p style="padding-left: 40px;">Yes, I am employed 5</p> |
|--|--|

Tell Us About You (Continued)

Your Health

16. During the **past 4 weeks** how much did **pain** interfere with your normal work(including both work outside the home and housework)? **(Circle One Number)**

Not at all 1
 A little bit..... 2
 Moderately 3
 Quite a bit 4
 Extremely 5

17. In general, would you say your health is **(Circle One Number)**:

Excellent.....1
 Very Good.....2
 Good.....3
 Fair.....4
 Poor.....5

The following items are about activities you might do during a typical day. Does **your health now** limit **YOU** in these activities? If so, how much? **(Circle One Number on Each Line)**.

Activities	Yes, I am	Yes, I am	No, Not
	Limited A Lot	Limited A Little	Limited At All
18. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
19. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
20. Lifting or carrying groceries	1	2	3
21. Climbing several flights of stairs	1	2	3
22. Climbing one flight of stairs	1	2	3
23. Bending, kneeling or stooping	1	2	3
24. Walking more than a mile	1	2	3
25. Walking several blocks	1	2	3
26. Walking one block	1	2	3
27. Bathing or dressing yourself	1	2	3

Help From Others In Bathing Your Family Member

EXTENT OF HELP

1. How many days in the past week did you spend time helping him or her? _____ days
2. On the days you help your family member with bathing, about how long do you spend helping him or her during bathing?
_____ hours _____ minutes
3. Altogether, how long has your family member needed extra help, from you or someone else, with bathing because of health or memory problems?
_____ years _____ month

HELP FROM RELATIVES

5. How much have relatives helped you with bathing him or her?
None at all0
A little1
Some2
Quite a bit3

HELP FROM FRIENDS AND NEIGHBOR

6. How much have friends and neighbors helped you with bathing him or her?
None at all0
A little1
Some2
Quite a bit3
A great deal4
7. Does help from others make it easier or harder for you ?
Easier.....0
Harder.....1

HELP FROM OTHERS IN BATHING YOUR FAMILY MEMBER

Now we would like to know if other people have helped you with bathing your family member?

HELP FROM PEOPLE WHOSE JOB IT IS

4. How much have people whose job it is (such as a health professional, a paid helper) helped you with bathing your family member?
None at all 0
A little 1
Some 2
Quite a bit 3
A great deal 4

HELP NOT RECEIVED

8. Is there a person you thought would help you more with bathing your family member, but who has **not** done so?
No..... 0
Yes 1
- 8a. If **YES**, how upsetting has it been for you that this person has **not** helped as you expected?
Not at all upsetting 0
A little upsetting 1
Somewhat upsetting 2
Quite upsetting 3
Extremely upsetting 4

Your Feelings During The Past Week

Using the scale below, **CIRCLE** the number which best describes how often you felt or behaved this way
— DURING THE PAST WEEK.

- 1 = Rarely or none of the time (less than 1 day)
 2 = Some or a little of the time (1–2 days)
 3 = Occasionally or a moderate amount of time (3–4 days)
 4 = Most or all of the time (5–7 days)

	Rarely or None	Some or A Little	Occasionally or Moderate	Most or All
During the PAST WEEK:				
1. I was bothered by things that usually don't bother me.....	1	2	3	4
2. I did not feel like eating; my appetite was poor.....	1	2	3	4
3. I felt that I could not shake off the blues even with help from my family or friends.....	1	2	3	4
4. I felt that I was just as good as other people.....	1	2	3	4
5. I had trouble keeping my mind on what I was doing.	1	2	3	4
6. I felt depressed.....	1	2	3	4
7. I felt that everything I did was an effort.....	1	2	3	4
8. I felt hopeful about the future.....	1	2	3	4
9. I thought my life had been a failure.....	1	2	3	4
10. I felt fearful.....	1	2	3	4
11. My sleep was restless.	1	2	3	4
12. I was happy.....	1	2	3	4
13. I talked less than usual.....	1	2	3	4
14. I felt lonely.....	1	2	3	4
15. People were unfriendly.....	1	2	3	4
16. I enjoyed life.....	1	2	3	4
17. I had crying spells.....	1	2	3	4
18. I felt sad.....	1	2	3	4
19. I felt that people disliked me.....	1	2	3	4
20. I could not get "going."	1	2	3	4

Your Overall Experience In Caregiving

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 do you feel because of all the caregiving things you do for your family member?	
	Not at all confined.....	0
	Confined a little.....	1
	Somewhat confined.....	2
	Confined a lot.....	3
	Extremely confined.....	4
2.	How often would you say that taking care of your family member is very difficult?	
	Never.....	0
	Rarely.....	1
	Sometimes.....	2
	Much of the time.....	3
	Always.....	4
3.	How much stress do you feel because of all your obligations, including taking care of your family member?	
	No stress.....	0
	Very little stress.....	1
	Some stress.....	2
	A lot of stress.....	3
	Overwhelming stress.....	4
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	4
	Positive outweighs the negative somewhat	3
	Positive and negative are about equal	2
	Negative outweighs the positive somewhat	1
	Negative outweighs the positive a lot	0
5.	What if your family member's care needs increase? How confident are you that you would be able to provide more care than you are doing now?	
	Not at all confident.....	0
	Not too confident.....	1
	Somewhat confident.....	2
	Pretty confident.....	3
	Very confident.....	4

6. What do you think about researchers coming into your home to observe you helping your family member with bathing?

7. What do you think about researchers videotaping you assisting your family member during bathing ?

8. What is most pleasurable for you about helping your family member with bathing?

9. What is the most difficult for you about helping your family member with bathing?

10. What kinds of things do you do to make bathing go smoothly?

11. What advice do you have for other caregivers who are having difficulties with their family member during bathing?

Date

TIME

DATE AND TIME YOU COMPLETED QUESTIONNAIRE

About how long did it take you to complete this questionnaire?

_____ hours _____ minutes

Thank you very much for sharing your experience and opinions with us. Your responses will be very helpful to us in getting a good idea of what it is really like for caregivers in your situation.

When you are done with the questionnaire, please return it to us in the enclosed stamped envelope.

Thank you again for your participation!

Purpose

Your expertise in gerontological nursing is needed to develop questionnaires designed for family members who have a relative with cognitive impairments and who assist that relative during bathing. The questions are designed to generate answers that will help us to understand the situation of family caregivers assisting cognitive impaired (CI) elders during bathing.

Directions

It should take about 30-40 minutes to answer these questions.

To estimate content validity, please review the items for clarity and consistency. Answer the questions as honestly as you can; there are no right or wrong answers. Please do not consult with other people before you answer the questions. It is your view that we need.

If you have comments on any questions, feel free to write in the blank spaces around the questions, on the back cover, or on other sheets of paper.

Questions?

If you have any questions, please contact:

Johannah Uriri at (501) 296-1939 Arkansas or (503) 494-1137 Oregon.

We thank you for your thoughtful input.

Expert Reviewers

This booklet contains scales designed for caregiver in the home setting who assist a cognitive impaired family member with bathing. Many scales were adapted from instruments originally developed for use with Certified Nursing Home Assistants (CNAs) in nursing home settings. We would like your help in evaluating these adapted scales.

The booklet is organized so that the scales to be evaluated is usually on the left hand page, and the content validity on the right hand page.

For each adapted scale, we will ask you to read the scale(usually on the right hand page).

- A. Item Clarity? Is each item clear?
- B. Consistency of Items? Do the items generally belong together.
- C. Should any items be deleted?
- D. Should any items be added?

Thank you for your help with this questionnaire.

Johannah Uriri

You And Your Family Member

Family member refers to your relative or friend who has health or memory problems. Please tell us about you and your family member. For all questions, fill in the blank or **CIRCLE** the answer that best describes you and your family member.

<p>1. How are you related to the family member you are helping?</p> <p>You are his or her:</p> <p>Wife 1</p> <p>Husband..... 2</p> <p>Daughter..... 3</p> <p>Son..... 4</p> <p>Daughter-in-law..... 5</p> <p>Son-in-law..... 6</p> <p>Other relative 7</p> <p>Neighbor or friend..... 8</p> <p>Other: _____</p> <p>2. About how many years have you and your family member known each other?</p> <p>_____ years _____ months</p> <p>3. How long have you personally been involved in caregiving for your family member because of his or her memory problems?</p> <p>_____ years _____ months</p> <p>4. At this time, do you and your family member live in the same household?</p> <p>Yes..... 1</p> <p>No..... 0</p> <p style="margin-left: 20px;">↓</p> <p>4a. If NO, how far away do you live from your family member?</p> <p>_____ miles</p>	<p>5. Do you assist your family member during bathing?</p> <p>Yes..... 1 No 0</p> <p>6. How often did you assist your family member during bathing the past month?</p> <p>Once or twice in the month..... 1</p> <p>Once a week..... 2</p> <p>2 or 3 times a week..... 3</p> <p>Every other day..... 4</p> <p>Everyday..... 5</p> <p>7-15 What are the reasons that your family member baths or washes up? CIRCLE NO or YES for each reason.</p> <p>7. Personal hygiene? Yes No</p> <p>8. Bladder or urine accident? Yes No</p> <p>9. Bowel movement or diarrhea gets on skin Yes No</p> <p>10. Bad odor or smelly? Yes No</p> <p>11. Sweaty skin or perspiration Yes No</p> <p>12. Food spilled on skin Yes No</p> <p>13. To get warm Yes No</p> <p>14. To get cool? Yes No</p> <p>15. Other reasons (please describe).</p> <p>_____</p> <p>_____</p>
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YOUR OPINIONS ABOUT QUESTIONS # 6 - 15 ON PAGE 2

Concepts being measured: Bathing assistance provided by the family caregiver.

- A. Is question # 6 on page 2 clear or confusing?
- 1). Very Clear
 - 2). Mostly clear; only a little confusing
 - 3). Somewhat confusing
 - 4). Very confusing
- B. Do you have any suggestions for improving the wording of Question #6? Please make your comments below or you may write directly on Question # 6.

Concepts being measured: Function of the bath.

ITEMS 7-15 ON PAGE 2

- A. Item Clarity? C (clear) or U (unclear)
Write C or U by #s 7 - 15 on page 2. Feel free to give any suggestions for revising unclear items if you wish.
- B. Consistency? Do items 7 - 15 on page 2 generally belong together?
Circle Yes or No.

Yes

No

If No, which items do not belong? _____

- C. Delete items? Should any items be deleted?

Yes

No

- D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Your Family Member And Bathing

Directions: Describe where and how often your family member bathes or washes up? **CIRCLE** one answer for each type of bathing.

	Doesn't use	Once or twice month	Once a week	2 or 3 times week	Every other day	Every day
1. Bathroom sink	0	1	2	3	4	5
2. Tub	0	1	2	3	4	5
3. Shower	0	1	2	3	4	5
4. Bedbath	0	1	2	3	4	5
5. Other (please describe) _____						

Your Family Member and Memory Problems

Now, we'd like to ask you some questions about your family member's memory and the difficulty he or she may have doing some things. (**CIRCLE** your answer.)

How difficult is it for your family member to:	Not At All Difficult	Just A Little Difficult	Fairly Difficult	Very Difficult	Can't Do At All
6. Remember recent events?	0	1	2	3	4
7. Know what day of the week it is?	0	1	2	3	4
8. Remember his or her home address?	0	1	2	3	4
9. Remember words?	0	1	2	3	4
10. Understand simple instructions?	0	1	2	3	4
11. Find his or her way around the house?	0	1	2	3	4
12. Speak sentences?	0	1	2	3	4
13. Recognize people that he or she knows?	0	1	2	3	4

YOUR OPINIONS ABOUT QUESTIONS #s 1 - 5 ON PAGE 4

Concepts being measured: Frequency of the bath.

ITEMS 1 - 5 ON PAGE 4

A. Item Clarity? C (clear) or U (unclear)
Write C or U by #s 1 - 5 on page 4. Feel free to give any suggestions
for revising unclear items if you wish.

B. Consistency? Do items 1-5 on page 4 generally belong together?
Circle Yes or No.

Yes

No

If No, which items do not belong? _____

C. Delete items? Should any items be deleted?

Yes

No

D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

**Because Questions 6 - 13 were developed by another
researcher, we do not need you to rate them.
(Please go to page 6)**

What You and Your Family Member Do During Bathing

Directions: Please circle yes or no if you or your family member perform any of the activities during bathing.

Bath Preparation						
Task	What Do You Do		What Does Your Family Member			
1. Obtain supplies (e.g., soap, wash cloth, towels, shampoo)	Yes	No	Yes	No		
2. Remove clothing	Yes	No	Yes	No		
3. Turn on the cold water	Yes	No	Yes	No		
4. Turn on the hot water	Yes	No	Yes	No		
5. Adjust Water Temperature	Yes	No	Yes	No		
6. Hold wash cloth	Yes	No	Yes	No		
7. Wet wash cloth	Yes	No	Yes	No		
8. Apply soap to the wash cloth	Yes	No	Yes	No		
9. Other (Please describe) _____						
Please: Circle Y(Yes) or N (No) to indicate if you or your family member wash or dries each body part.						
Body part	You wash		You Dry		Family member wash	Family member dry
10. Face	Y	N	Y	N	Y	N
11. Neck	Y	N	Y	N	Y	N
12. Ears	Y	N	Y	N	Y	N
13. Hands	Y	N	Y	N	Y	N
14. Underneath Arms	Y	N	Y	N	Y	N
15. Chest	Y	N	Y	N	Y	N
16. Stomach	Y	N	Y	N	Y	N
17. Back	Y	N	Y	N	Y	N
18. Bottom	Y	N	Y	N	Y	N
19. Private areas	Y	N	Y	N	Y	N
20. Legs	Y	N	Y	N	Y	N
21. Toes	Y	N	Y	N	Y	N
22. Hair	Y	N	Y	N	Y	N
23. Other (Please describe) _____						

YOUR OPINIONS ABOUT QUESTIONS # 1 - 5 ON PAGE 4

Concepts being measured: Bath Preparation

ITEMS 1 - 9 ON PAGE 6

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by #s 1 - 9 on page 6. Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items 1-5 on page 6 generally belong together?

Circle Yes or No.

Yes

No

If No, which items do not belong?

- C. Delete items? Should any items be deleted?

Yes

No

- D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Concepts being measured: Self-care behaviors of cognitive impaired elders during bathing

ITEMS 10 - 23 ON PAGE 6

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by #s 10 - 23 on page 6. Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items 10 - 23 on page 6 generally belong together?

Circle Yes or No.

Yes

No

If No, which items do not belong? _____

- C. Delete items? Should any items be deleted?

Yes

No

- D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Your Experience During Bathing

Directions: For each statement, **CIRCLE** the one response that best describes your experience when helping your family member with bathing during the last month.

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
1. I was confident in my ability to assist with bathing	1	2	3	4	5
2. I felt comfortable in the things I did to help my family member during bathing 1		2	3	4	5
3. I felt prepared to take care of his or her physical needs during bathing	1	2	3	4	5
4. I was patient while assisting	1	2	3	4	5
5. I felt relaxed while assisting	1	2	3	4	5
6. I felt I was doing a good job	1	2	3	4	5
7. I had an easy time doing the bath	1	2	3	4	5
8. I felt safe caring for my family member during bathing	1	2	3	4	5
9. Helping him or her during bathing was pleasurable	1	2	3	4	5
10. I thought things through when bathing my family member	1	2	3	4	5
11. I was comfortable with my ability to communicate with him or her during bathing	1	2	3	4	5

Your Experience During Bathing (continued)					
	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
12. I felt confident finding solutions for difficult situations during bathing.....	1	2	3	4	5
13. Taking care of my family member during bathing was satisfying.....	1	2	3	4	5
14. I felt unsure about my ability to help him or her during bathing.....	1	2	3	4	5
15. I was able to manage specific problems that occur during bathing.....	1	2	3	4	5
16. I understood what my family member needed during bathing.....	1	2	3	4	5
17. I felt confident in my ability to care for him or her during bathing.....	1	2	3	4	5
18. There were positive aspects of caring for my family member.....	1	2	3	4	5
19. Bathing my family member was done quickly.....	1	2	3	4	5
20. Bathing him or her went smoothly.....	1	2	3	4	5
21. I got frustrated when assisting my family member with bathing.....	1	2	3	4	5
22. I got frightened when assisting my family member with bathing.....	1	2	3	4	5
23. I thought the bath got my family member clean.....	1	2	3	4	5
24. I was able to manage unexpected events that occurred during bathing.....	1	2	3	4	5

YOUR OPINIONS ABOUT QUESTIONS # 1 - 24 ON PAGE 8 & 9

Concept being measured: Satisfaction and preparedness with assisting CI elders

A. Item Clarity? C (clear) or U (unclear)

Write C or U by #s 1 - 24 on pages 8 & 9. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 24 on pages 8 & 9 generally belong together? Circle Yes or No.

Yes

No

If No, which items do not belong? _____

C. Delete items? Should any items be deleted?

Yes

No

D. Add items? Should any items be added?

Yes

No

If Yes, give suggestions _____

Caregiving Hassles During Bathing

Directions: Sometimes when assisting your family member with bathing things can happen that annoy or bother you. These things are called hassles.

Think about the times you have bathed your family member in the past month. Some of the things may have been a hassle while others were not. For each question, **CIRCLE** NO if the event did not happen. **CIRCLE YES** if it did happen.

If you **CIRCLED** YES, indicate how much of a hassle it was for you

DID IT HAPPEN?		NOT A HASSLE	A SMALL HASSLE	A MEDIUM HASSLE	A BIG HASSLE
1. Family member criticizing or complaining	NO YES	1	2	3	4
2. Family member yelling or swearing	NO YES	1	2	3	4
3. Family member not cooperating	NO YES	1	2	3	4
4. Family member frowning or scowling	NO YES	1	2	3	4
5. Family member verbally inconsiderate; not respecting your feelings	NO YES	1	2	3	4
6. Just being with my family member during bathing	NO YES	1	2	3	4
7. Family member leaving tasks related to bathing uncompleted	NO YES	1	2	3	4
8. Family member hitting or pinching	NO YES	1	2	3	4
9. Overall, how much of a hassles was it to bathe your family member?		1	2	3	4

Comments

YOUR OPINIONS ABOUT QUESTIONS # 1 - 9 ON PAGE 11

Concept being measured: Caregiver distress

A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 9 on page 11. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 9 on page 11 generally belong together? Circle Yes or No.

Yes

No.

If No, which items do not belong? _____

C. Delete items? Should any items be deleted?

D. Add items? Should any items be added?

Yes

No.

If yes, give suggestions. _____

Family Caregiver Bathing Rating Scale

Directions: CIRCLE the number that best reflects what you think you do when helping your family member during bathing.

During bathing how often do you.....	Never					Often
1. Address your family member by name or title (mom, dad, etc.) to get his or her attention?	1	2	3	4	5	6
2. Praise your family member? For example, do you say "Good job, that's right, you smell nice"?	1	2	3	4	5	6
3. Confront your family member? For example, argue with him or her?	1	2	3	4	5	6
4. Keep your voice calm and soothing?	1	2	3	4	5	6
5. Speak disrespectfully to your family member?	1	2	3	4	5	6
6. Find yourself not paying attention to your family member?	1	2	3	4	5	6
7. Carry on a conversation with your family member during the bath? (even if you do most of the talking).....	1	2	3	4	5	6
8. Allow your family member to help with bathing tasks?	1	2	3	4	5	6
9. Tell your family member what is going to happen before each part of the bath?	1	2	3	4	5	6
10. Give a bath in a hurry?	1	2	3	4	5	6
11. Act as if you don't care about him or her?.....	1	2	3	4	5	6

YOUR OPINIONS ABOUT QUESTIONS # 1 - 11 ON PAGE 13

Concept being measured: Caregivers' verbal communication and task presentation style.

A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 11 on page 13. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 11 on page 13 generally belong together? Circle Yes or No.

Yes

No.

If No, which items do not belong? _____

C. Delete items? Should any items be deleted?

D. Add items? Should any items be added?

Yes

No.

If yes, give suggestions.

Your View of Bathing

Directions: Please read each statement and CIRCLE the number that describes how much you agree or disagree with the following statements. Be sure to answer every question.

	STRONGLY DISAGREE	DISAGREE SOMEWHAT	AGREE SOMEWHAT	STRONGLY AGREE
1. Taking a shower can frighten my family member	1	2	3	4
2. My family member needs to take his or her bath when it is scheduled	1	2	3	4
3. When my family member complains of pain during bathing, it is best to ignore it and go on with the bath	1	2	3	4
4. The best way to get someone clean is to bathe him or her in the tub or the shower	1	2	3	4
5. It helps to praise my family member when he or she is cooperative during bathing	1	2	3	4
6. Some people may feel like they are being sexually assaulted when their private parts are being bathed	1	2	3	4
7. If I start taking off my family member's clothes and he or she hits me, it may be because I didn't explain what I was doing	1	2	3	4
8. Bed baths don't clean people really well	1	2	3	4
9. It is okay for my family member to have only one bath a week even if he or she is accustomed to taking two or three baths a week.....	1	2	3	4
10. Looking at my family member's point of view helps me understand why he or she is difficult during bathing.....	1	2	3	4
11. My family member may think getting bathed is an invasion of privacy	1	2	3	4
12. My family member should have a choice about how and when the bath is done	1	2	3	4

YOUR OPINIONS ABOUT QUESTIONS # 1 - 12 ON PAGE 15

Concept being measured: Caregiver attitudes towards assisting with bathing.

A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 12 on page 15. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 12 on page 15 generally belong together? **Circle** Yes or No.

Yes

No.

If No, which items do not belong? _____

C. Delete items? Should any items be deleted?

D. Add items? Should any items be added?

Yes

No.

If yes, give suggestions. _____

Giving a Bath

Directions: Please read each statement and **CIRCLE** the number that best describes you. Be sure to answer every question.

	NEVER OR RARELY	SOMETIMES	OFTEN	ALMOST ALWAYS
1. I feel ready to deal with difficult problems when bathing my family member.....	1	2	3	4
2. When he or she complains of pain or discomfort, I apologize and change what I do.....	1	2	3	4
3. When talking to my family member during the bath, I make sure that we are face to face so he or she can see me.....	1	2	3	4
4. If my family member looks me straight in the face and tells me "no" that he or she doesn't want a bath, then I should respect that and postpone the bath.....	1	2	3	4
5. I use ways to make bathing my family member go smoothly without taking too much time.....	1	2	3	4
6. If something about the bathing process bothers my family member, I wait and do the bath another time.....	1	2	3	4
7. During the bath, I watch for signs that my family member is upset so that I can slow down or change what I do.....	1	2	3	4
8. When telling my family member it is time for a bath, I take the time to understand his or her body language.....	1	2	3	4
9. When my family member tells me she or he doesn't want bathe, I feel like I need to go ahead and bathe him or her to keep with the planned routine for that day.....	1	2	3	4
10. I take the time to make things really calm for my family member at bath time.....	1	2	3	4
11. I make eye contact before saying what I'm going to do to him or her during the bath.....	1	2	3	4

YOUR OPINIONS ABOUT QUESTIONS # 1 - 11 ON PAGE 17

Concepts being measured: Caregiver behaviors towards assisting with bathing.

- A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 11 on page 17 Feel free to give any suggestions for revising unclear items if you wish.

- B. Consistency? Do items # 1 - 11 on page 17 generally belong together?
Circle Yes or No.

Yes No.

If No, which items do not belong?

- C. Delete items? Should any items be deleted?

- D. Add items? Should any items be added?

Yes No.

If yes, give suggestions.

Your Family Member's Reaction During Bathing

When you help your family member during bathing, he or she may show a wide range of reactions. Think about the last month when you helped your family member during bathing. What types of reactions did you observe during the bath? Please **CIRCLE** Y (YES) N (NO).

1. Smiles at you?	Y	N	20. Pats you on the back or other places?	Y	N
2. Hugs you?	Y	N	21. Makes repetitious noises (repeats sound over and over again)?	Y	N
3. Jokes with you?	Y	N	22. Makes insulting, but not obscene, gestures (making faces, sticking out tongue, etc.)?	Y	N
4. Hits you with an object (with towels, wash cloths etc.)?	Y	N	23. Uses hostile accusatory language towards you?	Y	N
5. Scratches you (marks digs, tears the surface of your skin)?	Y	N	24. Has excessive motor activity (a great deal of movement of any body part)?	Y	N
6. Makes sexual advances (acts in way that encourages sexual contact)?	Y	N	25. Talks constantly (continuous talking)?	Y	N
7. Elbows you (uses elbow to push or shove)?	Y	N	26. Uses obscene or profane language (curses, uses dirty language)?	Y	N
8. Makes obscene gestures (uses hands or other body parts to make improper/indecent motions)?	Y	N	27. Repeats words (uses the same words or phrases over and over again)?	Y	N
9. Makes threats or attempts to physically harm self?	Y	N	28. Causes you to smile/laugh?	Y	N
10. Hits you (uses hands to strike you)?	Y	N	29. Praises/compliments you (good job, etc.)?	Y	N
11. Kicks (uses leg/foot to strike out)?	Y	N	30. Pinches/squeezes?	Y	N
12. Places inappropriate substances in mouth soap, etc.)?	Y	N	31. Make noises that were monotone, subdued and low pitched, but a definite unpleasant sound?	Y	N
13. Physically takes objects from you?	Y	N	32. Pushes/shoves (presses against you)?	Y	N
14. Kisses you?	Y	N	33. Paces (walks back and forth during bathing)?	Y	N
15. Spits at you (spits without hitting you)?	Y	N	34. Follows directions (does what is asked of him or her)?	Y	N
16. Bangs objects nondestructively (bangs objects without causing harm)?	Y	N	35. Gives orders?	Y	N
17. Has a pleasant peaceful expression?	Y	N			
18. Looks tranquil, at ease or serene?	Y	N			
19. Has frightened facial expression?	Y	N			

YOUR OPINIONS ABOUT QUESTIONS # 1 - 52 ON PAGES 19 & 20

Concept being measured: Care receiver's reactions to being assisted by the family caregiver during bathing.

A. Item Clarity? C (clear) or U (unclear)

Write C or U by # 1 - 52 on pages 19 & 20. Feel free to give any suggestions for revising unclear items if you wish.

B. Consistency? Do items # 1 - 22 on pages 19 & 20 generally belong together?

Circle Yes or No.

Yes No.

If No, which items do not belong? _____

C. Delete items? Should any items be deleted? _____

D. Add items? Should any items be added? _____

Yes No.

If yes, give suggestions.

You and Your Family Member's Feelings

Now we would like you to let us know how you and your family member feel about each other at the current time. Please **CIRCLE** the answer that describes you and your family member.

	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	2	3	4
2. How close do you feel to him or her?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4. How much does he or she express feelings of.....	0	1	2	3	4
5. How attached are you to him or her?	0	1	2	3	4
6. How much does he or she help you?.....	0	1	2	3	4
7. How much do you like to sit and talk with him or her?.....	0	1	2	3	4
8. How much love do you feel for him or her?.....	0	1	2	3	4
9. To what extent do the two of you share the same values?	0	1	2	3	4
10. When you really need it, how much does he or she comfort you?	0	1	2	3	4
11. How much do the two of you laugh together?	0	1	2	3	4
12. How much do you confide in him or her?.....	0	1	2	3	4
13. How much emotional support does he or she give you?	0	1	2	3	4
14. To what extent do you enjoy the time the two of you spend together?	0	1	2	3	4
15. How often does he or she express feelings of warmth toward you?	0	1	2	3	4

Your Family Member

"Family member" refers to your relative or friend with health or memory problems. Please tell us about your family member. (Fill in the blank or **CIRCLE** the answer that describes your family member.)

- | | |
|---|---|
| <p>1. How old is your family member?
 _____ years</p> <p>2. Is your family member female or male?</p> <p> Female 1</p> <p> Male 2</p> <p>3. What is your family member's race?</p> <p> African American/Black 1</p> <p> Asian/Pacific Islander 2</p> <p> Hispanic 3</p> <p> Native American 4</p> <p> White 5</p> <p> Other 6</p> <p> If other, write in _____</p> <p>4. What is the highest grade in school that your family member completed?</p> <p> Completed 6th grade or less 1</p> <p> Junior high school (7th-9th grade) 2</p> <p> Partial high school (10th-11th grade) 3</p> <p> High school graduate 4</p> <p> Partial college training 5</p> <p> Completed college 6</p> <p> Graduate professional training 7</p> | <p>5. What kind of work has your family member done most of his or her working life? _____</p> <p>6. What is your family member's current marital status ?</p> <p> Married 1</p> <p> Widowed 2</p> <p> Divorced 3</p> <p> Separated 4</p> <p> Never married 5</p> <p>7. With whom does your family member live?
 CIRCLE ALL that apply</p> <p> No one, lives alone 0</p> <p> With spouse 1</p> <p> With child(ren) 2</p> <p> With relative(s) 3</p> <p> With friend(s), housemate(s) 4</p> <p> In a nursing home or care facility 5</p> <p>8. Altogether, counting your family member, how many people live in your family member's household? _____ people</p> |
|---|---|

Tell Us About You

- | | |
|--|--|
| <p>1. In what year were you born? 19_____</p> <p>2. Are you female or male?</p> <p style="padding-left: 40px;">Female 1</p> <p style="padding-left: 40px;">Male 2</p> <p>3. What is your race?</p> <p style="padding-left: 40px;">African American/Black 1</p> <p style="padding-left: 40px;">Asian/Pacific Islander 2</p> <p style="padding-left: 40px;">Hispanic 3</p> <p style="padding-left: 40px;">Native American 4</p> <p style="padding-left: 40px;">White 5</p> <p style="padding-left: 40px;">Other 6</p> <p style="padding-left: 40px;">If other, write in _____</p> <p>4. What is the highest grade in school that you completed?</p> <p style="padding-left: 40px;">Completed 6th grade or less 7</p> <p style="padding-left: 40px;">Junior high school (7th - 9th grade) 6</p> <p style="padding-left: 40px;">Partial high school (10th - 11th grade) 5</p> <p style="padding-left: 40px;">High school graduate 4</p> <p style="padding-left: 40px;">Partial college training 3</p> <p style="padding-left: 40px;">Completed college 2</p> <p style="padding-left: 40px;">Graduate professional training 1</p> <p>5. What kind of work have you done most of your working life?</p> <p style="padding-left: 40px;">_____</p> <p style="padding-left: 40px;">_____</p> <p>6. What is your current marital status?</p> <p style="padding-left: 40px;">Married 1</p> <p style="padding-left: 40px;">Widowed 2</p> <p style="padding-left: 40px;">Divorced 3</p> <p style="padding-left: 40px;">Separated 4</p> <p style="padding-left: 40px;">Never married 5</p> | <p>7. Counting yourself, how many people live in your household?</p> <p style="padding-left: 40px;">_____ people</p> <p>8. Do you have children under age 18 living in your household or for whom you have caregiving responsibilities?</p> <p style="padding-left: 80px;">No 0</p> <p style="padding-left: 80px;">Yes 1</p> <p>9. Which of the following four statements describes your ability to get along on your income?</p> <p style="padding-left: 40px;">I can't make ends meet 1</p> <p style="padding-left: 40px;">I have just enough, no more 2</p> <p style="padding-left: 40px;">I have enough, with a little extra sometimes 3</p> <p style="padding-left: 40px;">I always have money left over 4</p> <p>10. For your own home, we are interested in whether you have to pay rent or make mortgage payments?</p> <p style="padding-left: 40px;">I pay rent 1</p> <p style="padding-left: 40px;">I make mortgage payments 2</p> <p style="padding-left: 40px;">I own my home outright and do not pay mortgage or rent 3</p> <p style="padding-left: 40px;">Other 4</p> <p style="padding-left: 40px;">If other, explain _____</p> <p style="padding-left: 40px;">_____</p> <p>11. Are you currently employed?</p> <p style="padding-left: 40px;">No, I am retired 1</p> <p style="padding-left: 40px;">No, I am looking for employment 2</p> <p style="padding-left: 40px;">No, I never have been employed 3</p> <p style="padding-left: 40px;">No, I quit work because of my family member's health condition 4</p> <p style="padding-left: 40px;">Yes, I am employed 5</p> |
|--|--|

Tell Us About You (Continued)

12. What is the total amount of your yearly **household** income? Please include money from jobs, net income from a business or farm, dividends, interest, net income from rent, social security, and any other money income.

Under \$5,000.....	1
\$5,000–\$5,999.....	2
\$6,000–\$6,999.....	3
\$7,000–\$7,999.....	4
\$8,000–\$9,999.....	5
\$10,000–\$12,499.....	6
\$12,500–\$14,999.....	7
\$15,000–\$17,499.....	8
\$17,500–\$19,999.....	9
\$20,000–\$24,499.....	10
\$25,000–\$34,999.....	11
\$35,000–\$49,999.....	12
\$50,000 and more.....	13

13. What is your religious affiliation?

Baptist.....	1
Catholic.....	2
Episcopalian.....	3
Holiness.....	4
Jewish.....	5
Lutheran.....	6
Methodist.....	7
Non-Denominational.....	8
Pentecostal.....	9
Presbyterian.....	10
Protestant.....	11
Do not Practice.....	12
Other.....	13

If other, write in _____

14. On a scale from 1 to 5, to what extent do you consider yourself to be religious or spiritual?

☐1 ☐2 ☐3 ☐4 ☐5

Not Very
religious or religious or
spiritual spiritual

15. Does your religion or spirituality make a difference or influence the care that you provide to your family member?

No 0

Yes 1

- 15a. If **YES**, please describe how or in what way your religion or spirituality makes a difference in the care you provide.

[illegible]

Tell Us About You (Continued)

Your Health

16. During the **past 4 weeks** how much did **pain** interfere with your normal work(including both work outside the home and housework)? **(Circle One Number)**

Not at all 1
 A little bit..... 2
 Moderately 3
 Quite a bit 4
 Extremely 5

17. In general, would you say your health is **(Circle One Number)**:

Excellent.....1
 Very Good.....2
 Good.....3
 Fair.....4
 Poor.....5

The following items are about activities you might do during a typical day. Does **your health now** limit **YOU** in these activities? If so, how much? **(Circle One Number on Each Line).**

Activities		Yes, I am Limited A Lot	Yes, I am Limited A Little	No, Not Limited At All
18.	Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
19.	Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
20.	Lifting or carrying groceries	1	2	3
21.	Climbing several flights of stairs	1	2	3
22.	Climbing one flight of stairs	1	2	3
23.	Bending, kneeling or stooping	1	2	3
24.	Walking more than a mile	1	2	3
25.	Walking several blocks	1	2	3
26.	Walking one block	1	2	3
27.	Bathing or dressing yourself	1	2	3

Help From Others In Bathing Your Family Member

EXTENT OF HELP	HELP FROM RELATIVES
<p>1. How many days in the past week did you spend time helping him or her? _____ days</p> <p>2. On the days you help your family member with bathing, about how long do you spend helping him or her during bathing? _____ hours _____ minutes</p> <p>3. Altogether, how long has your family member needed extra help, from you or someone else, with bathing because of health or memory problems? _____ years _____ month</p>	<p>5. How much have relatives helped you with bathing him or her?</p> <p>None at all 0 A little 1 Some 2 Quite a bit 3</p> <p style="text-align: center;">HELP FROM FRIENDS AND NEIGHBOR</p> <p>6. How much have friends and neighbors helped you with bathing him or her?</p> <p>None at all 0 A little 1 Some 2 Quite a bit 3 A great deal 4</p> <p>7. Does help from others make it easier or harder for you?</p> <p>Easier 0 Harder 1</p>
HELP FROM OTHERS IN BATHING YOUR FAMILY MEMBER	HELP <u>NOT</u> RECEIVED
<p>Now we would like to know if other people have helped you with bathing your family member?</p> <p>HELP FROM PEOPLE WHOSE JOB IT IS</p> <p>4. How much have people whose job it is (such as a health professional, a paid helper) helped you with bathing your family member?</p> <p>None at all 0 A little 1 Some 2 Quite a bit 3 A great deal 4</p>	<p>8. Is there a person you thought would help you more with bathing your family member, but who has not done so?</p> <p>No 0 Yes 1</p> <p>8a. If YES, how upsetting has it been for you that this person has not helped as you expected?</p> <p>Not at all upsetting 0 A little upsetting 1 Somewhat upsetting 2 Quite upsetting 3 Extremely upsetting 4</p>

Your Feelings During The Past Week

Using the scale below, **CIRCLE** the number which best describes how often you felt or behaved this way
—DURING THE PAST WEEK.

- 1 = Rarely or none of the time (less than 1 day)
 2 = Some or a little of the time (1–2 days)
 3 = Occasionally or a moderate amount of time (3–4 days)
 4 = Most or all of the time (5–7 days)

		Rarely or None	Some or A Little	Occasionally or Moderate	Most or All
During the PAST WEEK:					
1.	I was bothered by things that usually don't bother me.....	1	2	3	4
2.	I did not feel like eating; my appetite was poor.....	1	2	3	4
3.	I felt that I could not shake off the blues even with help from my family or friends.....	1	2	3	4
4.	I felt that I was just as good as other people.....	1	2	3	4
5.	I had trouble keeping my mind on what I was doing.	1	2	3	4
6.	I felt depressed.....	1	2	3	4
7.	I felt that everything I did was an effort.....	1	2	3	4
8.	I felt hopeful about the future.....	1	2	3	4
9.	I thought my life had been a failure.....	1	2	3	4
10.	I felt fearful.....	1	2	3	4
11.	My sleep was restless.	1	2	3	4
12.	I was happy.....	1	2	3	4
13.	I talked less than usual.....	1	2	3	4
14.	I felt lonely.....	1	2	3	4
15.	People were unfriendly.....	1	2	3	4
16.	I enjoyed life.....	1	2	3	4
17.	I had crying spells.....	1	2	3	4
18.	I felt sad.....	1	2	3	4
19.	I felt that people disliked me.....	1	2	3	4
20.	I could not get "going."	1	2	3	4

Your Overall Experience In Caregiving

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 do you feel because of all the caregiving things you do for your family member?

Not at all confined.....	0
Confined a little.....	1
Somewhat confined.....	2
Confined a lot.....	3
Extremely confined.....	4
2. How often would you say that taking care of your family member is very difficult?

Never.....	0
Rarely.....	1
Sometimes.....	2
Much of the time.....	3
Always.....	4
3. How much stress do you feel because of all your obligations, including taking care of your family member?

No stress.....	0
Very little stress.....	1
Some stress.....	2
A lot of stress.....	3
Overwhelming stress.....	4
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 <i>a lot</i>	4
Positive outweighs the negative <i>somewhat</i>	3
Positive and negative are about <i>equal</i>	2
Negative outweighs the positive <i>somewhat</i>	1
Negative outweighs the positive <i>a lot</i>	0
5. What if your family member's care needs increase? How confident are you that you would be able to provide more care than you are doing now?

Not at all confident.....	0
Not too confident.....	1
Somewhat confident.....	2
Pretty confident.....	3
Very confident.....	4

Thank you very much for completing this questionnaire. Would you take a few more minutes to give us your reactions to the questionnaire? (Please **CIRCLE** your answer). Also, included are questions that can help us plan for future studies.

1. How interesting or boring was this questionnaire?
- | | |
|---|---|
| Very interesting | 1 |
| Pretty interesting | 2 |
| Somewhat interesting and somewhat boring? | 3 |
| Pretty boring | 4 |
| Very boring | 5 |

2. Were the questions on this questionnaire clear or confusing?
- | | |
|--|---|
| Everything was very clear | 1 |
| Most questions were clear; only a few were confusing | 2 |
| Some questions were clear and some were confusing | 3 |
| Only a few questions were clear; most were confusing | 4 |
| Nearly all the questions were confusing | 5 |

What question or page of questions was most confusing to you? _____

3. Were any of the questions emotionally upsetting to you?
- | | |
|------------------|---|
| Not at all | 1 |
| A little | 2 |
| Some | 3 |
| A lot | 4 |

What question or page of questions was most emotionally upsetting to you? _____

Please complete the following sentences:

4. The thing I liked **most** about this questionnaire was: _____
- _____
- _____
- _____

5. The thing I liked **least** about this questionnaire was: _____
- _____
- _____

6. What do you think about researchers coming into your home to observe you helping your family member with bathing?

7. What do you think about researchers videotaping you assisting your family member during bathing ?

8. What is most pleasurable for you about helping your family member with bathing?

9. What is the most difficult for you about helping your family member with bathing?

10. What kinds of things do you do to make bathing go smoothly?

11. What advice do you have for other caregivers who are having difficulties with their family member during bathing?

Date

TIME

DATE AND TIME YOU COMPLETED QUESTIONNAIRE

About how long did it take you to complete this questionnaire?

_____ hours _____ minutes

APPENDIX D**ADL: BATHING PERFORMANCE SCALE**

APPENDIX E
MY VIEW OF BATHING SCALE

My View of Bathing

Directions: Please read each statement and **CIRCLE** the number that most accurately describes how much you agree or disagree with the following statements. Be sure to answer every question.

	STRONGLY DISAGREE	DISAGREE SOMEWHAT	AGREE SOMEWHAT	STRONGLY AGREE
1. Taking a shower can frighten some residents	1	2	3	4
2. Residents need to take their bath when it is scheduled	1	2	3	4
3. When residents complain of pain when I am bathing them, it is best to ignore it and go on with the bath	1	2	3	4
4. The best way to get someone clean is to bathe them in the tub or the shower	1	2	3	4
5. It helps to praise residents when they are cooperative during bathing	1	2	3	4
6. Some residents may feel like they are being sexually assaulted when their private parts are being bathed	1	2	3	4
7. If I start taking off a resident's clothes and they hit me, it may be because I didn't explain what I was doing	1	2	3	4
8. Bed baths don't clean residents really well	1	2	3	4
9. It is okay for most residents to have only one bath a week even if scheduled for two or three baths a week	1	2	3	4
10. Looking at the resident's point of view helps me understand why they are difficult during bathing	1	2	3	4
11. Some residents may think getting bathed is an invasion of their privacy	1	2	3	4
12. The resident should have a choice about how and when the bath is done	1	2	3	4

Rasin (1997)

APPENDIX F
CAREGIVER BATHING RATING SCALE

Caregiver Bathing Behavior Rating Scale

VERBAL COMMUNICATION

1. Addresses resident by name	often	1	2	3	4	5	6	never
2. Praises resident	often	1	2	3	4	5	6	never
3. Confronts resident	often	1	2	3	4	5	6	never
4. Emotional quality	calm	1	2	3	4	5	6	tense
5. Manner of speaking	respectful	1	2	3	4	5	6	disrespectful
6. Concern	interested	1	2	3	4	5	6	uninterested
7. Speaks to resident	often	1	2	3	4	5	6	never

TASK PRESENTATION STYLE

1. Encourages independence	often	1	2	3	4	5	6	never
2. Prepares resident for the task	often	1	2	3	4	5	6	never
3. Speed of bath	unhurried	1	2	3	4	5	6	rushed

NONVERBAL COMMUNICATION

1. Touch	gentle	1	2	3	4	5	6	rough
2. Flexibility of routine	flexible	1	2	3	4	5	6	unflexible
3. Social orientation	socially-oriented	1	2	3	4	5	6	not socially-oriented
4. Working proximity	close	1	2	3	4	5	6	removed

APPENDIX G
GIVING A BATH SCALE

Giving a Bath

Directions: Please read each statement and **CIRCLE** the number that best describes you. Be sure to answer every question.

	NEVER OR RARELY	SOMETIMES	OFTEN	ALMOST ALWAYS
1. I feel ready to deal with difficult problems when bathing residents	1	2	3	4
2. When residents complain of pain or discomfort, I apologize and change what I do	1	2	3	4
3. When talking to a resident during the bath, I make sure that we are face to face so the resident can see me	1	2	3	4
4. If someone looks me straight in the face and tells me 'no' that they don't want a bath, then I should respect that and postpone the bath	1	2	3	4
5. I use ways to make bathing residents go smoothly without taking too much time	1	2	3	4
6. If something about the bathing process bothers a resident, I wait and do the bath another time	1	2	3	4
7. During the bath, I watch for signs that the resident is upset so that I can slow down or change what I do	1	2	3	4
8. When telling residents it is time for a bath, I take the time to understand their body language	1	2	3	4
9. When residents tell me they don't want to be bathed, I feel like I need to go ahead and bathe them to keep on schedule ...	1	2	3	4
10. I take the time to make things really calm for my residents at bath time	1	2	3	4
11. I make eye contact before saying what I'm going to do to the resident during the bath	1	2	3	4

Rasin (1997)

APPENDIX H**HELP FROM OTHER IN CARING FOR YOUR FAMILY MEMBER**

HELP FROM OTHERS IN CARING FOR YOUR FAMILY MEMBER

On pages 2 through 8, we asked you questions about the kinds of things you do to help your family member. Now we would like to know if other people have helped out in these activities.

HELP FROM PEOPLE WHOSE JOB IT IS

1. How much help have people whose job it is (such as a health professional, a paid helper) given to your family member?
 None at all 0 (Go to Q. 4)
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4
2. About how many people whose job it is have helped out? _____ (Number of people)
3. How happy are you with the help given by people whose job it is?
 Very happy 4
 Pretty happy 3
 Somewhat happy and somewhat unhappy 2
 Pretty unhappy 1
 Very unhappy 0

HELP FROM FRIENDS AND NEIGHBORS

7. How much help have friends and neighbors given to him or her?
 None at all 0 (Go to Q. 10)
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4
8. About how many friends and neighbors have helped out? _____ (Number of friends and neighbors)
9. How happy are you with the help given by friends and neighbors?
 Very happy 4
 Pretty happy 3
 Somewhat happy and somewhat unhappy 2
 Pretty unhappy 1
 Very unhappy 0

HELP FROM RELATIVES

4. How much help have relatives given to him or her?
 None at all 0 (Go to Q. 7)
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4
5. About how many relatives have helped out? _____ (Number of relatives)
6. How happy are you with the help given by relatives?
 Very happy 4
 Pretty happy 3
 Somewhat happy and somewhat unhappy 2
 Pretty unhappy 1
 Very unhappy 0

HELP NOT RECEIVED

10. Is there a person you thought would help you more in caring for your family member, but who has **not** done so?
 No 0
 Yes 1
- 10a. If YES, how upsetting has it been for you that this person has **not** helped as you expected?
 Not at all upsetting 0
 A little upsetting 1
 Somewhat upsetting 2
 Quite upsetting 3
 Extremely upsetting 4

APPENDIX I

DISCOMFORT SCALE FOR ADVANCED DEMENTIA OF THE ALZHEIMER'S

TYPE

RATER ID BATH ID Today's Date

M M O D Y Y

Discomfort Scale Rating Form

	NA	None	MIN	MOD	EXT	Score
1. NEGATIVE VOCALIZATION	_____	_____	_____	_____	_____	_____
2. CONTENT FACIAL EXPRESSION	_____	_____	_____	_____	_____	_____
3. SAD FACIAL EXPRESSION	_____	_____	_____	_____	_____	_____
4. FRIGHTENED FACIAL EXPRESSION	_____	_____	_____	_____	_____	_____
5. FROWN FACIAL EXPRESSION	_____	_____	_____	_____	_____	_____
6. RELAXED BODY LANGUAGE	_____	_____	_____	_____	_____	_____
7. TENSE BODY LANGUAGE	_____	_____	_____	_____	_____	_____
8. FIDGETING BODY LANGUAGE	_____	_____	_____	_____	_____	_____

OVERALL ASSESSMENTCompletely
ComfortableExtremely
Uncomfortable

APPENDIX J
DISRUPTIVE BEHAVIOR SCALE

	Time:								
	12 am	1	2	3	4	5	6	7	8
17. Kicks									
18. Places inappropriate substances in mouth									
19. Hides/misplaces one's own objects									
20. Physically takes objects from another									
21. Eats others' food									
22. Makes insulting non-obscene gestures									
23. Spits									
24. Bangs objects (non-destructive)									
25. Pinches/squeezes									
26. Takes objects belonging to others									
27. Pushes/shoves									
28. Ambulates into inappropriate area(s)									
29. Paces									
30. Spits medication									
31. Makes repetitious noises									
32. Urinates/defecates inappropriately									
33. Disrobes/exposes self									
34. Uses hostile/accusatory language toward others									
35. Walks/runs with no apparent goal									
36. Makes threats implying physical harm to others									

	Time:								
	12 am	1	2	3	4	5	6	7	8
37. Screams/yells									
38. Excessive motor activity									
39. Talks constantly									
40. Refuses to eat/drink									
41. Refuses to follow directions									
42. Uses obscene or profane language									
43. Isolates self from others (physically)									
44. Repeats phrase(s)/word(s)									
45. Unkempt personal hygiene									

Operational Definitions of Disruptive Behavior Listing

1. **Injures self** - Causes damage to own body which results in the necessity of medical treatment (e.g. bruises, fractures bone, burn, etc...)
2. **Brandishes/Uses a weapon** - Bears or uses an implement normally considered dangerous (e.g. gun, knife, etc...)
3. **Tackles** - Plunges into someone with force
4. **Bites** - Seizes someone's skin using the teeth
5. **Damages objects in the environment** - Defaces or destroys walls, floors, fixtures or furniture (writes on walls, scratches furniture, breaks mirror, tears off wallpaper, etc...)
6. **Spits on others** - Ejects saliva from the mouth striking another person
7. **Displays inappropriate sexual behavior** - Takes part in activity of a sexual nature deemed unacceptable in specific environment or context (e.g. masturbates in public, etc...)
8. **Throws objects/food** - Hurls objects or food through space
9. **Strikes a person with an object** - Physically hits another person with force using something other than part of the body
10. **Scratches others** - Scrapes another person's skin with fingernails or other sharp object such as fork, etc...
11. **Makes sexual advances** -
12. **Elbows** - To push or shove with force using the elbow
13. **Makes obscene gestures** - Makes non-word sounds or displays motions of the body or limbs which are regarded as taboo, irreverent, or in poor taste by usual social standards
14. **Makes threats implying physical harm to self** - Verbally or otherwise expresses the intention of doing physical damage to own body
15. **Dresses unsuitably for environment/activity** - Wears articles of clothing which are considered inappropriate for either the time, place, or season (e.g. wears heavy coat during summer, wears pajamas/gown to public gathering place, wears underwear over other clothing, etc...)
16. **Hits others** - Strikes another person using either opened or closed hand(s)
17. **Kicks** - Strikes another person using the leg or foot area
18. **Places inappropriate substances in mouth** - Puts substances in the mouth which are considered unsuitable by social standards or are potentially harmful (dirt, cigarette butts, soap, chemical cleansers, feces, etc...)
19. **Hides/misplaces one's own objects** - Places one's own belongings in area so they later cannot easily be found
20. **Physically takes objects from another** - Forcibly takes objects which are in the physical possession of another
21. **Eats others' food** - Consumes food belonging to another person without that person's consent

22. **Makes insulting non-obscene gestures** - Makes gestures which are viewed as degrading but are not considered obscene (e.g. sticks out tongue, etc...)
23. **Spits** - Ejects saliva into the environment without striking another person
24. **Bangs objects (non-destructive)** - Strikes with a sharp noise or thump without defacing or destroying the environment, furniture, or fixture
25. **Pinches/squeezes** - To exert pressure or compress between finger(s) and thumb
26. **Takes objects belonging to others** - Takes objects which do not belong to self and are not in the physical possession of another (e.g. takes other's clothing out of closet, takes pen from nursing station, etc...)
27. **Pushes/shoves** - To press against using force
28. **Ambulates into inappropriate area(s)** - Walks or wheels self into area unsuitable or dangerous due to patient, time, or circumstance
29. **Paces** - Sustained, deliberate rhythmic walking
30. **Spits medication** - Ejects medication from mouth
31. **Makes repetitious noises** - Vocalizes non-words more than 3 times during any 5 minute interval
32. **Urines/defecates inappropriately** - Urinates or defecates in other than toilet in the absence of documented medical reason
33. **Disrobes/exposes self** - Removes clothing or reveals parts of the body not normally displayed in specific social or environmental context
34. **Uses hostile/accusatory language toward others** - Uses belligerent, argumentative, or blameful words/phrases when speaking to others(e.g. calling others names etc...)
35. **Walks/runs with no apparent goal** -
36. **Makes threats implying physical harm to others** - Verbally or otherwise expresses intention of doing physical harm to another person's body
37. **Screams/yells** - Produces loud noise or words
38. **Excessive motor activity** - Fidgets or shows excessive body movement
39. **Talks constantly** - Persistently verbalizes
40. **Refuses to eat/drink** - Rejects liquid or solid sustenance in absence of documented medical reason
41. **Refuses to follow directions** - Does not comply with requests, directions or expectations of staff
42. **Uses obscene or profane language** - Uses words regarded as taboo, irreverent, or in poor taste by usual social standards
43. **Isolates self from others (physically)** - Separates self from others/secludes self in room
44. **Repeats phrase(s)/word(s)** - Verbalizes phrase(s)/word(s) repetitively more than 3 times in any 5 minute interval
45. **Unkempt personal hygiene** - Exhibits odor, dirt or untidiness

APPENDIX K
CAREGIVER'S EXPERIENCE DURING BATHING SCALE

CNA's Experience During Bathing

Directions: For each statement, **CIRCLE** the one response that best describes your experience as a CNA when assisting with bathing _____ during today's bath.
(insert resident's name)

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
1. I was confident in my ability to assist with bathing	1	2	3	4	5
2. I felt comfortable in the things I did to help this resident	1	2	3	4	5
3. I felt prepared to take care of this resident's physical needs during bathing	1	2	3	4	5
4. I was patient	1	2	3	4	5
5. I felt relaxed	1	2	3	4	5
6. I felt I was doing a good job	1	2	3	4	5
7. I had an easy time doing the bath	1	2	3	4	5
8. I felt safe caring for this resident during bathing	1	2	3	4	5
9. Caring for this resident was pleasurable	1	2	3	4	5
10. I thought things through when bathing this resident	1	2	3	4	5
11. I was comfortable with my ability to communicate with this resident	1	2	3	4	5

CNA's Experience During Bathing

(continued)

Directions: For each statement, **CIRCLE** the one response that best describes your experience as a CNA when assisting with bathing _____ during today's bath.
(insert resident's name)

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
12. I felt confident finding solutions for difficult situations during bathing	1	2	3	4	5
13. Taking care of this resident was satisfying	1	2	3	4	5
14. I felt self-assured	1	2	3	4	5
15. I was able to manage specific problems	1	2	3	4	5
16. I understood what this resident needed during bathing	1	2	3	4	5
17. I felt confident in my ability to care for this resident	1	2	3	4	5
18. There were positive aspects of caring for this resident	1	2	3	4	5
19. Bathing this resident was quickly done	1	2	3	4	5
20. Bathing this resident went smoothly	1	2	3	4	5
21. I got frustrated when assisting with bathing ...	1	2	3	4	5
22. I got frightened when assisting this resident with bathing	1	2	3	4	5
23. I thought the bath got the resident clean	1	2	3	4	5

Adapted by Rasin (1997) from Archbold & Stewart (1993) and Feldt & Ryden (1992)

APPENDIX L
THE CAREGIVING HASSLES SCALE

Caregiving Hassles During Bathing

Directions: Sometimes when bathing a resident things can happen that annoy or bother you. These things are called hassles. This questionnaire lists things that can be hassles when assisting with bathing

(insert resident's name)

During today's bath, some of these things may have been a hassle while others have not. For each question, CIRCLE **NO** if the event did not happen. CIRCLE **YES** if it did happen. If you CIRCLED **YES**, indicate how much of a hassle it was for you during today's bath.

If YES, CIRCLE how much of a hassle it was for you.

DID IT HAPPEN?

DID IT HAPPEN?		NOT A HASSLE	A SMALL HASSLE	A MEDIUM HASSLE	A BIG HASSLE
1. Resident criticizing or complaining	NO YES	1	2	3	4
2. Resident yelling or swearing	NO YES	1	2	3	4
3. Resident not cooperating	NO YES	1	2	3	4
4. Resident frowning or scowling	NO YES	1	2	3	4
5. Resident verbally inconsiderate; not respecting others' feelings	NO YES	1	2	3	4
6. Just being with the resident during bathing.	NO YES	1	2	3	4
7. Resident leaving tasks related to bathing uncompleted	NO YES	1	2	3	4
8. Resident hitting or pinching	NO YES	1	2	3	4
9. Overall, how much of a hassle was it to bathe	?	1	2	3	4

Adapted from Kinney & Stephens (1989)

Comments

Thank you!

APPENDIX M
MEMORY PROBLEMS SCALE

Your Family Member and Memory Problems

Now, we'd like to ask you some questions about your family member's memory and the difficulty he or she may have doing some things. (CIRCLE your answer.)

	Not At All Difficult	Just A Little Difficult	Fairly Difficult	Very Difficult	Can't Do At All
How difficult is it for your family member to:					
1. Remember recent events?	0	1	2	3	4
2. Know what day of the week it is?	0	1	2	3	4
3. Remember his or her home address? ..	0	1	2	3	4
4. Remember words?	0	1	2	3	4
5. Understand simple instructions?	0	1	2	3	4
6. Find his or her way around the house?	0	1	2	3	4
7. Speak sentences?	0	1	2	3	4
8. Recognize people that he or she knows?	0	1	2	3	4

Adapted from Pearlin, Mullan, Semple, &
Skaff, 6 - 13 (1990)

APPENDIX N
PHASE 1 COVER LETTER

[Date]

Dear,

YOUR ASSISTANCE IS NEEDED!

Hello! My name is Johannah Uriri.

You are invited to participate in a research study, titled "Family Caregivers' Perceptions of Assisting Cognitively Impaired Elders During Bathing: Instrument Development" because you are a caregiver of a family member who has some form of dementia. We need family caregivers to assist us in the development of this important questionnaire. The purpose of this study is to develop questions that will be used to examine perceptions of family caregivers when assisting a family member with dementia during bathing.

Little is known about what family caregivers experience when assisting a family member with memory problems during bathing in the home. We know that caregivers in nursing homes experience stress and burden when assisting some nursing home residents during bathing. You have been selected from the Pennebaker Adult Day Center, Reynold's Center Alzheimer's Disease Clinic, or you volunteered by answering an advertisement to participate in this project.

Included with this booklet of questions is a consent form and instructions to complete the booklet. A stamped return envelope addressed to me is included for returning the booklet and consent form. You are asked to complete the booklet of questions to examine your perceptions of assisting a family member with dementia during bathing. The booklet of questions will take approximately 30–45 minutes to complete. It is suggested that you stop in 15-minute intervals to rest. You will have two weeks to complete the questionnaire. Some questions can be answered by checking yes or no and other or you may have three or more options. The following are two examples of questions on the questionnaire: 1) Taking care of my family member is satisfying (*not at all, a little, some, quite a bit, a great deal*); and 2) does your family member wash, rinse, and dry their face? Your responses will help us learn about your experiences and later develop questionnaires that will help nurses and other health care providers ask appropriate questions that will help with any problems that may occur in bathing.

Although you are free not to participate, we hope you will take the time to complete the booklet of questions and return it in the enclosed self-addressed envelope. The information that you give is confidential. Neither your name nor your identity will be used for publication or publicity purposes. A summary of the answers on the questionnaires will be kept indefinitely and may be used in future research.

If you have any questions feel free to call me at (501) 296-1939. If I am not available, please leave a message and I will return your call as soon as possible.

Thank you in advance for your assistance.

Most Sincerely,

Johannah Uriri, MNsc, RN
Principal Investigator
University for Medical Sciences College of
Nursing Dept. of Research
Doctoral Candidate in Nursing
Oregon Health Sciences University

APPENDIX O
INTERVIEW QUESTIONS

Interview Questions

Interviewer:

The following questions were developed in response to family caregivers who completed the booklet of questions. The purpose of the interview is to clarify responses and to improve the questions in the booklet.

1. How do you determine what time of day to give the bath?
2. Does the time you chose make a difference of how the smoothly the bath goes?
3. What does a partial bath mean to you?
4. What does a complete bath mean to you?
5. Do you think the following questions would be good questions to add to the questions?
 - a. How often does your family member take a complete bath (total body bath)? (e.g., tub, shower, or bedbath)?
 - b. How much help is required from you to help your family member during the complete bath?

None not at all a little some quite of bit a great deal

- c. How much help is required from you to help your family member during the complete bath?

None not at all a little some quite of bit a great deal

- d. How hard is it for you to help your family member during the complete bath?

Easy Not to hard Some what Hard Pretty Hard Very Hard

- e. How often does your family member take a partial bath (e.g., underarms, private parts)?

- e. How much help is required from you to help your family member during the partial bath?

None not at all a little some quite of bit a great deal

- f. How much help is required from you to help your family member during the partial bath?

None not at all a little some quite of bit a great deal

- h. How hard is it for you to help your family member during the partial bath?

Easy Not to hard Some what Hard Pretty Hard Very Hard

Describe what is hard about it.

- j. Which method, the complete bath or partial bath, is easiest?

6. What does the term personal hygiene mean to you?
7. Which is clearer bladder or urine accident or urine on skin?
8. Do you view bathing to cool or warm your family member is a function of the bath?
9. Should the following terms be added for reasons to bathe?

- a. Diversion
 - b. To feel better
 - c. To sooth
 - d. To help wake up
 - e. To get through the day
10. When you see setting water temperature does it mean adjusting the hot and cold faucets or pre set water temperature?
11. Please compare the two forms which form appears to be easier to complete?
Hairwashing?
12. In your experiences with assisting your family member during bathing what type expressions does your family member display during bathing to indicate:
- a. pleasure?
 - b. discomfort?
13. Do you believe if your family member could help and cooperate more during the bath would make bathing easier?

APPENDIX P**POST CARD**

Post Card

[Date]

Dear,

About two weeks ago, we sent you a questionnaire about your experience of assisting a family member during bathing. Your name was selected or you volunteered to participate. If you have already returned the questionnaire, please accept my sincere thanks. If not, will you return it today? Your thoughts and comments are very important. If you did not receive the questionnaire, or it got misplaced, please call me at (501) 296-1939 and I will get another one in the mail to you immediately.

Thanks for your assistance,

Johannah Uriri, MNSc, RN

Principal Investigator

College of Nursing, University of Arkansas for Medical Sciences

APPENDIX Q
ADVERTISEMENTS

Research Volunteers Needed

"Needed: family caregivers who help a relative during bathing"

The University of Arkansas for Medical Sciences College of Nursing is seeking volunteers to participate in a research study of family caregivers' experiences of helping a family member during bathing.

The purpose of the study is to develop questions, so that nurses can ask family caregivers the best questions that will quickly lead to a solution to problems family caregivers may have when helping a relative during bathing at home.

There are no immediate benefits in participating in this study, but a \$10 token of appreciation will be sent with the booklet of questions to family caregivers to answer.

Call Johannah Uriri, RN at (501) 296-1939 04 405-3182 for more information.

Methodology

Family caregivers will be recruited from Alzheimer's Disease support groups sponsored by the local chapter of the Alzheimer's and Related disorders Association located in Little Rock, AR. and Portland, OR. The investigator will post an advertisement in The Alzheimer's Association newsletters.

Research Volunteers Needed

"Needed: family caregivers who help a relative during bathing"

The Oregon Health Sciences University School of Nursing is seeking volunteers to participate in a research study of family caregivers' experiences of helping a family member during bathing.

The purpose of the study is to develop questions, so that nurses can ask family caregivers the best questions that will quickly lead to a solution to problems family caregivers may have when helping a relative during bathing at home.

There are no immediate benefits in participating in this study, but a \$10 token of appreciation will be sent with the packet of questions to family caregivers to answer.

Call Johannah Urii RN at (503) 494-1136 for more information.

Date 08/1/00

Dear,

As you may know, caregivers of persons with dementia experience varying degrees of stress and physical changes as a result of their caregiving activities. Researchers are trying to understand these changes in order to develop programs to enhance caregiving satisfaction. Johannah Uriri has received support from the National Institute Nursing Research to conduct a study on how changes in the patient affect the caregiver.

Caregivers of persons cared for at the Oregon Alzheimer's Disease Center at Oregon Health Sciences University are being asked if they would like to participate in this study. The project will involve completing a questionnaire relating to your experiences as a caregiver. Full details of the project are included in the attached letter written by Johannah Uriri.

Thank you for considering participation in this project. Your agreement or refusal to participate will in no way impact the care provided through the Oregon Alzheimer's Disease Center. In appreciation for your time, you will receive ten dollars for your participation.

If you have any questions regarding this study, please do not hesitate to call me at (503) 494-6976. We appreciate your time and consideration.

Sincerely,

Jeffrey Kaye, M.D.
Director, Aging & Alzheimer Disease Center

APPENDIX R
MUTUALITY SCALE

YOU AND YOUR FAMILY MEMBER

Now we would like you to let us know how you and your family member feel about each other at the current time.

	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	2	3	4
2. How close do you feel to him or her?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4. How much does he or she express feelings of appreciation for you and the things you do?	0	1	2	3	4
5. How attached are you to him or her?	0	1	2	3	4
6. How much does he or she help you?	0	1	2	3	4
7. How much do you like to sit and talk with him or her?	0	1	2	3	4
8. How much love do you feel for him or her?	0	1	2	3	4
9. To what extent do the two of you share the same values?	0	1	2	3	4
10. When you really need it, how much does he or she comfort you?	0	1	2	3	4
11. How much do the two of you laugh together?	0	1	2	3	4
12. How much do you confide in him or her?	0	1	2	3	4
13. How much emotional support does he or she give you?	0	1	2	3	4
14. To what extent do you enjoy the time the two of you spend together?	0	1	2	3	4
15. How often does he or she express feelings of warmth toward you?	0	1	2	3	4

APPENDIX S
THE CENTER FOR EPIDEMIOLOGICAL STUDIES OF DEPRESSION SCALE
(CES-D)

YOUR FEELINGS DURING THE PAST WEEK

Using the scale below, **CIRCLE** the number which best describes how often you felt or behaved this way — **DURING THE PAST WEEK.**

- 1 = Rarely or none of the time (less than 1 day)
 2 = Some or a little of the time (1–2 days)
 3 = Occasionally or a moderate amount of time (3–4 days)
 4 = Most or all of the time (5–7 days)

During the PAST WEEK:		Rarely or None	Some or A Little	Occasionally or Moderate	Most or All
1.	I was bothered by things that usually don't bother me.	1	2	3	4
2.	I did not feel like eating; my appetite was poor.	1	2	3	4
3.	I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4
4.	I felt that I was just as good as other people.	1	2	3	4
5.	I had trouble keeping my mind on what I was doing.	1	2	3	4
6.	I felt depressed.	1	2	3	4
7.	I felt that everything I did was an effort.	1	2	3	4
8.	I felt hopeful about the future.	1	2	3	4
9.	I thought my life had been a failure.	1	2	3	4
10.	I felt fearful.	1	2	3	4
11.	My sleep was restless.	1	2	3	4
12.	I was happy.	1	2	3	4
13.	I talked less than usual.	1	2	3	4
14.	I felt lonely.	1	2	3	4
15.	People were unfriendly.	1	2	3	4
16.	I enjoyed life.	1	2	3	4
17.	I had crying spells.	1	2	3	4
18.	I felt sad.	1	2	3	4
19.	I felt that people disliked me.	1	2	3	4
20.	I could not get "going."	1	2	3	4

APPENDIX T**THE RAND CORPORATION MEDICAL OUTCOMES STUDY SHORT-FORM****36 HEALTH STATUS QUESTIONNAIRE (MOS SF-36)**

YOUR HEALTH (cont.)

1. In general, would you say your health is
(Circle One Number):

Excellent 1
 Very Good 2
 Good 3
 Fair 4
 Poor 5

2. Compared to one year ago, how would you
rate your health in general now ? (Circle One
Number)

Much better now than one year ago 1
 Somewhat better now than one year ago 2
 About the same 3
 Somewhat worse now than one year ago 4
 Much worse now than one year ago 5

The following items are about activities you might do during a typical day. Does your health now
limit YOU in these activities? If so, how much?

(Circle One Number on Each Line)

Activities	Yes, I am Limited A Lot	Yes, I am Limited A Little	No, Not Limited At All
3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports 1	1	2	3
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf 1	1	2	3
5. Lifting or carrying groceries 1	1	2	3
6. Climbing several flights of stairs 1	1	2	3
7. Climbing one flight of stairs 1	1	2	3
8. Bending, kneeling or stooping 1	1	2	3
9. Walking more than a mile 1	1	2	3
10. Walking several blocks 1	1	2	3
11. Walking one block 1	1	2	3
12. Bathing or dressing yourself 1	1	2	3

APPENDIX U
GLOBAL ROLE STRAIN

YOUR OVERALL EXPERIENCE

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 do you feel because of all the caregiving things you do for your family member?

Not at all confined	0
Confined a little	1
Somewhat confined	2
Confined a lot	3
Extremely confined	4
2. How often would you say that taking care of your family member is very difficult?

Never	0
Rarely	1
Sometimes	2
Much of the time	3
Always	4
3. How much stress do you feel because of all your obligations, including taking care of your family member?

No stress	0
Very little stress	1
Some stress	2
A lot of stress	3
Overwhelming stress	4
4. How much of the time do you feel you are patient in caring for your family member?

Never	0
Rarely	1
Sometimes	2
Most of the time	3
Always	4
5. 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 <i>a lot</i>	4
Positive outweighs the negative <i>somewhat</i>	3
Positive and negative are about <i>equal</i>	2
Negative outweighs the positive <i>somewhat</i>	1
Negative outweighs the positive <i>a lot</i>	0
6. The needs of people who are receiving care change with time as do yours. Would you say that, as time goes on, giving care to your family member has:

Become much easier for you	4
Become somewhat easier for you	3
Stayed about the same for you	2
Become somewhat more difficult for you ..	1
Become much more difficult for you	0
7. What if your family member's care needs increase? How confident are you that you would be able to provide more care than you are doing now?

Not at all confident	0
Not too confident	1
Somewhat confident	2
Pretty confident	3
Very confident	4

APPENDIX V
PHASE 2 COVER LETTERS

[Date]

Dear,

YOUR ASSISTANCE IS NEEDED!

Hello! My name is Johannah Uriri.

You are invited to participate in a research study, titled "Family Caregivers' Perceptions of Assisting Cognitively Impaired Elders During Bathing: Instrument Development" because you are a caregiver of a family member who has some form of dementia. We need family caregivers to assist us in the development of this important questionnaire. The purpose of this study is to develop questions that will be used to examine perceptions of family caregivers when assisting a family member with dementia during bathing.

Little is known about what family caregivers experience when assisting a family member with memory problems during bathing in the home. We know that caregivers in nursing homes experience stress and burden when assisting some nursing home residents during bathing. You have been selected from the Pennebaker Adult Day Center, Reynold's Center Alzheimer's Disease Clinic, or you volunteered by answering an advertisement to participate in this project.

Included with this booklet of questions is a consent form and instructions to complete the booklet. A stamped return envelope addressed to me is included for returning the booklet and consent form. You are asked to complete the booklet of questions to examine your perceptions of assisting a family member with dementia during bathing. The booklet of questions will take approximately 30–45 minutes to complete. It is suggested that you stop in 15-minute intervals to rest. You will have two weeks to complete the questionnaire. Some questions can be answered by checking yes or no and other or you may have three or more options. The following are two examples of questions on the questionnaire: 1) Taking care of my family member is satisfying (*not at all, a little, some, quite a bit, a great deal*); and 2) does your family member wash, rinse, and dry their face? Your responses will help us learn about your experiences and later develop questionnaires that will help nurses and other health care providers ask appropriate questions that will help with any problems that may occur in bathing.

Although you are free not to participate, we hope you will take the time to complete the booklet of questions and return it in the enclosed self-addressed envelope. The information that you give is confidential. Neither your name nor your identity will be used for publication or publicity purposes. A summary of the answers on the questionnaires will be kept indefinitely and may be used in future research.

If you have any questions feel free to call me at (501) 296-1939. If I am not available, please leave a message and I will return your call as soon as possible.

Thank you in advance for your assistance.

Most Sincerely,

Johannah Uriri, MNSc, RN
Principal Investigator
University for Medical Sciences College of
Nursing Dept. of Research
Doctoral Candidate in Nursing
Oregon Health Sciences University

[Date]

Dear,

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Little is known about what family caregivers experience when assisting a family member with memory problems during bathing in the home. We know that caregivers in nursing homes experience stress and burden when assisting some nursing home residents during bathing. You have been selected from the Oregon Health Sciences Aging and Alzheimer's Disease Center or you volunteered by answering an advertisement to participate in this project.

Included with this booklet of questions is a consent form and instructions to complete the booklet. A stamped return envelope addressed to me is included for returning the booklet and consent form. You are asked to complete the booklet of questions to examine your perceptions of assisting a family member with dementia during bathing. The booklet of questions will take approximately 30–45 minutes to complete. It is suggested that you stop in 15-minute intervals to rest. You will have two weeks to complete the questionnaire. Some questions can be answered by checking yes or no and other or you may have three or more options. The following are two examples of questions on the questionnaire: 1) Taking care of my family member is satisfying (***not at all, a little, some, quite a bit, a great deal***); and 2) does your family member wash, rinse, and dry their face? Your responses will help us learn about your experiences and later develop questionnaires that will help nurses and other health care providers ask appropriate questions that will help with any problems that may occur in bathing.

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If you have any questions feel free to call me at (503) 491-1136. If I am not available, please leave a message and I will return your call as soon as possible.

Thank you in advance for your assistance.

Most Sincerely,

Johannah Uriri, MNsc, RN
Principal Investigator
University for Medical Sciences College of
Nursing Dept. of Research
Doctoral Candidate in Nursing
Oregon Health Sciences University

APPENDIX W
PHASE 2 QUESTIONNAIRE BOOKLET

Purpose

These questions are designed for family members who have a relative with memory problems and who assist that relative during bathing. In these questions, we use the term **family member** to refer to your relative who has memory problems.

Your answers will help us to better understand the situation of family caregivers like you. Your view will be very helpful to nurses, doctors, and other people who work with family caregivers.

Directions

It should take about 30-40 minutes to answer these questions.

Answer the questions as honestly as you can; there are no right or wrong answers. Please do not consult with other people before you answer the questions. It is **your** view that we need.

If you have comments on any questions, feel free to write in the blank spaces around the questions, on the back cover, or on other sheets of paper.

Your role as a caregiver

We will be asking you many detailed questions surrounding bathing, because we would like to have a good picture of what you do to assist your family member during bathing.

In some questions, we use the term **family caregiver** to refer to you.

Although you may not think of yourself as a caregiver, we use the term caregiver very broadly as someone who assists a family member during bathing because of the family member's health or memory problems.

Questions?

If you have any questions, please contact:

Johannah Uriri (501) 296-1939 Arkansas, (503) 494-1137 Oregon

You And Your Family Member

Family member refers to your relative or friend who has health or memory problems. Please tell us about you and your family member. For all questions, fill in the blank or **CIRCLE** the answer that best describes you and your family member.

<p>1. How are you related to the family member you are helping?</p> <p><u>You</u> are his or her:</p> <p>Wife 1</p> <p>Husband..... 2</p> <p>Daughter..... 3</p> <p>Son..... 4</p> <p>Daughter-in-law..... 5</p> <p>Son-in-law..... 6</p> <p>Other relative 7</p> <p>Neighbor or friend..... 8</p> <p>Other: _____</p> <p>2. About how many years have you and your family member known each other?</p> <p>_____ years _____ months</p> <p>3. How long have you personally been involved in caregiving for your family member because of his or her memory problems?</p> <p>_____ years _____ months</p> <p>4. At this time, do you and your family member live in the same household?</p> <p>Yes..... 1</p> <p>No..... 0</p> <p style="margin-left: 20px;">↓</p> <p>4a. If NO, how far away do you live from your family member?</p> <p>_____ miles</p>	<p>5. Do you assist your family member during bathing?</p> <p>Yes..... 1 No 0</p> <p>6. How often did you assist your family member during bathing the past month?</p> <p>Once or twice in the month..... 1</p> <p>Once a week..... 2</p> <p>2 or 3 times a week..... 3</p> <p>Every other day..... 4</p> <p>Everyday..... 5</p> <p>7-15 What are the reasons that your family member baths or washes up? CIRCLE NO or YES for each reason.</p> <p>7. Personal hygiene? Yes No</p> <p>8. Bladder or urine accident? Yes No</p> <p>9. Bowel movement or diarrhea gets on skin Yes No</p> <p>10. Bad odor or smelly? Yes No</p> <p>11. Sweaty skin or perspiration Yes No</p> <p>12. Food spilled on skin Yes No</p> <p>13. To get warm Yes No</p> <p>14. To get cool? Yes No</p> <p>15. Other reasons (please describe).</p> <p>_____</p> <p>_____</p>
---	---

Your Family Member And Bathing

Directions: Describe where and how often your family member bathes or washes up? **CIRCLE** one answer for each type of bathing.

	Doesn't use	Once or twice month	Once a week	2 or 3 times week	Every other day	Every day
1. Bathroom sink	0	1	2	3	4	5
2. Tub	0	1	2	3	4	5
3. Shower	0	1	2	3	4	5
4. Bedbath	0	1	2	3	4	5
5. Other (please describe) _____						

Your Family Member and Memory Problems

Now, we'd like to ask you some questions about your family member's memory and the difficulty he or she may have doing some things. (**CIRCLE** your answer.)

How difficult is it for your family member to:	Not At All Difficult	Just A Little Difficult	Fairly Difficult	Very Difficult	Can't Do At All
6. Remember recent events?	0	1	2	3	4
7. Know what day of the week it is?	0	1	2	3	4
8. Remember his or her home address?	0	1	2	3	4
9. Remember words?	0	1	2	3	4
10. Understand simple instructions?	0	1	2	3	4
11. Find his or her way around the house?	0	1	2	3	4
12. Speak sentences?	0	1	2	3	4
13. Recognize people that he or she knows?	0	1	2	3	4

What You and Your Family Member Do During Bathing								
Directions: Please circle yes or no if you or your family member perform any of the activities during bathing.								
Bath Preparation								
Task	What Do You Do		What Does Your Family Member					
1. Obtain supplies (e.g., soap, wash cloth, towels, shampoo)	Yes	No	Yes	No				
2. Remove clothing	Yes	No	Yes	No				
3. Turn on the cold water	Yes	No	Yes	No				
4. Turn on the hot water	Yes	No	Yes	No				
5. Adjust Water Temperature	Yes	No	Yes	No				
6. Hold wash cloth	Yes	No	Yes	No				
7. Wet wash cloth	Yes	No	Yes	No				
8. Apply soap to the wash cloth	Yes	No	Yes	No				
9. Other (Please describe) _____								
Please: Circle Y(Yes) or N (No) to indicate if you or your family member wash or dries each body part.								
Body part	You wash		You Dry		Family member wash		Family member dry	
10. Face	Y	N	Y	N	Y	N	Y	N
11. Neck	Y	N	Y	N	Y	N	Y	N
12. Ears	Y	N	Y	N	Y	N	Y	N
13. Hands	Y	N	Y	N	Y	N	Y	N
14. Underneath Arms	Y	N	Y	N	Y	N	Y	N
15. Chest	Y	N	Y	N	Y	N	Y	N
16. Stomach	Y	N	Y	N	Y	N	Y	N
17. Back	Y	N	Y	N	Y	N	Y	N
18. Bottom	Y	N	Y	N	Y	N	Y	N
19. Private areas	Y	N	Y	N	Y	N	Y	N
20. Legs	Y	N	Y	N	Y	N	Y	N
21. Toes	Y	N	Y	N	Y	N	Y	N
22. Hair	Y	N	Y	N	Y	N	Y	N
23. Other (Please describe) _____								

Your Experience During Bathing

Directions: For each statement, **CIRCLE** the one response that best describes your experience when helping your family member with bathing during the last month.

	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
1. I was confident in my ability to assist with bathing1	2	3	4	5	
2. I felt comfortable in the things I did to help my family member during bathing1	2	3	4	5	
3. I felt prepared to take care of his or her physical needs during bathing1	2	3	4	5	
4. I was patient while assisting1	2	3	4	5	
5. I felt relaxed while assisting1	2	3	4	5	
6. I felt I was doing a good job1	2	3	4	5	
7. I had an easy time doing the bath1	2	3	4	5	
8. I felt safe caring for my family member during bathing1	2	3	4	5	
9. Helping him or her during bathing was pleasurable1	2	3	4	5	
10. I thought things through when bathing my family member1	2	3	4	5	
11. I was comfortable with my ability to communicate with him or her during bathing.....1	2	3	4	5	

Your Experience During Bathing (continued)					
	NOT AT ALL	A LITTLE	SOME	QUITE A BIT	A GREAT DEAL
12. I felt confident finding solutions for difficult situations during bathing.....1	2	3	4	5	
13. Taking care of my family member during bathing was satisfying.....1	2	3	4	5	
14. I felt unsure about my ability to help him or her during bathing.....1	2	3	4	5	
15. I was able to manage specific problems that occur during bathing.....1	2	3	4	5	
16. I understood what my family member needed during bathing.....1	2	3	4	5	
17. I felt confident in my ability to care for him or her during1	2	3	4	5	
18. There were positive aspects of caring for my family member.....1	2	3	4	5	
19. Bathing my family member was done quickly.....1	2	3	4	5	
20. Bathing him or her went smoothly.....1	2	3	4	5	
21. I got frustrated when assisting my family member with bathing.....1	2	3	4	5	
22. I got frightened when assisting my family member with bathing.....1	2	3	4	5	
23. I thought the bath got my family member clean.....1	2	3	4	5	
24. I was able to manage unexpected events that occurred during bathing.....1	2	3	4	5	

Caregiving Hassles During Bathing

Directions: Sometimes when assisting your family member with bathing things can happen that annoy or bother you. These things are called hassles.

Think about the times you have bathed your family member in the past month. Some of the things may have been a hassle while others were not. For each question, **CIRCLE** NO if the event did not happen. **CIRCLE YES** if it did happen.

If you **CIRCLED YES**, indicate how much of a hassle it was for you

DID IT HAPPEN?

DID IT HAPPEN?				NOT A HASSLE	A SMALL HASSLE	A MEDIUM HASSLE	A BIG HASSLE
1. Family member criticizing or complaining	NO	YES	1	2	3	4	
2. Family member yelling or swearing	NO	YES	1	2	3	4	
3. Family member not cooperating	NO	YES	1	2	3	4	
4. Family member frowning or scowling	NO	YES	1	2	3	4	
5. Family member verbally inconsiderate; not respecting your feelings	NO	YES	1	2	3	4	
6. Just being with my family member during bathing	NO	YES	1	2	3	4	
7. Family member leaving tasks related to bathing uncompleted	NO	YES	1	2	3	4	
8. Family member hitting or pinching	NO	YES	1	2	3	4	
9. Overall, how much of a hassles was it to bathe your family member?			1	2	3	4	

Comments

Family Caregiver Bathing Rating Scale

Directions: CIRCLE the number that best reflects what you think you do when helping your family member during bathing.

During bathing how often do you.....	Never					Often
1. Address your family member by name or title (mom, dad, etc.) to get his or her attention?	1	2	3	4	5	6
2. Praise your family member? For example, do you say "Good job, that's right, you smell nice"?	1	2	3	4	5	6
3. Confront your family member? For example, argue with him or her?	1	2	3	4	5	6
4. Keep your voice calm and soothing?	1	2	3	4	5	6
5. Speak disrespectfully to your family member?	1	2	3	4	5	6
6. Find yourself not paying attention to your family member?	1	2	3	4	5	6
7. Carry on a conversation with your family member during the bath? (even if you do most of the talking).....	1	2	3	4	5	6
8. Allow your family member to help with bathing tasks?	1	2	3	4	5	6
9. Tell your family member what is going to happen before each part of the bath?	1	2	3	4	5	6
10. Give a bath in a hurry?	1	2	3	4	5	6
11. Act as if you don't care about him or her?.....	1	2	3	4	5	6

Your View of Bathing

Directions: Please read each statement and CIRCLE the number that describes how much you agree or disagree with the following statements. Be sure to answer every question.

	STRONGLY DISAGREE	DISAGREE SOMEWHAT	AGREE SOMEWHAT	STRONGLY AGREE
1. Taking a shower can frighten my family member	1	2	3	4
2. My family member needs to take his or her bath when it is scheduled	1	2	3	4
3. When my family member complains of pain during bathing, it is best to ignore it and go on with the bath	1	2	3	4
4. The best way to get someone clean is to bathe him or her in the tub or the shower	1	2	3	4
5. It helps to praise my family member when he or she is cooperative during bathing	1	2	3	4
6. Some people may feel like they are being sexually assaulted when their private parts are being bathed	1	2	3	4
7. If I start taking off my family member's clothes and he or she hits me, it may be because I didn't explain what I was doing	1	2	3	4
8. Bed baths don't clean people really well	1	2	3	4
9. It is okay for my family member to have only one bath a week even if he or she is accustomed to taking two or three baths a week	1	2	3	4
10. Looking at my family member's point of view helps me understand why he or she is difficult during bathing	1	2	3	4
11. My family member may think getting bathed is an invasion of privacy	1	2	3	4
12. My family member should have a choice about how and when the bath is done	1	2	3	4

Giving a Bath

Directions: Please read each statement and **CIRCLE** the number that best describes you. Be sure to answer every question.

	NEVER OR RARELY	SOMETIMES	OFTEN	ALMOST ALWAYS
1. I feel ready to deal with difficult problems when bathing my family member.....	1	2	3	4
2. When he or she complains of pain or discomfort, I apologize and change what I do.....	1	2	3	4
3. When talking to my family member during the bath, I make sure that we are face to face so he or she can see me.....	1	2	3	4
4. If my family member looks me straight in the face and tells me "no" that he or she doesn't want a bath, then I should respect that and postpone the bath.....	1	2	3	4
5. I use ways to make bathing my family member go smoothly without taking too much time.....	1	2	3	4
6. If something about the bathing process bothers my family member, I wait and do the bath another time.....	1	2	3	4
7. During the bath, I watch for signs that my family member is upset so that I can slow down or change what I do.....	1	2	3	4
8. When telling my family member it is time for a bath, I take the time to understand his or her body language.....	1	2	3	4
9. When my family member tells me she or he doesn't want bathe, I feel like I need to go ahead and bathe him or her to keep with the planned routine for that day.....	1	2	3	4
10. I take the time to make things really calm for my family member at bath time.....	1	2	3	4
11. I make eye contact before saying what I'm going to do to him or her during the bath.....	1	2	3	4

Your Family Member's Reaction During Bathing

When you help your family member during bathing, he or she may show a wide range of reactions. Think about the last month when you helped your family member during bathing. What types of reactions did you observe during the bath? Please **CIRCLE** Y (YES) N (NO).

1. Smiles at you?	Y	N	20. Pats you on the back or other places?	Y	N
2. Hugs you?	Y	N	21. Makes repetitious noises (repeats sound over and over again)?	Y	N
3. Jokes with you?	Y	N	22. Makes insulting, but not obscene, gestures (making faces, sticking out tongue, etc.)?	Y	N
4. Hits you with an object (with towels, wash cloths etc.)?	Y	N	23. Uses hostile accusatory language towards you?	Y	N
5. Scratches you (marks digs, tears the surface of your skin)?	Y	N	24. Has excessive motor activity (a great deal of movement of any body part)?	Y	N
6. Makes sexual advances (acts in way that encourages sexual contact)?	Y	N	25. Talks constantly (continuous talking)?	Y	N
7. Elbows you (uses elbow to push or shove)?	Y	N	26. Uses obscene or profane language (curses, uses dirty language)?	Y	N
8. Makes obscene gestures (uses hands or other body parts to make improper/indecent motions)?	Y	N	27. Repeats words (uses the same words or phrases over and over again)?	Y	N
9. Makes threats or attempts to physically harm self?	Y	N	28. Causes you to smile/laugh?	Y	N
10. Hits you (uses hands to strike you)?	Y	N	29. Praises/compliments you (good job, etc.)?	Y	N
11. Kicks (uses leg/foot to strike out)?	Y	N	30. Pinches/squeezes?	Y	N
12. Places inappropriate substances in mouth soap, etc.)?	Y	N	31. Make noises that were monotone, subdued and low pitched, but a definite unpleasant sound?	Y	N
13. Physically takes objects from you?	Y	N	32. Pushes/shoves (presses against you)?	Y	N
14. Kisses you?	Y	N	33. Paces (walks back and forth during bathing)?	Y	N
15. Spits at you (spits without hitting you)?	Y	N	34. Follows directions (does what is asked of him or her)?	Y	N
16. Bangs objects nondes- tructively (bangs objects without causing harm)?	Y	N	35. Gives orders?	Y	N
17. Has a pleasant peaceful expression?	Y	N			
18. Looks tranquil, at ease or serene?	Y	N			
19. Has frightened facial expression?	Y	N			

Your Family Member's Reaction During Bathing (Continued)

36.	Makes threats implying physical harm to you? (uses words or body movements to harm you)?	Y	N	49.	Does not follow directions (will not do what is asked of him or her)?	Y	N
37.	Screams, yells?	Y	N	50.	Makes sounds like a moan or a groan?	Y	N
38.	Repeats the same words over and over in a mournful manner, expressing hurt or pain?	Y	N	51.	Other reactions during bathing		
39.	Has a frowning facial expression?	Y	N				
40.	Has relaxed body language?	Y	N				
41.	Has tense body language?	Y	N				
42.	A fidgeting body language (moving a lot)?	Y	N				
43.	Tackles (jumps on you with force)?	Y	N				
44.	Bites(grabs your skin with teeth or gums)?	Y	N				
45.	Spits on you (saliva hits you)?	Y	N				
46.	Displays inappropriate sexual behavior?	Y	N				
47.	Thanks you?	Y	N				
48.	Makes noises of speech that are "hushed low sounds" like constant muttering?	Y	N				

You and Your Family Member's Feelings

Now we would like you to let us know how you and your family member feel about each other at the current time. Please **CIRCLE** the answer that describes you and your family member.

	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	0	1	2	3	4
2. How close do you feel to him or her?0	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?0	0	1	2	3	4
4. How much does he or she express feelings of.....0	0	1	2	3	4
5. How attached are you to him or her?0	0	1	2	3	4
6. How much does he or she help you?.....0	0	1	2	3	4
7. How much do you like to sit and talk with him or her?.....0	0	1	2	3	4
8. How much love do you feel for him or her?.....0	0	1	2	3	4
9. To what extent do the two of you share the same values?0	0	1	2	3	4
10. When you really need it, how much does he or she comfort you?0	0	1	2	3	4
11. How much do the two of you laugh together?0	0	1	2	3	4
12. How much do you confide in him or her?.....0	0	1	2	3	4
13. How much emotional support does he or she give you?0	0	1	2	3	4
14. To what extent do you enjoy the time the two of you spend together?0	0	1	2	3	4
15. How often does he or she express feelings of warmth toward you?0	0	1	2	3	4

Your Family Member

"Family member" refers to your relative or friend with health or memory problems. Please tell us about your family member. (Fill in the blank or **CIRCLE** the answer that describes your family member.)

1. How old is your family member?

_____ years

2. Is your family member female or male?

Female 1

Male 2

3. What is your family member's race?

African American/Black 1

Asian/Pacific Islander 2

Hispanic 3

Native American 4

White 5

Other 6

If other, write in _____

4. What is the highest grade in school that your family member completed?

Completed 6th grade or less 1

Junior high school (7th-9th grade) 2

Partial high school (10th-11th grade) 3

High school graduate 4

Partial college training 5

Completed college 6

Graduate professional training 7

5. What kind of work has your family member done most of his or her working life? _____

6. What is your family member's current marital status ?

Married 1

Widowed 2

Divorced 3

Separated 4

Never married 5

7. With whom does your family member live?

CIRCLE ALL that apply

No one, lives alone 0

With spouse 1

With child(ren) 2

With relative(s) 3

With friend(s), housemate(s) 4

In a nursing home or
care facility 5

8. Altogether, counting your family member,

how many people live in your family

member's household? _____ people

Tell Us About You

- | | |
|--|---|
| <p>1. In what year were you born? 19_____</p> <p>2. Are you female or male?</p> <p style="padding-left: 40px;">Female 1</p> <p style="padding-left: 40px;">Male 2</p> <p>3. What is your race?</p> <p style="padding-left: 40px;">African American/Black 1</p> <p style="padding-left: 40px;">Asian/Pacific Islander 2</p> <p style="padding-left: 40px;">Hispanic 3</p> <p style="padding-left: 40px;">Native American 4</p> <p style="padding-left: 40px;">White 5</p> <p style="padding-left: 40px;">Other 6</p> <p style="padding-left: 40px;">If other, write in _____</p> <p>4. What is the highest grade in school that you completed?</p> <p style="padding-left: 40px;">Completed 6th grade or less 7</p> <p style="padding-left: 40px;">Junior high school (7th - 9th grade) 6</p> <p style="padding-left: 40px;">Partial high school (10th - 11th grade) 5</p> <p style="padding-left: 40px;">High school graduate 4</p> <p style="padding-left: 40px;">Partial college training 3</p> <p style="padding-left: 40px;">Completed college 2</p> <p style="padding-left: 40px;">Graduate professional training 1</p> <p>5. What kind of work have you done most of your working life?</p> <p style="padding-left: 40px;">_____</p> <p style="padding-left: 40px;">_____</p> <p>6. What is your current marital status?</p> <p style="padding-left: 40px;">Married 1</p> <p style="padding-left: 40px;">Widowed 2</p> <p style="padding-left: 40px;">Divorced 3</p> <p style="padding-left: 40px;">Separated 4</p> <p style="padding-left: 40px;">Never married 5</p> | <p>7. Counting yourself, how many people live in your household?</p> <p style="padding-left: 40px;">_____ people</p> <p>8. Do you have children under age 18 living in your household or for whom you have caregiving responsibilities?</p> <p style="padding-left: 40px;">No 0</p> <p style="padding-left: 40px;">Yes 1</p> <p>9. Which of the following four statements describes your ability to get along on your income?</p> <p style="padding-left: 40px;">I can't make ends meet 1</p> <p style="padding-left: 40px;">I have just enough, no more 2</p> <p style="padding-left: 40px;">I have enough, with a little extra sometimes 3</p> <p style="padding-left: 40px;">I always have money left over 4</p> <p>10. For your own home, we are interested in whether you have to pay rent or make mortgage payments?</p> <p style="padding-left: 40px;">I pay rent 1</p> <p style="padding-left: 40px;">I make mortgage payments 2</p> <p style="padding-left: 40px;">I own my home outright and do not pay mortgage or rent 3</p> <p style="padding-left: 40px;">Other 4</p> <p style="padding-left: 40px;">If other, explain _____</p> <p>11. Are you currently employed?</p> <p style="padding-left: 40px;">No, I am retired 1</p> <p style="padding-left: 40px;">No, I am looking for employment 2</p> <p style="padding-left: 40px;">No, I never have been employed 3</p> <p style="padding-left: 40px;">No, I quit work because of my family member's health condition 4</p> <p style="padding-left: 40px;">Yes, I am employed 5</p> |
|--|---|

Tell Us About You (Continued)

12. What is the total amount of your yearly **household** income? Please include money from jobs, net income from a business or farm, dividends, interest, net income from rent, social security, and any other money income.

Under \$5,000.....	1
\$5,000–\$5,999.....	2
\$6,000–\$6,999.....	3
\$7,000–\$7,999.....	4
\$8,000–\$9,999.....	5
\$10,000–\$12,499.....	6
\$12,500–\$14,999.....	7
\$15,000–\$17,499.....	8
\$17,500–\$19,999.....	9
\$20,000–\$24,499.....	10
\$25,000–\$34,999.....	11
\$35,000–\$49,999.....	12
\$50,000 and more.....	13

13. What is your religious affiliation?

Baptist.....	1
Catholic.....	2
Episcopalian.....	3
Holiness.....	4
Jewish.....	5
Lutheran.....	6
Methodist.....	7
Non-Denominational.....	8
Pentecostal.....	9
Presbyterian.....	10
Protestant.....	11
Do not Practice.....	12
Other.....	13

If other, write in _____

14. On a scale from 1 to 5, to what extent do you consider yourself to be religious or spiritual?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Not religious or spiritual Very religious or spiritual

15. Does your religion or spirituality make a difference or influence the care that you provide to your family member?

No 0

Yes 1

- 15a. If **YES**, please describe how or in what way your religion or spirituality makes a difference in the care you provide.

[illegible]

Tell Us About You (Continued)

Your Health

16. During the **past 4 weeks** how much did **pain** interfere with your normal work(including both work outside the home and housework)? (Circle One Number)

Not at all 1
 A little bit..... 2
 Moderately 3
 Quite a bit 4
 Extremely 5

17. In general, would you say your health is (Circle One Number):

Excellent.....1
 Very Good.....2
 Good.....3
 Fair.....4
 Poor.....5

The following items are about activities you might do during a typical day. Does **your health now** limit **YOU** in these activities? If so, how much? (Circle One Number on Each Line).

Activities		Yes, I am Limited A Lot	Yes, I am Limited A Little	No, Not Limited At All
18.	Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
19.	Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
20.	Lifting or carrying groceries	1	2	3
21.	Climbing several flights of stairs	1	2	3
22.	Climbing one flight of stairs	1	2	3
23.	Bending, kneeling or stooping	1	2	3
24.	Walking more than a mile	1	2	3
25.	Walking several blocks	1	2	3
26.	Walking one block	1	2	3
27.	Bathing or dressing yourself	1	2	3

Help From Others In Bathing Your Family Member

EXTENT OF HELP	HELP FROM RELATIVES
<p>1. How many days in the past week did you spend time helping him or her? _____ days</p> <p>2. On the days you help your family member with bathing, about how long do you spend helping him or her during bathing? _____ hours _____ minutes</p> <p>3. Altogether, how long has your family member needed extra help, from you or someone else, with bathing because of health or memory problems? _____ years _____ month</p>	<p>5. How much have relatives helped you with bathing him or her?</p> <p>None at all 0 A little 1 Some 2 Quite a bit 3</p> <p style="text-align: center;">HELP FROM FRIENDS AND NEIGHBOR</p> <p>6. How much have friends and neighbors helped you with bathing him or her?</p> <p>None at all 0 A little 1 Some 2 Quite a bit 3 A great deal 4</p> <p>7. Does help from others make it easier or harder for you ?</p> <p>Easier.....0 Harder.....1</p>
HELP FROM OTHERS IN BATHING YOUR FAMILY MEMBER	HELP <u>NOT</u> RECEIVED
<p>Now we would like to know if other people have helped you with bathing your family member?</p> <p>HELP FROM PEOPLE WHOSE JOB IT IS</p> <p>4. How much have people whose job it is (such as a health professional, a paid helper) helped you with bathing your family member?</p> <p>None at all 0 A little 1 Some 2 Quite a bit 3 A great deal 4</p>	<p>8. Is there a person you thought would help you more with bathing your family member, but who has not done so?</p> <p>No..... 0 Yes 1</p> <p>8a. If YES, how upsetting has it been for you that this person has not helped as you expected?</p> <p>Not at all upsetting 0 A little upsetting 1 Somewhat upsetting 2 Quite upsetting 3 Extremely upsetting 4</p>

Your Feelings During The Past Week

Using the scale below, **CIRCLE** the number which best describes how often you felt or behaved this way
—DURING THE PAST WEEK.

- 1 = Rarely or none of the time (less than 1 day)
 2 = Some or a little of the time (1–2 days)
 3 = Occasionally or a moderate amount of time (3–4 days)
 4 = Most or all of the time (5–7 days)

		Rarely or None	Some or A Little	Occasionally or Moderate	Most or All
During the PAST WEEK:					
1.	I was bothered by things that usually don't bother me.....	1	2	3	4
2.	I did not feel like eating; my appetite was poor.....	1	2	3	4
3.	I felt that I could not shake off the blues even with help from my family or friends.....	1	2	3	4
4.	I felt that I was just as good as other people.....	1	2	3	4
5.	I had trouble keeping my mind on what I was doing.	1	2	3	4
6.	I felt depressed.....	1	2	3	4
7.	I felt that everything I did was an effort.....	1	2	3	4
8.	I felt hopeful about the future.....	1	2	3	4
9.	I thought my life had been a failure.....	1	2	3	4
10.	I felt fearful.....	1	2	3	4
11.	My sleep was restless.	1	2	3	4
12.	I was happy.....	1	2	3	4
13.	I talked less than usual.....	1	2	3	4
14.	I felt lonely.....	1	2	3	4
15.	People were unfriendly.....	1	2	3	4
16.	I enjoyed life.....	1	2	3	4
17.	I had crying spells.....	1	2	3	4
18.	I felt sad.....	1	2	3	4
19.	I felt that people disliked me.....	1	2	3	4
20.	I could not get "going."	1	2	3	4

Your Overall Experience In Caregiving

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 do you feel because of all the caregiving things you do for your family member?

Not at all confined..... 0

Confined a little..... 1

Somewhat confined..... 2

Confined a lot..... 3

Extremely confined..... 4

2. How often would you say that taking care of your family member is very difficult?

Never..... 0

Rarely..... 1

Sometimes..... 2

Much of the time..... 3

Always..... 4

3. How much stress do you feel because of **all** your obligations, including taking care of your family member?

No stress.....0

Very little stress.....1

Some stress.....2

A lot of stress.....3

Overwhelming stress..... 4

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..... 4

Positive outweighs the negative
somewhat..... 3

Positive and negative are about
equal..... 2

Negative outweighs the positive
somewhat..... 1

Negative outweighs the positive
a lot..... 0

5. What if your family member's care needs increase? How confident are you that you would be able to provide more care than you are doing now?

Not at all confident..... 0

Not too confident..... 1

Somewhat confident..... 2

Pretty confident..... 3

Very confident..... 4

Thank you very much for completing this questionnaire. Would you take a few more minutes to give us your reactions to the questionnaire? (Please **CIRCLE** your answer). Also, included are questions that can help us plan for future studies.

1. How interesting or boring was this questionnaire?
- | | |
|---|---|
| Very interesting | 1 |
| Pretty interesting | 2 |
| Somewhat interesting and somewhat boring? | 3 |
| Pretty boring | 4 |
| Very boring | 5 |

2. Were the questions on this questionnaire clear or confusing?
- | | |
|--|---|
| Everything was very clear | 1 |
| Most questions were clear; only a few were confusing | 2 |
| Some questions were clear and some were confusing | 3 |
| Only a few questions were clear; most were confusing | 4 |
| Nearly all the questions were confusing | 5 |

What question or page of questions was most confusing to you? _____

3. Were any of the questions emotionally upsetting to you?
- | | |
|------------------|---|
| Not at all | 1 |
| A little | 2 |
| Some | 3 |
| A lot | 4 |

What question or page of questions was most emotionally upsetting to you? _____

Please complete the following sentences:

4. The thing I liked **most** about this questionnaire was: _____

5. The thing I liked **least** about this questionnaire was: _____

6. What do you think about researchers coming into your home to observe you helping your family member with bathing?
7. What do you think about researchers videotaping you assisting your family member during bathing ?
8. What is most pleasurable for you about helping your family member with bathing?
9. What is the most difficult for you about helping your family member with bathing?
10. What kinds of things do you do to make bathing go smoothly?
11. What advice do you have for other caregivers who are having difficulties with their family member during bathing?

Date

TIME

DATE AND TIME YOU COMPLETED QUESTIONNAIRE

About how long did it take you to complete this questionnaire?

_____ hours _____ minutes

Thank you very much for sharing your experience and opinions with us. Your responses will be very helpful to us in getting a good idea of what it is really like for caregivers in your situation.

When you are done with the questionnaire, please return it to us in the enclosed stamped envelope.

Thank you again for your participation!

APPENDIX X
COMPUTATION OF SCORES

APPENDIX X
COMPUTATION OF SCORES

Title 'JU 2002Jan01_computescales--01-07-02'.

Subtitle 'CG characteristics'.

Compute CGage= 2000-cyear.

Compute CGphysfu = ((mean.8 (actvigor, actmodrt, actlift, actstrs, actstr, actbend, actmile, actblks, actblk,actbath))-1)*50.

Compute CGdepres=((mean.15(depbothr, depapoor, depblues, depeffrt, depmind, depress, depfail, depfear,depsleep, deptalks, deplone, depufriy, depcry, depsad, depdislk, depgoin, depgoodr, dephoper, depenjor, dephappr))*20)-20.

compute Yrsknown= cgyears + (cgmonths/12).

Compute CGmutual=mean.12(muteye, mutclose, mutpast, mutapprc, mutattch, muthelp, muttalk,mutlove,mutshare,mutcomft,mutlaugh,mutcnfde,mutsuppt,mutenjoy,mutwarm).

Subtitle 'CR characteristics'.

Compute CRmemory=mean.6(memeven, memwday, memaddr, memwords, memsimp, memfway, memsent, mempeopl).

Subtitle 'Caregiving in General'.

Compute YrsCGing= cginvcg + (cgmonth/12).

Compute YrsBath= eohyears + (eohmonth/12).

Compute Global=mean.3(globconf, globdiff,globstrs, globalnr).

Subtitle 'Bathing Situation'.

Compute Wishes=mean.7(gabslow, gabwait, gabapol, gabresp, gabface, gabbody, fctell, gabcalm, fcralm).

Compute SelfPrep=mean.3 (prepcold, preptemp, prepwash, prepsoap).

Compute SelfWash=mean.8(washface, washneck, washear, washhand, washarm, washches, washstom, washback, washpriv, washlegs, washtoes).

Compute SelfDry=mean.8(dryface, dryneck, dryears, dryhand, dryarms, drychest, drystom, dryback,drypriv, drylegs, drytoes).

Compute SelfHair=mean.2(washhair, dryhair).

Compute SelfCare=mean.21(prepcold, preptemp, prepwash, prepsoap, washface, washneck, washear, washhand, washarm, washches, washstom, washback, washpriv, washlegs, washtoes, dryface, dryneck, dryears, dryhand, dryarms, drychest, drystom, dryback,drypriv, drylegs, drytoes, washhair, dryhair).

Compute Cleans=mean.4(reaurine, reabowel, reasweat, reafood, reador)*5.

Compute Comfort=mean.3(reagood, reasooth, reawake, reagday)*4.

Compute Freqsink = locsink * 1000.

Compute Freqtub = loctub * 100.

Compute Freqshow = locshow * 10.

Compute SiTuShBe=freqsink+freqtub+freqshow+locbedb.

Compute HrsBath= eohours + (eohmins/60).

Compute ActMPref = Timepbat - timebath.

If (ActMPref eq -1) ActMPref = 1.

If (ActMPref le -2) ActMPref = 2.

If (ActMPref eq 0) Match = 3.

If (ActMPref eq 1) Match = 2.

If (ActMPref ge 2) Match = 1.

Value labels Match 3 'high match' 2 'medium match' 1 'low match'.

COMPUTE helpothr = Mean.2(hfjob,hroreltv,hrofrien).

Variable Labels

Wishes 'CR Wishes Considered'

SelfPrep 'Self-Care Bath Prep--0=CG.1=both,2=CR'

SelfWash 'Self-Care Washing--0=CG.1=both,2=CR'

```
SelfDry 'Self-Care Drying--0=CG,1=both,2=CR'
SelfHair 'Self-Care Wash&Dry Hair--0=CG,1=both,2=CR'
SelfCare 'CR Self-Care in Bathing--0=CG,1=both,2=CR'
Cleans '# Cleansing Function of the Bath'
Comfort '# Comfort Function of the Bath'
helpothr 'Help from Others in Bathing'.
```

Subtitle 'CG Response to Assisting CR with Bathing'.

```
Compute CGsatis=mean.7(exppati,exprelax, expsafe, expsmoot, expquick, expplea,
  expeasy,expsatis, exppost).
Compute CGconfid=mean.8 (expabil, exphelp, expprep, expgood, expsolut, expprob,
  expneed,expcare, expunexp, expclean, expcomun).
Compute CGstrain=mean.3(expfrust, expusure, expfrigt, hardbath).
Compute Hassles = mean.5 (hascrit,hasyell, hascoop, hasfrown, hasverb, haspinch,
  hasover).
```

Subtitle 'CR Response During Bathing'.

```
Compute CRdiscom=mean.6(behmono, behmuttr, behmoans, behpain, behfrown, behfidgt,
  behtense,behfrigh).
Compute CRvocal=mean.7(behnoise, belangu, behtalk, behwords, behorder, behthret,
  behyells, behprof,behharm).
Compute CRphynon=mean.5(behobsc, behsexul, behspits, behbangs, behdispy,
  behndire, behmouth).
Compute CRphyagg=mean.8(behhito, behscrat, behelbow, behhits, behtakes,
  behpinch, behshove,behbites, behspito, behkicks).
Compute CRconten=mean.3(behsmile, behpeace, behease, behrelax).
Compute CRapprec=mean.5 (behhugs, behjoke, behkiss, behpats, behprais,
  behlaugh, behthank).
Compute CRdscom#=mean.6(behmono, behmuttr, behmoans, behpain, behfrown, behfidgt,
  behtense,behfrigh)*8.
Compute CRvocal#=mean.7(behnoise, belangu, behtalk, behwords, behorder, behthret,
  behyells, behprof,behharm)*9.
Compute CRphnnon#=mean.5(behobsc, behsexul, behspits, behbangs, behdispy,
  behndire, behmouth)*7.
Compute CRphagg#=mean.8(behhito, behscrat, behelbow, behhits, behtakes,
  behpinch, behshove,behbites, behspito, behkicks)*10.
Compute CRcnten#=mean.3(behsmile, behpeace, behease, behrelax)*4.
Compute CRaprec#=mean.5 (behhugs, behjoke, behkiss, behpats, behprais,
  behlaugh, behthank)*7.
```

Variable labels

```
CRdiscom 'CR Discomfort During Bathing'
CRvocal 'CR Vocal-Verbal Agitated Behaviors'
CRphynon 'CR Physically Non-Aggressive Behaviors'
CRphyagg 'CR Physically Aggressive Behavior'
CRconten 'CR Contentment During Bathing'
CRapprec 'CR Appreciative & Affectionate Behaviors'
CRdscom# 'CR # Discomfort During Bathing'
CRvocal# 'CR # Vocal-Verbal Agitated Behaviors'
CRphnnon# 'CR # Physically Non-Aggressive Behaviors'
CRphagg# 'CR # Physically Aggressive Behavior'
CRcnten# 'CR # Contentment During Bathing'
CRaprec# 'CR # Appreciative & Affectionate Behaviors'.
```

Subtitle 'Freq Dist of Bathing Scales'.

FREQUENCIES

VARIABLES= cgdepres cgmutual crmemory global wishes selfprep selfwash selfdry
selfhair SelfCare helpothr

cleans comfort cgsatis cgconfid cgstrain hassles crdiscom crvocal crphynon

crphyagg crconten crapprec cgage cgphysfu yrsknown yrscging yrsbath freqsink

freqtub freqshow situshbe hrsbath actmpref match CRdscom# CRvocal#

CRphnon# CRphagg# CRcnten# CRaprec#

/STATISTICS=STDDEV VARIANCE RANGE MINIMUM MAXIMUM SEMEAN MEAN MEDIAN MODE

SKEWNESS SESKEW KURTOSIS SEKURT

/HISTOGRAM NORMAL

/ORDER= VARIABLE .

Save

/OUTFILE='Macintosh HD:Johannah Uriri:JU SPSS:JU2002Jan01Scales.SAV'.