

**THE COGNITIVELY-IMPAIRED INSTITUTIONALIZED ELDERLY:
SPOUSAL PERCEPTIONS AND EXPECTATIONS OF NURSING CARE**

BY

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Abstract

This study was conducted to determine the relationship between the spouses' perceptions and expectations of nursing care delivered to their cognitively-impaired institutionalized elderly mate. Data were collected by means of a self-administered questionnaire, based on the concept of caring, designed to elicit spouses' perceptions and expectations of certain identified nursing care activities. These nursing care activities pertain to the Instrumental, Expressive, and Communicative components of a Total Transactional System, the conceptual framework. Data were analyzed using descriptive and inferential statistics in the form of a central tendency analysis and a multivariate approach using profile analysis. Results demonstrated that there was a difference between the spouses' perceptions and expectations. There was a statistically significant difference between the spouses' perceptions and expectations in that the perceptions were less than the expectations. Specifically, in the provision of physical care, the spouses' perceptions were below their expectations. In addition, nursing staff did not consistently achieve the goal of meeting the communicative and emotional needs of residents as perceived by their spouses. The conclusions support the need for nurses to consider improvements in nursing care through nursing research, specifically, in ascertaining the quality of care concept in this context. Through education, the impact of cognitive impairment as a chronic illness on the elderly person and his/her family could be better understood. Through practice, an improvement in the manner of physical and psychological care delivery could be realized. Finally, through administration, an examination of the structures supporting the delivery of nursing care to the cognitively-impaired elderly could lend motivation and assistance to the nurses responsible for care at the bedside.

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CHAPTER ONE

Introduction

Background to the Study

The Canadian population is rapidly aging. In 1900, only 5% of Canadians were over 65 years of age. This proportion has now more than doubled and by the year 1995 those who will be 65 years or older will comprise 12% of the Canadian population (Organizing Committee, Canadian Consensus Conference on the Assessment of Dementia, 1991). In particular, the so-called "old-old", those aged 85 years or more, will increase at a disproportionately higher rate than the population overall (Pillay, personal communications, June 13, 1991). The greying of Canadians will be accompanied, for some, by cognitive impairment. Since the incidence of cognitive impairment increases with age, the absolute numbers of such cases will continue to rise well into the middle of the next century (Mortimer, Schuman & French, 1981). About 10% of those over 65 years and up to 40% of those over 85 years suffer from cognitive impairment (Evans, Funkenstein, & Albert, 1989). Thus, there are now at least 250,000 Canadians with cognitive impairment and more than 25,000 new cases annually (Organizing Committee, Canadian Consensus Conference on the Assessment of Dementia, 1991). Inevitably, a proportion of these elderly persons are cognitively impaired to the extent that their families are unable to care for them at home and they will require institutionalization.

Cognitive impairment can be defined as the inability to process information (Rohs, 1986). With cognitive impairment, the elderly person is unable to store information to the extent that it can be registered, retained over time, and recalled to consciousness (Rohs, 1986). The experience of daily living depends on effectively

functioning cognitive processes. Consequently, the affected elderly person will be unable to communicate effectively, to be safely and independently mobile, to perform activities of daily living, to eat safely, to be continent, and to be emotionally stable (Harvis, 1990; Hutner Winograd & Jarvik, 1986; Minister of National Health and Welfare, 1984; Reisberg, 1986;). The many manifestations of cognitive impairment challenge optimal nursing care delivery. This challenge is further intensified in view of the limited human and material resources available in long term care institutions. Since medical cure is not likely in the future for dementing chronic illnesses, nurses will need to continue to provide for their care needs (Vuori, 1987).

Traditionally, care of the elderly has been perceived philosophically as basic nursing requiring low skill and low technical expertise. As a result, nursing care of the institutionalized elderly has been generally reduced to the delivery of the basics of physical care such as washing, positioning, and assisting at meal times. Staffing patterns in long term care facilities have long been reflective of such a philosophy, that is: the care of the elderly requires neither extensive training nor skills. This is the only area of nursing service where "hands-on" nursing care is delivered primarily by nonprofessional staff. As overseers of care, the disproportionately small number of professional staff are responsible for all nursing care received by residents.

As recipients of institutional nursing care they receive, residents have perceptions and expectations of that care. Since physical and mental incapacities of the cognitively-impaired elderly render them inconsistent or even unable to express judgment on the quality of their nursing care delivery, the spouses who have been in the position of caregiver are the ones appropriate to determine the perceptions and expectations of institutional nursing care.

Spouses may lack the scientific and technical knowledge and the general awareness of institutional policy associated with the nursing care needs of their institutionalized husbands or wives. This affects how accurately they evaluate all aspects of the quality of nursing care (Vuori, 1987). Spouses, nonetheless, have been shown to make some valid assessments of the nursing care received (Eriksen, 1987; Petersen, 1989; Vuori, 1987).

To a great extent, the spouses' definition of "care quality" may be linked to their own caregiving activities prior to institutionalization and may be influenced by the emotional burden associated with the decision to institutionalize. Further, the perception may also be influenced by factors important to their husband's or wife's physical and psychological comfort (Spitzer, 1988). Spouses may concur with the demented elderly persons' expressed satisfaction with the nursing care received. Based on the researcher's clinical experience, satisfiers may include caregivers' attending to the resident's questions and concerns, returning to the resident as promised instead of keeping him/her waiting for long periods, calling the resident by name and speaking with colleagues in English rather than in the caregiver's own native language, if other than English, in the resident's presence. Other favourable aspects of care may include speaking to the resident in an adult manner, respecting his/her wishes, giving the resident choices, personalizing his/her care, answering call bells promptly, assisting the resident to be clean and well groomed, and anticipating his/her needs without being told. Thus, spouses as consumers value courtesy, technical quality, professional knowledge, communication of information, and the availability of the nurse as indicators of good nursing care delivery (Vuori, 1987). Spouses may be the ultimate authorities on the criteria of good care in all

nontechnical matters (Vuori, 1987). To determine the quality of care without some notion of the spouses' views and experiences is both impractical and unwise (Petersen, 1989).

A perspective on the quality of care necessitates an examination of perceptions as well as expectations. Perceptions can be described as the subjective observations of the phenomenon of nursing care delivery; they answer the question: "What is happening out there?" Spousal perceptions could be used in defining the present status of institutional care, determining various trends in resource utilization, and identifying patterns of care that need to be modified or enforced (Petersen, 1989). Expectations, on the other hand, are concerned with "What is the consumer looking for?". Expectations may originate from the spouses' ideal, or preferred vision; or they may be related to practical, or anticipated expectations that are "learned" from experience (Doering, 1983). A knowledge of both perceptions and expectations from the person who knows the resident best can help to sensitize nurses to the needs and wants of the institutionalized elderly. Frequently, the delivery of nursing care is determined by professional standards alone and not in concert with the consumer. Given the complexity of the care of the cognitively-impaired elderly, the emotional burden of institutionalization, the limited resources on hand, and the rise in consumerism, the expectations have surpassed those standards and criteria delineated for previous periods. Consequently, assumption of a possible gap between spousal perceptions and expectations may be reasonable. Knowing the family perspective may assist nurses to develop greater empathy and to better accept the need for changes or improvements in nursing care. Congruence between

spousal perceptions and expectations denotes agreement with "what is" and "what it could be" and may be construed as a quality attribute (Petersen, 1989).

Historically, nursing care in institutions has been appraised by the extent to which a resident is cared for physically. Spouses and family members, for example, value the merits of cleanliness in basic hygiene. In addition to demanding good physical care, spouses and families place equal, or greater, emphasis on the psychosocial needs of residents. Frequently, the evidence of caring behaviours form the basis by which nursing care quality is determined (Gallman, 1988; Sullivan & Decker, 1988). Caring can be defined as "the intentional actions and attitudes that convey physical care, emotional concern, and promote a sense of safety and security in another" (Larson & Dodd, 1991. p. 61). When consumers feel a sense of caring from the nurse, nursing care is more likely to be construed as being of good quality.

Since caring is concerned with attitudes, its presence within nursing practice is reflected in the behaviours of the nurse-patient* interaction (Gallman, 1988). The demonstration of confidence, attentiveness, and sensitivity to physical and emotional needs, willingness to answer questions and explain procedures, and competent technical performance, especially from ancillary nursing staff such as the patient care aides, convey the perception that the nurse "cares" (Gallman, 1988). For example, taking the time to keep the spouse informed of the state of a resident's common seasonal illness may be a demonstration of good nursing care. Meeting the resident's physical and psychosocial needs involves knowledge as well as communication, sharing, and empathy supported by caring. Caring is useful in

*The terms "patient" and "resident" will be used interchangeably in this thesis.

providing a context for the conceptual framework in viewing the spouses' perspective of nursing care.

Conceptual Framework

Bloom (1963), a sociologist, identified a Total Transactional System in the doctor-patient relationship. This system is applicable today to nursing in light of the concerns of spouses with physical and psychosocial care delivery in long term care institutions.

Bloom (1963) posited that there is a psychosocial aspect to health care delivery. This author views the doctor and the patient as a dyad "drawn together" out of compelling health care needs (Bloom, 1963, p. 24). He identifies two components in this relationship which apply equally well in the nurse-patient relationship. They are the instrumental and expressive transactions of care delivery. According to Bloom (1963), the instrumental transaction is associated with the application of technical knowledge and clinical skills to solving problems at hand. The expressive transaction pertains to the affective or interpersonal aspects of the doctor-patient relationship. Further, Bloom alludes to another aspect of this relationship which has not been formalized in his Total Transactional System. This aspect is associated with the communication needs of the patient.

Petersen (1989), a nurse, studied the notion of patient satisfaction and noted the importance of the patient's need to be informed. Petersen expanded on Bloom's framework by labelling the patient's need for information as the communicative transaction in a nurse-patient relationship. Petersen has added this transaction as the third component in Bloom's Total Transactional System and it relates to imparting

information relevant to the resident and his/her family. Peterson further identifies the following descriptors as contributing significantly to the perception of quality nursing care, and each one can be categorized under one of the three aforementioned transactions:

1. Descriptors related to the instrumental transaction

- Being comfortable
- Learning how to participate in care
- Feeling safe
- Receiving professional help with activities of daily living.

2. Descriptors related to the expressive transaction

- Being treated as individuals
- Maintaining dignity and independence
- Having staff available to tend to them
- Feeling reassured.

3. Descriptors related to the communicative transaction

- Being listened to
- Being informed about what will happen
- Feeling more in control
- Decreasing stress
- Understanding treatment and unit routines.

Bloom's framework serves to emphasize that technical expertise is but one aspect of nursing care delivery. The psychosocial component of care delivery

requires the demonstration of caring behaviours, supported by knowledge and skill, to address the emotional and social needs of the cognitively-impaired resident.

Problem Statement

The cognitively-impaired elderly enter institutions because their complex care needs can no longer be adequately met at home by their families. Even as the physical care is relinquished to caregivers, the emotional attachment to their husbands/wives residing in institutions remains strong. The spouses' past caregiving history, their emotional burden, the presence or absence of perceived caring demonstrated by nursing staff, and the limited financial and human resources available to institutions may be some of the factors which shape spousal perceptions of institutional nursing care. Since expectations are reflective of the ideal circumstance to begin with, incongruity between perceptions and expectations of institutional nursing care can be anticipated. As family and advocate for the cognitively-impaired institutionalized elderly, and "most common caretaker", spouses of residents are in a unique position to speak on their behalf and to shed light on the issue of care quality in institutions (Hayter, 1982, p. 84).

Purpose of the Study

The purpose of this study was to determine the differences between the spouses' perceptions and expectations of nursing care delivered to their cognitively-impaired institutionalized elderly.

Research Question

This study sought to solicit the spouses' perceptions and expectations of certain identified nursing care activities. The specific question that directed this study was:

"What are the differences between spouses' perceptions and expectations of nursing care delivered to their cognitively-impaired institutionalized elderly?"

Definition of Terms

The following conceptual definitions were used in the study:

1. Spouse: husband or wife of the institutionalized cognitively-impaired elderly.
2. Perceptions: the spouses' subjective observations of the phenomenon of nursing care delivery to the cognitively-impaired institutionalized elderly:
What is happening out there?
3. Expectations: the spouses' own subjective, preconceived suppositions of the phenomenon of nursing care: What they believe nursing care ought to be and what they are looking for in nursing care.
4. Quality: congruence between perception and expectation of nursing care.
5. Nursing care: an activity performed by the nurse to meet the physical, psychosocial, communication, and caring needs of the institutionalized elderly.
6. Institutionalized elderly: husband or wife of the informant who is 65 years or older and who has resided in the long term care facility for at least six months.
7. Cognitively-impaired: any resident who has difficulty processing information associated with, but not limited to, a number of dementing processes,

including Alzheimer's Disease, dementia, organic brain syndrome, and strokes/cerebral vascular accidents (CVAs).

Assumptions

The study was approached with the following assumptions:

1. Views expressed by the informants may also include those of the institutionalized elderly.
2. Nursing staff referred to may include Registered Nurses, Licensed Practical Nurses, and Nursing Care Aides.

Limitations

1. This study examined only selected aspects of the spouses' perceptions and expectations of nursing care.
2. The nursing actions referred to in this study could have indicated activities performed by more than one aggregate of nursing staff.
3. The respondents may have articulated their perceptions based on nursing actions in general and they may have been unable to differentiate the level of nursing staff or their functional responsibilities.
4. Due to the small sample size, the findings from this study are not generalizable.

Significance of the Study

Scientific Significance

As nursing care is always delivered within a social context, a quantitative study can help to identify the areas which may be a source of difficulty for families of the cognitively-impaired institutionalized elderly. The knowledge generated from this study may encourage other research initiatives to continue to study the notion of quality care delivery. The results from this study may assist in the development of quality care studies from the caregiver perspective and resident satisfaction with nursing care.

Practical Significance

Because providing quality nursing care service is extremely important, it is critical to recognize that residents and families have varying degrees of service expectations and that they may not be congruent with those conceptualized by managers of nursing care (Rempusheski, Chamberlain, Picard, Ruzanski, & Collier, 1988). Knowledge of any differences between expectations of nursing care and actual nursing care received from the spousal viewpoint can foster a stronger nurse-consumer relationship and improve resident care by providing the opportunity for nurses to explore those expectations. Moreover, accepting the perceptual component of quality also helps caregivers change their focus from defending their actions to determining how to influence the families' expectations in a more positive manner (Petersen, 1989). At the same time, consumers may need to modify their expectations toward a goal that is no longer excellence at any cost, but rather, optimal quality within available resources (Vuori, 1980). Because the hospital and

institutional sector remain the area of greatest cost in health care, this sector has become the most sophisticated resource conscious sector in the health care system (Hastings, 1985). The elderly, who use a disproportionately greater amount of in-house care support, (as much as 30% for those 85 years of age and over), are often residents of British Columbia's long term care* facilities (Seaton, Evans, Fyke, Sinclair, & Webber, 1991). Even though the care of the chronically ill elderly is one of the most critical elements within the health care system, it is not immune to the driving force of cost and expenditure containment (Hastings, 1985; Seaton et al., 1991). Results from this study may assist in future definitions of "quality" institutional nursing care by generating knowledge from a consumer perspective is significant to the care of the cognitively-impaired institutionalized elderly rather than merely concerned with the satisfaction of the care received (Eck, Meehan, Zigmund, & Pierro, 1988).

Summary

There is a growing number of older people requiring institutional care as a result of a cognitive impairment associated with increasing age. As a vulnerable and incapacitated group of care recipients, the institutionalized elderly may not be physically/mentally able to comment on the state of institutionalized nursing care. Their spouses have been identified as the key spokespersons for the institutionalized elderly. A conceptual framework using Bloom's Total Transactional System was selected to describe the context of nursing care quality. The findings of this study may provide information to assist in the development of further studies pertaining to

*Long term care is also known as extended care/continuing care/nursing home care.

quality care issues. Knowledge of any differences between perceptions and expectations may foster a stronger nurse-consumer relationship in addition to the improvement of resident care. The next chapter presents a review of the pertinent literature.

CHAPTER TWO

Literature Review

Overview

The spouses' perspective on nursing care for the cognitively-impaired institutionalized elderly has not received wide spread attention in the literature. As the population ages and more elderly persons enter long term care facilities, there is increasing scrutiny in the way institutions deliver nursing care. The institutionalized cognitively-impaired residents are confined by their disabilities and are unable to provide an evaluation of the quality of care received. Their marital partners possess intimate knowledge of the residents' needs and the spouses' emotional attachment well qualifies them to advocate on the resident's behalf. The notion of nursing care quality must include a definition from the perspective of the consumer if it is to be meaningful and valid. Improvement in care requires an understanding of the spouses' perceptions and expectations and the influences that might impact on them (Johnson, Morton, & Knox, 1992).

The spouses' perceptions and expectations, however, are influenced by many factors. The following is a review of the limited literature pertaining to those factors which may influence the way nursing care is perceived and expected in institutions.

The literature review is organized into four sections. The first section describes the increasing dominance of institutional care of the cognitively-impaired, since increased aging is associated with increased institutional care. This section includes future population aging trends and statistics and their relevance to institutionalization. The second section pertains to the spouse as caregiver, and the factors that eventually necessitate the institutionalization of the demented elderly in care facilities.

In order to appreciate the spouses' perspective as consumers of health care, there must be an understanding of their stresses and overriding concerns as caregivers. In section three, research regarding the effects of institutionalization will be presented. In particular, the assumption that institutionalization impacts negatively on the life of residents is explored. Section four is concerned with studies of the impact of different approaches to nursing care of the cognitively-impaired elderly in institutions. Caring is supported as the underlying attribute upon which the components of the conceptual framework, the instrumental, expressive, and communicative transactions are based. Taken together, the burdens, stresses, and responsibilities associated with caregiving, the documented impacts of institutionalization, and the limited resources available in institutions, provide support for the study of spousal expectations.

Trends in Population Aging and the Reasons for Institutionalization

Palmore (1986) asserted that as life expectancy increases, this longevity is accompanied by an even greater proportion of disability. Canadian census figures for 1986 projected a 4% annual growth rate for those aged 80 and over for the rest of this century (Ministry of Supply and Services, 1988). Strong growth, equalling 3% per annum, will continue into the first decade of the twenty-first century (Ministry of Supply and Services, 1988). The projections forecasted a sharp increase in the over 85 age group for the period between 1991 to 2011. After 2011, the "Baby Boom" generation will have reached 65 years of age. Therefore, by the year 2021, nearly one in every five Canadians will be aged 65 years or over (Ministry of Supply and

Services, 1988). According to the Health and Activity Limitation Survey, 78.9% of persons with disabilities living in institutions were aged 65 and over (Statistics Canada, 1991). The incidence rate for cognitive impairment has been estimated to be 1% among individuals over 65 years and 1.9% to 2.5% among those over 80 years (Canadian Task Force on the Periodic Health Examination, 1991). Since cognitive impairment occurred most frequently among the "old-old", the prevalence rate among those over 80 years with cognitive impairment was estimated to be 12.1 to 22 percent (Canadian Task Force on the Periodic Health Examination, 1991). A staggering 47% of those over 90 years will also be afflicted (Canadian Task Force on the Periodic Health Examination, 1991). Difficulty with nursing care at home as a result of cognitive impairment often accounts for admissions to long term care institutions (Canadian Task Force on the Periodic health Examination, 1991). Consequently, at least 50% of the elderly in institutions suffer from cognitive impairment (Canadian Task Force on the Periodic Health Examination, 1991). The factors most frequently necessitating institutionalization include the inability to dress, bathe, and toilet independently, as well as deficits in memory and other behavioral disturbances (Reisberg, 1986).

Institutional care as defined by Statistics Canada refers to "facilities with four beds or more, funded, licensed or approved by provincial or territorial departments of health/social services and provide nursing/counselling services as well as personal care to residents, in contrast to the active medical treatment provided in hospitals" (Institute for Health Care Facilities of the Future, 1990, p. 240).

Chenoweth and Spencer (1986) explored the concerns associated with problems of caregivers of family members with dementia from early symptoms,

diagnosis, home care, and institutionalization. The authors found that the most consistent predictor of institutionalization appears to be caregiver stress resulting in facility care as the final resort (Crossman, London, & Barry, 1981; Johnson & Werner, 1982; Mathew, Mattocks, & Slatt, 1990; Stephens, Kinney, & Ogrocki, 1991; Stone, Caffererata, & Sangl, 1987; Tobin & Kulys, 1981; Zarit, Reeves, Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986).

From initial occurrence of symptoms to the point of diagnosis, the families were ill prepared to care for their relatives, especially the "behavioral changes that occur as a consequence of the disease" (Chenoweth & Spencer, 1986, p. 269). Other problems described by the respondents which led the spouse to the decision to institutionalize included personality changes, demands of 24-hour care, isolation from friends, and embarrassment in public.

One of the concerns most frequently cited by families was a problem associated with institutional care. Some facilities were staffed by "untrained staff, particularly the lack of training about caring for patients with dementia" (Chenoweth & Spencer, 1986, p. 271). This perceived difficulty, along with dwindling numbers of personnel staffing institutions, engendered feelings of anxiety, frustration, entrapment, and guilt in families when a transfer of the cognitively-impaired elderly to an institution was necessary (Barer & Johnson, 1990; Johnson & Werner, 1982; Riffle, 1989; Schwartz & Vogel, 1990). The notion that the families were "putting their relative away" was cited by respondents in the study by Schwartz and Vogel (1990, p. 53). Hayter (1982) reported that families were often accused of "dumping" their elderly relatives into institutions (p. 84). As a result, there is a compelling need by some family members to maintain continual involvement as an

insurance that proper care for their aged relative is maintained at all times.

Sometimes, family members became over-protective in an attempt to do "what is right" (Shuttlesworth, Rubin, & Duffy, 1982, p. 200).

Chenoweth and Spencer (1986) cited the following reasons for institutionalization from their study of caregiver experiences. They include "24-hour care was too difficult, couldn't take it anymore" (72%), incontinence (18%), and combative behaviour or angry outbursts were mentioned (15%). These reasons were supported by other literature (Sanford, 1975; Zarit et al., 1980, p. 271). Main symptoms which necessitated families to seek help in the first place were memory loss and disorientation (52%). "The gradual, insidious nature of dementia produces a mystifying clinical picture, causing families to mistrust their own perceptions or to deny the gravity of the changes" (Chenoweth & Spencer, 1986, p. 272). The results of this study supported those already revealed in the literature: Spouses, in particular, constantly struggle to adapt and adjust to the increasingly dependent cognitively impaired elderly to the point that physical resources have been exhausted (Cox, Kaeser, Montgomery, & Marion, 1991; Crossman et al., 1981; Fitting, Robins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Getzel, 1982; Golander, 1987; Pagel, Becker, & Coppel, 1985; Stephens et al., 1991, York & Calsyn, 1977; Zarit et al., 1980; Zarit et al., 1986). Fengler and Goodrich (1979) referred to caregiving spouses as the hidden victims. Many of the caregivers require help and support as much as their disabled family members. Literature focused on the impact of caregiving upon the spouses (Crossman et al, 1981; Johnson & Werner, 1982; Mathew et al., 1990; Purchno & Potashnik, 1989; Stephens et al., 1991; Stone et al, 1987; Tobin & Kulys, 1981; Zarit et al, 1980; Zarit et al, 1986). The physical

and emotional demands of caregiving are superimposed on stresses already existing: the spouses own aging process and its attendant changes, a sense of isolation and loss of control, self-blame, loneliness, depression, and role overload (Crossman et al., 1981; Pagel et. al., 1985; Pruchno & Potashnik, 1989). Few studies, however, defined specifically the spouse's role as caregiver (Klein, Dean, & Bogdonoff, 1967; Lezak, 1978; Sainsbury & Grad de Alarcon, 1970; Sanford, 1975). The following discussion explores the implications of the spouse as caregiver and its associated tasks within that role.

The Spouse as Caregiver

Spousal caregivers frequently go to great lengths to avoid institutionalization of their husband/wife (Riffle, 1989). Particularly, these feelings stem from a reduced choice to institutionalize especially if there is still one other choice that is viable, for example, home nursing care. On the other hand, Johnson and Werner (1982) studied 153 families who had admitted an elderly family member to a facility and found that admissions due to the symptoms of immobility or failure to recognize persons were associated with lower guilt and anxiety.

The stresses of caring for a cognitively-impaired elderly are considerable (Chenoweth & Spencer, 1989; Crossman et al., 1981; Fortinsky & Hathaway, 1990; Johnson & Werner, 1982; Lezak, 1978; Riffle, 1989). Spouses feel chronically tied down since they must be continually available to provide care and treatment and to oversee the disabled elderly's daily activities (Lezak, 1978; Riffle, 1989). To add to the physical and emotional burden, these feelings are often complicated by guilt. Wives sometimes wish for their husbands' death and at times resent their presence (Crossman et al., 1981). One wife stated: "I sometimes wish he had died after his

stroke. He is miserable because he can't walk and can't talk, and I'm wearing down under the strain of all the constant work" (Crossman et al., 1981, p. 466). These caregivers often fulfilled their roles for years without outside information, services, or support (Fortinsky & Hathaway, 1990). As a result, there was little opportunity to meet their own needs, to take vacations, or to make future plans (Riffle, 1989).

Although the fact that caregiving poses stress, strain, and burden is well established, the criteria used to identify the caregiver are not as well delineated (Barer & Johnson, 1990). According to the authors, there is a range of meanings attributed to the term "caregiver". Arbitrary definitions may be based on the type of help provided, such as those who provide "hands-on" physical care and those who provide occasional or emergency assistance (Hooyman, Gonyea, & Montgomery, 1985), to those who "mediated with the bureaucracy" (Sussman, 1976). Each meaning identified a diverse way of viewing the caregiver role and the accompanying attributions associated with that particular role. For example, those who provided backup support, took the elderly person to appointments or tended to day-to-day routines can all be described as caregivers (Barer & Johnson, 1990; Chenoweth & Spencer, 1986). One of the more explicit and useful definitions of caregiver was described by Stone et al. (1987). The authors assigned the term primary to describe a caregiver as one who had total responsibility for the provision of care, while secondary caregivers did not have that responsibility. For example, "care" on one occasion of assistance was significantly different than round-the-clock hands-on "care".

Studies focusing on the caregiver tended to be limited to the spouse (Fitting et al., 1986; Getzel, 1982; Zarit et al., 1986). For an elderly couple with health

problems, the caregiver was most likely to be the wife since women tended to be younger than their husbands and lived longer (Shanas, 1979; Mathew et al., 1990). Also, a majority of women in this age group had been socialized to occupy the caregiver role and this pattern will persist into later life (Crossman et al., 1981). In studies pertaining to caregiving, many authors reported that a majority of family caregivers were women. Silliman, Fletcher, Earp, and Wagner (1986) found that of the primary caregivers they interviewed, 84% were women. In another study by Scott, Roberto, and Hutton (1986), women constituted 65% of the respondents. Seventy-one percent of the caregiving subjects in George and Gwyther's (1986) study were female. Caserta, Lund, Wright, and Redburn (1987) reported 73.5% of their subjects were women. Women subjects accounted for 76% in a study by Horowitz (1985). Gilhooly (1986) reported 81% of his caregivers were women. Finally, Zarit et al. (1980) reported that female subjects made up 86% of the sample in their study of the caregiving experience. Little is known, however, about the male caregiving experience (Mathew et al., 1990). Fitting et al. (1986) studied the caregiving experience in husbands and wives and found that female caregivers were more distressed than male ones, and younger caregivers were more resentful of their role than older ones. Vinick (1984) found that men were more stoic and tended to minimize the hardships including feelings of isolation. Both husband and wife caregivers institutionalized their family members when they perceived their spouses to be severely impaired (Mathew et al., 1990). The study conducted by Mathew et al. (1990) suggested that men represented a minority in studies on caregiving. The authors reported that it was difficult to identify and to obtain consent from male caregivers and their responses were generally brief. More studies appear to be

needed in order to understand and appreciate the husband's role in spousal caregiving.

Clark and Rakowski (1983) identified four categories of caregiver tasks: direct physical care to the elderly family member, dealing with the caregiver's own concerns and difficulties, interpersonal ties with other family members, and dealing with members of the health care community. Very little was found in the literature regarding the specific activities spouses must contend with while caring for their impaired husband/wife at home. Sandford (1975) studied 50 family caregivers to identify the problems with which the caregivers find it impossible to cope. The author found that the problems identified fell into three categories: the elderly's behaviour patterns, the caregiver's own limitations such as insufficient strength for lifting, arthritis, back strain, personality conflicts, anxiety and depression; and environmental and social conditions (Sandford, 1975). The management problems which resulted from the elderly individual's disability were directly related to the person's diagnosis of senile dementia (62% of respondents) and its accompanying manifestations (Sandford, 1975). The percentage of nursing care which family members found intolerable included: helping the family member to walk (87%), assisting with getting on the commode (78%), and off the commode (79%), shouting (80%), incontinence (57%), daytime wandering (67%), sleep disturbances (84%), managing physically aggressive behaviour (56%), communication (50%), and dealing with dangerous behaviour (62%). Caregivers' own limitations included those of a psychosocial origin. These personal difficulties were directly related to caregiving and included anxiety and depression (35%), inability to leave dependant for more than one hour (29%), and restriction of social life (43%).

Very often, meeting the spouse-caregiver's own needs is in direct contravention of meeting the elderly person's requirement for survival. Caring for a cognitively-impaired elderly spouse exacts a heavy toll on the caregiver's emotional, physical, and social well-being (George & Gwyther, 1986; Pagel et al., 1985; Riffle, 1989; Stevens et al., 1991; Zarit et al., 1986; Zarit et al., 1980).

Unfortunately, even when family caregivers institutionalize their cognitively-impaired elderly in an effort to improve their own health and psychosocial well-being, their stress often continues and may even be exacerbated after admission (George & Gwyther, 1984; Pagel et al., 1985). This finding contradicted common sense expectations that as the care shifts from family to professional nursing staff, caregiving stress would be decreased or eliminated. Instead, research has indicated that spouses do not necessarily relinquish their caregiving role even though their husband/wife no longer lives with them (Shuttlesworth et al., 1982; York & Calsyn, 1977). The "pay-off" to spouses for their continued involvement includes opportunities to demonstrate caring behaviours to their institutionalized elderly. In other words, families obtain satisfaction from providing emotional comfort when they are able to tend to those needs rather than the technical aspects of their resident's physical care. By being involved, families of residents also ensure that they do not leave the achievement of psychosocial aspects of care to chance (Bennett, 1980). "When families remain involved with their relative in the nursing home, the quality of nursing home care appears to benefit" (Shuttlesworth et al., 1982, p. 200). Several authors suggest that residents whose families visit them regularly receive better care from staff; have higher morale and life satisfaction; and, feel less lonely and forgotten (Gottesman, 1974; Harel, 1981). Partly for these reasons, spouses often maintain their close emotional ties even after institutional placement (Montgomery,

1982; Smith & Bengtson, 1979; Tobin & Kulys, 1981; York & Calsyn, 1977). These spouses continued to visit regularly; the visiting patterns were stable over time and they did not increase or decrease when the institutionalized elderly became progressively impaired (Stephens et al., 1991). In addition, the spouses continued to assist with such caregiver tasks as grooming, walking, and doing laundry for their family member. This continual involvement with facility care may explain the reason for the similarity in stress levels between in-home family caregivers and those whose relative has been institutionalized (Montgomery, 1982; Smith & Bengtson, 1979; Tobin & Kulys, 1981; York & Calsyn, 1977).

The Effects of Institutionalization

The spouse is the key variable in determining whether a cognitively-impaired elderly person will remain in the community or be institutionalized (Brody, Poulshock, & Mascioschi, 1978; Palmore, 1976; Townsend, 1965). The spouse's level of burden very often impacts on the family's ability to cope with the extent of care required by the impaired elderly. At the same time, as previously stated, even as the spouses relinquish their primary caregiving role, they carry with them the burden of caregiving in their secondary role. Feelings of frustration, entrapment, and guilt may influence the way spouses view institutional nursing care delivery and their preconceived notions of acceptable care quality. In addition, family members are not generally knowledgeable about the restrictions, norms, and the way "things operate" in institutions.

The negative effects of institutionalization were well documented in the literature (Golander, 1987; Huss, Buckwalter, & Stolley, 1988; Zarit et al., 1980). The relocation process itself, the question of nursing care quality provided in

institutions, the lack of meaningful relationships, and the maintenance of a self identity contribute to the immense adjustment required to cope with institutional life. This negativity remains pervasive: "Institutionalization is often associated with, if not accused of, high mortality and morbidity rates of aged residents" (Golander, 1987, p. 27). Institutionalization was often linked with regimented and impersonal care (Huss et al., 1988). Other negative effects cited include depersonalization of the individual, loss of identity, increased disorientation, helplessness, and depression (Golander, 1987; Huss et al., 1988). Indeed, the quality of care in institutions has been questioned. Yet for some spouses of the cognitively-impaired elderly, alternative 24-hour care arrangements other than institutionalization may be impossible to attain. Spouses often feel caught "between a rock and a hard place".

While the functional aspect of caregiving will have been resolved by institutionalization, the emotional dilemma of placement may very well be compounded. Unlike the elderly person's home environment, there is a "collectiveness" and "impersonality" to facility care (Golander, 1987). For example, the awareness that physical discomfort is often not immediately relieved, as it is at home, is difficult to accept. This may be evident when the resident is not assisted as soon as his/her meal tray arrives on the unit, or is not changed the very minute he/she is discovered wet or soiled. What is "good enough" for one resident is also adequate for every other resident seems to be another prevailing attitude. The loss of individuality and not being catered to may be some of the intolerable traits of total institutional nursing care.

Nursing Care of the Institutionalized Elderly

From the literature review thus far, the disabilities generated as a result of cognitive impairment more than suggest that this elderly population would require institutionalization and special nursing care. Frequently, standards of nursing care had been formulated in the clinical setting without input from the consumers served (Hanson Frost, 1992). A major concern is whether consumer expectations and professional standards are compatible: Do the cognitively-impaired elderly require an increase in the scope and quantity of nursing care as compared to those who are physically disabled?

According to Gustafson (1984), nursing care was defined as the specific activities performed by nurses as caregivers to the patient. Nursing care activities encompassed a variety of tasks which the nurse performs. For example, Shook and Beck (1991) compared the nursing care needs of the cognitively-impaired elderly and those with only physical disabilities. The authors posited that the likelihood is that the needs of the cognitively-impaired will present a heavier workload for nursing staff not only in time but also in characteristics of care delivery. Through a direct observational pilot study, the authors addressed the "instrumentalities" of four activities of daily living: bathing, grooming, eating, and toileting. A considerable amount of patience was required to modify the environment, to provide reassurance and encouragement, and to focus attention to the task at hand, be it eating or grooming. Not surprisingly, assistance rather than "doing for" requires more nursing care. As well, the impaired elderly may be disinhibited, becoming boisterous, disruptive, and aggressive. This behaviour may pose a safety risk to themselves, other residents, and staff. Their moods and temperament may fluctuate widely,

making it difficult for nurses to establish nursing care routines (Shook & Beck, 1991). When routines are not followed due to lack of cooperation, spouses can become defensive of their institutionalized husband/wife.

Because these authors did not make known their research methodology, the merits of extrapolating these research findings and their applicability to clinical practice are difficult to evaluate. Practically, however, health professionals familiar with the care of the demented elderly will likely concur that while the instrumental activities are vital to quality care delivery, the "expressive" component, that is the interactionary processes of nursing staff, is equally critical to positive outcomes for residents. Without constant, respectful verbal and nonverbal cues, little constructive response will be elicited from the cognitively-impaired elderly. The findings from the Shook and Beck (1991) study may provide the basis necessary for replicating a study conducted in a more controlled manner.

At present, very little literature is available which examines the exact conditions that will enhance the nursing care specific to this group of complex residents. However, Burgener and Barton (1991) studied the essence of the nurse-resident interactional process. The Interaction Behaviour Measure (IBM) was used as the major instrument. It contained 12 items describing interaction behaviours on a seven-point semantic rating scale (Burgener & Barton, 1991). This instrument was considered internally consistent, with alpha estimates ranging from .64 to .92 (Burgoon & Aho, 1982). The numbers of resident subjects were small (N = 12). The residents were selected from the institution's Alzheimer's dementia unit, according to high or low mental functioning as ascertained by the Mini-Mental State Exam (MMSE), which the authors have found to be consistently reliable with this

population. Nursing assistants and residents were observed in one of two situations: dressing the resident and during an interpersonal contact of "no specific task" purpose. This method of observation resulted in 239 interactions. Findings indicated that several nursing staff behaviours were important in the attempt to have the resident dress, with significant correlations ranging from $r = .24$ to $r = .69$ (Burgener & Barton, 1991). Although a cause and effect relationship cannot be established, it appeared that an increase in interpersonal transaction from nursing staff facilitated greater participation on the part of the elderly resident. In addition, the manner in which the verbal stimulation was delivered was critical. A personal rather than an authoritarian communicative mode appeared more effective with this client group. In task interactions, staff tended to do more for the client than was actually necessary, instead of inviting active participation or assisting in the performance of the resident's own care. This was especially important for the more cognitively-alert resident. Armstrong-Esther (1986) asserted that caregivers spent less time with confused rather than lucid residents. Yet, confused residents spent only 16% of their time in purposeful activities. Because families placed great emphasis on the holistic treatment of their cognitively-impaired institutionalized elderly, the families' expectations of nursing care may well have exceeded some nursing care practice domains.

Avorn and Langer (1982) found that overly intrusive impatient assistance beyond the clinical requirements in self-care reduces the elderly person's ability to perform simple psychomotor tasks unaided. Excessive infantilization, including paternalization, led to "learned helplessness" and a perceived lack of control and autonomy with further disability (Cox et al., 1990). The use of praise, humour, and

a positive caring tone of voice with eye contact were generally greeted with positive resident behaviours. "If any behaviour seemed to be able to "turn a resident around", it was a show of positive regard expressed in this way, "You know I really care about you" (Burgener & Barton, 1991, p. 41).

Mayer (1987) defined caring as "the direct and indirect nurturant and skilful activities, processes, and decisions related to assisting people to achieve or maintain health" in a professional nurse-patient relationship (p. 48). These included the attributes of the caregivers, the caring process, and specific behaviours that convey a sense of caring underlying the delivery of nursing care (Mayer, 1987).

Watson, Burckhardt, and Brown (1979) described caring as both expressive and instrumental in the nurse-patient interactionary process. Expressive activities were characterized by support and rapport based on sensitivity, compassion, warmth, genuineness, comfort, protection, and respecting and accommodating privacy and territorial needs. Instrumental activities included: "physical action-oriented helping behaviours such as administering medications, following policies and procedures, maintaining a safe environment, and teaching" (Mayer, 1987). In communicative and expressive transactions, nursing staff may concentrate on the content of the interaction rather than addressing the underlying emotions in the resident. Undoubtedly, the message is important especially if the purpose of the interaction is to impart information or to offer guidance and direction. By not paying attention to the affective component of the message and how this message might be understood by the recipient, interaction will remain superficial and be carried out with an apparent lack of caring (Watson, 1979). For residents and their families, staff

involvement may be perceived as "going through the motions", consistent with what one might expect in institutions.

In a study conducted by Hamilton (1989), patients with some degree of cognitive impairment in a chronic geriatric hospital commented that lack of decision making pertaining to their own care or initiative in informing them about who would be looking after them on the next shift were conditions that affected their comfort level in addition to being returned to bed when requested or being positioned on a particular side. A lack of understanding of the residents' situation and how they were feeling and to their basic physical care needs was frustrating and upsetting to residents and their families alike (Hamilton, 1989). This study suggested that the single most critical indicator of care quality was the one-to-one interaction between the nurse and the cognitively-impaired resident.

Not surprisingly, there appeared to be a prevailing attitude among elders and families that affordable institutions did not provide care with a focus on maintaining or enhancing the elder's quality of life (Cox et al., 1991). Cox et al. (1991), in a longitudinal nonequivalent control group study, tested the effects of the experimental Quality of Life Nursing Care (QLNC) model on quality of life outcomes of elderly cognitively-alert residents in long-term care facilities. The authors posited that nursing care can be provided to all institutional residents without additional cost to either the institution or the resident. In this study, nursing assistants were permanently assigned to residents; each resident had a case manager who worked the same shifts as the nursing assistants, and shift schedules are altered to accommodate residents activity routines. For example, there were 0600 hours to 1400 hour day shifts. The staff informed the resident and their families about who

was on duty and when there were changes to the staffing. The goals of nursing action were optimal resident functioning, social and psychological well-being, health maintenance and promotion, and control over decisions.

A systematic random sample of 23 experimental and 23 control residents, who were cognitively intact, was selected from all residents in two units respectively. The final post-intervention sample consisted of 21 experimental and 18 control residents who had completed both the pre- and post-intervention measures. Several measures were used. They included the Locus and Range of Activities Checklist, the Self-Management Scale, and the General Well-Being Schedule used to measure psychological well-being. Satisfaction with care included services, routines, and privileges within the nursing home. A Likert scale was used to measure this component of the study. Cronbach's alpha less than 0.65 on either the pre- and post-intervention measures were not used in subsequent analyses as these scores defined the instruments as being unsuitable. The results of this study demonstrated that the nursing care should focus on the holistic needs of the resident rather than on the tasks and procedures of "body" care. Often there is a misconception amongst nonprofessional nursing staff that visible care when carried out properly is all that is entailed in caring for the elderly (Huss et al, 1988). It is "personhood" care such as offering choices and control of everyday activities that makes the difference between a sense of life satisfaction or the "stripping away the very essence of a person - his/her dignity and self-worth" (Huss et al., 1988). Clearly, consumers may have played only a limited role in voicing their expectations of nursing care (Eck, Meehan, Zigmund, & Pierro, 1988). Although cognitively-intact residents can play a role in

their own care, cognitively-impaired residents may need an advocate. Spouses often fulfil this role.

Langer and Rodin (1976) in a field experiment to assess the effects of enhanced personal responsibility and choice on a group of nursing home residents, found that residents who were encouraged to take responsibility in their daily activities by engaging in plant care showed significant improvement in their well-being and behavioral measures than their control group counterparts.

Chang (1978) and Pohl and Fuller (1980) examined the notion of choice within institutions. Chang (1978) found that perceived situational control was the positive interactive effect which contributed to the increased morale of residents. Similarly, Pohl and Fuller (1980) found that choice within an institution contributed to a higher morale in their study of 50 nursing home residents. These findings were supported by Moos (1981) who also determined that choice and control foster independence and social functioning especially among female residents.

The literature revealed that residents in long term care institutions cope with three interrelated concerns: physical comfort, maintaining a sense of mastery, control, and self identity, and feelings of being cared for (Golander, 1987; Hamilton, 1989; Higgins Vogel & Mercier, 1991; Mayer, 1987; Larson, 1984, 1986, 1987; Larson & Dodd, 1991; Larson & Ferketich, 1989). Theoretical foundations have supported caring as the underlying attribute upon each of the instrumental, expressive, and communicative transactions of the nurse-patient relationship is viewed.

Gustafson (1984) defined caring as the totality of service rendered through the nurse-patient interaction. Gaut (1984) surmised that caring is a mediated action,

in that it is often indirectly accomplished through nursing care activities which provide physical care, comfort, and emotional support. According to Larson (1986), "caring is an essential and universally accepted concept of nursing practice" (p. 86). It was defined as the "intentional actions and attitudes that convey physical care, emotional concern, and promote a sense of safeness and security in another" (Larson & Dodd, 1991, p. 61). The authors further stated that the inherent components of caring, which include behaviour, process, and outcome, have not yet received an "analytic description" and current definition within the context of nursing practice (p. 86). Nevertheless, Larson and other authors reported that patients also equate much of nursing with caring (Larson, 1987, 1986, 1984; Larson & Dodd, 1991; Larson & Ferketich, 1989). Specifically, patients have identified the following nursing behaviours of being accessible, monitoring and following through, providing surveillance, and demonstrating professional knowledge and skills as being important behaviours in making them feel cared for (Larson, 1986). Brown (1982) studied 50 hospitalized medical-surgical patients for their response on feeling cared for. Eight themes evolved as a result: recognition of individuality, reassuring presence, provision of information, demonstration of professional knowledge and skill, assistance with pain, spending time with, and promotion of autonomy.

These findings demonstrated an array of responses to what constitutes caring. Caring as an attribute was not always evident to the recipient, since not all intended caring behaviours are perceived as meaningful. However, from the assertions found in the literature, it may be assumed that caring nurse behaviours can coincide with the spouse's perception of quality in nursing care delivery. The potential for perceptual congruency led to Larson's (1984) study of cancer patients

and nurses to identify what would constitute caring behaviours. The author provided a definition of the outcome of caring for the patient as: "a sensation of well-being and safeness which is the result of enacted behaviour of another" (p. 5). To achieve this outcome, Larson further stated that nurses must convey concern and attention through their actions, conduct, and mannerisms. Through several studies with adult medical/surgical and cancer patients, Larson (1984, 1986, 1987) has generated six themes of caring: comfort, trusting relationship, anticipates, explains, and facilitates, accessible and monitors, and follows through. These themes were incorporated in the author's caring assessment instrument, the Care-Q II. Particular behaviours were then determined which reflected the patient's feeling of being cared for.

Studies concerning caring from the perspective of both the nurse and the patient have been addressed in the literature (Ford, 1981; Larson, 1984, 1986, 1987). No studies were found which surveyed the perspective of spouses of cognitively-impaired residents. Among cognitively-impaired residents, spousal viewpoints may be the only reliable means to draw conclusions of care quality. Since nursing is faced with the challenge of staying as close as possible to consumers' wishes, there is the necessity to integrate consumers' perspective with their own yet still remain within the confines of limited available resources. Consequently, quality may no longer be an absolute ideal, but rather a functional concept (Vuori, 1987). Moreover, in the practice setting, an evaluation of the perceptions and expectations of nursing service is also a partial evaluation of the care provider. The notion that care quality is linked with the care provider will influence the way each nurse's practice is actualized in the future delivery of quality nursing care to the elderly (Fine, 1988).

Summary

The literature has demonstrated that the institutionalization of the cognitively-impaired elderly stems from a sociological rather than a medical context. Normative data reveal that the more aged the elderly individual, the more likely he/she will be cognitively-impaired and institutionalized.

As spousal caregivers are predisposed to stress and burden, their inability to deliver the complex nursing care needs of their husband or wife ultimately determines the need for institutionalization. The negative effects of institutionalization, the stigma attached to institutional nursing care delivery, and the spouses' valiant attempts to maintain their cognitively-impaired elderly at home, for as long as possible, impact on their perception of facility care. In addition, the spouses' experiences as caregivers, their difficulty with relinquishing their caregiver role even when their husband or wife has been institutionalized, and their often longstanding guilt feelings may affect their expectations of nursing care.

The phenomenon of nursing care quality incorporates the concept of caring and the instrumental, expressive, and communicative components of the Total Transactional System. Together, these attributes may be fundamental to the spouses' perceptions and expectations of the quality of nursing care delivery. Whether caring is demonstrated with the cognitively-impaired institutionalized elderly may influence their spouses' perceptions of the quality of the nursing care rendered.

The researcher was unable to find in the literature any quantitative studies of spouses' perspectives of nursing care delivered to the institutionalized cognitively-impaired. What the literature has yielded are quantitative reports that define the notion of quality from the caregiver and professional viewpoint. This quantitative study

addresses the viewpoint from the perspective of those most intimately related to the cognitively-impaired institutionalized elderly - the spouse, to generate knowledge which will assist nurses in planning and delivering the best nursing care possible in congruence with the family's expectations.

CHAPTER THREE

METHOD

Research Design

The comparative descriptive survey design was selected to investigate and describe the phenomena of spousal perceptions and expectations of nursing care provided to the cognitively-impaired institutionalized elderly. The descriptive component of the design is appropriate in collecting and describing the degree of conformance to the selected activities of nursing care delivery; while the comparative component contrasted the two dependent variables under study, specifically, the subjects' perceptions and expectations. Data were collected by means of a self-administered questionnaire. The setting and sample, the questionnaire, human subject protection process, data collection procedure, and data analysis are described and discussed in this chapter.

Setting and Sample

The study was conducted within the Continuing Care Nursing Services of two large multi-site tertiary care hospitals in the city of Vancouver, British Columbia, Canada. A convenience sample of 50 subjects was targeted through this service area with the assistance of the directors of nursing. Direct referrals to those spouses who might be interested in participating was carried out through the nursing unit managers/unit directors.

Subjects were selected using the following inclusion criteria: (1) Spouses of the cognitively-impaired elderly residing in selected long term care facilities. (2) In order to acquire adequate knowledge of their husband or wife's care in an institution,

the impaired elderly must have been a resident of the facility for six months or more.

(3) Subjects were able to read and understand English.

The Questionnaire

Data were collected by means of the Caring Assessment Instrument (Care-Q II) developed by Larson (1984) and adapted by the researcher. The Care-Q II instrument was selected because caring was the key concept underlying the selected nursing care activities. Developed by inductive methodology, the Care-Q II instrument was originally a visual analogue measure with six subscales and 50 items. The six subscales include: Accessible (6 items), Explains and Facilitates (6 items), Comforts (9 items), Anticipates (5 items), Trusting Relationship (16 items), and Monitors and Follows Through (8 items). Larson defined accessibility as nurses being readily available to the patient and his family. Explains and Facilitates are descriptive of those behaviours that teach, clarify, and advocate in the interest of the patient. Comfort is defined as both physical and emotional support to patients and families. Anticipation is described as putting action plans into place when a change in the patient's condition is expected. Trusting Relationship denotes the demonstration of a sense of commitment and understanding to the patient and his situation. Monitors and Follows Through are defined as the demonstration of professional and technical competency and assurance that nursing actions delegated to others would be responsibly carried out (Larson, 1989). Larson used this instrument with cancer patients to rate the nursing care they received during their hospital stay. Because the instrument was used to study the perceptions of the recipients of care, the wording was modified so that the questions would be addressed from the spousal

point of view, to be in keeping with the purpose of the study as the cognitively-impaired recipients of care cannot respond for themselves.

Although the 50 items originally developed represent the behavioral domain of caring and the theoretical categorizations as reasonable representations of the major dimension of nurse caring behaviour, "there is a strong possibility that the 50 behavioral items may include some duplication" (Larson, 1989, p. 7). Consequently, the Care-Q II contained 34 items which describe the role activities of the nurse toward the patient. Permission was obtained from Larson to adopt and modify the instrument as follows: (1) Some of the questions were reworded so that the first person in the questionnaire will refer to the institutionalized elderly. (2) Instead of using a visual analogue scale ranging from "strongly disagree to strongly agree", a more definitive Likert scale was used in the form of a forced choice distribution requiring participants to select from a field of 8 choices, from strongly disagree, disagree, somewhat disagree, neither agree nor disagree, somewhat agree, agree, strongly agree, and not applicable. (3) The same questions were repeated twice, the first time to capture the perceptions and the second time to solicit the expectations of nursing care. Included with the questionnaire was a request for demographic information. Variables in relation to the respondents' age, gender, the institutionalized elderly's length of stay and reason for institutionalization, as well as the age, diagnosis, and activities of daily living (ADL) requirements of the spouse-resident were solicited. A copy of the revised instrument and request for demographic information appears in Appendix A.

Validity and Reliability

Validity describes the degree to which an instrument measures what it purports to measure (Woods & Catanzaro, 1988). Reliability refers to the stability, dependability, and predictability of an instrument's ability to produce the same results on repeated measurement occasions (Woods & Catanzaro, 1988). Larson (1984) reported that the instrument was valid and reliable. Using the Cronbach's Alpha as the measure of internal consistency, the instrument was stable at .85 or above in most clinical settings including Medical/Surgical and Oncology (Larson, 1984). Hence, there is homogeneity of the measuring instrument since the "greater the reliability coefficient reflecting internal consistency, the greater the likelihood that the scale measures the attribute of interest and nothing else" (Woods & Catanzaro, 1988, p. 249). An alpha coefficient falling within a range of .60 to .80 is indicative of good reliability (Lord & Novick, 1968).

Face validity was established by using a Delphi Survey of practising nurses on the caring components of nursing, and a study of cancer patients' perceptions of nurse caring behaviours (Larson, 1984). Content validity was reviewed by an expert nurse panel and they verified that the 50 items were "understandable representative nurse caring behaviours" (Larson, 1984, p. 88). Further testing resulted in the deletion of some 16 items due to duplication. Furthermore, the majority of the behaviours had been identified and categorized by the patients themselves (Larson, 1984).

In view of the purpose of this study, this instrument was seen to have construct validity. Since the underlying concept supporting the perceptions and expectations of quality care was based on the presence or absence of caring

attributes, satisfaction with nurse caring behaviours would further strengthen this theoretical foundation. Criterion validity, on the other hand, was not established due to the lack of similar existing instruments (Larson, 1986).

Reliability of the Care-Q II was addressed by Larson (1984) with registered nurses (N=82) in a test-retest situation. The nurses were randomly selected from the membership of a national organization of oncology nurses. No changes of the instrument resulted since item-ranking consistency for the five most important items and for the five least important items were 79% and 63% respectively, between Test 1 and Test 2 (Larson, 1986; Larson & Ferketich, 1989). "This instrument, carefully developed and refined in a series of research studies, provided a patient satisfaction measure that was based on the theoretical premise of caring at the behavioral level of nursing practice" (Larson & Ferketich, 1989, p. 12). It was noted, however, that with instrument modification, an impact on both validity and reliability can be anticipated. To address these potential difficulties, a pilot study was proposed to refine the instrument and to demonstrate the degree of validity and reliability by running a reliability coefficient on a sample of spousal subjects of the modified Care-Q II. Because only five subjects could be recruited, this number was deemed too few to compute a reliability coefficient - the Cronbach's Alpha. Nevertheless, the pilot sample proved to be invaluable in the refinement of the wording of the instrument.

Human Subject Protection Process

The approval of the University of British Columbia's Screening Committee for Research and Other Studies Involving Human Subjects was obtained, as well as

approval of the two facilities selected for the study. The researcher, who is a nursing unit manager in one of the participating facilities, requested permission to attend a management meeting held on selected sites for the purpose of personally introducing the study to the directors and unit managers/unit directors. During the meeting, the researcher presented the proposed research project, the study's purpose, its benefits, the respondents' rights including the refusal to answer any question, the study method, and the time and effort requirements to participate in this study. Based on the selection criteria, a list was drawn up of those spouses who could be included in the study by each of the nursing unit managers/unit directors. The spouses, excluding those from the researcher's unit, who demonstrated an interest in participating were asked to contact their nursing unit manager/unit director. The subjects were formally recruited using a letter of information (Appendix B) explaining the purpose, benefits, and relevant aspects of the study including a description of the questionnaire. Although not explicitly stated in the letter of information, the return of the questionnaires served as an implied consent.

During the recruitment process, the following ethical considerations were explained to the prospective respondents: participation is voluntary, the respondent has the freedom to refuse any questions or to discontinue participation at anytime, and most importantly, participation or non-participation in the study would not affect provision of care or in any way impact on the status of the spouse-resident in the institution. Assurances of confidentiality were secured in the following manner: no names or initials were used on the questionnaires and if any identifying features did exist, they were promptly removed.

Data Collection Procedure

The questionnaire and the letter of information were mailed/delivered to the prospective subjects along with the instructions for the return of the questionnaire (Appendix C). A time frame of two weeks was suggested for completion. A stamped self-addressed envelope was included for the return of the questionnaire.*

Data Analysis

The categorization of the respondents' demographic information and the items in the completed questionnaire was coded, edited, and entered into the Statistical Package for the Social Sciences (SPSS). Because this study pertained to behavioural research, and in particular the measurement of attitudes, interval level data were obtained as follows: A Likert scale was ordered as a seven-point measuring instrument, ranging from "strongly disagree" to "strongly agree", with "not applicable" responses excluded from the collation process.

Strongly Disagree	1
Disagree	2
Somewhat disagree	3
Neither agree nor disagree	4
Somewhat agree	5
Agree	6
Strongly agree	7
Not applicable	N/A

Since descriptive statistics report what has been observed in a sample, the use of frequency distributions, percentages, and measures of central tendency were used to provide precise, standard ways to summarize, understand, and communicate the complex information collected (Woods & Catanzaro, 1988). The use of

*Since the names and addresses of all respondents were not available, it was not possible to send a planned follow-up letter two weeks after the initial mailing.

parametric statistics was selected to ensure more power and more flexibility.

Overall, data were found to be normally distributed.* According to Skodol Wilson (1987), interval level data minimize distortion of the results. In fact, an advantage in using parametric statistics is that they are more likely to find a significant difference if one does exist (Munro, Visintainer, & Page, 1986). Therefore, Munro et al. (1986) advocate the use of parametric techniques for data at the ordinal level or higher, unless the assumptions for parametric use are seriously violated. Since the sample size under consideration was greater than 20, a two-tailed dependent t-test was performed on the means of each statement of the six subscales pertaining to the spousal perceptions in comparison with expectations to determine any differences. A significance level of .05 was used. As with any research undertaking, the hope was to demonstrate validity of the claims made. The potential of risk when setting the significance level must be considered. In fact, a Type II error, or error of over-conservatism, should be avoided. In setting the significance level at the conventional .05 level, there will not be a risk of committing one type of error over another. According to Bratcher, Moran, and Zimmer (1970), at an alpha level of .05, a power of .90 and an effect size of 1, the sample size required per cell would be 23. With the addition of 10% drop-out rate, the minimal number required would be 25. Therefore, targeting 50 subjects as the optimal sample size would most certainly guarantee a return of 25 or more questionnaires. The difficulty, as will be noted later, was with receiving an insufficient number of responses initially, but according to Bratcher et al. (1970), if the sample size is larger than is necessary, any

*The explanation for the aptness of the MANOVA model can be found in Appendix D, supported by Appendices E and F. The MANOVA model will be introduced and discussed later on in this chapter.

differences whether they are subtle or not will be detected. All results, even the most trivial, would have been significant. Consequently, not only will the findings be difficult to interpret, they will not be sufficiently credible to respond to critics.

A multivariate analysis of variance model (MANOVA), specifically a profile analysis, a multivariate analogue of the univariate analysis of variance (ANOVA), using the SPSS multivariate method instead of the repeated measures methodology was performed. Inferential statistics were used to ascertain if the variance between perceptions and expectations are parallel/interactional (the test of parallelism), or otherwise coincidental or due to chance occurrences (the test of coincidence). Because the sensitivity of the test allowed simultaneous analysis of multiple dependent variables, a multivariate approach was favoured. In this case, profile analysis was used because the subjects are measured repeatedly on the same dependent variables, their perceptions and expectations. To apply profile analysis, all measures must have the same range of possible scores as well as having the same score value with the same meaning on all the measures (Tabachnick & Fidell, 1983). This is the assumption of commensurability. For this reason, profile analysis is an appropriate alternative to univariate repeated measures ANOVA. Another advantage in using a profile analysis is that a graphic presentation was included in the presentation of the results. Multivariate techniques permitted a single analysis instead of a series of univariate or bivariate analyses (Tabachnick & Fidell, 1983). Ordinarily, a profile analysis calls for a statistical hypothesis. Because this is a level I study, the use of a hypothesis would be inappropriate.

Summary

This chapter has addressed the research design to be used in the study. This study was a comparative descriptive inquiry using the CARE-Q II questionnaire modified to suit the purpose of the study and to capture the phenomenon of spousal perceptions and expectations of selected aspects of nursing care. Ethical considerations including the right to participate or not in the study and such decision having no influence on the care of the spouse-resident have also been addressed. Taking into account an effect size of 1, a power of .90, and the significance level of .05, to detect significant differences required a sample size of 25. Data analysis using descriptive and inferential statistics including the two-tailed dependent t-test and a profile analysis using the multivariate approach, will conclude with the comparative analysis and discussion of the data findings in Chapter Four.

CHAPTER FOUR

Presentation and Discussion of Findings

Overview

The findings of this study are presented and discussed in four sections: The first section presents demographic information pertaining to the spouses and their institutionalized elderly. This information provides the context of the study in terms of the circumstances for admission of the cognitively-impaired elderly, the age and diagnoses, and the assistance required for the activities of daily living.

The second section presents a profile analysis of the perceptions and expectations to ascertain if the mean profiles of the 34 statements are similar in the sense that the means are parallel, that there is no group response interaction. This is the test of parallelism. The means of the perceptions and expectations are presented graphically.

In the third section, the test of parallelism is applied to the mean difference of the perceptions and expectations for each of the six subscales: Accessible, Explains and Facilitates, Comforts, Anticipates, Trusting Relationship, Monitors and Follows Through. A general discussion of the data findings constitutes the fourth section and will conclude this chapter of the study.

Demographic Information

Spouses of residents of two facilities, located in five different sites, participated in the study. Fifty questionnaires were distributed and by the end of the fifth week of the data collection process, fear of receiving less than 25 questionnaires was becoming a reality. Consequently, subjects from the researcher's

unit were also recruited to participate. The total number of questionnaires returned was 29 for a response rate of 58%. There were 12 male and 11 female spouses in the sample. Of the 29 spouses in the sample, only 23 provided their ages. The ages of 22 spouses ranged between 62 to 92 years with a mean age of 76.1 (N=22) years. One spouse reported himself to be 39 years while his wife was 75 years. This age was not included in the tabulation of the spouses' mean age since it was probable that the spouse was assisted by a younger family member who marked his own age instead of the respondent's age. The mean age of the cognitively-impaired institutionalized elderly was 78.6 (N=22). Of the 24 responses received, the following conditions were the most prevalent reasons for admission: strokes/CVA (52.4%), Alzheimer's Disease (33.3%), and inability to care for the husband/wife at home (14.3%). Other diagnoses included cancer, status epilepticus, dementia, and post hip-fracture, and Huntington's Chorea. One respondent was particularly direct in his assessment of his wife's medical condition. This gentleman wrote of his wife that "she lost her mind....I saw her brain, was X rayed and I saw it". Another respondent stated that:

"My wife was diagnosed as having Huntington's corea (sic). It is a progressive neurological disorder and it just became too difficult to care for her at home. She is now completely bed ridden and is dependent on someone for all her needs. I visit 4 times a week and get my wife up in a recliner. I feed her lunch on the days I visit. I spend 4 1/2 hours with her and try and get her outside, when possible, or to any events that might be taking place."

The residents' length of stay ranged from 6.5 months to 7 years. Assistance required included feeding, dressing, help to get up, and toileting. Many of the respondents wrote "total care" and one wrote "almost everything" in relation to activities of daily living.

As noted in the literature, the early symptoms of dementia which often include sleep and mood disorders, agitation, paranoia, and belligerence to later stages of profound cognitive and motor impairment, spouses frequently experience a loss of control over the major segments of their husbands/wives' behaviour (Mace & Rabins, 1981). These deficits in cognitive functioning, together with the spouses' own aging process and attendant changes, frequently necessitate admission to a care facility (Brody et al., 1978; Palmore, 1976; Townsend, 1965). Spouses found that they were no longer able to provide the major assistance required by the cognitively-impaired such as dressing, bathing, and toileting (Cox et al., 1991; Crossman et al., 1981; Fitting et al, 1986; George & Gwyther, 1986; Getzel, 1982; Golander, 1987; Pagel et al., 1985; Reisberg, 1986; Stephens et al, 1991; York & Calsyn, 1977; Zarit et., 1980; Zarit et al., 1986).

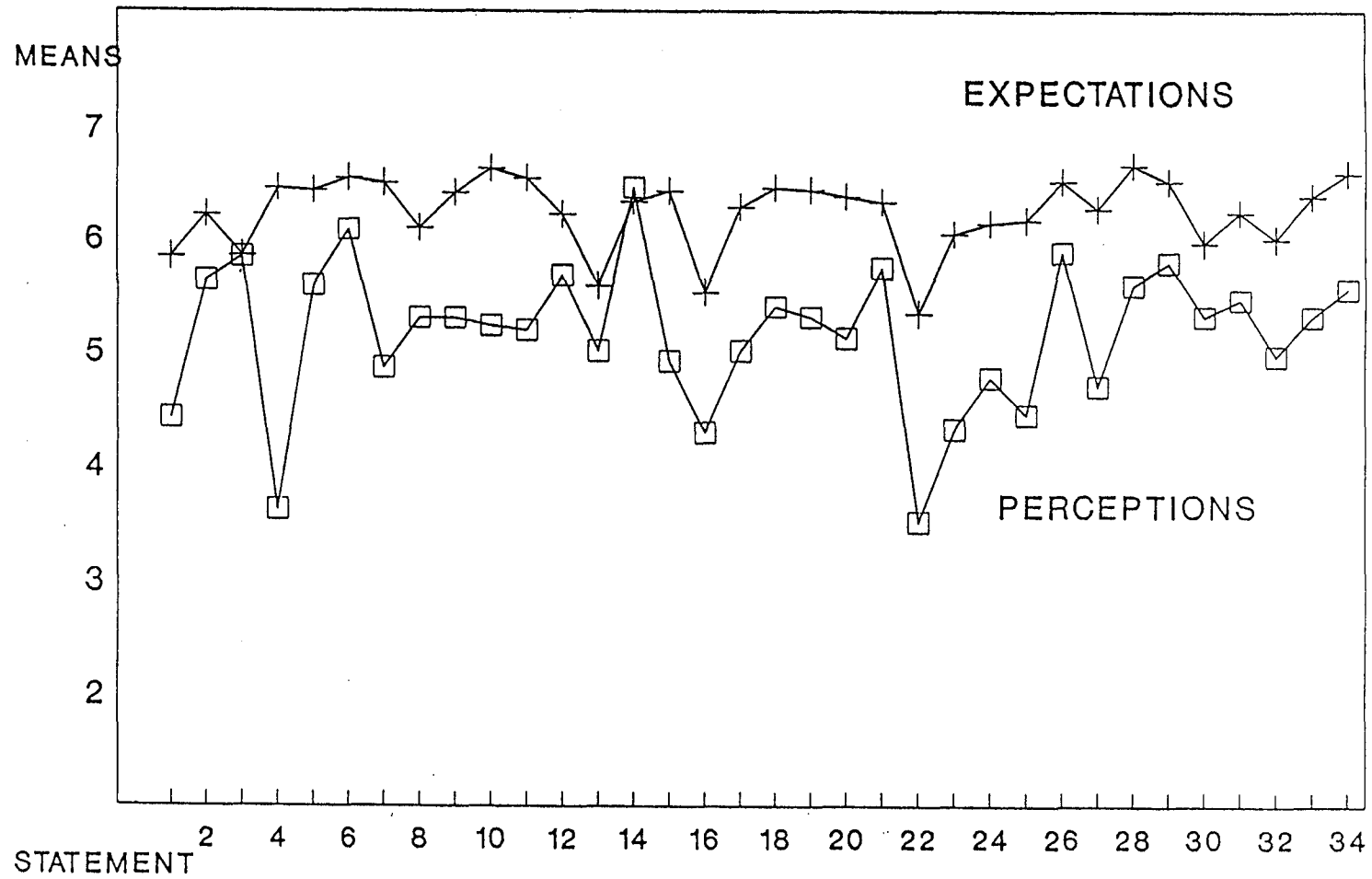
Profile Analysis of the Differences Between Means of the Perceptions and expectations

The responses to the 34 statements on the two questionnaires differ across items. The grand means for perceptions and expectations are 5.16 and 6.24 respectively, with a mean difference of -1.08. However, there is one common characteristic: the expectation scores consistently exceed the perception scores, sometimes notably and on other occasions only a 0.1 difference sets perception and expectation apart. This is found in statement 3 (Talked to each other in English and not in their native language, in my spouse's presence). Because the parallelism is so irregular, for example between statements 3, 14, and 22 of perceptions (Figure 1), the summary statistics reveal an interaction effect, that is, the two variables, perceptions and expectations may be related in some way. As shown by statement 14 (Called my spouse by his/her name), there was a visible graphic interaction effect

since perception and expectation intersect each other. This was the only incidence where the value for perception exceeded that of expectation. From the context of the research problem, the likelihood of an interaction effect between perceptions and expectations is highly plausible. The ravages of cognitive impairment and its sequelae on the elderly person, the stress and burden faced by the spouse-caregiver, the associated guilt and anxiety of admission, and the negative effects of institutional care, are all factors that may well have influence on the perceptions and expectations of nursing care delivery. With Statement 14 (Called my spouse by his/her name), the reverse was true: The perceptions exceeded the expectations. It may be that while spouses heard their husbands/wives' names called, conversation may not have ensued .

This is true with the exception of four statements which elicited low expectation scores: These are statements 3 (Talked to each other in English and not in their native language, in my spouse's presence), 13 (Allowed choices for my spouse), 16 (Put my spouse first, no matter what else happened), and 22 (Volunteered to do "little" things such as bringing my spouse a cup of coffee, sitting with my spouse, etc.).

The reason for the low expectation score for statement 3 is not entirely clear since speaking the language of the workplace is common courtesy and a show of respect for the residents. The relatively high corresponding perception score is also unclear. It may be that spouses have never heard foreign languages spoken in their presence. This statement will be discussed further under the Anticipates subscale. The means and standard deviations for perceptions and expectations are displayed on Table 1.



STATEMENT	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34
EXPECTATIONS N=	23	24	25	20	21	24	24	23	22	24	24	23	19	24	21	23	25	24	25	18	24	21	22	22	24	23	15	21	21	23	25	20	23	25
PERCEPTIONS N=	22	26	24	15	26	29	27	28	24	27	28	24	16	28	23	25	28	28	27	18	27	26	26	21	25	24	16	17	19	26	26	23	26	27

Figure 1

Graphed Means of Perceptions and Expectations

Statement 13 (Allowed choices for my spouse) has a mean expectation score and a corresponding perception score of 5.58 (N=19) and 5.00 (N=16) (Table 1). These scores are low relative to the respective grand means of 6.24 and 5.16. Given that the response rate for expectations was only 19 out of 29, the explanation for the data could be that while choices have not been perceived as offered sufficiently to the institutionalized elderly, cognitive impairment may have rendered this statement inapplicable in some cases. Some residents may have been cognitively-impaired to the extent that they are not able to make choices.

Statement 16, (Put my spouse first, no matter what else happened), also elicited a low expectation score (mean = 5.52) and a very low perception score (mean = 4.28) (Table 1). While physical care of the cognitively-impaired elderly may have been relinquished to nursing staff, the literature states that the spouses' continual involvement in the psychosocial realm remains strong (Montgomery, 1982; Smith & Bengtson, 1979; Tobin & Kulys, 1981; York & Calsyn, 1977). Spouses obtain emotional comfort when they assign themselves as the primary caregiver in attending to the residents' psychological nurturing (Bennett, 1980). It may be unrealistic to expect that staff put the institutionalized elderly first, "no matter what happened". Given the constraints of the workplace, the spouses themselves may be in the best position to fulfil this role. Their responses to this statement may well be reflective of this interpretation.

TABLE 1**Central Tendency Analysis****Perceptions and Expectations: The Means and Their Standard Deviations****Coding:**

Strongly disagree	1
Disagree	2
Somewhat disagree	3
Neither agree nor disagree	4
Somewhat agree	5
Agree	6
Strongly agree	7

Standard Deviation (SD)

	<u>Perceptions</u>		<u>Expectations</u>	
	Mean	SD	Mean	SD
<u>Accessible:</u>				
4. Answered call lights quickly	3.60	1.96	6.45	0.89
22. Did "little" things	3.50	1.68	5.33	1.65
25. Checked on spouse frequently	4.44	1.53	6.17	1.17
26. Gave treatments on time	5.88	1.23	6.50	2.79
<u>Explains and Facilitates:</u>				
1. Told me of support systems	4.41	2.13	5.83	1.47
5. Told spouse in adult language	5.58	1.27	6.40	3.75
24. Explained things to spouse	4.76	1.84	6.17	1.04
27. Encouraged spouse to ask questions	4.96	1.25	6.27	1.10
<u>Comforts:</u>				
2. Provided basic comfort measures	5.62	1.17	6.21	1.22
6. Talked to spouse	6.07	0.96	6.50	4.66
12. Were patient with spouse	5.67	1.37	6.20	2.80
19. Were comforting to spouse	5.30	1.59	6.40	4.77
20. Listened to spouse	5.11	1.49	6.39	0.78
<u>Anticipates:</u>				
3. Talked in English	5.83	1.55	5.84	1.57
15. Anticipated the shock	4.91	1.47	6.43	0.98
23. Knew spouse's needs	4.31	1.83	6.04	1.00
<u>Trusting Relationship:</u>				
7. Talked about disease and treatment	4.85	1.72	6.50	0.78
8. Did not appear busy or upset	5.29	1.38	6.09	0.95
9. Introduced themselves to spouse	5.29	1.33	6.41	0.67

TABLE 1 (continued)

	<u>Perceptions</u>		<u>Expectations</u>	
	Mean	SD	Mean	SD
11. Created a sense of trust	5.18	1.52	6.54	0.78
13. Allowed choices	5.00	1.55	5.58	1.43
14. Called spouse by name	6.46	0.58	6.33	1.31
16. Put spouse first	4.28	1.70	5.52	1.44
21. Knew spouse as a person	5.74	1.23	6.33	0.87
31. Were consistent in treat. of spouse	5.46	1.53	6.24	1.05
32. Involved spouse in care	5.96	1.55	6.00	0.92
34. Treated spouse as an individual	5.56	1.42	6.60	0.71
<u>Monitors and Follows Through:</u>				
10. Knew when to call doctor	5.41	1.62	6.62	0.58
17. Knew how to care for spouse	5.10	1.24	6.28	0.79
18. Gave spouse good physical care	5.48	1.53	6.46	0.83
28. Knew how to give shots	5.59	1.18	6.67	0.73
29. Made sure procedures were realistic	5.79	1.36	6.52	0.75
30. Were professional in appearance	5.31	1.59	5.96	1.43
33. Were organized	5.31	1.26	6.39	0.84

Statement 22 (Volunteered to do "little" things such as bringing my spouse a cup of coffee, sitting with my spouse, etc.) is noteworthy because this statement has the lowest scores for both perception and expectation. Consistent to the preceding line of reasoning, doing "little" things might be seen primarily as the spouses' own area of responsibility (Shuttlesworth et al., 1982; York & Calsyn, 1977). Or, it may also mean that staff is just not as available as the spouses expect that they should be for the elderly person.

Two statements, 4 and 22, elicited a neutral response, the overall response to both statements being neither agree nor disagree. This is an interesting finding. Often neutral responses obtained in psychometric research are not really neutral; that is, neutral responses tend to lean toward some direction, either a yes or no, or agree

or disagree (Boldt, personal communications, March 17, 1993). When the overall results of the study have been taken into consideration, the inclination may well be leaning in a negative direction, that is, nursing staff were not able or willing to make some accommodations for residents under their care.

As shown by Table 2, the t values or t-statistics (derived from the t-test formula) indicate that there is a significant difference between perceptions and expectations across all statements with the exception of statements 26, 29, 28, 14, 13, and 3. What this means is that there is a considerable gap between perception and expectation levels. In particular, statements 17, 22, 7, 10, 18, 23, 25, and 15 are already significant at the 0.000 level (as indicated by *). These results indicate opposing opinions for perceptions and expectations. Statements 5, 9, 8, 19, 33, 34, 16, 6, 20, 27, 32, 21, 24, and 4 are statistically significant at the .01 level (as indicated by bold print). Only statement 31, statistically significant at 0.046 (underscored), closely to the level of significance set at .05. All in all, the degree of congruency between the aforementioned statements is found to be low. On the other hand, statements 26, 29, 28, 14, 13, and 3 are not statistically different at .05 indicating congruence between perceptions and expectations.

TABLE 2

T Value Analysis for Each Statement

<u>Statement</u>	<u>t Value</u>	<u>Sig. Level</u>	<u>Subscale</u>
<u>Perceptions and expectations significantly different at .05</u>			
17. Care for spouse	-5.56	0.000*	Monitors
22. Do "little" things	-5.30	0.000*	Accessi.
7. Disease & treatment	-4.83	0.000*	Trusting
10. When to call doctor	-4.69	0.000*	Monitors

TABLE 2 (continued)

<u>Statement</u>	<u>t Value</u>	<u>Sig. Level</u>	<u>Subscale</u>
<u>Perceptions and expectations significantly different at .05</u>			
18. Good physical care	-4.48	0.000*	Monitors
23. Knew spouse's needs	-4.47	0.000*	Anticip.
25. Checked on spouse	-4.33	0.000*	Accessi.
15. Anticipated the shock	-4.26	0.000*	Anticip.
5. Adult language	-3.69	0.001	Explains
9. Introduce themselves	-3.60	0.001	Trusting
8. Not busy or upset	-3.49	0.002	Trusting
19. Were comforting	-3.47	0.002	Comforts
33. Were organized	-3.29	0.003	Monitors
34. Treat as individual	-3.10	0.004	Trusting
16. Put spouse first	-3.10	0.004	Trusting
6. Talked to spouse	-3.08	0.005	Comforts
20. Listened to spouse	-3.00	0.006	Comforts
27. Ask questions	-2.82	0.009	Explains
32. Involvement in care	-2.76	0.010	Trusting
21. Knew spouse as person	-2.72	0.011	Trusting
24. Explained things	-2.69	0.012	Explains
4. Call lights	-2.68	0.012	Accessi.
2. Comfort measures	-2.25	0.032	Comforts
1. Support systems	-2.34	0.027	Explains
30. Professional in appearance	-2.20	0.036	Monitors
31. Consistent treatment	-2.09	0.046	Trusting

Perceptions and expectations not significantly different at .05

26. Treatments on time	-1.84	0.076	Accessi.
29. Realistic for spouse	-1.28	0.211	Monitors
28. How to give shots	-1.20	0.240	Monitors
14. Called by name	-0.88	0.387	Trusting
13. Allowed choices	-0.21	0.835	Trusting
3. Talked in English	-0.09	0.930	Anticip.

Profile analysis is an application of multivariate analysis of variance (MANOVA) in which two or more dependent variables are measured on the same

scale (Tabachnick & Fidell, 1983). The major inquiry addressed by profile analysis using the Hotellings Test is whether or not profiles of groups differ on a set of measures, in this case, the spouses' perceptions and expectations (Tabachnick & Fidell, 1983).

According to the Hotellings Test, the profiles are not parallel since the F-statistic (derived from the one-way analysis of variance) is tenable at .002 (Table 3). What this means is that since the F value is already tenable at .002; at .05, this value is also tenable. Therefore, parallelism is rejected at the .05 level of significance. The perceptions and expectations may be similar, but the mean segments are not parallel. In other words, there is a group interaction effect between the perceptions and expectations. As previously discussed, the means between perceptions and expectations do not intersect except for one point in the graph (Figure 1). In statement 14, the perception actually exceed the expectation. The result of non-parallelism is reasonable.

TABLE 3

Test For Parallelism

Multivariate Test of Significance					
Analysis of Variance for Perceptions and Expectations					
<u>Test</u>	<u>Value</u>	<u>Exact F</u>	<u>Hypoth. DF</u>	<u>Error DF</u>	<u>Sign. of F</u>
Hotellings	.55686	4.26926	6.00	46.00	.002 *

*Significant at .05
Perceptions and expectations are non-parallel.

Given that parallelism is rejected, a group response interaction effect is present and further testing of coincidence and flatness of profiles no longer has meaning (Morrison, 1976). Since line segments are not parallel, they will neither be at the same level nor will the means be uniform. As noted on Table 4 below, the perceptions and expectations are significantly different from each other for all six subscales with the significance of the F-statistic ranging from .000 to .002. The next section addresses the mean profiles by subscales beginning with the Accessible subscale.

TABLE 4

Profile Analysis of the Subscales

<u>Variable</u>	<u>Significance of the F-statistic</u>
Accessible	.000*
Explains and Facilitates	.001*
Comforts	.002*
Anticipates	.002*
Trusting Relationship	.000*
Monitors and Follows Through	.000*

*Perceptions and expectations are significantly different at .05

Profile Analysis of the Subscales

Accessible

The significance of the F-statistic is .000 (Table 4) for this subscale and the means are 4.52 and 6.41 respectively for the perceptions and expectations (Table 5). Of the four statements found in this subscale, the variability of the scores between perceptions and expectations is very wide for statement 4 (Answered my spouse's call light quickly.) and statement 22 (Volunteered to do "little" things such as bringing my spouse a cup of coffee, sitting with my spouse); the mean difference is 2.85 for statement 4 and 1.83 for statement 22. Because the response rate for statement 4 is small (N = 15), the power of the MANOVA test is decreased. There are two possible explanations for the results. A number of residents may not be able to use call bells due to profound cognitive and motor impairments (Pagel et al., 1985). Although the standard deviation was high at 1.96, spouses who responded to this statement generally disagreed with it. In this respect, the responses were consistent across subjects. The mean scores on statements 4 and 22 (2.85 and 1.83) represent the largest differences between perceptions and expectations. These findings are so incongruent that they can be construed not only as dissatisfaction with care provided but also as failings in nursing service delivery.

TABLE 5**Profile Analysis of Perceptions and Expectations****Cell Means**

Subscale	MEANS			
	<u>Perception</u>	<u>N</u>	<u>Expectation</u>	<u>Mean Difference</u>
Accessible	4.52	25	6.41	-1.89
Explains and Facilitates	4.95	24	6.50	-1.55
Comforts	5.63	26	6.61	-0.98
Anticipates	5.02	25	6.30	-1.28
Trusting Relationship	5.34	26	6.48	-1.14
Monitors and Follows Through	5.38	25	6.60	-1.22

Standard Deviation Between Subscales

Subscale:	Perception		Expectation		2-tail Prob.
	SD	SE	SD	SE	
Accessible	1.28	.257	1.06	.214	0.00*
Explains & Facilitates	1.40	.285	0.88	.181	0.00*
Comforts	0.98	.191	0.68	.132	0.00*
Anticipates	1.31	.262	0.69	.139	0.00*
Trusting Relationship	0.95	.186	0.79	.155	0.00*
Monitors & Follows Through	0.82	.165	0.68	.136	0.00*

*Significant at .05

Standard Deviation (SD)

Standard Error (SE)

Probability (Prob.)

Statement 26 (Gave my spouse's medications or treatments on time) was better received. The mean difference was 0.64. However, this statement has an instrumental overtone. Being available to respond to needs is a critical responsibility in the care of the demented resident since the cognitively-impaired elderly cannot make their needs known. This concern is supported by the responses to statement 25: the spouses did not agree that their institutionalized elderly were checked frequently. Again, the gap here is large; the means are 6.17 and 4.44 respectively (Figure 2).

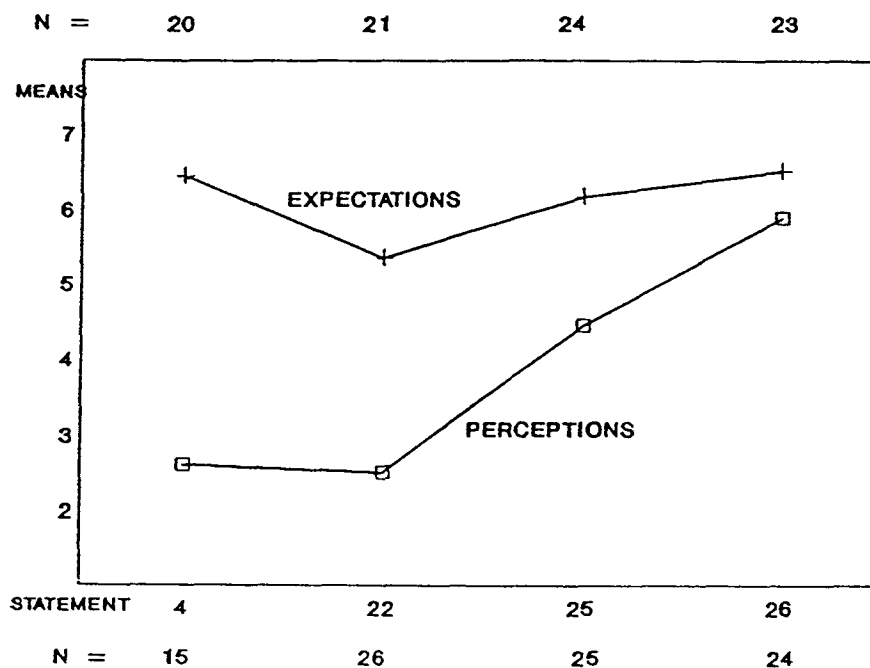


Figure 2

Graphed Means of the Accessible Subscale

Explains and Facilitates

The statements within this subscale are descriptive of the communicative transaction of the conceptual framework. They relate to the understanding of treatments and routines pertaining to care delivery (Bloom, 1963; Petersen, 1989).

Figure 3 shows that the gap in the mean profiles between perceptions and expectations is considerable, signifying a disagreement between what is perceived and expected. The significance of the F-statistic at .001 found in Table 4 supports this interpretation.

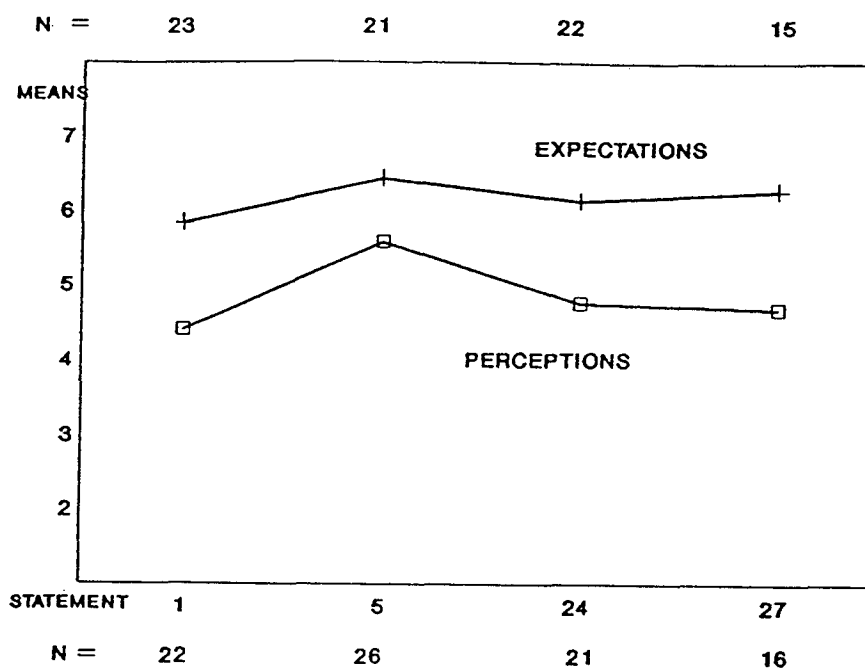


Figure 3

Graphed Means of the Explains and Facilitates Subscale

Strong feelings of inadequate communication flow between spouses and staff, pertaining to the availability of support groups for the families of the

cognitively-impaired, is noted from the data. Further, in light of the low perception scores (4.41, 5.58, 4.76, and 4.69, Figure 3), and the correspondingly higher expectation scores (5.83, 6.42, 6.14, and 6.27, Figure 3) the results may indicate that the presence of impaired mental function should not preclude the nurse from respectful communication with the resident. The importance of communication as a therapeutic instrument is supported by a study conducted by Hamilton (1989) which suggested that the single most critical indicator of care quality was the one-to-one interaction between the nurse and the cognitively-impaired resident.

Comforts

Overall, the mean difference between perceptions and expectations in this subscale is consistently small, ranging from a mean of 5.11 (lowest perception score) to a mean of 6.54 (highest expectation score) (Figure 4). The standard deviation scores are .98 and .68 respectively for perceptions and expectations which is indicative of a consistent opinion across subjects (Table 5). Because the standard error is .19, there is very little sampling error (Table 5). Therefore, the perceptions and the expectations can be said to be the most congruent among these subscales. This finding is also supported by the mean difference of -.98, the smallest difference found of the six subscales (Table 5).

The residents are physically provided for in terms of appropriate lighting, control of noise in the environment, and the provision of blankets. Nurses talked to residents and were patient with the cognitively-impaired resident even when difficult behaviours were encountered. According to the literature, these behaviours may include: verbal or physical aggression directed to caregivers, resistance to care,

emotional lability and other behavioral disturbances (Harvis, 1990; Hutner Winograd & Jarvik, 1986; Minister of National Health and Welfare, 1984; Reisberg, 1986).

The spouses, however, only somewhat agreed that nursing staff were comforting to residents (statement 19). The means for the perception and the expectation were 6.44 and 5.30 respectively (Figure 4). The difference between the means increased when spouses also somewhat agreed that nursing staff listened to the resident. The means were 8.38 and 5.11 for the perception and the expectation. These findings suggest that institutions may be staffed by personnel ill-equipped to look after the cognitively-impaired resident (Hasselkus, 1988). Nursing staff, especially patient care aides, may lack the skill to carry through the expressive and communicative aspects of nursing care delivery, in particular, the demonstration of psychological comfort to the elderly with dementia. It may have been easier for nursing staff to distance themselves rather than make sense of the behaviours of the cognitively-impaired (Hasselkus, 1988).

With the exception of statements 19 and 20, the other three line segments in this subscale would have been equally parallel (Figure 4).

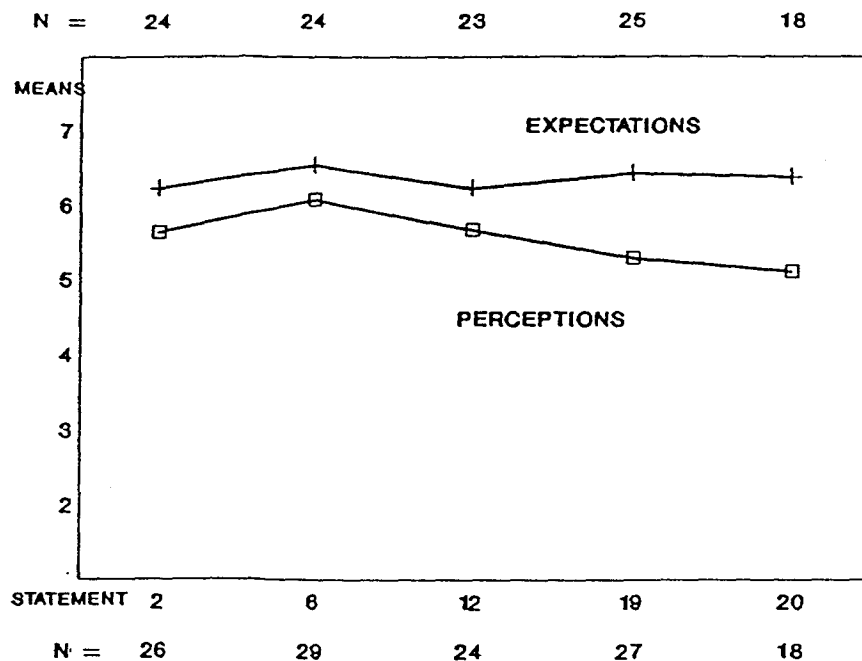


Figure 4

Graphed Means of the Comforts Subscale

Anticipates

This subscale contains only three statements. The mean differences among the three border on extremes, as illustrated by Figure 5.

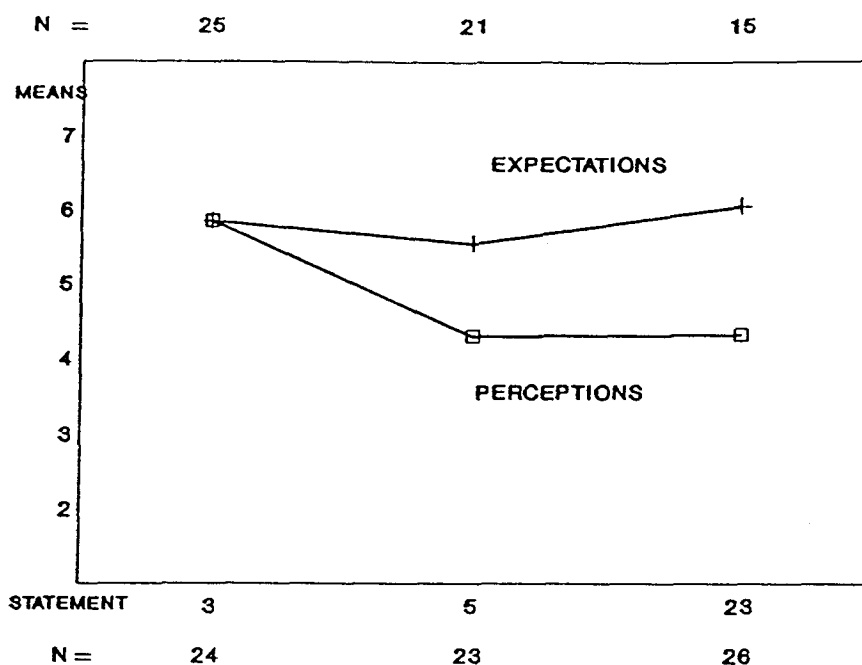


Figure 5.

Graphed Means of the Anticipates Subscale

There is little difference between the perceptions and expectations for statement 3 (Talked to each other in English and not in their native language, in my spouse's presence). The expectation for staff to speak English in the residents' presence was low compared to most other items. One explanation could be that since many of the non-professional staff are visible minorities, spouses may feel that it could be reasonable to hear foreign languages spoken. Graphically, if the proximity of the line segments were any closer, there would have been a visible interaction effect since the difference between perception and expectation is only 0.1 (Figure 5). Since the perception and the expectation means (5.84 and 5.83) match almost perfectly, this result represents a deviation from the usual pattern of responses

found. The difference is generally greater among other items. Consequently, interpretation of this finding is difficult. There are several speculations, however. The spouses may have heard only English spoken; they may have elected to believe that only English is spoken; or the spouses may have guessed according to their own expectations. It would seem that the response to this statement is positive, whether it reflects reality is uncertain.

On the other hand, for statements 15 (Anticipated the shock over my spouse's disease progression and planned opportunities, individually or as a group, to talk about it) and 23 (Knew my spouse's needs without my spouse having to ask, offering pain medication, toileting, etc.), the differences between the means are very wide, 1.24 and 1.73 respectively. This indicates a concern that nursing staff's anticipatory care may be inadequate for the cognitively-impaired population that is not able to indicate its needs. Nursing staff may be required to provide for residents without the luxury of cues. Bowers (1987), using a grounded theory approach to the study of the caregiving experience, found that anticipatory caregiving was regarded as vital even after institutionalization of the elderly family member. Nursing staff's ability to anticipate needs of residents so that the residents' biological and emotional needs are satisfied without undue discomfort and delay may be viewed even more importantly than the actual task itself.

Trusting Relationship

This subscale is the embodiment of the interrelated concerns that residents in long term care institutions must cope with: maintaining a sense of mastery, control, and self identity, and most critically, the feeling of being cared for as described by

Golander (1987), Hamilton (1989), Higgins Vogel (1991), Mayer (1987), Larson (1987, 1986, 1984), Larson & Dodd (1991), Larson & Ferketich, (1989). As shown in Figure 6, the mean vectors are varied between perceptions and expectations, indicating that the opinions are divergent and varied across subjects.

Some statements were congruent while others were not. In fact, for statement 14 (Called my spouse by his/her name), the perception mean exceeded the expectation mean (6.46 and 6.33). As a result, non-parallelism is substantiated graphically here by the overlap of means for perception and expectation. By calling the institutionalized elderly by name and allowing choices, nursing staff acknowledge the institutionalized elderly's personhood and need for self identity.

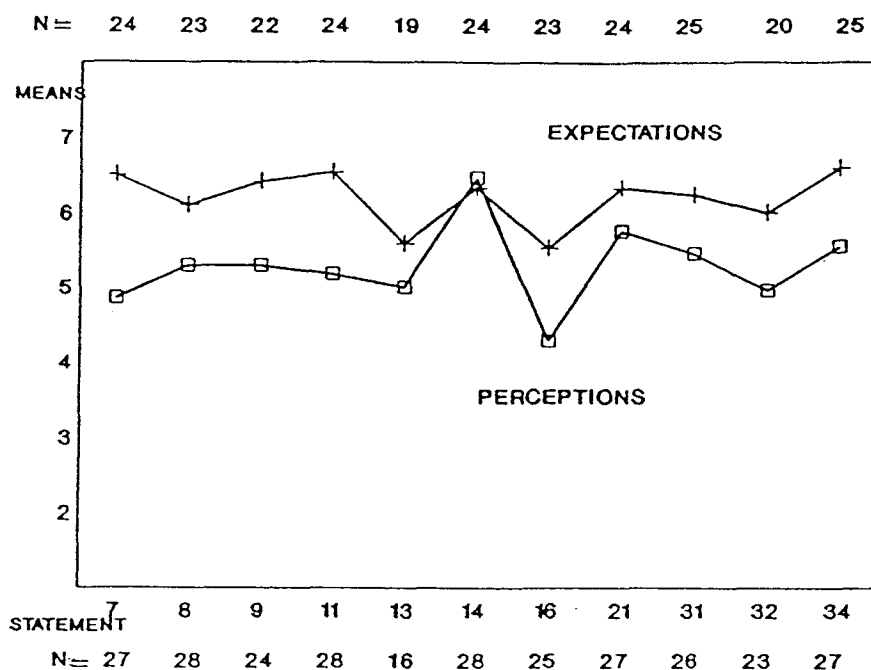


Figure 6

Graphed Means of the Trusting Relationship Subscale

These findings demonstrate that there is little incongruency between the perceptions and expectations in these two areas of caring behaviour. Further, spouses perceived the nursing staff's involvement in the care of the elderly person. For these three statements, the responses were unanimously positive across subjects in both perceptions and expectations. This finding is supported by a study conducted by Langer and Rodin (1976). These authors found that residents who were encouraged to take responsibility in their daily activities showed a significant improvement in their well-being and behavioral measures. Chang (1978), Pohl and Fuller (1980), and Moos (1981) attributed increased morale, independence, and social functioning to the interactive effect of choice and perceived situational control by residents. From the responses generated, the spouses appeared positive in their perception of care pertaining to the promotion of autonomy of their institutionalized spouse.

On the other hand, spouses felt that nursing staff did not know their institutionalized elderly as persons and did not create a sense of trust for the couple. Spouses also felt that nursing staff did not talk to them about the institutionalized elderly's disease and treatments and did not put the elderly person first, no matter what happens. As noted by Brown (1982), recognizing individuality, reassuring presence, spending time with, providing information, and showing positive regard expresses the sentiment that I really care for you (Burgener & Barton, 1991). These are essential themes underlying the notion of caring behaviours found in the nurse-patient relationship.

All the statements in this subscale addressed the concept of caring as well as some elements within the communicative and expressive transactions of the Total Transactional System.

Monitors and Follows Through

This subscale pertains almost exclusively to the instrumental transaction of the therapeutic relationship, in particular, the knowledge, skill, and technical performance of the registered nurse. The perceptions and expectations were not as congruent as was anticipated across items associated with the care from professional staff. The spouses were not sure whether the registered nurse knew when to call the doctor (statement 10) nor were they certain that professional staff made sure others knew how to care for their spouses (statement 17). Means for the perceptions and expectations were 5.22 and 6.62 (mean difference of 1.40); and 5.00 and 6.28 (mean difference of 1.28) for statements 10 and 17 respectively (Figure 7).

Statement 18, however, which pertained solely to patient care aide staff (Gave my spouse good physical care), was also not well received, the means being 5.39 and 6.46 (mean difference of 1.07) for perception and expectation. Spouses did not feel that good physical care was delivered to the institutionalized elderly. As discussed in the Trusting Relationship subscale, the expressive treatment of the cognitively-impaired elderly requires knowledge, skills, and expertise. The proper administration of the instrumental aspect of care, especially physical care, should be taken for granted. For this reason alone, the above finding is alarming. If visible care is not being carried out properly, very good holistic care of the individual might be that much more difficult to attain.

What is disturbing also is that spouses did not express approval of the professional appearance of staff nor did they feel that staff was organized. Overall, both descriptive and inferential statistical findings, that is, the means and the profiles, were found to be very supportive of the claims made for this subscale: The spouses found the technical aspect of care less than it should be.

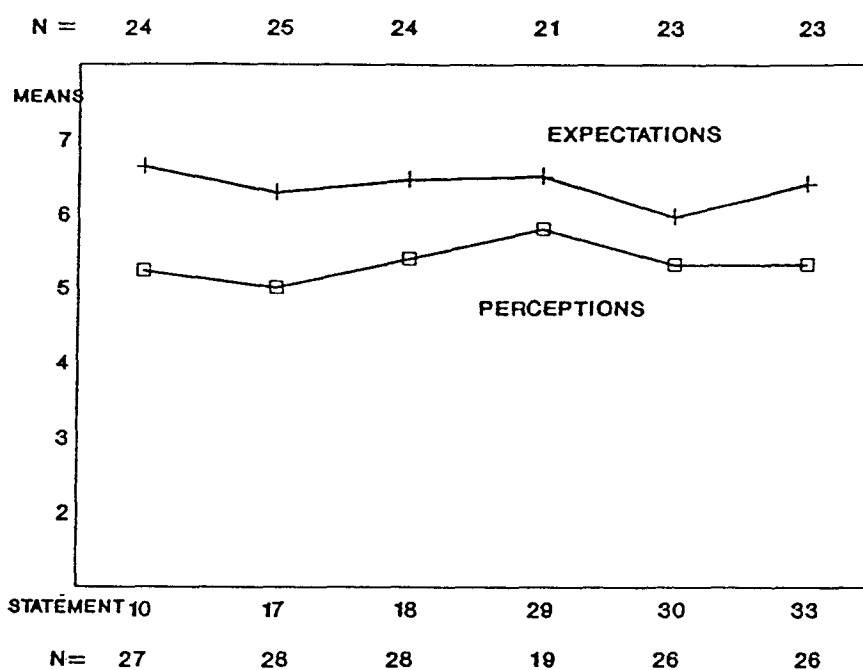


Figure 7

Graphed Means of the Monitors and Follows Through Subscale

General Discussion of the Data Findings

The spouses' perceptions and expectations, as measured by the Caring Assessment Instrument, the Care-Q II, are significantly different. Because the overall mean difference between perceptions and expectations is large, this means that the spouses "somewhat agreed" across the 34 statements in terms of the perceptions, while they "agreed" in their expectations. Therefore, the spouses' expectations of nursing care were higher than what they saw being delivered in the institution.

Most notable are the consistently large mean difference and standard deviation found in the Accessible, Explains and Facilitates, and Anticipates subscales between perceptions and expectations; these three subscales represent the biggest areas of concern (Table 5). However, expectations tend to be set higher to begin with so that such a finding cannot be considered a major deviation, nor can it be considered a particularly alarming disagreement with the expectation of nursing care. As noted on Table 2, the means of the perceptions were not uniform, which may be indicative of the mixed feelings felt about the manner of nursing care received by the institutionalized elderly.

The overall findings from this study are now considered in relation to the conceptual framework: the instrumental, expressive, and communicative components of the Total Transactional System (Bloom, 1963; Petersen, 1989).

The Instrumental Transaction

When the statements applicable to this transaction and the Monitors and Follows Through subscale were taken into consideration, the results indicated that the spouses had concerns regarding the technical aspect of care delivery. The

concern over quality in physical care was strongly apparent while the concern with the activities of professional staff appeared peripheral in comparison. There might have been some question regarding nursing staff's ability to deliver an optimal level of nursing care, and the actual care delivery itself, as well as the availability of staff when assistance was needed to address basic needs and activities of daily living (Bloom, 1963). These findings are consistent with families' concerns that facilities may be staffed by improperly trained nursing personnel (Chenoweth & Spencer, 1986; Hasselkus, 1988; Huss et al., 1988). These personnel may have been professional or non-professional staff.

The Expressive Transaction

According to Bloom (1963), the expressive transaction pertains to the interpersonal component between the nurse and the patient. Essentially, this component addresses the personhood of the cognitively-impaired elderly. For the elderly person who has difficulty relating to the environment and his/her spouse, this component is crucial. Of most concern is the finding that spouses did not feel that staff knew the resident as a person. Since the cognitively-impaired elderly person is communicatively disabled, positive interaction requires purposeful strategies. The responses indicate some perceived difficulties with the availability of skilful interventions required to foster therapeutic communications and positive feelings for residents who are impaired (Chenoweth & Spencer, 1986; Golander, 1987). According to Hamilton (1989), the single most critical indicator of care quality is the interaction between the nurse and the cognitively-impaired. Knowing the institutionalized elderly as persons and showing an appreciation of their situation are

behaviours that demonstrate a caring attitude congruent with acceptable nursing care quality. While the quality of physical care is important, spouses appear to have emphasized the psychosocial needs of residents since many more variabilities were found in the trusting relationship subscale. The notion of emotional comfort, anticipatory regard, trust, and respect for the essence of a person, despite the extent of cognitive impairment, appeared critical to spouses of the institutionalized elderly. Golander (1987) and Huss et al. (1988) asserted that positive treatment made the difference between a sense of life satisfaction or the depersonalization of the individual with the prospect of further impairment and helplessness for the institutionalized elderly.

The Communicative Transaction

Petersen (1989) identified the following descriptors related to the communicative transaction:

- Being listened to
- Being informed about what will happen
- Feeling more in control
- Decreasing stress
- Understanding treatment and unit routines.

Of these descriptors, being listened to, being informed about what will happen, and understanding treatment and unit routines were concepts captured in the research instrument. The results indicated a discrepancy between the spouses' perceptions and expectations in regards to the quantity and quality of communication flow between the residents and staff as well as between the families and staff.

Although residents were called by name more often than expected, the fact that they were not listened to but talked to may be indicative of distancing and

avoidance behaviour toward the elderly who were not cognitively conversant.

According to Cox et al. (1991), excessive infantilization, including paternalization, leads to learned helplessness and a perceived lack of control and autonomy with further disability. In turn, spouses thought that their own feelings pertaining to their institutionalized elderly's disease and treatment had not been addressed adequately. Spouses appeared to be in need of additional information pertaining to the course of a dementing illness. The stresses associated with the institutionalized elderly's disease progression and direction of treatment were likely to continue and may even become intensified with facility care (George & Gwyther, 1984; Pagel et al., 1985). The spouses' need to be informed was critical to the notion of meeting the expressive and communicative needs of residents and families. As noted by Fengler and Goodrich (1979), spouses as caregivers, required help and support as much as their disabled family member.

Summary

The results revealed that there is a statistically significant difference between the spouses' perceptions and expectations of selected activities of nursing care delivered to the cognitively-impaired institutionalized elderly. Comparisons of the subscale means indicated that the spouses' expectations consistently exceeded their perceptions in each of the six subscales including Accessible, Explains and Facilitates, Comforts, Anticipates, Trusting Relationship, and Monitors and Follows Through.

Of the identified areas of concern within the Instrumental component of the conceptual framework is a perceived deficit in the delivery of physical care and the limited access of nursing personnel. For the expressive component, the concepts of

personhood, individuality, anticipation, trust, and caring within the interactionary nurse-resident relationship could be more congruent with the spouses' expectations. The scope and quality of information flow were also deemed less than what was perceived adequate within the communicative component. On the other hand, nursing staff was acknowledged for comforting the institutionalized elderly, sometimes by allowing choices, other times by being patient even when the impaired elderly person was difficult.

CHAPTER FIVE

Summary, Conclusions, Implications and Recommendations for Future Research

Summary

The aging of the Canadian population has implications pertaining to the institutional care of the elderly. The possibility of cognitive impairment increases with age and cognitive impairment is associated with institutionalization of the elderly. Cognitive impairment affects an individual's information processing abilities. Consequently, the elderly person requires much assistance with activities of daily living. His or her spouse is often the most common caregiver. Spouses, who are often elderly themselves, may also suffer from age-related changes. Other superimposing factors are the stresses and burdens associated with around-the-clock care. In many instances, the spouses find no recourse but to eventually institutionalize the husband/wife who is cognitively-impaired.

Institutionalization is associated with regimented care and its negative effects include helplessness and depersonalization of the individual. As recipients of institutional nursing care, residents may have perceptions and expectations of that care. Since cognitive impairment prevents the institutionalized elderly from providing that information, the spouses who are also advocates for the resident, are in a unique position to shed light on the state of nursing care delivery.

The concept of caring is inherent to the quality of nursing care delivered. Caring has been described as the intentional actions and attitudes that conveyed physical care, emotional concern, and warm regard for another (Larson & Dodd, 1991). Within this context, nursing care activities are conceptualized in terms of a

Total Transactional System, identifying three components within the nurse-patient relationship (Bloom, 1963; Petersen, 1989). This system consists of the instrumental, expressive, and communicative transactions of nursing care delivery. These transactions pertain to the technical, affective, and informative components of caring for the cognitively-impaired elderly (Bloom, 1963; Petersen, 1989).

The study method was a comparative descriptive survey design using a purposive sampling technique. Twenty-nine spouses, whose cognitively-impaired elderly husband/wife has resided in an institution for six months or more comprised the sample. The subjects were drawn from two large multi-site tertiary care hospitals in Vancouver. The subjects ranged in age from 62-92 years with the mean age of 78.7 years.

The subjects completed a self-administered, modified Care-Q II Questionnaire that consisted of 34 questions, repeated twice, to elicit the spouses' perceptions and expectations of selected aspects of nursing care activities (Larson, 1984). The responses were recorded using a seven-point Likert scale.

Because the responses to the questionnaire were commensurable, that is, the responses were measured on the same scale, a profile analysis was used to ascertain the difference between the perceptions and expectations. This MANOVA technique of profile analysis was presented graphically as well as statistically. Descriptive statistics were also used to assist in the interpretation of the spouses' perceptions and expectations according to the six subscales.

In terms of the Accessible subscale, there were significant irregularities. There were extremes in the data set between perceptions and expectations to the point that a result of non-parallelism of profiles was demonstrated. Three out of the

four statements in the subscale elicited a common negative response across subjects. Although the fourth statement was favourable for a majority of residents who require anticipatory assistance, the perceived lack of availability of nursing staff is a serious concern. The spouses' own caregiving experiences may have aggravated their perceptions of the care rendered.

A parallelism of profiles was shown in the Explains and Facilitates subscale. Although there is an element of non-applicability for two of the four statements in terms of how much the cognitively-impaired can communicate, the gap between perceptions and expectations overall is too large to be ignored. Some dissatisfaction with the dissemination of information to both the institutionalized elderly and spouse is indicated. The results demonstrate that nurses should continue to interact with residents in the usual manner regardless of the degree of cognitive impairment.

Overall, subjects responded most positively on the Comforts subscale. A sense that nursing staff made attempts to physically and emotionally comfort residents was apparent here. Whether staff were actually successful in "comforting" their residents in the manner that addressed the residents' need for comprehensive respectful treatment was somewhat less certain. The notion that nursing staff is well-meaning but ill equipped to communicate effectively with the cognitively-impaired has been suggested by the findings. Most disturbing is the finding that spouses only somewhat agree that their institutionalized husband/wife is listened to. However, nurses demonstrated patience with difficult residents.

Similarly, in the Accessible subscale, the spouses appeared dissatisfied with the anticipatory treatment of residents. Unlike other patient populations, cognitively-

impaired residents rely heavily on nursing staff for a majority of their care needs. Incongruence in this subscale can be construed as a failure in nursing care delivery.

The Trusting Relationship subscale is associated with the caring concept and the manner this attribute is conveyed to the elderly resident through purposeful mediated actions. Nursing staff was perceived as having difficulties in both the expressive and communicative components of the nurse-patient relationship. Specifically, communication regarding the resident's disease and treatment, recognition of individuality, spending time with, and showing positive regard have not been adequately established. The Monitors and Follows Through subscale clearly describes the instrumental component of nursing care delivery. Spouses overwhelmingly acknowledged the technical competence of professional staff while they questioned the physical care rendered.

The results of this study demonstrate that there was a discernable difference between the two dependent variables, perceptions and expectations. Although the difference cannot be construed as being highly incongruent, nonetheless the gap existed. The spouses' own experiences with caregiving, cognitive impairment, and the nature of institutionalization accounted for the group response interaction effect, so that each statement cannot be discussed in isolation, in terms of just the perceptions or just the expectations. Moreover, the statements within each subscale can be applied to a number of subscales so that an interpretation of main effects pertaining to each item and to each subscale is impossible. For example, "Gave my spouse's medications or treatments on time" would be appropriate if found under the Monitors and Follows Through subscale as well as the Accessible subscale.

Conclusions

The following conclusions have been drawn from the findings of the study:

1. Spouses' expectations of nursing care are higher than their perceptions of the nursing care actually delivered.
2. Nurses demonstrated patience with difficult residents.
3. Spouses perceive that nursing staff do not consistently achieve the goal of meeting the communicative and emotional needs of residents.
4. Nurses are not available when needed and they do not anticipate residents' needs to the extent perceived necessary by the spouses.
5. Provision of physical care is below the spouses' expectations.

Implications

Where perceptions and expectations are concerned, it is highly unlikely that perceptions ever live up to expectations. However, because perceptions are delineated below expectations, it will be necessary to narrow the gap not only to improve care but also to meet the expectations of care recipients. Otherwise enormous difficulties including dissatisfaction with nursing care quality may ensue with serious consequences, for example, unsolicited communications from residents and family members to institutional administrators and the involvement of the media and Ministry of Health. Similarly, the displeasure with physical care is another major finding from this study. Considering that basic nursing is fundamental to long term care, dissatisfaction necessarily calls for new insights and perspectives pertaining to nursing education, practice, and administration in the nursing care of the cognitively-impaired elderly.

Nursing Education

The fact that the perceptions of nursing care are not what the spouses feel they ought to be can be appreciated if the prevalence and scope of cognitive impairment as a chronic illness and its impact on the individual and on intimate family members are better understood. Deficits in the cognitive domain require special skills in communication, such as active listening, patience, and the ability to enter the world of the cognitively-impaired, even if momentarily. On occasion, nursing staff may refrain from conversing with the cognitively-impaired or ignore them altogether because the individual is unable to interpret or recall what has been said to him/her. Or, staff might "talk down" to the individual in an attempt to be personable or to give directions in a simple manner. Although these gestures are generally well-meaning, these behaviours are frequently construed by family members as thoughtless and "uncaring".

Nursing curricula for professional and non-professional staff should encompass theory on the manifestations and implications of cognitive impairment and the associated disease processes such as Alzheimer's Disease and CVA. Nursing staff should be instructed on ways to effectively and sensitively approach and care for residents with cognitive impairment, including techniques to access abilities as well as disabilities. Nurses should be well aware of the underlying etiology of certain behaviours in order to address them in a way conducive to improving life satisfaction of the elderly living in a long term care facility. For example, individuals afflicted by CVAs often have cognitive impairment which may be manifested by disinhibited behaviour such as verbal or physical abuse toward staff.

Nursing Practice

The quality of care provided to the institutionalized elderly is a critical issue (Roberts, LeSage, & Radtke Ellor, 1987). According to Connington and Dupuis (1990), quality is a relative measure so therefore, its nature is contextual. A well-developed quality management program may assist in operationally defining standards of care or expected resident outcomes, and standards of practice or manner of nursing care delivery (Connington & Dupuis, 1990). Scope of care and major clinical functions performed by nurses need to be formulated so that they can serve as resident and practitioner frameworks in care delivery within the evaluative process. The scope of care identifies and defines the resident population and the type of services required (Connington & Dupuis, 1990). Consequently, aggregate care quality as well as the accountability and compliance of the individual nurse with respect to continuous improvement initiatives could be addressed. An example of such a program would be a unit-based type quality management structure, process, and outcome model.

Nursing care of the cognitively-impaired institutionalized elderly must be viewed from a physical and psychosocial perspective, these two attributes are equally important. To this end, the finding that physical care is incongruent with expectations warrants a critical review of nursing practice issues pertaining to basic nursing care delivery. Practitioners must meet acceptable standards in the delivery of basic nursing techniques including skin care and oral hygiene. Certifying competencies pivotal to the care of the cognitively-impaired elderly such as turning, positioning, and transfer techniques, and the incorporation of a continence protocol,

may also be helpful. Psychosocial issues may include quality of life concerns and residents and families' rights and responsibilities within the institutional setting.

Interpersonal skills such as those pertaining to the supervision of ancillary staff and the ability to communicate with the cognitively-impaired person can be dealt with from a motivational as well as from an educational level. For example, skills in reminiscence and validation may be useful in tapping into the world of the cognitively-impaired elderly.

Nursing Administration

When there is a discrepancy between perceptions and expectations of nursing care, the problem of limited resources is likely to be at the forefront of discussion. The funding of 2.5 nursing care hours for each long term care resident is inadequate in view of the extent of disability accompanying cognitive impairment. Moreover, many long term care units are attached to, and administered by, acute care hospitals. Funding for long term care may be part of the global hospital budget. Even as the acuity and average care levels rise, "the units' resources and the quality of nursing care available depend on the importance the acute care hospital places on long term care" (Seaton et al., 1991, p. C-166). Long term care special units and multi-level service units will also increase costs. The implementation of a workload measurement system within the institution would assist in obtaining data to lobby funding agencies to increase financial resources allocated to long term care. The success of such an endeavour would have long term implications in the quality of nursing care for the elderly since cognitive impairment is associated with increased facility care (Canadian Task Force on the Periodic Health Examination, 1991).

At the service level, the mix of nursing personnel and the nursing care delivery system may be factors to explore administratively. Presently, long term care facilities are staffed by a large patient care aide staff and a disproportionately smaller registered nurse staff. A change in the proportion or the use of another category of staff such as licensed practical nurses might be another alternative. As asserted in the recent provincial health care commission report, British Columbia, Canada, the most critical factor influencing quality care delivery is the effective and efficient use of resources (Seaton et al., 1991).

The most effective strategy, however, may be the appeal to the professionalism of nurses. The fostering of pride in good work ethics, innovations in quality management, altruistic/ethical behaviours with respect to the treatment of persons, and the need to care and nurture are traits essential to nursing care quality. In the final analysis, systems may support the structure of care delivery, but it is the people who will make the difference.

Limitations of the Study

The following difficulties were encountered in the course of conducting this study. The use of a modified instrument originally designed for another subject population may not capture identically the constructs of interest, that is, the selected nursing care activities associated with the care of cognitively-impaired elderly. For example, "knew when to call the doctor" may not be totally applicable since spouses may only learn of this activity indirectly. Spouses do not really know exactly when the nurse calls the doctor. This concern also has an impact on the validity and reliability of the instrument since the response to this question is likely based on

subjective judgement unsupported by knowledge. Furthermore, any manipulation of a tool will only have an adverse effect on the credibility of the claims. A Cronbach's Alpha would have assisted in the refinement of the Care-Q II and the effect such revisions might have on reliability. Finally, response bias from certain spousal subjects is a distinct possibility.

Recommendations for Future Research

In view of the divergent meanings generated by some of the statements, research using a Q-Sort methodology to capture the nursing care activities of interest in the care of the cognitively-impaired institutionalized elderly is warranted. From the constructs found using Q-Sort, the present study could be replicated using the nursing care activities of interest to define the quality care concept. In the process, many "not applicable" responses could be eliminated.

A study centred on the relationship of family caregiving to health care usage by the elderly could be conducted. Bowers (1987) found that anticipatory caregiving, that is, decision-making based on anticipated possibilities, was within the invisible world of the caregiving experience. From a later study, Bowers (1988) confirmed the belief by family caregivers that institutional staff did not have adequate skills or background knowledge to carry out care. Families perceived that good quality care in an institution was largely dependent on family participation and input (Bowers, 1988; Johnson et al., 1992). The need for family caregivers to teach staff how to provide protective care such as the promotion of self image was deemed necessary (Bowers, 1988). Ethnographic interviews could be conducted to elicit data on the meaning of the caregiving experience. The information gained may

assist professional caregivers to gain insight and understanding into the family's perceptions and expectations. In a study conducted by Miller (1987) to examine the relationship between caregiver gender and caregiving experience, the author found that female spouses tended to focus on the changing relationship brought about by the elderly person's infirmities while men focused on caregiver tasks and projects.

With the growing demand of the public to have a voice in health care delivery, a study using a qualitative methodology, focusing on the physical care needs of the cognitively-impaired institutionalized elderly could be conducted from a familial viewpoint to ascertain which aspects of the physical care component are problematic. The same study may be replicated from the perspective of the practitioner.

A study capturing the critical aspects of the nurse-resident-family interactional relationship, specifically with a focus on the imparting of information and the demonstration of the caring attribute through mediated actions and behaviours, is a logical step in light of the results found from this research endeavour. The expressive and communicative components of the interactional system is consistent with the experiential work of caregiving, even more so than with a task-based orientation. Insights indicate more training is required in recognizing and communicating support for residents and families alike. Improvement in care is contingent on family involvement with residents and staff, as well as on the quality of staff performance (Johnson et al., 1992). An appropriate research methodology might be in the form of a semi-structured interview.

Finally, a study could be undertaken to examine ways to increase the resources available in the delivery of nursing care to the cognitively-impaired elderly

in a facility. As mentioned previously, issues such as funding and operational support have a profound impact on how nursing care is administered and generally perceived.

In conclusion, this study has demonstrated that improvement of nursing care to the cognitively-impaired institutionalized elderly should be considered. Nurses, in collaboration with the family, can contribute significantly to the quality of life in long term care facilities.

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APPENDIX A

THE UNIVERSITY OF BRITISH COLUMBIA SCHOOL OF NURSING

Thank you for participating in my study entitled:

THE COGNITIVELY-IMPAIRED INSTITUTIONALIZED ELDERLY:

SPOUSAL PERCEPTIONS AND EXPECTATIONS OF NURSING CARE

Should you require clarification regarding the following questionnaire, I can be reached during weekdays at 822-7518 and at all other times at 272-4418.

Susan Fong, Investigator. The chair of my thesis committee is Marilyn Dewis, Assistant Professor, telephone 822-7496.

CARING ASSESSMENT QUESTIONNAIRES (CARE-Q II)

The purpose of this questionnaire is to have spouses of residents rate the nursing care their husband or wife received during their institutional stay. The spouses' impressions may help nurses in deciding ways to improve resident care.

Your participation is voluntary and you have the freedom to refuse any questions or to discontinue participation in the study will not affect provision of care or in any way impact on the status of your husband/wife in the institution. Names or initials will not be used on the questionnaires and if any identifying features do exist, they will be promptly removed. This will help keep your responses confidential.

Each statement contained in this questionnaire refers to an action associated with resident care. Based on your experiences during your husband/wife's institutional stay, decide how much you agree or disagree with the view expressed. Circle the response that best describes how much you agree or disagree with the statement.

APPENDIX A (continued)

The same questions are asked twice. The first time will solicit your responses pertaining to how you perceive the nursing your husband/wife received during his/her institutional stay. In other words, what you see is happening with the nursing care receive by residents is termed your perceptions. The same questionnaire is repeated again for the second time for your expectations of that care. Expectations pertain to what you are looking for or what you feel nursing care ought to be. There are no right or wrong answers. Your response is a matter of your personal opinion. This study will require about 45 minutes of your time. Once the questionnaire is completed, please mail both parts in the self-addressed stamped envelope. The return of the questionnaire implies that you have given your consent to participate in this study.

APPENDIX A (continued)

The following legend of responses will assist you in answering the questionnaire.

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

BELOW IS AN EXAMPLE WHICH MAY HELP YOU IN RESPONDING TO THE QUESTIONNAIRE. IF THIS QUESTION WERE ON THE QUESTIONNAIRE, YOU WOULD HAVE CIRCLED THE NUMBER THAT CORRESPONDS TO THE LEGEND OF AGREEMENT. CIRCLE "N/A" IF THE QUESTION IS NOT APPLICABLE.

A. DURING MY HUSBAND/WIFE'S INSTITUTIONAL STAY THE NURSES ON THIS UNIT:

GAVE MY SPOUSE'S BATH ON TIME	1	2	3	4	5	6	7	N/A
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WHAT YOU ARE LOOKING FOR (YOUR EXPECTATIONS OF NURSING CARE):**"TO WHAT EXTENT NURSING CARE OUGHT TO BE" MEANS TO YOU.****LEGEND:**

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

DURING MY HUSBAND/WIFE'S STAY THE NURSES ON THIS UNIT:

1.	TOLD ME OF SUPPORT SYSTEMS AVAILABLE SUCH AS SELF-HELP GROUPS.	1	2	3	4	5	6	7	N/A
2.	PROVIDED BASIC COMFORT MEASURES, SUCH AS: APPROPRIATE LIGHTING; CONTROL OF NOISE; BLANKETS; ETC.	1	2	3	4	5	6	7	N/A
3.	TALKED TO EACH OTHER IN ENGLISH AND NOT IN THEIR NATIVE LANGUAGE, IN MY SPOUSE'S PRESENCE.	1	2	3	4	5	6	7	N/A
4.	ANSWERED MY SPOUSE'S CALL LIGHT QUICKLY.	1	2	3	4	5	6	7	N/A
5.	TOLD MY SPOUSE IN UNDERSTANDABLE BUT ADULT LANGUAGE WHAT THE NURSE WAS ABOUT TO DO.	1	2	3	4	5	6	7	N/A
6.	TALKED TO MY SPOUSE.	1	2	3	4	5	6	7	N/A
7.	TALKED TO ME ABOUT MY SPOUSE'S FEELINGS AND ABOUT MY SPOUSE'S DISEASE AND TREATMENT.	1	2	3	4	5	6	7	N/A
8.	DID NOT APPEAR BUSY AND UPSET.	1	2	3	4	5	6	7	N/A
9.	INTRODUCED THEMSELVES TO MY SPOUSE AND TOLD MY SPOUSE WHAT THEY DO.	1	2	3	4	5	6	7	N/A

APPENDIX A (continued)

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

10. KNEW WHEN TO CALL THE DOCTOR	1	2	3	4	5	6	7	N/A
11. CREATED A SENSE OF TRUST FOR MY SPOUSE AND ME.	1	2	3	4	5	6	7	N/A
12. WAS PATIENT EVEN WHEN MY SPOUSE WAS DIFFICULT.	1	2	3	4	5	6	7	N/A
13. ALLOWED CHOICES FOR MY SPOUSE.	1	2	3	4	5	6	7	N/A
14. CALLED MY SPOUSE BY HIS/HER NAME.	1	2	3	4	5	6	7	N/A
15. ANTICIPATED THE SHOCK OVER MY SPOUSE'S DISEASE PROGRESSION AND PLANNED OPPORTUNITIES, INDIVIDUALLY OR AS A GROUP, TO TALK ABOUT IT.	1	2	3	4	5	6	7	N/A
16. PUT MY SPOUSE FIRST, NO MATTER WHAT ELSE HAPPENED.	1	2	3	4	5	6	7	N/A
17. MADE SURE OTHERS KNEW HOW TO CARE FOR MY SPOUSE.	1	2	3	4	5	6	7	N/A
18. GAVE MY SPOUSE GOOD PHYSICAL CARE.	1	2	3	4	5	6	7	N/A
19. WERE COMFORTING TO MY SPOUSE.	1	2	3	4	5	6	7	N/A
20. LISTENED TO MY SPOUSE.	1	2	3	4	5	6	7	N/A
21. KNEW MY SPOUSE AS A PERSON.	1	2	3	4	5	6	7	N/A

APPENDIX A (continued)

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

22.	VOLUNTEERED TO DO "LITTLE" THINGS SUCH AS BRINGING MY SPOUSE A CUP OF COFFEE, SITTING WITH MY SPOUSE, ETC.	1	2	3	4	5	6	7	N/A
23.	KNEW MY SPOUSE'S NEEDS WITHOUT MY SPOUSE HAVING TO ASK, OFFERING PAIN MEDICATION, TOILETING, ETC.	1	2	3	4	5	6	7	N/A
24.	EXPLAINED THINGS TO MY SPOUSE IMPORTANT TO HIS/HER CARE.	1	2	3	4	5	6	7	N/A
25.	CHECKED ON MY SPOUSE FREQUENTLY.	1	2	3	4	5	6	7	N/A
26.	GAVE MY SPOUSE'S MEDICATIONS OR TREATMENTS ON TIME.	1	2	3	4	5	6	7	N/A
27.	ENCOURAGED MY SPOUSE TO ASK ANY QUESTIONS HE/SHE MIGHT HAVE.	1	2	3	4	5	6	7	N/A
28.	KNEW HOW TO GIVE SHOTS, ETC. AND HOW TO MANAGE THE EQUIPMENT, LIKE THE SUCTION MACHINES, ETC.	1	2	3	4	5	6	7	N/A
29.	MADE SURE MY SPOUSE'S APPOINTMENT SCHEDULES, FOR X-RAYS, OR SPECIAL PROCEDURES WERE REALISTIC FOR MY SPOUSE'S CONDITION AND SITUATION.	1	2	3	4	5	6	7	N/A
30.	WERE PROFESSIONAL IN APPEARANCE.	1	2	3	4	5	6	7	N/A
31.	WERE CONSISTENT IN HOW THEY TREATED MY SPOUSE.	1	2	3	4	5	6	7	N/A

APPENDIX A (continued)

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

32.	INVOLVED MY SPOUSE IN THEIR CARE.	1	2	3	4	5	6	7	N/A
33.	WERE ORGANIZED.	1	2	3	4	5	6	7	N/A
34.	TREATED MY SPOUSE AS AN INDIVIDUAL.	1	2	3	4	5	6	7	N/A

APPENDIX A (continued)

WHAT YOU SEE IS HAPPENING (YOUR PERCEPTION OF NURSING CARE):

TO WHAT EXTENT YOU THINK YOUR HUSBAND/WIFE IS RECEIVING THE KIND OF CARE DESCRIBED BELOW.

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

DURING MY HUSBAND/WIFE'S STAY THE NURSES ON THIS UNIT:

1.	TOLD ME OF SUPPORT SYSTEMS AVAILABLE SUCH AS SELF-HELP GROUPS.	1	2	3	4	5	6	7	N/A
2.	PROVIDED BASIC COMFORT MEASURES, SUCH AS: APPROPRIATE LIGHTING; CONTROL OF NOISE; BLANKETS; ETC.	1	2	3	4	5	6	7	N/A
3.	TALKED TO EACH OTHER IN ENGLISH AND NOT IN THEIR NATIVE LANGUAGE, IN MY SPOUSE'S PRESENCE.	1	2	3	4	5	6	7	N/A
4.	ANSWERED MY SPOUSE'S CALL LIGHT QUICKLY.	1	2	3	4	5	6	7	N/A
5.	TOLD MY SPOUSE IN UNDERSTANDABLE BUT ADULT LANGUAGE WHAT THE NURSE WAS ABOUT TO DO.	1	2	3	4	5	6	7	N/A
6.	TALKED TO MY SPOUSE.	1	2	3	4	5	6	7	N/A
7.	TALKED TO ME ABOUT MY SPOUSE'S FEELINGS AND ABOUT MY SPOUSE'S DISEASE AND TREATMENT.	1	2	3	4	5	6	7	N/A
8.	DID NOT APPEAR BUSY AND UPSET.	1	2	3	4	5	6	7	N/A
9.	INTRODUCED THEMSELVES TO MY SPOUSE AND TOLD MY SPOUSE WHAT THEY DO.	1	2	3	4	5	6	7	N/A

APPENDIX A (continued)

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

10. KNEW WHEN TO CALL THE DOCTOR	1	2	3	4	5	6	7	N/A
11. CREATED A SENSE OF TRUST FOR MY SPOUSE AND ME.	1	2	3	4	5	6	7	N/A
12. WAS PATIENT EVEN WHEN MY SPOUSE WAS DIFFICULT.	1	2	3	4	5	6	7	N/A
13. ALLOWED CHOICES FOR MY SPOUSE.	1	2	3	4	5	6	7	N/A
14. CALLED MY SPOUSE BY HIS/HER NAME.	1	2	3	4	5	6	7	N/A
15. ANTICIPATED THE SHOCK OVER MY SPOUSE'S DISEASE PROGRESSION AND PLANNED OPPORTUNITIES, INDIVIDUALLY OR AS A GROUP, TO TALK ABOUT IT.	1	2	3	4	5	6	7	N/A
16. PUT MY SPOUSE FIRST, NO MATTER WHAT ELSE HAPPENED.	1	2	3	4	5	6	7	N/A
17. MADE SURE OTHERS KNEW HOW TO CARE FOR MY SPOUSE.	1	2	3	4	5	6	7	N/A
18. GAVE MY SPOUSE GOOD PHYSICAL CARE.	1	2	3	4	5	6	7	N/A
19. WERE COMFORTING TO MY SPOUSE.	1	2	3	4	5	6	7	N/A
20. LISTENED TO MY SPOUSE.	1	2	3	4	5	6	7	N/A
21. KNEW MY SPOUSE AS A PERSON.	1	2	3	4	5	6	7	N/A

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

22.	VOLUNTEERED TO DO "LITTLE" THINGS SUCH AS BRINGING MY SPOUSE A CUP OF COFFEE, SITTING WITH MY SPOUSE, ETC.	1	2	3	4	5	6	7	N/A
23.	KNEW MY SPOUSE'S NEEDS WITHOUT MY SPOUSE HAVING TO ASK, OFFERING PAIN MEDICATION, TOILETING, ETC.	1	2	3	4	5	6	7	N/A
24.	EXPLAINED THINGS TO MY SPOUSE IMPORTANT TO HIS/HER CARE.	1	2	3	4	5	6	7	N/A
25.	CHECKED ON MY SPOUSE FREQUENTLY.	1	2	3	4	5	6	7	N/A
26.	GAVE MY SPOUSE'S MEDICATIONS OR TREATMENTS ON TIME.	1	2	3	4	5	6	7	N/A
27.	ENCOURAGED MY SPOUSE TO ASK ANY QUESTIONS HE/SHE MIGHT HAVE.	1	2	3	4	5	6	7	N/A
28.	KNEW HOW TO GIVE SHOTS, ETC. AND HOW TO MANAGE THE EQUIPMENT, LIKE THE SUCTION MACHINES, ETC.	1	2	3	4	5	6	7	N/A
29.	MADE SURE MY SPOUSE'S APPOINTMENT SCHEDULES, FOR X-RAYS, OR SPECIAL PROCEDURES WERE REALISTIC FOR MY SPOUSE'S CONDITION AND SITUATION.	1	2	3	4	5	6	7	N/A
30.	WERE PROFESSIONAL IN APPEARANCE.	1	2	3	4	5	6	7	N/A
31.	WERE CONSISTENT IN HOW THEY TREATED MY SPOUSE.	1	2	3	4	5	6	7	N/A

APPENDIX A (continued)

LEGEND:

Strongly disagree.....	1
Disagree.....	2
Somewhat disagree.....	3
Neither agree nor disagree.....	4
Somewhat agree.....	5
Agree.....	6
Strongly agree.....	7
Not applicable.....	N/A

32. INVOLVED MY SPOUSE IN THEIR CARE.

33. WERE ORGANIZED.

34. TREATED MY SPOUSE AS AN INDIVIDUAL.

APPENDIX A (continued)

REQUEST FOR DEMOGRAPHIC INFORMATION

Please fill in the following information; your responses will provide information important for the study.

1. Your age: _____
2. Your gender: _____

INFORMATION PERTAINING TO YOUR HUSBAND/WIFE:

3. Reason for the admission: _____

4. Length of stay to date (in months): _____
5. Your husband/wife's age: _____
6. His/Her diagnosis(es): _____

7. Help required for activities of daily living: _____

Thank you for your assistance and participation.

APPENDIX B

Letter of Information

My name is Susan Fong. I am a Registered Nurse currently working on my thesis for the Master of Science in Nursing Degree at the University of British Columbia. I am interested in studying the spouses' perceptions and expectations of nursing care delivered to the institutionalized elderly who are mentally confused. The quality of nursing care is of special interest to me as a Nursing Unit Manager. Information can be found from the nurses' viewpoint but little is known from the spouses' perspective. Spouses are in a unique position to offer insight on what is happening in institutions and what consumers are looking for in nursing care. The knowledge generated from the study will assist nurses to improve their nursing care delivery.

This letter is my invitation to you to participate in my study. You are under no obligation to participate, however. Your participation or non-participation will not in any way affect the health care that your husband/wife is receiving.

If you are a spouse of a resident who has any type of dementing process caused by a number of illness conditions including Alzheimer's Disease and dementia, and who has lived in the facility six months or more, I would like your participation in completing a questionnaire. The questionnaire will take approximately 45 minutes of your time to complete and you have the freedom to refuse to answer any questions. Anonymity is guaranteed as no identifying information is required on the questionnaire. The questionnaire will be destroyed once the study is completed. Upon completion of the study, a summary of the findings can be forwarded on request.

I would be pleased to answer any questions you may have about the study and I can be reached at home at 272-4418, or at work at 822-7518. The chair of my thesis committee is Marilyn Dewis, Assistant Professor, telephone 822-7496.

Sincerely,

Susan Fong, R.N., B.S.N.
Graduate Student
The University of British Columbia

APPENDIX C

INSTRUCTIONS TO THE PARTICIPANTS OF MY STUDY ENTITLED:THE COGNITIVELY-IMPAIRED INSTITUTIONALIZED ELDERLY:
SPOUSAL PERCEPTIONS AND EXPECTATIONS OF NURSING CARE

Thank you for participating in my study. Please complete study within two weeks upon receipt of the questionnaire.

As soon as possible kindly return the completed questionnaire to me using the self-addressed stamped envelope.

Thank you.

Susan Fong
Investigator

822-7518 Work
272-4418 Home

APPENDIX D

Aptness of the MANOVA Model

In order to make inferences to the study population, there should be no serious violations of the assumptions of parametric statistics and the MANOVA model. The assumptions of normality, including homogeneity of variance and outliers, skewness, and kurtosis (asymmetry and peakedness) and independent observations should be fairly well met.

In terms of the homogeneity of variance and outliers of the normality assumption, all residuals were within three standard deviations. The highest value is found in statement 1 (Told me of support systems available such as self-help groups), where the standard deviation for perception is 2.13. In terms of skewness and kurtosis, the skewness coefficient should not exceed plus or minus two, and for kurtosis, the coefficient should be found within three standard deviations to either side. A standard deviation of zero indicates a symmetrical or normal distribution. The plus or minus on one side or the other of the normal curve signifies a bipolar orientation of the data distribution. Skewness and kurtosis indicate the numbers of respondents who generally agree or disagree with a statement. Those statements exceeding the acceptable limits for both skewness and kurtosis are listed on Appendices E and F respectively.

To summarize, models are seldom perfect and this particular model is no exception. Some skewness and kurtosis violations were found. In particular, statement 26 (Gave treatments on time) and statement 14 (Called spouse by his/her name) were highly peaked (11.16 and 12.37). What this indicates is that many spouses agreed with these two statements. Moreover, statement 14 (Called my spouse by his/her name) was the only dependent observation seen, even though some of the means for perceptions and expectations were very close together (Figure 1). Put another way, the data are

normally distributed with mean μ and variance σ^2 . In general, there were no serious violations of the normality assumption. As a result, some inferences can be made pertaining to the sample under study.

APPENDIX E

Statements with Skewness Coefficients Greater Than Plus or
Minus Two Standard Deviations

<u>Perception</u>	<u>Skewness</u>
3. Talked in English	-2.06
26. Gave treatments on time	-2.98
 <u>Expectation</u>	
14. Called spouse by name	-3.23
28. Knew how to give shots	-2.78
29. Made sure procedures were realistic	-2.06
30. Were professional in appearance	-2.17

APPENDIX F

Statements with Kurtosis Coefficients Greater Than Plus
or Minus Three Standard Deviations

<u>Perception</u>	<u>Kurtosis</u>
3. Talked in English	4.28
5. Told spouse in adult language	3.50
26. Gave treatments on time	11.16
34. Treated spouse as an individual	3.09
 <u>Expectation</u>	
3. Talk in English	3.58
11. Created a sense of trust	4.02
14. Called spouse by name	12.37
26. Gave treatments on time	3.75
28. Knew how to give shots	8.74
29. Made sure procedures were realistic	5.43
30. Were professional in appearance	5.79
