Resident's Self-Reported Perceptions of Care Outcomes in a Personal Care Home

by

Cheryl Ellen Walker

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ABSTRACT

Limited research has been done on personal care home residents' involvement in their care. An exploratory-descriptive research design was implemented to identify factors of quality of care outcomes important to the institutionalized elderly within a self-care framework. The study examined three intermediate outcomes: resident competence and knowledge, resident satisfaction, and resident adherence to the care plan, using the resident as the primary source of information. The design consisted of a semi-structured, face to face interview with residents (N=30). Findings based on the review of residents' charts indicated no collaborative action between residents and nursing staff in development of individualized care plans. The findings from the interviews indicated that the residents perceive themselves as the primary motivator in self-care, with nursing supportive in times of crisis and available for the more frail elderly. The determination of who had decision-making choices associated with care was affected by the personal care home environment, health status of the individual resident and availability of family and friend support systems. Areas where residents had the most decision-control were activities and ambulation. Self-care in grooming was affected by the resident level of dependency. No self-care was perceived in the areas of diet and medication.

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Chapter I

STATEMENT OF THE PROBLEM

Nursing and other health professions in North America have been faced with the complex challenge of monitoring quality of care. Nowhere is this concern more relevant than in the care of the elderly. As a group, those in Canada over 65 years of age use 40% of health services (Adams & Lefebvre, 1980). However, a small proportion of this over-65 group accounts for a large share of utilization. Shapiro and Roos (1981), in a study of health use by older people in Manitoba, demonstrated that a small minority of high users was identified. This group was characterized by advanced age, low self-perceived health status and several self-reported health problems. Studies demonstrate that although 5% of the elderly population was found in nursing homes at some time in any given calendar year (Manton, Woodbury & Liu, 1984), the life-time risk of an individual over 65 being in a nursing home exceeds 25% (Palmore, 1976). Since institutional care for the elderly is and will continue to be a necessary part of health care utilization, quality of care within the institutional environment needs to be addressed.

These patterns of health care utilization by the elderly present the nursing profession (and other health care professionals) with a significant challenge in providing quality resident-centred health care. Since nursing is the major discipline providing care of the aged in institutional settings, it is important that nurses look at methods of evaluating quality of care. Williamson (1971) suggests that nurses have much to offer in prognostic judgment based on their more detailed and frequent patient contacts than other health professionals. Kane and Kane (1978) see the geriatric nurse practitioner as the primary care giver, as the traditions of nursing lie closer to the nurturing requirements in long term care.

Quality in long term care has been generally measured by defining standards of care. An example is "Standards for Accreditation for Canadian Long Term Care Centres" (Canadian Council on Hospital Accreditation, 1985), which focuses on requirements in the physical environment, staffing, development of quality assurance programs and health record keeping. The facility's ability to meet the Canadian Council on Hospital Accreditation (CCHA) standards is reflected in the length of accreditation award which varies from a one to three year period.

From an organization perspective, assessment of quality of care is rendered increasingly difficult when more than one person is involved in the provision of care. Then we are confronted with the problem of assessing the separate and joint contributions of each. Delivery of care has become highly organized and complex; thus, attributes such as "continuity" and "coordination" become important constituents of the concept of quality. These attributes are difficult to define and measure, yet there is little doubt that they influence the achievement of health care objectives (Luke & Modrow, 1983).

Along with delivery of health care being complex, the personal care home environment has specific staffing concerns. The personnel tend to be less well paid, more poorly trained and less satisfied with their work than those in other parts of the health care system (Kane & Kane, 1978). Professional nursing coverage is minimal. Social workers, occupational therapists and other professionals appropriate to serving a setting where social needs are so admixed with health needs are in short supply and are often hired, like physicians, as consultants.

Evaluators of quality of care use three types of measures: measures of structure, process and outcome. Measures of structure or process assess factors that are presumably directly related to outcome. Measures of outcome are designed to assess the effects of care on the population served. Outcomes refer to the result of care: some measurable aspect of health status. However, Brook, Davies and Kamberg (1980) observed that favorable outcome measures are based on the assumption that they result from high quality care. This assumption remains subject to empirical verification of the specific linkages between measures of health care process and resident outcomes. Further, the utilization of resident outcomes as indicators of health care quality may overlook the effects of intervening factors including the resident's prior health status and his/her degree of cooperation with the prescribed regimen (Given, Given & Simoni, 1979).

Some indicators of resident outcomes are easy to recognize, such as death; others are more difficult to assess, such as knowledge and understanding of illness. Unfortunately it is the latter indicators that would seem to hold the greatest promise as quality measures of long term nursing care. Since multiple irreversible or chronic health problems are common in long term care, resident outcomes need to be a reflection of limited resident outcome goals. For example, a cure for stroke victims is currently unrealistic. However, the intervention of a systematic exercise plan can prevent further deterioration of muscle strength and loss of mobility. Therefore improvement or maintenance of mobility is the expected limited outcome. Strategies are needed to identify those factors that have the greatest probability of effecting improvement in outcomes.

Research on quality of care has generally focussed on hospital and, to a lesser extent, on ambulatory care (Brook, 1973). Extended, long term, or nursing home care has received relatively little research attention (Kane, 1982; Stevens, 1983). Most studies have been cross-sectional and relate characteristics of the homes to conditions of the residents in the personal care environment. According to Lang and Clinton (1984), gerontological nursing has received the least quality of care research attention compared to other specialties in nursing. However, it has had the largest proportion of studies evaluating cost factors. With the increasing number of aged, more recent interest is being generated in examining quality of care factors in the field of gerontology.

Other factors have hindered the outcome approach in long term care. Outcome is difficult to define. In its purest sense, outcome refers to a final positive consequence such as recovery, restoration of function, or survival (Donabedian, 1966). Although 'cure' is not always the only goal of hospital care, improvement in health status is associated more often with acute care than with long term care.

Shapiro modified the definition of outcome to include intermediate states: "some measurable aspect of health status which is influenced by a particular element or array of medical care" (1967, p.28). Outcome is multi-dimensional, and suggests the development of a "profile," rather than a single "index," for describing health status (Starfield, 1974).

Generally, quality of care research has focussed on the hospitalized adult. Little work has been done in seeking the resident's perspective on outcomes of care in personal care homes. Anderson (1974) suggests that quality of care for older persons might better be defined by patient choice. In later work, assessment of nursing home residents by Kane, Bell, Riegler, Wilson and Kane (1983) demonstrated that it is possible to obtain valid data from personal care home residents. For many elderly, the long term care facility represents their permanent residence, not a hospital. Therefore, the approach in long term care should focus on functional and social outcomes, and quality of life criteria rather then traditional hospital based methods (Kane & Kane, 1978). Outcome measures are difficult to define and there is lack of empirical verification between process and outcome. As well, the outcome approach in long term care needs to differ from current explicit quality of care criteria such as mortality and morbidity rates.

The purpose of the present study is to identify salient indicators of quality of care outcomes for the institutionalized elderly. The study will examine three intermediate outcomes: resident competence and knowledge, resident satisfaction, and resident adherence to care plan within a self-care conceptual framework, using the resident as the primary source of information. Intermediate outcomes represent summary measures of the effect of the health care delivery activities on the resident at a given point in the intervention, as opposed to the final point of the intervention (Given, Given & Simoni, 1979). They are the parameters a health care professional uses to modify and revise therapeutic activities in response to the course of a disease. Examples of intermediate outcomes are restoration of specific functions, increase in resident information and knowledge about their disabilities, or mastery of adaptive skills in self-care to promote independence.

The first component of outcomes which was examined is resident competence and knowledge. In long term care, performance of a skill needs to be emphasized over capacity, as the former is more likely to be sensitive to the environment, for example, someone with a capacity to do a task may not be allowed to use it. It therefore becomes important to determine the resident's knowledge base of his/her illness and dysfunction in order to evaluate performance levels. Kane et al. (1983) research in the domain of activities of daily living suggest self-reported data are less trustworthy than the demonstration of the activities; nevertheless, an increase in knowledge is a prerequisite for helping a resident assume responsibility for self-care.

The second component of intermediate outcomes examined is resident satisfaction. This is due to recognition and confirmation that patient satisfaction constitutes a legitimate measure of quality of care (Donabedian 1981; Scherer, Farrell & Sinha, 1985). If the philosophy of nursing quality of care is to include the patient fully, then patient satisfaction becomes a measure of care delivered to the patient.

Stimson and Webb (Locker & Dunt, 1978 p.288) have suggested that satisfaction is related to perception of the process of care and the extent to which it meets the patient's expectations. Support for this association can be found in data provided by Korsch, Gozzi & Francis (1968), who found satisfaction to be lower when physicians failed to meet the patient's expectations that they be communicative and friendly. Locker and Dunt (1978) suggest that expressions of satisfaction are the end product of a process of evaluation in which expectations figure to some degree.

The third component in the evaluation of outcomes is the resident's adherence to the plan of care. Adherence, is an important outcome in long term care, as adherence to a plan of care is necessary in preventive/maintenance health programs for many chronic diseases, such as hypertension and diabetes. Hence adherence to a treatment plan is necessary for improved outcome status.

In self-care, the resident is the primary decision-maker, with professional care used in conjunction as required. Thus resident adherence includes the decision to enter into a treatment program, to terminate a program, or to implement a mutally agreed on plan of care. This approach to adherence defines the limitations of medical care since the individual assumes a large portion of controlling and maintaining the care. Resident role expectations are a key factor in adherence (Chang, 1980). Adherence can be enforced in an institutional environment through rigid rules and procedures (Kane & Kane, 1978). This is in direct conflict with nursing's more holistic approach that focusses on the individual as opposed to the disease entity.

The need for nurses to investigate outcomes of care for the elderly in long term care institutions is supported by further studies in nursing. Elbeik (1985) revealed that patients, nursing and administrative staff scored patient diagnosis and treatment of great importance in hospital care. However, only patients continued to score patient care and counselling/teaching as very important. Simpson's (1985) two and one half year study of hospital opinion surveys in British Columbia revealed that a large number of patients are not given the opportunity to be involved in the planning of their care. This lack of opportunity lead to dissatisfaction with various aspects of their care, in particular teaching and discharge planning. Nurses need to understand resident perceptions if they are to evaluate quality of care effectively and record the care given.

The questions addressed in this research were:

1. To what extent do resident self-reported levels of participation and decision-making in their plan of care lead to the outcome of knowledge and competence in self-care?
2. To what extent do resident self-reported levels of participation and decision-making in their plan of care lead to the outcome of satisfaction?
3. To what extent do resident self-reported levels of participation and decision-making in their plan of care lead to the outcome of adherence to plan of care?
4. Are the self-reported levels, identified by the residents, documented in the nursing notes on either the residents' charts and/or kardex?

Nursing as the major discipline providing care of the aged in institutional settings could contribute significantly towards quality of care by assisting the elderly in the practice of self-care. Self-care, with its goals of forestalling the progression of chronic illness, prevention of complications, and maintenance of health at the highest possible level enhances the holistic approach which the nursing profession advocates. This study is directed towards gaining knowledge regarding residents' perceptions of care and their evaluation of care.

Specifically, factors influencing the elderly persons' perceptions of their health status and satisfaction or dissatisfaction with care were examined. As well, the extent to which resident-reported indicators of participation and decision-making in their plan of care leads to competence and knowledge, satisfaction and adherence was explored. Finally, examination of the residents' records, identified to what extent nursing notes reflect the self-reported levels identified by the residents.

Chapter II

CONCEPTUAL FRAMEWORK

Chang's (1980) framework, which incorporates aspects of Orem's model of self-care, was the main conceptual model that guided the thesis. Chang's model included three major dimensions for identifying, clarifying and evaluating self-care: (1) individual layperson characteristics, (2) health professional characteristics, and (3) patient outcomes (Fig 1). The last dimension, patient outcomes is influenced by the preceding two. In her model, patients determine the desired outcomes in accordance with their decisions. While this does not preclude the patients from obtaining relevant information from health care professionals, it does shift the decision-making responsibility to the patients. The responsibility is based on patients' perceptions of the risks involved in treatment and illness. The evaluation of outcomes of self-care can be used to identify components of health care on patient and health care professional interactions that contribute most to measurable outcomes, Chang identifies outcomes as patient competence, satisfaction and adherence to a health care plan.

2.1 DIMENSIONS OF CHANG'S SELF-CARE FRAMEWORK

Chang (1980) incorporated Orem's work in part, but also based her framework on other literature related to the evaluation of quality of care. One of the most well established frameworks in self-care in nursing was articulated by Orem in Nursing: Concepts in Practice (1971, 1985). The central concept of Orem's theory of nursing is that nursing offers a service to people who are not able to provide continuous self-care for themselves or their dependents because of a health related limitation. In order to manage or maintain self-care for patients, nurses prescribe, design, and provide for patients. Chang's model focusses on evaluation of health care professionals in facilitating self-care. Some revision in the second dimension was required to better identify the areas of concern for the institutionalized elderly.

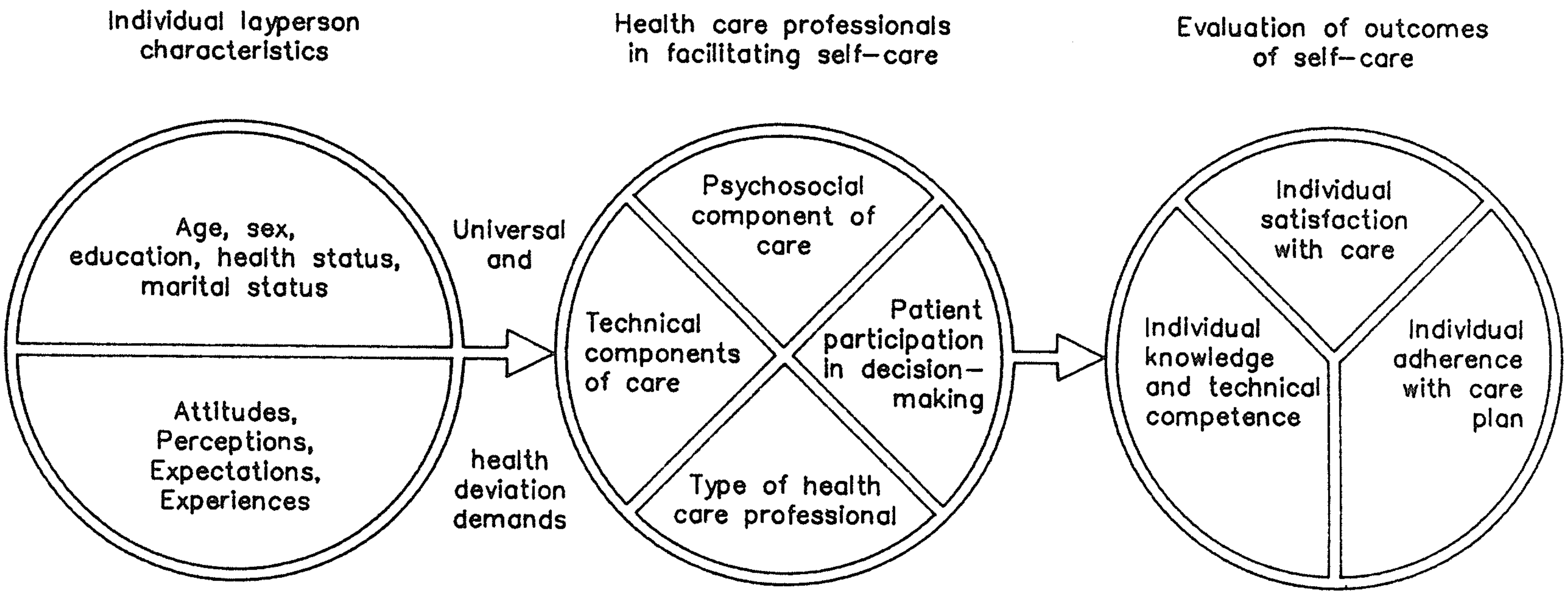

Figure 1. Framework for evaluation of health care professionals in self–care. Evaluation of health care professionals in facilitating self–care: Review of the literature and a Conceptual Model, by B.L. Chang, 1980. Advances in Nursing Science, 3(1), p.45.

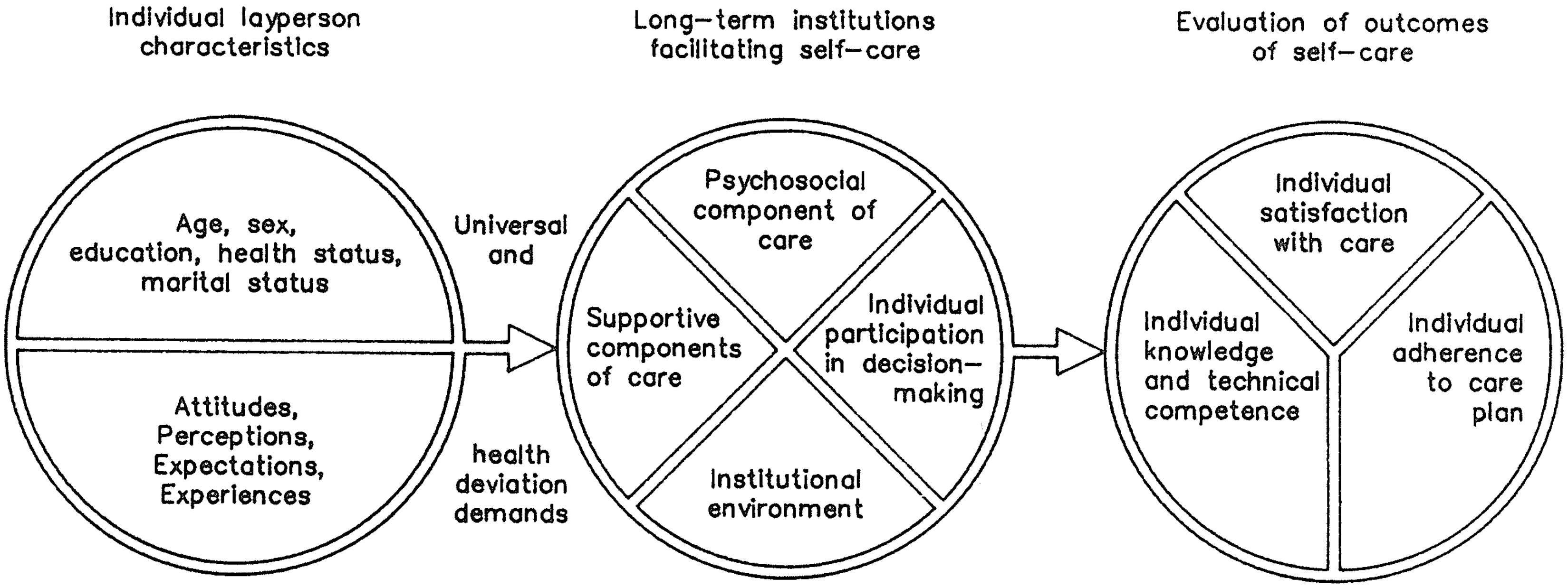

Figure 2. Adaptation of B.L. Chang's conceptual model. Framework for evaluation of resident outcomes in self–care.

2.1.1 Individual Laypersons Characteristics

Chang's first dimension relates to individual layperson characteristics. Expectations of residents and their entry and performance in the 'resident role' reflect complex judgments regarding the expectations and satisfactions with the role. Factors found to influence residents' needs, expectations and perceptions include age, sex, level of education, health status and marital status (Chang, Uman, Linn, Ware, & Kane, 1984; Linn & Greenfield, 1982). In addition, any health care or potential self-care activities are evaluated by individuals in relation to their own value systems, culture, beliefs, expectations and attitudes (Francis, Korsch & Morris, 1969; Hulka, Cassell, Kupper & Burdette, 1976; Locker & Dunt, 1978). These characteristics are represented by the first circle in Fig 1 and Fig 2.

Chang adopted Orem's definitions for universal and health deviation. Orem delineates two kinds of self-care: universal, and health deviation (Consult Fig 1). Universal self-care is the behavior that helps people to meet universal or basic human needs, such as air, food, water, elimination, solitude, social interaction, activity and rest, protection from hazards, and normalcy. These are the ordinary things we do in ordinary ways, which are noticed or acknowledged only in their absence. A host of body rituals like brushing teeth and bathing are examples. They are culturally fused behaviors, for the most part routine, self-initiated, self-maintained and self-monitored (Levin, Katz & Holst, 1979).

Health deviation self-care as described by Orem, is the behavior that arises from illness, injury, or life cycle events such as senescence. Health deviation self-care may also arise from the therapy or procedures prescribed to treat injury or illness or assist people during the life cycle event. The patient or family member can provide the universal and health deviation self-care requirements if he/she has the ability to do so based on appropriate knowledge, skill and motivation.

2.1.2 Long Term Institutions Facilitating Self-Care

The second dimension of Chang's framework relates to characteristics of the health care professional in facilitating self-care and is represented by the revised middle circle in Fig 2. For purposes of this study, Chang's component "type of health professional" was modified to "the institutional environment" and its' effects on facilitating self-care. The revised dimension included (1) supportive components of care, (2) psychosocial component of care, (3) resident participation in decision-making and (4) institutional environment.

1. The supportive components of care: This aspect of care in the original framework referred to the practitioners' understanding and application of medical science and technology (See Fig 1). A focus on medical-technical care fails to address many of the concerns present in a personal care home environment. Long term care facilities present a threat to self-directed functioning of residents, not only because it is the almost exclusive environment for many residents, but also because they tend to operate under a medical model that historically emphasizes authoritarian powers. The phrase, "It's the doctor's order....," is commonly used to justify the behavior of staff in limiting decision-making by residents.

Care of some forms of chronic disease, for example, hypertension, respiratory ailments, and diabetes, require a high proportion of lay (individual and family) care relative to professional care. The objectives for nursing in long term care are not skilled application of medical science and technology, but rather support to increase the coping ability and social competence of the residents. Orem views nursing care as designed to supplement patient self-care requisites in the absence of capabilities to do so by the patient. This enhancement of resident goals through support and cooperation is represented by "supportive components of care" in the middle circle in Fig 2.

2. Psychosocial Component: A second component of care is the psychosocial aspect, remains unchanged from the original framework. This component includes attention to patients' feelings, and responses to their health, treatment and other factors in the environment (Chang, 1980). The approach in long term care should focus on functional and social outcomes and quality of life criteria, rather then focus only on medical diagnosis. The problem of autonomy and self-control in long term care settings is intensified by the fact that many residents have marked physical and mental impairment. The challenge for caregivers is how to help such persons to maintain some sense of control over their daily activities.

3. Resident Participation in Decision-Making: The third component, resident participation in decision-making varies from Chang's original framework only in changing the word "patient" to resident, which more accurately reflects the personal care home population. Resident participation in decision-making requires that the nurse assist residents in participating in their own care when necessary to meet universal or health deviation demands. Self-care is viewed as a decision-making process which involves self-observation, symptom perception and labeling, judgment of severity, and choice and assessment of treatment options (Levin, 1978). In long term care the focus of decision-making is shifted from the health provider to the resident

and/or family. Decision-making is part of the layperson's resources to be used in conjunction with professional care as required.

Chronic care disease constitutes a clear and comprehensive model for self-care practice, as persons with long standing illnesses living in personal care homes require intensive lay initiatives to be managed successfully. Self-care practice provides an opportunity for laypersons to develop extensive self-care skills on a continuous and progressive basis. Professionals interested in self-care will need to tread a narrow line between offering essential technical knowledge, education and assistance on the one hand and on the other avoiding the appearance or reality of dominating the content or process of self-care development.

4. Institutional Environment: In the original framework Chang stated, the type of health care professional involved in assisting individuals in self-care may influence resident evaluations of health care. To date, the research that has been done on resident's perspectives, offers little in understanding of that influence (Ingham & Fielding, 1985; Linn, 1975). One limitation in using Chang's "type of health professional," is the lack of professional staff available in personal care homes. The majority of the care is done by poorly trained non-professional staff. "Type of

health professional," fails to capture the reality of the personal care environment. Process and outcomes of care are to a large extent determined by the environmental context within which care occurs. A personal care home facility is the almost exclusive environment for many of the residents, and has the potential to exert a powerful influence on perceived control. A considerable proportion of the dependency of elderly residents can be iatrogenic and arise from environmental conditions rather than their physical or mental condition. These effects of environmental conditions, as opposed to type of professional, in the original framework, are represented by the middle circle in Fig 2.

2.1.3 Evaluation of Outcomes of Self-Care

The third dimension deals with the evaluation of intermediate outcomes in relation to self-care. No changes were made to the original components in this dimension. Intermediate outcomes represent summary measures of the effect of the health care delivery activities on the resident at a given point in the intervention, as opposed to the final point of the intervention (Given, Given & Simoni, 1979). The outcome measures must reflect the dysfunction level for which nursing care is provided and the age of the patients under care and not be susceptible to varying interpretations due solely to the passage of time. For example, an outcome of further deterioration from a stroke, can be evaluated to identify if the deterioration was due to lack of appropriate interventions, such as rehabilitation therapy to forestall the progress of the disease, or due to increased dysfunction as part of the disease process. Since multiple health problems are common in long term care, health outcomes are a reflection of intermediate outcome measures such as, rehabilitation and maintenance, rather then cures. The evaluation of outcomes is represented by the circle to the far right in Fig 1 & 2. The framework proposes an examination of three components in terms of individual layperson outcomes.

1. Individual Knowledge and Technical Competence

This component of evaluation would include information and skills obtained by residents in order to forestall progression of chronic illnesses, prevent complications and maintain health at the highest possible level. The evaluation of resident competence may be done by the individual themselves or with the assistance of the health care provider.

2. Individual Satisfaction with Care

The second component is the evaluation of resident satisfaction with care received. Satisfaction with care may be obtained as a global rating by the residents as well as a more specific rating for each component of care. Evaluating specific components of care may be particularly helpful to health care providers, so that information obtained may help determine which factors are highly associated with resident satisfaction. In measuring resident satisfaction, as with other outcomes, it is important to take into consideration the resident's pre-existing characteristics that influence evaluation (Chang, 1980; Locker & Dunt, 1978). From the resident's perspective self-care offers it's own satisfactions derived from sensing one's own capability to act on personally determined priorities.

3. Individual Adherence to Care Plan

The third component in the evaluation of health care professionals in facilitating self-care is the resident's adherence to the self-care plan (Fig 1 & 2). In chronic disease, the central role of self-care is reduction and control of disability and dependence. To be effective, much of the control requires the contribution of the individual and family. Residents and/or family need to be informed as to the resident's health status, the meaning of signs and symptoms, and kinds of treatment or options available, each with its own set of consequences (i.e. health deviation demands).

The resident can then select a plan, implement the plan and adhere to the plan. It is the resident who determines the desired outcomes in accordance with his/her decision as to which risks he/she chooses to avoid (or not avoid). The crucial point is that the decision-making process is "self-interested, self-initiated and self-maintained" (Levin, 1976 p. 13), with nursing care supplementing /supporting the continuous primary role of residents to control disability and dependence.

2.1.4 Summary

Chang's model is a suitable conceptualization for the research questions. The framework is a nursing model which enhances the holistic approach that the nursing profession advocates. The self-care model is an effective guide for chronic care, as it focusses on the individual as the primary decision-maker in developing extensive self-care skills. According to the model, resident participation and decision-making in their plan of care are important factors in achieving the intermediate outcomes of knowledge and competence, satisfaction and adherence. As well, the model offers a guide for nursing documentation of resident self-reported levels of participation and decision-making leading to intermediate outcomes. Nurses, as the main group of health workers in long term care, can impede or enhance the self-care development by their perceptions of the resident's role. The self-care conceptual framework has identified one way of viewing chronic care that assists in reduction and control of disability and dependence and reduces the negative potential of professional dominance.

Chapter III

LITERATURE REVIEW

3.1 INTRODUCTION

There are no standard measurements or norms for evaluating outcomes of quality of care. Depending on the theoretical framework, different descriptions and explanations are offered. This examination and analysis of quality of care will focus first on, medical care frameworks and methodologies that have influenced the study of nursing care. Then it will look at the historical perspective and trends that have evolved specific to nursing research of quality of care. Lastly, the literature review will examine self-care and quality of care under the three dimensions of individual characteristics, the long term care environment and evaluation of outcomes, in Chang's self-care framework.

3.2 QUALITY OF MEDICAL CARE

Donabedian (1966,1968) was one of the first researchers to examine the complex interactions between client behaviors and provider behaviors. His framework of structure, process and outcome is perhaps the most widely used frame of reference in the quality assessment literature. Within

Donabedian's framework, structure refers to those essential supports, such as facilities, equipment, organization, and number and mix of providers of care. Process refers to those activities health personnel perform for integrated management of health and illness and also attributes of the client-provider relationship. He conceptualizes the measurement of outcome to include health outcomes and patients' and health professionals' satisfaction with care. Donabedian (1966) operationalizes outcomes as recovery, restoration of function and survival. In long term care it may be difficult to define health outcomes in this ultimate sense. Recovery and full restoration of function are not always attainable for the chronically ill elderly. A peaceful death with dignity may be considered a more positive outcome of care than mere survival.

Shapiro (1967) modified the definition of outcome to include intermediate states that may be a measure of a particular element or array of medical care. Evaluation cannot depend upon long term outcome measurements, such as death from hypertensive disease, but instead must depend upon less certain, intermediate term outcomes such as blood pressure control. Only then he argues, can we begin to see what behaviour is appropriate to achieve a desirable end point.

Starfield (1974) described outcomes as a "profile" rather than a single index. She developed seven categories: longevity, activity, comfort, satisfaction, disease, achievement and resilience. She feels an appropriate scheme for measuring outcome, apart from being concerned with elements of health status, should allow for measurement of both the maintenance of good health and the relief of illness. Consequently, she and later researchers, Brook, Davies and Kamberg (1980), argue that a scheme for evaluating outcome should not be restricted to specific medical diagnosis.

Multiple diagnoses and certainly multiple health problems are common in long term care; therefore, outcomes should focus on the resident's impairment, rather than on pathophysiologic causes. The activities of nonphysician health personnel, as well as those of physicians, need to be included in outcome evaluation. Lastly, Starfield suggests that an appropriate scheme needs to recognize the interrelationship between mental and physical ill health.

Williamson's (1971) health outcome model, extends Donabedian's framework to include diagnostic, therapeutic and educational outcomes. He recognized that a strategy is needed to identify those factors that have the greatest probability of effecting improvement in health status. Diagnostic outcomes are defined as outcomes resulting from medical assessment, and therapeutic outcomes are the result of medical intervention at specified periods of time, following the initiation of care. He later expanded this framework to include educational outcomes that results from the teaching-learning process directly related to health care (Williamson, 1978). Educational outcomes included alteration in both knowledge about health problems and attitudes or behaviours toward managing health problems.

Williamson (1971), and later Brook (1973), argue that quality assessment should, if possible, be built upon outcomes. Brook (1973) included information from the medical record and directly from patients, as well as health professionals assessments of outcomes. He found no relationship between outcome measures of function, morbidity, or mortality and the natural history of disease or medical therapy. Thus, he concluded, it might be better to state anticipated or expected treatment outcomes in advance, and to measure the extent to which these expectations are met, rather than to concentrate on the measurement of diffuse health care processes.

Brook and Stevenson (1970), in using Williamson's model, showed that focussing on process does not necessarily result in high quality care. In their study, Brook and Stevenson discovered the primary objective of the inner city emergency rooms was in processing of test results, rather than provision of necessary services for the patients. Brook, Davies and Kamberg (1980) in examining quality of medical care see outcome measurement as valuable as it tends to focus on the patient, rather than the caregiver's process of care.

3.2.1 Methodological Issues in Medical Outcome Studies

Despite the reasons for using outcomes in assessment of care, outcome specifications are plagued with problems of validity. Donabedian (1981) identified several difficulties with outcome measurement, including determination of (a) relevance, (b) timing of measurement, (c) separate outcomes related directly to the discipline of medicine, and (d) the definition of patient attitudes. After all, it is recognized that many factors other than professional health care affect outcomes. Utilization of patient outcomes as the only indicators of health care quality may overlook the effects of intervening factors, such as patient's prior health status and expectations of care.

To increase the validity of outcome assessment, other methodologies such as tracer studies (Kessner, Kalk & Singer, 1973), health accounting (Williamson, 1978), staging (Gonnella & Goran, 1975), criteria mapping (Kaplan & Greenfield, 1978) and the identification of sentinel health events (Rutstein, Berenberg & Chalmers, 1976) were developed to introduce more precision into defining outcome assessment. Analysis of these methodologies is beyond the scope of this thesis. However, it is important to realize that although each methodology varies in focus and approach, the establishment of objective criteria and the development of systematic review procedures are elements common to all the methodologies (Roberts & Walczak, 1984). The medical practitioners reliance on objective, validated data was accepted as a requirement for effective quality of care.

The lack of a strong relationship between process and outcome assessment of care has received considerable discussion in the literature (Brook et al., 1980; McAuliffe, 1978; Romm & Hulka, 1979). McAuliffe (1978, 1979), in a critique of studies of process-outcome correlations in medical care, identified numerous methodological flaws in the studies. He argues that there is little reason for believing outcome measures are more valid than process measures. Scott, Flood and Ewy (1979), examined 603,000 patient charts and found a low and/or inconsistent association between structure, process and outcome. Nevertheless, an important methodologic problem that must be faced is the identification of process measures which can be appropriately used as indicators of eventual outcomes.

Unfortunately there is a paucity of medical research on the quality of care in long term care institutions. Most studies done by medicine occur in acute care settings and ambulatory care settings. The population studied is generally hospitalized adults. Kane and Kane (1978) see medicine as having generally abandoned long term care. If this is the case, medicine, in North America at least, exhibits little interest in examining the needs of the elderly and chronically ill.

3.3 TRENDS IN NURSING QUALITY OF CARE STUDIES

There has been formal interest in the assessment and assurance of the quality of nursing care since Florence Nightingale (Lang & Clinton, 1984) used a set of standards to assess the care provided during the Crimean War. By comparing mortality experience in the British armed forces during the Crimean War with experience in civilian populations, Nightingale forcefully brought to the attention of the government and the public the atrocious standards of care for military personnel. Since that time, objective and systematic evaluation of nursing care has mainly been in the past two decades. A Delphi study conducted by Lindeman (1975) showed that the research priority of nursing educators and service practitioners was identification of indicators and factors contributing to quality nursing care. This study stimulated considerable research efforts on the development of criteria-based, process-orientated tools for measuring the quality of nursing care (Haussman & Hegyvary, 1976a; Phaneuf, 1972; Wandelt & Ager, 1974).

Research on the structural aspects of care focussed on the relationships among qualification and numbers of various types of health workers, physical facilities and equipment, and the quality of nursing care delivered. In long term care, Mech (1980) found higher quality of care correlated with more licensed personnel versus non-licensed personnel and utilization of a larger number of support services. Linn, Gurel and Linn (1977), in examining structural variables, found that only two variables - more registered nurse (R.N.) hours per patient and meal services were found to be associated with positive outcomes such as, improved mortality rates for patients transferred to nursing homes from a general medical hospital. Structural studies frequently compared the nurses' performance to organizational goals and objectives, which may or may not have been in conflict with patients' goals.

The introduction in the 1960s of the nursing process was a reflection of nursing's change from the traditional 'ritualistic' approach to a more enquiring scientific approach, based upon the patient's individual needs. On an operational basis, nursing process refers specifically to the activities of nurses in assessment, planning, implementation and evaluation that relate to the achievement of specific patient goals in the delivery of care. This trend towards accountability meant practitioners needed to develop standards of care, to monitor the care they gave and to act upon the findings. The Manitoba Association of Registered Nurses (Scherer, Farrell, Sinha, 1985) in their examination of nurses' compliance to generic nursing standards discovered that health problems identified by the individual patient were rarely recorded. Where actual health problems were identified by the nurses, suspected health problems were seldom recorded. Nurses were however, recording the nursing interventions (i.e. what the nurse does). Such charting behavior suggests lack of awareness (in written form) of patients' perceptions of their health problems. This type of documentation relegates the patient to being a passive recipient of care, where the focus of care is on the nursing task, and fails to acknowledge the patient's role in determining health needs and expected outcomes. Although not discussed in the study, one possible reason for this method of documentation, is the habitual recording format which has traditionally focussed on the health professional's interventions. A another possible influencing factor may have been the desire for control on the part of the nurses. Hospitals and personal care homes tend to function with a medical model of fairly rigid hierarchical structure.

Studies of nursing process usually focussed on either the care given by nurses or the care received by patients (Bloch, 1980). In the former, the nurses' competencies were measured against a set of standards, such as those included in the Slater Nursing Competencies Rating Scale (Wandelt and Stewart, 1975). The Quality of Patient Scale (QualPacs) developed by Wandelt and Ager (1974) originated from the Slater Nursing Performance Rating Scale. The QualPacs is a seven page instrument designed to measure the quality of nursing care received by the patient and the patient's family. The assessment of process variables is based on lists of explicit criteria applicable to a specific population of patients for whom the quality of care will be evaluated. The extent to which these criteria are or are not met determines the quality of care delivered to those patients.

Phaneuf's (1972) Nursing Audit, is also a nursing process instrument consisting of an explicit, categorical set of criteria. A validation study done by Ventura, Hageman, Slakter and Fox (1982) of the Quality of Patient Scale (QualPacs) and the Phaneuf Nursing Audit revealed no relationship between the two instruments. The investigators strongly suggest that the two instruments may not be measuring the same dimensions of nursing care pertaining to quality, which reflects the idea that quality of nursing care is complex and multi-dimensional. One could also argue that the measures are based on separate definitions of nursing care. Another alternative explanation is that the methodology was not appropriate for evaluating quality of care.

The development of outcomes studies was slower to emerge in nursing. However, as early as 1962, Aydellotte examined nursing practice in terms of outcome criteria. The study found no significant relationships between the size of the nursing staff, or in-service education and such patient welfare outcomes as number of days in the hospital, number of days with fever, doses of medication, mental attitude and physical independence, or skin condition. Aydellotte's investigation constituted a landmark in the attempt to establish outcomes which result specifically from nursing care. Despite this initial attempt, it was not until well into the 70's that nursing began to challenge the assumption that if nursing tasks were properly carried out, the quality of nursing care would be good. In addition, during that time an enlightened public and the spiraling cost of health services demanded greater individual accountability from all segments of the health care field. This brought the study of quality of care out of the circle of the health professions into a more public arena. However, today quality of care assessment is still professionally controlled through setting of standards, research and quality assurance programs.

A comprehensive research effort by Horn and Swain (1978) developed and tested 435 patient outcome criteria amenable to nursing influence. They demonstrated a method for evaluating the outcomes of nursing care process as reflected by the patient's health status. Data collection was designed to use the patient as the primary source of data, using direct observation and interviews. A wealth of empirically testable criteria for nursing emerged for the development of measures of patients' physical and emotional status and their knowledge and ability to perform self-care (Jacquerye, 1984).

The present trend in nursing is toward the conduct of studies which evaluate structure and/or process standards of care which are expected to impact favorably on one or more patient outcomes. Nurse researchers stress the importance of linking health care processes with patient outcomes, especially with reference to the evaluation of nursing process (Bloch, 1980; Lindeman, 1978; Zimmer, 1974). Few empirical studies exist in nursing to measure the impact of processes of care on patient outcomes. Haussmann and Hegyvary (1976c) in their study of the relationship of the nursing process and patient outcomes in two patient populations found that the relationship is somewhat inconsistent and may differ with various types of patients.

A cluster of studies generated by the Regional Program for Nursing Research Development of the Western Interstate Commission for Higher Education focussed on the development of outcome measures which were subsequently used to evaluate the process-outcome relationship (Lindeman, 1978). In summarizing this cluster of studies, Nelson (1978) found in general, psychosocial outcome criteria were relatively sensitive measures. Patient health status prior to hospitalization was highly predictive of outcome status, such as adherence to treatment plan, early discharge and mortality. Finally, Nelson identified that institutional variables and patient characteristics were related to outcomes. These studies, plus others, continue to identify a lack of knowledge about the causal relationship between health service variables, patient characteristics, nursing care processes and patient outcomes (Lindeman, Hagen and Krueger, 1976).

A nursing study carried out by Given, Given & Simoni (1979), attempted to examine the relationship of process of care to patient outcomes. The researchers concluded that although process variables are important, patient compliance is necessary to achieve desired outcomes.

Some work has been done attempting to incorporate the resident's point of view in outcome studies. Gallant and McLane (1979) tested a Patient Self-Rating Scale for use by patients and nurses to assess patients' health knowledge and self-care skills. The investigators found that nurses were twice as likely as patients to say an outcome had been achieved when it had not. The example given was observation of patients' proper application and use of elastic stockings. Only 54% were able to do it accurately, as opposed to nurses stating 90% of the patients had been taught the proper method. This indicates a discrepancy between the patient's perceptions of an outcome (knowledge of proper application) and the nurse's perception of the achieved outcome.

The Sickness Impact Profile (Gilson, Gilson, Bergner, Bobbitt, Kressel, Pollard and Vesselago, 1975) incorporates both professional and lay perspectives of the disabling effects of illness. The Sickness Impact Profile (SIP) instrument focusses on performance of usual daily activities in functional assessment measures, but many of the 312 items are not applicable to the personal care home environment. Items such as problems at work and not looking after household business affairs are more applicable to persons living in the community than the institutionalized.

Nursing care of the hospitalized adult is the clinical area with the largest volume of nursing quality assurance studies. The majority of these focussed on instrument development or evaluation of nursing assignment patterns (Lang & Clinton, 1984). There has been a proliferation of large and expensive studies of nursing care (Hegyvary & Haussmann, 1976b; Horn & Swain, 1978; Lang, 1974; Phaneuf, 1980; Wandelt & Ager, 1974). These studies consist of explicit, categorical sets of criteria applicable to specific populations of patients. In reviewing studies on process or outcome or combinations of structure, process and outcome, Padilla and Grant (1982) found that assessments of only one class of criteria permit only one kind of quality evaluation. These assessments do not permit evaluation of the effectiveness of process to outcome relationships. The authors feel that to determine the predictive validity of structure and/or process to outcome, both should be monitored concurrently.

Nursing and medicine share many similar problems of definition and measurement in the evaluation of care. Such explicit, categorical criteria are difficult to incorporate within the long term care setting. Multiple chronic problems, the interrelationship between illness and health, the impact of a permanent environment and the ultimate outcome of deterioration and death reflect the need for a different emphasis on the measurement of quality of care in long term care. Chang's self-care framework, which focusses on the resident as the primary decision-maker, and the supportive role of nursing, offers conceptual guidance for the development of quality of care criteria that are important in long term care.

3.4 SELF-CARE

Levin, Katz and Holst (1976) defined self-care as a process by which a layperson functions on his/her own behalf to promote health, to prevent illness, and to detect and treat disease when it occurs. According to their definition, the layperson is a self-provider and the primary health resource in the health care system. Conceptually this does not present self-care and professional care as mutually exclusive, but instead depicts self-care as including "... behaviors which both supplement and substitute for professional health care procedures," (Levin, Katz & Holst, 1976, p.13). According to Levin, chronic care constitutes a clear and comprehensive model for self-care practice. Due to the decline in acute morbidity and the emergence of chronic diseases as leading causes of death and disability, many individuals need to develop extensive self-care skills on a continual and progressive basis.

John Fry (Levin, Katz & Holst, 1979 p. 11) identified four roles for self-care: (a) health maintenance, (b) disease prevention, (c) self-diagnosis, self-medication and self-treatment, and (d) patient participation in professional care. These four roles have some underlying common premises: self-care is a voluntary, self-limited, non-organized, universal, varying complex of behaviors evolved through a mixture of socializing and cognitive experiences (Levin, Katz & Holst, 1979). Thus, self-care may be viewed as involving both the continuous substrate of behavior (custom, life style) and discrete or episodic actions (self-diagnosis, self-treatment). Self-care is a concept with deep roots in self-control and self-determination of health behavior. The effective limits of self-care development are unknown, but are theoretically limited only by society's interest in educational investment in self-care and definitions of tolerable risk/benefit ratio (Levin, 1978).

Dean (1981) in her selected review of self-care responses to illness, identified the need for clarification of factors shaping self-care practices of older people. She goes on to state that especially important is the extensive use of medications among the elderly. At the present time, there are very few studies on self-care that do not stem from a professional orientation (Dean, 1981). According to Dean, the individual as an active participant in the health care process has been ignored and decision-making by the patient was considered only in terms of complying with medical directives.

Orem (1971, 1985) developed a complex, but well articulated conceptualization of the components of self-care and their relationship to the nursing profession. Her theoretical explanation of self-care and its relationship to the nursing profession has guided numerous nursing studies on quality of care (Chang et al., 1984; Gallant & McLane, 1979; Horn & Swain, 1978; Kearney & Fleischer, 1979; Padilla & Grant, 1982). According to Orem, the most important outcome criteria relate to self-care. She defines nursing as an art which assists people when they cannot care for themselves, and attempts to return the patient to a self-care state through support and teaching.

Self-care's focus on active participation and resident decision-making responsibility, is based on residents' perceptions of the risks involved in the illness, treatment or various activities (rest, exercise, diet). Chang's (1979) doctoral study of 30 residents indicated that resident determination of daily care and activities emerged as the strongest contributor to morale. In later research on the satisfaction of elderly ambulatory women, Chang et al. (1984) found patient participation in planning care had the most significant effect on global satisfaction.

Self-care is based on a set of assumptions that differ in some ways from those of the professionally trained. The development of health and illness criteria have been established almost exclusively by professionals. (Levin, Katz & Holst, 1976). These criteria may or may not coincide with lay ideas or beliefs. There is little knowledge of the nature and degree of chronic illness which has never been professionally managed. It would be clearly helpful to have data on this point as a basis for understanding lay activity in chronic care.

Barofsky (1978) proposes that for the individual, self-care has at least four functions: to alleviate illness, to alleviate symptoms, to prevent disease and to regulate bodily processes. Two of his defined behaviors, preventative and regulatory are similar in concept to Orem's universal self-care. Preventative self-care includes all those individual health behaviors that contribute to, or maintain a person's optimal capacity to function. The behavior occurs in absence of illness and is self-initiated and self-selected. An example of preventative self-care would be routine breast examination. In the regulatory model, each time we eat or drink or protect ourselves from an environmental extreme we are caring for ourselves and avoiding adverse effects.

Barofsky, as well, identifies health deviation self-care as often a consequence of loss of control or power on the health and well-being of the individual, which often leads to iatrogenic diseases. Orem's health deviation self-care again bears some similarity to Barofsky's typology, focussing on his illness and symptom-induced self-care models. In the illness form, self-care behaviors are reactive, either temporary or chronic (depending on the illness) in duration, but almost always initially imposed on the individual. This varies somewhat from Orem's model, in that Orem identifies the individual as often meeting his/her own health deviation requisites. A second form of self-care occurs when an individual experiences symptoms that have not yet been labelled by a physician as an illness, but for which the patient has initiated treatment. An example is self-medication. This type of self-care is also reactive and may be either temporary or chronic in duration, but always self-initiated.

3.5 INDIVIDUAL LAYPERSONS CHARACTERISTICS IN RELATION TO OUTCOMES

Orem (1971) recognized that potential self-care activities are evaluated by patients/residents, in relation to their personal value systems, beliefs, expectations and demographics such as, age and sex. She perceived that individual differences were important in responding to feelings about health status, which in turn will affect decisions and self-care actions. Factors found to influence individuals' needs and perceptions include (1) age, sex, level of education, occupation, marital status, support networks, and (2) individual beliefs, expectations and attitudes (Chang, 1980).

Locker and Dunt (1978) in their review of the patient satisfaction literature found patients hold different expectations of care. In some instances patients are able to talk in detail about what they expect, while others may have very little conception of what they may expect. According to the authors this seemed to be related to the patient's knowledge and experience with the health care they received in the past.

Research indicates that patient characteristics are associated with patient satisfaction. Linn and Greenfield's (1982) examination of a patient population with serious debilitating chronic disease showed that the patients who were more depressed and rated their general health to be poorer, were significantly less satisfied with their care. These findings together with characteristics of patients' social situation or demographic data - age, sex, educational background, race, marital status, employment status and mode of transportation taken to and from the medical centre, were significantly associated with patient evaluation of providers of health care services.

Contradictory findings have been reported regarding the relationship of demographic characteristics and resident satisfaction. Simpson (1985), in her opinion survey of patients' perceptions of care found the oldest age group (over 75) were least satisfied. They also perceived that they were not given explanations about what to expect regarding treatments, procedures and care; were not able to eat or enjoy their food; and did not have enough energy to carry out self-care activities at home. These findings are generally not supported in the literature, where the older patient (over age 60) is frequently more satisfied with the care than younger patients (Fleming, 1981; Linn, 1975; Linn & Greenfield, 1982; Locker & Dunt, 1978). However, as Chang (1980) points out, the investigators often do not differentiate the elderly (over age 60) into age subgroups.

Gerontologists have shown that the elderly cannot be considered a homogeneous group. Important differences exist between "young-old age" (60-75) and "old-old age" (over 75). For example, there is more physical disability in the latter group; a higher incidence of widowhood and living alone; and a higher incidence of mental decline. It is possible that the greater incidence and severity of illness in the older old age group might make their perceptions of health care different from those of the younger old age group. Edwards and Klemmack (1973), however, found that when controls are introduced for factors such as decreased health, decreased financial resources, widowhood, loss of friends and decreased activity, which often accompany aging, the association between age and well-being disappears.

Chang et al. (1984) found higher levels of education were associated with lower levels of satisfaction. She suggests one possible explanation for this may be that subjects with higher education tend to be more critical of nurse-patient interaction then those with lower levels of education. This finding is supported by Linn (1975). Linn's study found that patients with less formal education (some high school or less) were significantly more likely to be highly satisfied on the Index of Satisfaction with physicians than patients with more education. However, Chang's findings are contrary to the findings of Korsch et al. (1968) in which no correlation was found between education and satisfaction.

Simpson's (1985) study of hospital patients' perceptions of nursing care found responses differed by sex, with male patients more satisfied with the care then female patients. Linn and Greenfield (1975) found no correlation between sex, marital status or religion and satisfaction with health providers. Sex has been found an important factor in self-care and self-asessments of health. Women tend to report a larger number of problems, take a greater variety of medications and suffer from more illnesses then do men with identical self-assessed health (Dean, 1981; Fillenbaum, 1979).

With regard to marital status, single patients and those separated, divorced or widowed, tend to be less satisfied with health care (Linn & Greenfield, 1982; Miller & Russell, 1980). When these same variables along with age, sex and intelligence, are examined in the life satisfaction literature, they are found to have no relationship with life satisfaction (Larson, 1978; Palmer & Luikart, 1972).

Research examining the various correlates of life satisfaction have usually included health, activity level, formal and informal group participation and education and income levels (Edwards & Klemmack, 1973). Of all the correlates studied, self-assessed health has been found to be one of the most significant predictors of life satisfaction (Edwards & Klemmack; Larson, 1978; Palmore & Luikart, 1972; Wolk & Telleen, 1976).

Others have attempted to differentiate between the perceived health status of the "young-old" and the "old-old" (Ferraro, 1980; Linn & Linn, 1980). Of particular interest is the finding of Ferraro's that although members of the "old-old" category (75+) report more health related problems than the "young-old" (60-74), they tend to be more positive in rating their own health.

A qualifying note to this extensive research on self-assessed health was a study done by Fillenbaum (1979) on social context and self-assessments of health among the elderly. The study consisted of randomly selected mentally capable older persons in the community (N=937) and in institutions (N=61). In the community there was a relationship between objective measures of health and subjectively assessed health. This type of consistent relationship was rarely found among the institutionalized residents. Fillenbaum suggests that perhaps objective measures used - number of health problems, medicines, illnesses - may not be appropriate where the institutionalized are concerned or may have a different meaning in institutions. It is also possible that the institution itself may impose certain constraints. Possibly in the institution, it is not the number of illnesses that are important, but, rather, the severity of any one of the illnesses or disabilities present. He further states that the number of medicines taken may not be a true indicator of health in the institutional environment.

When examining self-care and sociodemographic factors, age, sex and occupational differences were systematically related to self-care (Dean, 1981). In further analysis of family characteristics and self-care behavior, Dean found family characteristics of support, high levels of interaction and encouragement among family members important factors in health practice. More recent work (Segall, 1987) explored age differences in lay conceptions of health and self-care responses to illness. The researcher found the relationship between age and self-care responses to illness to be a rather complex one, and residents' age alone explained little of the variance in any of the dependent measures studied.

In general, there is a lack of consistent findings between psychological, social and demographic factors and their relationship to outcomes and self-care, especially when dealing with the elderly population. This may be due to the use of different definitions for outcomes and self-care. As well, the complex nature of layperson characteristics and their relationship to health beliefs and practices may lead to lack of consistency in findings.

3.6 THE INSTITUTIONAL ENVIRONMENT

Personal care homes or 'nursing homes' in Canada imply some form of supervised care for medical and medically-related problems. For the most part, the level of care is defined by the level of nursing effort required. The personal care home environment has the potential to exert a powerful influence on resident self-directed functioning. The problem of autonomy in long term settings is intensified by the fact that many nursing home residents vary enormously along a continuum of physical impairment and mental deterioration and tend to suffer from multiple chronic conditions.

Although several social-psychological variables are documented as important correlates of successful aging. What is less obvious is whether these variables consistently relate to satisfaction across the types of settings in which the elderly often reside. Larson (1978), in a review of research on the subjective well-being of older Americans over the past thirty years, identified a significant relationship between well-being and people's living situations, such as access to transportation and location of residence. Unfortunately, he cited no studies that relate resident well-being to factors in an institutional environment.

Vicente, Wiley and Carrington (1981) in a follow-up study of 521 persons over a nine year period, examined what happens to people after they enter a nursing home. The most common pattern that emerged, was a single stay terminated by death, or a transfer to an acute hospital where the person died. Their data further suggest that the number of days spent as a nursing home resident was significantly associated with certain characteristics prior to admission: lower incomes, single, divorced or widowed, and chronic health problems and disabilities.

Linn, Gurel and Linn (1977) in their longitudinal study of 1000 males in nursing homes found 30% of all deaths occurred within thirty days of placement. In contrast, Donaldson, Clark and Palmer (1983) argue that demographic characteristics are less important in analyzing survival rates than functional capacity. In their three year mortality study of 4490 people aged 65 and over, in all types of hospitals and homes within a defined geographical area they found that the rate of survival consistently fell with increasing incapacity in mobility, incontinence, washing/dressing and feeding. The effect was independent of differences in age, sex and duration of stay.

Kahana (1973) and Moos and Ingra (1980) found that within the institutional setting, social environmental factors such as the support from staff and cohesion among residents and staff, the amount of conflict among residents, and the extent to which residents are encouraged to exercise responsibility and self-direction are important to resident well-being. Unfortunately there is a paucity of nursing research to guide the care-level staff in assessing aged residents' perceived need for more involvement in their total activities, or their expectations of their role within the institutional environment (i.e. active participant versus inactive participant).

Golander (1987) used an anthropological fieldwork approach in examining residents over a two year period. She concluded that institutionalization by itself does not necessarily bring despair, low morale or depersonalization. Rather, she described the active role the disabled aged have in shaping their lives in the institutional environment. Her study did not deny the existence of hopelessness or passivity, but the emphasis of her study was on the dynamic and active behavior of the aged living in an institution.

3.6.1 Supportive Role of Nursing within the Institution

Miller (1985) seriously questions the assumption that patient dependency in an institutional setting arises primarily from the patient's medical or physical condition. She would argue that it is possible for a considerable proportion of the measured dependency of elderly patients in hospital wards to arise from outdated and inappropriate nursing practices.

Miller compared death and discharge rates for a 12 month period on wards using traditional and individualized nursing care. She was able to show an association between traditional nursing (task allocation) and increased mortality. Patients coming into the two types of wards were similar in dependency and there was no appreciable change in medical policy, admissions or staffing levels over this time period. It seemed that patients stay longer in traditional wards (mean stay 33 days longer) and their chances of dying were marginally greater, whilst their chances of being discharged were significantly less than those of patients in wards using individualized care.

Barton, Baltes and Orzech (1980) observational design study of dependence of nursing home residents revealed that residents exhibit a higher level of independent behavior than dependent behavior. Nursing home staff behavior, on the other hand, demonstrated the reverse relationship.

Staff showed four times as many dependent-supportive behaviors than independent-suppportive behaviors. Dependent-supportive behaviors refers to staff assistance in a resident's personal maintenance, praise for a resident's acceptance of assistance, or discouragement of a resident's attempts to execute personal maintenance tasks without help. Independent-supportive behaviors refers to staff verbal than independent-supportive behaviors (this concept refers to staff verbal encouragement or praise for a resident's execution of personal maintenance tasks without help. The authors inferences were that independent behavior in self-care is not maintained by staff behavior, but perhaps by intrinsic reinforcers; whereas, dependent behavior by residents is directly maintained by staff reinforcement.

3.7 OUTCOME STUDIES IN LONG TERM CARE

Abdellah (1977) stressed the importance of special research efforts in long term care to design quality assessment tools that will take into account the different patient outcome goals and complex treatment processes characteristic of much of long term care. The nature of long term care means deficiencies related to physical comfort and inability to maintain a satisfactory life style creates permanent, not temporary hardships (Kane, 1982).

Kurowski and Breed (Bergman & Golander, 1982, p.204) in their analysis of quality assurance programs in long term care, stated that comparisons of outcomes in long term care should take into account the initial characteristics of the residents and the expected outcome (i.e. prognosis) of the individual resident. Chambers, Caulfield, Magenheim, Mohide, Rudnick and Tugwell (1984) noted that the approach in long term care should focus on functional and social problems, and quality of life criteria rather then medical diagnosis. Kane et al. (1983) attempted to address this issue in a longitudinal study. They developed multi-dimensional measures of nursing home patients' functioning, by gathering information directly from the patients and observing demonstrated ability. Six domains were tapped: physiologic, activities of daily living, affective, cognitive, social and satisfaction. Their results demonstrated that, within the nursing home environment, it is possible to obtain valid data from nursing home residents.

Since this study is looking at three intermediate outcomes, identified in Chang's (1980) self-care framework, a review of the literature will be done under her components in the last dimension, evaluation of outcomes.

3.7.1 Competence and Knowledge

Very little is known about existing self-care behavioural practices (Dean, 1981). Although it is clear that laypersons do indeed routinely self-evaluate and self-treat many of their health problems as part of daily living, the nature and extent of these self-care practices are not well understood (Levin, Katz & Holst, 1976). For the most part, the self-care movement has emphasized the teaching of skills and has placed little emphasis on evaluating the competence of the individual (Chang, 1980). Many of the elderly have some form of chronic illness and over the years have become experienced at managing their condition. According to Leventhal (1984) this long term coping has provided the elderly with an opportunity to develop and assess alternative coping strategies.

Health professionals lack of understanding of the elderly person's maintainence of chronic care is coupled with lack of current methods used to facilitate individuals in gaining the necessary knowledge and skills. Lack of communication of information about illness and treatment appeared to be the most frequent sources of dissatisfaction (Korsch et al. 1968; Hulka et al. 1976; Locker & Dunt, 1978). Blackwell's (1976) review of treatment adherence feels that education addresses itself not only to knowledge, but also to motivation and self-management skills. According to the author the acquisition of new information by patients is facilitated by clarity, brevity and dialogue in the communication process, and is impaired by anxiety, social distance and technical terminology. Further, Blackwell identifies that the most important factor in information retention is involvement in the information exchange.

3.7.2 Satisfaction

Studies of patient satisfaction with health care have looked at general practitioner, hospital in-patient and out-patient services, nursing homes and the influence of a variety of personal and institutional characteristics on patient satisfaction.

The importance of patient expectations was illustrated in Locker and Dunt's (1978) review of consumer satisfaction with health care. In one study identified in their review, approximately 10% of the respondents reported needing more help to perform a variety of tasks than they were currently receiving from care providers, but only 2% reported dissatisfaction. The respondents rationalized this inconsistency by stating that although the service did not meet their needs, the physician was doing the best he/she could do. In these cases, expressed satisfaction said more about the patients' expectations than the service actually received. This is consistent with findings of Linn

(1975)and Chang et. al (1984), that individuals tend to have a mind-set toward health services either positively or negatively. The above studies support the link between Chang's first circle, individual characteristics and the third circle, evaluation of outcomes.

In hospital opinion surveys of patient satisfaction, nursing care is frequently measured in very general, global statements, for example, "How satisfied were you with the courtesy and consideration shown to you by the nurses at the hospital?" (Fleming, 1981). Doering (1983) and Walker and Restuccia (1984) have both identified patient satisfaction with nursing services as being most highly correlated with an overall satisfaction with hospital services and departments. Resident interviews done by Kahn, Hires, Woodson and Burkham-Armstrong (1977) in long term care facilities, indicated over-all resident satisfaction with their life situation. However, using more structured probes revealed 1/3 of residents were upset by behavior of other residents while 1/2 expressed the desire to leave the facility more often than they currently were doing.

3.7.3 Adherence

The literature on adherence generally focusses on individuals living in the community and with a particular focus on compliance to drug regimens (Blackwell, 1976).

Despite the inability to generalize the findings on adherence to the institutionalized elderly (for example, adherence to medications is not considered a problem as health professionals control this area), two issues can be identified.

The first issue identified by Blackwell is that it is possible to recognize "risk factors" which contribute to low adherence. They include immutable demographic variables (such as age, sex, race and socio-economic status). Others are amenable to improvement (such as drug regimen and clinic management) while others are more resistant to change (resident attitudes and physician behavior). Knowledge of these risk factors may aid health care workers in developing appropriate education strategies which aid in resisting professional dominance over resident adherence.

The second issue is the caregiver's view of adherence as a passive state, such as following the treatment regimen, rather then as an active state, such as involvement in the decisions about their treatment regimen. This was discovered in a study by Ryden (1985) of environmental support for autonomy in the institutionalized elderly. Data from 137 caregivers revealed that they see themselves as the predominant decision-makers. Although the caregivers stated they preferred a slightly higher level of self-determination for residents, they still wanted to retain a considerable share in the decision-making about daily activities.

A study on communication, compliance and concordance between physicians and patients by Hulka et al. (1976) questions health professionals' assumptions about noncompliance in patients taking prescribed medication. They concluded that good communication of instructions and information about the drugs from physician to patient is associated with low levels of all types of medication errors. Perhaps to some degree noncompliance is merely the lack of congruity between what the patient thinks he/she is supposed to do and what the physician thinks the patient is doing. The key points in their study are that neither characteristics of patients nor the severity of disease are influential in determining the extent of medication errors, but rather good communication of instruction and information are instrumental in high levels of compliance.

3.8 SUMMARY AND CONCLUSION

It is the general consensus in the literature that health and social demands of the institutionalized elderly are not being measured by the current medical/nursing approaches to quality of care assessment. Meaningful criteria that monitor important process-of-care dimensions are difficult to create and apply to the personal care home environment and may fail to capture the true priorities of the residents. Consequently one answer to these constraints may be to shift the focus of evaluation from the process of giving care to outcomes that care should achieve. Nurses, as the main caregivers are in a position to assist in the development of intermediate outcomes for use in evaluation.

Given the morbidity and mortality rates and the limited research on resident perceptions of care, current research perspectives need to be widened. At this point, the role of the personal care home resident in evaluation of nursing care has been a limited one. Current indicators of quality of care, such as standards and quality assurance packages are designed by providers and policy-makers. If personal care homes are truly the resident's 'home', then they should be allowed to define their own priorities and evaluate their care accordingly, rather than having those criteria selected only by professionals.

Chapter IV

DESIGN

4.1 INTRODUCTION

In view of the limited research examining the resident's perspectives of the quality of care within a personal care home environment this study was at the exploratory-descriptive level of inquiry. The purpose of the study was to identify some salient indicators in quality of care outcomes, using the resident as the primary source of information. The conceptual framework provided the infrastructure for the research design. The components previously identified in Chang's conceptual framework were explored in detail through the use of the interview guide.

4.1.1 Theoretical Definitions

Self-Care: Self-care is a well established behavior; a prominent element of our behavioral repertoire (Barofsky, 1978). The behaviors that can be labeled as self-care vary over a wide range, from the selection of appropriate clothing to the self-administration of insulin. Self-care may be viewed as involving both the continuous substrate of behavior (custom, life style) and discrete or episodic actions (self-diagnosis, self-treatment). Self-care is a measure of our socialization into the health care system, reflecting the adaptation of our self-care capacity to a specific therapeutic regimen. At the core of this socialization is a sense of losing personal control over oneself in order to become part of a system that is to restore health. Self-care proposes that individuals can retrieve some of the power they lost when they were socialized into the health care system by assuming more responsibility for their personal health. Chang defines self-care as a decision-making process whereby the individual functions on his/her behalf in health promotion and prevention, and in disease detection and treatment. The concept involves self-control and self-determination in choice and assessment of treatment options. The definition acknowledges that cultural input and social environment play major roles in the perception of self-care.

Outcomes: Outcomes refer to the result of care, a measurable aspect of health status which is influenced by a particular array of health care. For this study, consideration of outcomes includes competence, satisfaction and adherence; that is, cognitive, psychosocial and behavioral factors. Admittedly, such factors have a tenuous relationship to health status, and will be termed intermediate outcomes. Outcomes are multidimensional and resident competence, satisfaction and adherence are distinctly more difficult to measure than health status variables such as infection rates and mortality rates, but do offer nursing more information on quality of care within the personal care home.

4.1.2 Hypotheses

The following hypotheses have been formulated to guide the research.

1. Resident involvement in the decision-making process of their care will be related to their knowledge and competence in applying their expected outcomes of care.
2. Resident participation in their plan of care will be related to satisfaction with their care.
3. Resident involvement in the development of their care plan, with support from nursing, will be related to adherence to the plan of care.

The dependent variable was the outcomes of care defined as self-reported competence, satisfaction and adherence. The independent variable was the process of self-care, defined as resident decision-making and participation in plan of care, with a supportive role from nursing.

4.2 OPERATIONAL DEFINITIONS

Self-care: Self-care was operationalized by asking the resident to relate perceptions of involvement in care, and perceptions of care received in specific areas. In the Interview Guide (Refer to Appendix B), these include 5 questions in the section on grooming, questions 1, 2, and 4 in the section on ambulation, question 5 in the section on diet, question 5,6, and 8 in the section on medication, question 1, 2, and 3 in the activities section and question 10 in the satisfaction with care section. An example of a question addressing self-care is: "If you wished to go out more, how would you do this?"

The majority of the operational questions are concerned about decision control of activities of daily living and were adapted from the Perceived Situational Control of Daily Activities tool (Chang, 1978). An example of this type of question is: "Who determines when you do your personal grooming?. Theoretically these questions relate to Orem's universal health care demands.

The evaluation of outcomes was operationalized by:

Resident competence: This component of evaluation included self-reports of knowledge and skills obtained by residents regarding their treatments, medication and plan of care. These include questions 3 and 5 from the section on ambulation; question 1 and 3 from the section on diet;

questions 1 to 4, plus question 7 and 9 from the medication section (Refer to Appendix B). An example of a question addressing resident competence and knowledge is: "Could you tell me something about your prescribed medication?"

<u>Resident satisfaction</u>: The second component was the evaluation of resident satisfaction with care received. Resident satisfaction refers to the extent to which residents experience an inner state of "feeling good" about their care. Question 12, 15, and 16 are global questions while questions 7,8, 9, 11, and 14 are specific (Refer to Appendix B). An example of a question addressing resident satisfaction with their health status is: "Compared to others your age, would you say your health is poor, fair, good, very good? Studies employing self-assessment of health, typically ask this question and the answers have been highly correlated with the elderly person's overall incapacity score (Edwards & Klemmack, 1973; Larson, 1978). The remaining global and specific questions on satisfaction were based on the prior research of Chang et al. (1984), in their examination of satisfaction with nursing care in elderly ambulatory women. An example of a question addressing satisfaction with care is: If you require assistance from a nurse, does help come within a reasonable time?"

Resident adherence: This third component of evaluation includes behaviors of residents who enter into a plan of care, implement the plan of care and follow or terminate their plan of care. Self-reports from the resident were incorporated into the interview questionnaire and used to evaluate adherence. These include questions 6 and 7 in the section ambulation, 6 in the activities section and question 13 in the satisfaction with care section. An example of a question addressing resident adherence is: "During the course of an average day, who determines most of your routine activities?"

4.3 RESEARCH SETTING AND SELECTION OF SUBJECTS

The study site was a religious non-profit personal care home located in a large urban center. Originally the home had 100 residents, but in April 1987 more residents were gradually admitted due to the new building addition completed in February 1987. During this transition, new staff were also employed. New admissions occurring during the research time period were not included in the study.

According to the director of the home, 80 of the 100 residents were cognitively well. From this population of 80, approximately 1/3 spoke only German, 1/3 spoke only English and 1/3 spoke English and German.

In an attempt to increase sample size, a German speaking translator was hired, through assistance from the Centre on Aging, University of Manitoba. A sample of 30 residents was selected. The rationale for this number was that it allowed for representation of the three language groups: 10 English speaking, 10 German speaking and 10 that spoke English and German. Also, a sample size of 30 provides a wider base for the identification of common themes regarding participation in care.

Due to the nature of the research the investigator interviewed only the most cognitively competent personal care home residents residing in one personal care home in an urban center. Criteria for resident selection were:

1. 60 years of age or over
2. cognitively competent - orientated to person, place and time (it is recognized that residents differ in their degree of physical disability, the nature of participation in their daily activities and the range of the decisions they can make. Being cognitively intact was required for the potential for involvement in decision-making).
3. have sufficient energy to participate in the interview
4. able to understand English or German

Initially, random selection of 30 residents from a list of approximately 80 cognitively well residents was anticipated. Selection of residents was required to be done by the charge nurses. This generated a list of only 33 residents within the personal care home population that the nurses judged were cognitively well enough to participate in the study. Therefore the investigator was unable to randomly select potential participants for the study. The selection of the residents by the charge nurse introduces the possibility of sample selection bias. The staff's perceptions about the capability of residents to make decisions about their daily activities and care may have influenced their selection process. Although competency was defined as orientated to person, place and time, selection by the charge nurses may have elicited only the most cooperative or most favorable residents.

All 33 residents were approached by the nursing staff to participate in the study. Two residents refused due to illness and one was deemed by her husband unable to understand the questions appropriately. The charge nurse approached potential participants, requesting their involvement in the study and permission for the investigator to have access to their health records. Due to the selection process, the sample cannot be said to be representative of the larger population of residents living in personal care homes.

The investigator explained the consent form to the 30 volunteer participants and had them sign it (Consult Appendix C). For those who spoke German, the consent form was written in German and the translator was available to explain and sign the consent form (Consult Appendix D). A copy of the consent form was placed on each volunteer resident's chart.

4.4 ETHICAL CONSIDERATIONS

The protection of individual rights was addressed through the provision of consent forms, the charge nurses at the home not the investigator approaching possible research subjects and a signed consent form outlining:

1. the purpose of the study;
2. the voluntary nature of the study;
3. assurance of confidentiality;
4. the ability to withdraw from the study at any time;
5. the availability of the results to participants upon request.

Consent forms were written in German and English and were signed one week prior to the interview.

All collected data were held in strict confidence and were prudently secured in a locked filing cabinet. Tapes were destroyed after transcription and information that could have identified subjects was coded, with access to this coded information limited to the principal investigator. Individual residents are not identifiable in published materials. The personal care home receives a copy of the thesis but collected raw data was not made available to the institution.

Three residents agreed verbally to participate in the study, but refused to sign the consent form until after the interview. In these cases, the interviews themselves provoked little or no stress - it was the signing of the consent form that caused the problem. One woman stated that in Russia in the 1920s, she once signed an official form, after which they took her husband away and she never saw him again. According to her, ever since then she has been wary of signing her name to forms. The problem of some respondents perceiving the act of signing a consent form as more undesirable than being interviewed was also reported by Strain and Chappell (1982). Only one resident refused to be taped and field notes were taken. This permitted as accurate as possible a recall of the information obtained.

Where a translator was necessary for interviewing (N=15), the translator, not the resident, was recorded directly. When the resident understood both English and German the interviews were done in the language of their preference. Remuneration was offered to the translator for professional services and she was asked to consider the interview confidential. The translator was selected from a list of interviewers generated by the Centre on Aging. She has had previous interviewing experience, and her cultural background is German Mennonite. She was fluent in both high and low German and had a warm, caring, patient manner toward the residents she interviewed.

4.5 DATA COLLECTION TECHNIQUE

The design was exploratory-descriptive. The information collected was cross-sectional and causal links are unwarranted. Prior to data collection, approval was received from the following agencies:

1. The Ethical Review Committee of the University of Manitoba
2. The Centre on Aging, University of Manitoba

The data collection instruments included:

1. An audit form for the chart, developed by the researcher (refer to Appendix A)
2. An open-ended, semi-structured, interview developed by the researcher (refer to Appendix B)

Data gathering at the personal care home was completed within six weeks.

4.5.1 Chart Review

Information related to demographic factors was obtained from the charts and kardexes by the investigator. Any information missing on the charts was then requested from the resident directly. The examination of charts was for contextual data needed for interpretation, explanation and avoidance of fatigue of the residents. The other reason for the chart review, was to examine if nurses were aware of residents' perceptions about their care, and had written the expected outcomes, developed in collaboration with the resident, on the individual's care plan. The literature (Elbeik, 1986; Simpson, 1985) suggests that nurses and residents have different perceptions of care; therefore, similarities and differences are important to identify, as they affect the collaborative relationship in self-care.

4.5.2 Interviews

The personal interview strategy was crucial to the study, as individual perceptions were the focus of the study. The purpose of the interview was to explore the institutionalized resident's self-report of participation and competence in care, knowledge and information about care, satisfaction with the care and adherence to the care plan. The interview also permitted the resident to share their perceptions of nursing care and self-care.

The face-to-face semi-structured interview is appropriate when the interviewer has a general plan of inquiry, but not a specific set of questions that must be asked in particular words or in a particular order (Babbie, 1983). Strain and Chappell (1982) suggest that the face-to-face interview format is more congruent with the sensory and cognitive capabilities of older people then a mailed questionnaire or a telephone interview. The open-ended questions allow subjects to respond in their own words. This method permitted an opportunity to obtain information that was not pre-conceived by the researcher and generated rich data.

Examination of competence, satisfaction and adherence was done in five broad areas: ambulation, diet, grooming, medication and activities. A sixth area, satisfaction with care was included as perceptions of care are known to be important in the study of quality of care. To isolate resident self-reported levels of quality of care in a group that has marked mental and physical impairment and which has experienced many losses, may be particularly insightful to health care providers on what outcomes are valued.

Only one resident complained of fatigue and requested the interview in two parts. The interviews were completed in 30-60 minutes. Generally, the residents wished to continue the conversation long after the interview and many expressed pleasure that someone was asking them for information. All residents attempted to answer each question carefully.

4.5.2.1 Reliability and Validity

In this study, reliability and validity are concerned with the thoroughness and range of data obtained and the credibility of the theoretical framework. The issue of reliability in this study is also concerned with reliability of the sources of data, recording the data, and the use of a translator. The sources of data included only the most competent residents, and therefore does not allow for generalizing to a larger population. However, the researcher attempted to address the other concerns in a number of ways.

In terms of the reliability of the recording the data, interviews were tape-recorded which provided a reliable method of retrieving the information. Only one person, the researcher was involved in the chart review and fifteen of the interviews. This led to a relatively consistent approach in examining the charts and interviewing the residents. Where a translator was required, the researcher was available during the interviewing process to answer any areas of concern. There is no way of eliminating the problems posed by language differences between informant and investigator, but it is possible to decrease this source of contamination by making sure the translator is competent in the language of the informants and is of the same cultural background as the respondents (Brislin, 1975).

The researcher observed that respondents did try to make data more accessible to the interviewer in some cases. Participants would explain their reasoning behind a decision or their response to a decision. Therefore, the therapeutic value of the interview was observed, but the degree to which this affected the reliability of the data is unknown.

Internal validity of the interview process was addressed by obtaining face validity of the interview schedule from three nursing experts. This was done by asking nurse researchers if the interview schedule would, in their opinion, access the concepts of Chang's model that the investigator wished to study. The interview schedule was developed after a review of the literature. A pretest of the interview schedule in both English and German in the personal care home allowed the interviewer to identify whether or not respondents were able to articulate the information sought.

External validity refers to the extent to which the method of data collection provides data compatible with other relevant evidence. The findings of this study supported other related research findings in the literature. External validity is considered in the discussion of the theoretical framework. Certain components of Chang's framework were compatible with the data collected. However, other findings of the study were not described or supported in the theoretical framework.

The integrated theoretical framework and the density of data obtained support the validity of the study. The final validity test will be the extent to which the modified theoretical framework is a useful guide for clinicians and researchers in the substantive area of self-care for the institutionalized elderly.

4.6 LIMITATIONS OF THE STUDY

There are limitations inherent in the nature of the research design and methodology. The limitations identified are as follows:

4.6.1 One Setting

A study in one personal care home, which viewed as a case study, could lead to much learning and insight. To sample in two settings where the sizes are too small for comparison (N=15), would run the risk that findings could be misinterpreted and comparisons between the places may be used unjustifiably and to the detriment of one of the homes. Also, the research design does not allow for generalizability to some larger population.

4.6.2 Resident Selection

The selection criteria immediately excluded many of the personal care home residents. This cognitively-well sample must be viewed with caution as it limits generalizations to other personal care home residents. Also, selection of the 30 non-random residents by the charge nurses, may have been biased toward residents the nurses felt were the 'best' to interview. The investigator had to accept the nurse's judgment that only 33 residents of the total personal care home residents were cognitively well. However, the sample size was sufficient to generate rich data. The intent was not to correlate or compare groups, but to assess the range and depth of data within the various categories.

4.6.3 Language Barrier

There is always a potential for misunderstanding when communication is not direct between investigator and the research subject. It is hoped that the research questions were transferred accurately in German and back again into English. Because of the investigator's language deficit, it was necessary to employ a translator. As previously mentioned, the translator had prior interviewing experience with the elderly, as well as having a common religious and cultural background with many of the residents she interviewed.

4.6.4 Research Design

The research design suffers from the possibility that some factor other than the independent variable (process of self-care) might cause differences in the dependent variable (outcomes). Since no data were available prior to institutionalization, how does one know if, for example, those residents more involved in self-care were more knowledgeable prior to admission, than those residents showing less involvement in care?

4.7 DATA ANALYSIS TECHNIQUE

The research purpose of the study was to identify some salient indicators of quality of care outcomes, as perceived by the residents. Content analysis is one data technique for this exploratory-descriptive study. The study describes the current situation and the data cannot identify what causes a change or variation in any of the factors examined.

The interviews were transcribed and reviewed in detail to identify phrases, examples and descriptions that reflected themes. Categories were constructed based on the indicators identified in the self-care framework and theoretical definitions. The indicators were self-reported levels of knowledge and competence, satisfaction with care and adherence to the care plan. The individual residents are the units of analysis, about whom descriptive statements were made. A frequency count of responses occurring in each category was done and represented in percentage distribution.

Descriptive statistics were used on the demographic information. Non-parametric measures were undertaken that are appropriate for exploratory-descriptive designs. The level of measurement was nominal and ordinal. Two tests of association employed were Kendall's tau and Cramer's V. These tests can be used as descriptors of the two sample subgroups. The tests were also used to make comparisons within the sample. The SPSSX computer program will be used for these cross tabulations.

Chapter V

THE FINDINGS - CHART REVIEW

5.1 INTRODUCTION

The patient record consists of both the chart, the permanent record of care received, and the kardex where daily changes in the care plan are recorded. Validity of quality of care assessment through examination of patient records has been questioned because the assessment of care is limited to information written in the record. In commenting on physician record keeping, Donabedian (1968, p.184) has stated: "There is some evidence that good care and good recording are related". In nursing, the completion of the record is also a factor to consider as recording of care by nurses is influenced by the type of record used and the amount of time available for charting.

The data collected from the records and presented in this section of the study have a two-fold purpose. The first purpose was to gain demographic and personal information about the subjects. The second purpose of the chart examination was to examine indirectly if nurses are aware of residents' perceptions about their care and had written the expected outcomes, developed in collaboration with the resident on the individual care plan.

5.2 CHARACTERISTICS OF THE SAMPLE

Demographic characteristics of the sample are presented in the following tables.

Table 5.1

Demographic Characteristics

Average Age	Sex	Language	Marital Status	Religion	Education
M=79	M=7	German=15	W=19 S=5	Menn.=18	0-7gr=23
F=87	F=23	English=15	M=5 D=1	Other=12	8-12gr=5
					Degree=2

The next table outlines some background information on residents.

Table 5.2

Residency and Living Arrangements

Residence prior to placement		Living arrangements		Length of residency	
Own home/apart	15	Alone	13	1-5yrs	17
Child's home	4	Spouse	8	6-10yrs	7
Hospital	5	Relatives	3	11-15 yrs	2
Other	6	Children	4	16-over	4
		Institution	2		

The mean age of the respondents was 85 years, with a median value of 87. When examined as a subpopulation by age and sex, the mean age for males was 79 and for females was 87. The age range was from 63 to 99 years of age. Twenty-three residents (76.6%) were females and seven residents (23.3%) were males. Nineteen of the residents were widowed (63.3%), five were married (16.7%) or single (16.7%), and one resident was divorced (3.3%).

Being a Mennonite personal care home, not surprisingly 60% (N=18) of the respondents had a Mennonite background. Six participants (20%) were United; four (13.4%) were Roman Catholic; one was Baptist (3.3%); and one was Lutheran (3.3%). Fifteen (50%) of the residents main language was English and fifteen residents (50%) main language was German. However, 1/3 (N=10) could converse well in either German or English. The average length of residency in the personal care home was six years with a median value of five. The length of residency ranged from one to eighteen years.

The majority of the participants (N=17, 56.6%) have resided in the personal care home from one to five years. Seven residents (23.3%) have lived in the home from six to ten years and two residents (6.7%) have lived within the home from eleven to fifteen years. Four (13.3%) of the participants have been there for sixteen years or more. Age was inversely related to length of residency. The mean age of residents who had resided in the personal care home the shortest time (1:5 years) was 89. The mean age of residents who had resided within the home for the longest period of time (16:over years) was 71.

As a group, this population had little formal education. Three residents (10%) had no formal schooling at all. One was born in Canada and had a physical handicap. His parents lived on a farm and he was kept at home, as no transportation to school was available. He revealed a lonely childhood, where learning to read and write was dependent on his siblings teaching him after school. The other two residents had to flee from Russia during the revolution and once in Canada, never went to school. They stated that when their children went to school, they studied the childrens' books to learn to read and write.

Twenty residents (66.6%) had less than grade eight education. Six of these residents had schooling in Russia, which was interrupted due to the Russian revolution. Two residents (6.6%) had some high school, giving a total of 83.2% (N=25) having less then a high school diploma. These findings are similar to Statistics Canada (1981) where over half of the elderly reported less than nine years of schooling. This rises to 61% in the age group 85 years and over. Three residents (10%) completed high school. Two women (6.6%) had a B.A. degree. Twenty-four (80%) resident records (i.e. either charts or kardex) failed to identify the residents education and this information was solicited during the interview.

Further demographic data prior to admission to the personal care home were briefly explored. Information was sought on how many owned their own homes or lived in an apartment prior to admission. Fifty percent (N=15) had lived independently, while 13.3% (N=4) lived with their children, and 16.7% (N=5) had been in hospital for a lengthy period of time, waiting for placement in a personal care home. Six residents (20%) were in the other category in terms of living arrangements. One had lived in a guest home; three lived with parents or relatives; and two lived in a mental institution prior to admission to the personal care home (See Appendix E). Thirteen of the individuals (43.3%) lived alone prior to coming to the personal care home, eight (26.6%) lived with a spouse and four residents (3.3%) lived with their children (See Appendix F). Further analysis of the data revealed that those participants residing with their children tended to be the eldest age group (mean=90), while those living with relatives or in an institution or guest home tended to be the youngest age group (mean=80). This finding suggests the importance of family support systems in keeping the elderly in the community.

In examining the resident records, limited information was available on residents' past lives. In fact, six charts (20%) did not identify the reasons for admission to the personal care home. Background data were generally available on the community case coordinator's assessment prior to admission to the personal care home. Seven charts (23.3%) did not state the individual's previous residency before admission and 30% (N=10) did not identify whom the resident lived with prior to admission to the personal care home. Due to this lack of information it was difficult to ascertain if admissions were due to social reasons (e.g. spouse had died and individual unable to cope on own) or for health related reasons (e.g. diabetic and blind). Individual staff often appeared to have this information and were able to communicate verbally to the investigator about resident backgrounds, but such information was lacking in the written documentation.

All residents stated that they received visitors. Possible reasons for this social support may reflect the cultural background of strong family and community involvement found in the Mennonite community. The number of visitors received varied from only an occasional visit, to others who received almost daily visits from family and friends. The majority of visitors tended to be family (66.6%). Often residents stated that their visitors were family because many of their friends had died, or it was difficult for their friends to get out due to their own infirmities or due to poor weather.

The resident records frequently stated "receives visitors", but rarely were visitors defined as family, friends or other. Six charts (20%) made no mention of visitors and thirteen charts (43.3%) did not identify how often residents received visitors. The remaining charts stated visitation in terms of "receives visitors frequently", "seldom" or"occasionally".

The data set was checked for overrepresentation of specific demographic characteristics of the sample by comparing the sample with all residents residing within the home. Further, demographic information was compared to the elderly at large in Canda (those 65 years and older).

Table 5.3

Comparison of the Sample to the Population in the Institution

	Sample Demographics	Demographics of Personal Care Home
Average Age	M 79 F 87	M 80 F 81
Sex	M 23% (7) F 77% (23)	M 32% (43) F 68% (91)
Language	G 50% (15) E 50% (15)	G 52% (70) E 48% (64)
Marital Status	W 63% (19) M 17% (5) S 17% (5) D 3% (1)	W 67% (90) M 18% (24) S 13% (18) D 2% (2)
Religion	Menn. 60% (18) Other 40% (12)	Menn. 57% (76) Other 43% (58)
Length of Residency	less 1yr 0 1-5yrs 57% (17) 6-10yrs 23% (7) 11-15yrs 7% (2) 16-over 13% (4)	less 1yr 44% (59) 1-5yrs 34% (46) 6-10yrs 10% (13) 11-15yrs 4% (6) 16-over 8% (10)
Total	30	134

* percentages have been rounded off

There were almost no differences in the ages of males between the two groups. The sample had a slightly higher average age for females. While females comprised 76% (N=23) of the sample, 68% (N=91) of the resident population was female. These sex ratios are further suppported in that for the over 85 group, there are two women for every man in

Canada (Statistics Canada, 1981). Language was very similar in comparison with 52% (N=70) German speaking and 48% (N=64) English speaking in the personal care home population. Comparison of marital status was also similar with widowed being the largest group. Sixty-seven percent (N=90) of all residents were widowed, while in the study 63% (N=19) were widowed. When examining the elderly in Canada, both sexes are approximately 10% single and 1% divorced. Interesting differences occur in that 69% of all elderly men are married compare to only 26% of women. As well, 63% of women are widowed compared to 21% of men (Statistics Canada, 1981). The study demographics are similar, in that the majority of residents are widowed.

The primary religious group of the home (57%, N=76) and the sample (60%, N=18) was Mennonite. Since residents who had been in the home for less than one year were not included in the sample, the sample percentages were higher in the other groupings (one year and more) than those of the personal care home population.

Cramer's V and Kendall's tau revealed little association between education and language. Half the sample being German speaking and Mennonite is not representative of personal care homes at large, but does express the accurate representation of the religious and ethnic resident population of this particular personal care home studied

(See Appendix G). One crosstabulation between length of residency and language, did exhibit an overrepresentation of English speaking residents at the 16:over years level (See Appendix H). Given the small sample size (N=4), this finding must be viewed with caution. Another overrepresentation was identified in the cross tabulation of marriage status and length of residency. Divorced and single residents (N=7) tended to have been in the institution for longer periods of time then widowed members (See Appendix I). This finding suggests that single or divorced elderly have fewer supports to keep them in the community when compared to those who are widowed.

In summary, analysis of specific demographic characteristics of the sample revealed a normal representation of the institutional elderly. Where overrepresentation did occur, such as between German speaking and Mennonite, this was viewed as a natural occurrence within a religious non-profit personal care home. This cultural overrepresentation may have had some affect on the resident responses to the interview.

Similar to the elderly in general the participants in this study tended to have little formal education and half the sample lived independently prior to admission. The majority of participants received visitors, which tended to be family members.

The demographic analysis must be viewed with caution due to the small sample size, as cross-sectional data do not reveal trends. The data suggest that family supports may be important in keeping the elderly in the community and that longer stay residents appear to be admitted for different reasons then shorter stay residents.

5.3 NURSES CHARTING

As well as examining resident records for demographic and personal information, the investigator briefly explored the extent to which nursing notes reflect the self-reported factors identified by the residents.

Nursing documentation on specific demographics, such as resident backgrounds and reasons for admission was sparse and inconsistent. The majority of this information was obtained from the resident interviews.

Nurses charting at the personal care home basically appears in five areas on the resident records. The nursing history sheet and bimonthly charting on the progress notes are part of the resident's permanent record, while the kardex, expected outcomes sheet, and nursing care plan are temporary records that are updated and reviewed as required.

5.3.1 Permanent Records

Nineteen (63.3%) of the thirty permanent records examined contained no information on resident perceptions of institutionalization nor their perceptions of the care provided in the personal care home. Where some note of resident perceptions was identified, five (16.6%) were not written by the personal care home nursing staff. Two of these charts (6.6%) contained information on family and resident perceptions of personal care home placement prior to admission to the home. Valuable information on resident perceptions was found in three charts (10%) within the chaplain's observations stated on the case conference sheet. Unfortunately some of this information dated from 1984, with no further update. Only six charts (20%) acknowledged some nursing awareness of resident perceptions. For example, one chart stated the resident understood why her family could not take her into their home and placement was the only alternative.

Generally, the nurses charting reflected their perceptions of the resident. Frequently found were statements such as:
"she likes to visit with the staff"
"appears depressed"
"appears confused"

How these assessments were derived was unclear and plans to deal with these perceptions were not charted.

The primary source of permanent nursing documentation on resident health status is the bimonthly charting on the progress notes. The information gathered follows specific guidelines of ambulation, activities of daily living (ADLs), eating, elimination, physical status, family visiting, mental status, sleeping patterns, activities and response to treatment. All charts examined contained up-to-date bimonthly charting.

Within the bimonthly charting resident outcomes were rarely charted, or were too vague to offer insight into need, resident expectations or resident involvement in their plan of care. Examples tended to be "maintain at present level" or "encourage to be more independent". One excellent example should be noted: "Tries very hard to be independent in all ADLs, but requires more care lately as she becomes more disabled with her arthritis". This example displays nursing's awareness of the resident's change in status and the resident's perceptions or desires for involvement in her care. Unfortunately other examples displayed, in charting at least, nurses' failure to offer a supportive role in care of residents. One chart stated that the resident's spouse had recently died and the nurses should watch for depression. This concern was never addressed again in the next six months of nurses charting.

Stating of time frames for achieving outcomes are considered an important factor in evaluating outcomes. Within the bimonthy charting, terms such as "ongoing", "when necessary" (prn), and "frequently", were generally the only acknowledgment of time frames. Emotional or psychosocial problems were rarely acknowledged other than statements such as depressed, paranoid, or confused due to the aging process. Resident perceptions and expectations were seldom documented.

The second source of permanent nurses charting is the nursing history, which is a pre-printed form. The history sheet contains short blank spaces beside headings such as diagnosis, allergies, medication, x-rays, activities of daily living, diet and elimination. The main focus of the form is medical and functional assessment. Generally, much of the information is repeated on the medical history sheet and the bimonthly charting. Sixty percent (N=18) of the nursing histories were completed or partially completed. The purpose of the nursing history is not clear on examination, unless it is used as baseline data on admission. The frequent omission of a date as to when the information was obtained makes it difficult to identify the value of this form in assessment, implementation or evaluation of resident outcomes.

In summary, examination of the permanent resident records indicated that whether or not individuals were involved directly in planning their care related to health problems identified by the individual, such involvement was not usually recorded. There was no identification of priority setting of health problems, and there was no indication of residents receiving information or education about their illnesses or aspects of the aging process, despite virtually all residents having chronic illnesses requiring various levels of self-care. The bimonthly charting was the main source of nursing information about the resident. The nursing history frequently lacked a date or full information. Also, the purpose of this documentation was not clear. Generally within the permanent nursing records, residents were subjectively evaluated by the staff and based on their manageability, with a relative absence of references to their past life.

5.3.2 Temporary Records

Temporary records are written in pencil and reviewed and updated as required in the plan of care. The first temporary record that was examined was the kardex from which the demographics were obtained.

The second source of temporary records was the nursing care plan. Similar to the nursing history, the nursing care plan is a pre-printed form, which contains small boxes under the headings: allergies, hygiene, elimination, diet, ambulation, sleep, orientation, activities, restraint, communication, prosthesis, hearing, sight, special orders and nurse alerts. In theory, the nursing care plan is a guide and referral for all nursing staff to assure individuality of care and continuity of care in collaboration with the resident. At the personal care home the nursing care plan is generally posted above the bed of each resident. Nursing care plans were current but often contained limited information.

The third form of temporary record keeping is another pre-printed form on expected outcomes. At the top of the sheet are listed date, problem, expected outcome, review date, nursing orders and time. The nurses are to fill out the information under each heading. Such a record is in keeping with the Manitoba Association of Registered Nurses (1980) generic standards for nursing care. Development of the form is to be applauded, but unfortunately the sheet was rarely filled out to reflect:

1. resident expected outcomes
2. resident involvement in the plan of care
3. resident achievement of outcomes

The quality of the information on the expected outcomes form varied and evaluation of expected outcomes was virtually non-existent. It was not possible to identify if residents were the primary decision-makers or if they even had input into their nursing care plan.

5.3.3 Summary and Conclusion

Orem's (1985) theory of nursing is that nursing offers a service to people who are not able to provide continuous self-care for themselves because of a health related limitation. In order to manage or maintain self-care for patients, nurses prescribe, design and provide for patients. This brief examination of the resident records did not reveal a consistent pattern or design in the care of residents to enhance self-care development. Genuine attempts were made to focus on expected outcomes as witnessed on the expected outcome form and the bimonthly charting. However, the nurses' charting remained inconsistent and generally lacked evaluation of achieving resident outcomes.

It was noted that resident involvement in their care was rarely documented despite the chronic illnesses of virtually all residents. The issues of adherence to the plan of care and satisfaction with care were not addressed in the charting. There was no mention of residents receiving information about their treatments, medications or plan of care. The investigator realizes it would be unrealistic to expect the cognitively impaired to participate wholly in the decision-making process of their care. However, for purposes of this study only the cognitively well resident records were examined and it would be reasonable to expect their input or self-direction of their care.

Institutionalization is recognized as a major life event yet nurses charting failed to identify the possible effects on resident and families of permanent placement in a personal care home in 80% (N=24) of the charts examined. The fact that residents had a past existence before institutionalization was rarely acknowledged.

There were attempts within the nurses charting, to identify goals for the resident and what action was required to achieve the goals. However, a goal such as "keep at present level" is so vague that it offers little insight into the needs, perceptions, expectations and abilities of the resident.

The above findings are consistent with the study on nursing care done by Scherer, Farrell and Sinha (1985) where they urge the examination of quality of care not be limited to written documentation only. The mentioned shortcomings in the brief exploratory findings may exist in documentation only and may be an expression of nurses' busy schedules that does not allow for quality in charting to be a priority.

Chapter VI

THE FINDINGS - RESIDENT INTERVIEW

6.1 INTRODUCTION

The entire cognitively well population at the personal care home, with the exception of three residents was interviewed (N=30). An open-ended interview was used to examine resident perceptions in the six broad areas of: (1) grooming, (2) ambulation, (3) diet, (4) medication, (5) activities, and (6) satisfaction with care. The open-ended questions allowed the subjects to state their expected outcomes in each of the areas tapped, in their own words. These data were analyzed for the three dimensions identified in Chang's conceptual framework: (1) individual characteristics, (2) the institution facilitating self-care, and (3) evaluation of outcomes of self-care.

Examination of individual characteristics was discussed in the previous chapter. This chapter will focus mainly on the latter two dimensions of the self-care framework, realizing that individual characteristics do have an affect on perceptions in these dimensions of the framework.

6.2 LONG TERM INSTITUTIONS FACILITATING SELF-CARE

Long term care institutions facilitating self-care is the second dimension of Chang's framework. The findings will be examined in relation to the four components within the second dimension. Self-care was seen as a decision-making process whereby the resident had power over choices related to care. Within the institutional environment the independent variable was the process of self-care, defined as resident decision-making and participation in plan of care, with the supportive role of nursing. The determination of who was involved in the decisions was associated with the personal care home environment, health status of the resident and availability of psychosocial support systems for the resident. Hence, decision-making control depended on the level of dependency of the resident. More dependent residents required the more supportive role of nursing.

6.2.1 Resident Participation in Decision-Making

Resident decision-making began with the decision to enter the personal care home. Reasons for admission varied and were frequently a combination of health and social factors. The most frequently identified pattern prior to admission (N=19, 63.3%) was an individual living on his own, who experienced some health crisis, such as a stroke or fractured hip, that occurred required hospitalization. During hospitalization a decision was made to enter a personal care home. A common example was: "I lived with my husband until he died and after I had a stroke, so I was unable to live on my own any longer." Only one resident was a long standing psychiatric patient admitted directly from a mental institution. Three respondents (10%) could not remember the reason for admission.

Forty-seven percent (N=14) of decisions about placement involved the resident's children. For example one resident described her passive role in decision-making: "My children felt I was unable to look after things on my own, so I agreed to move in when a bed became available."

Decision-making about admission into a personal care home between husband and wife occurred in 20% (N=6) of the cases.

> We were no longer able to look after our household anymore. We were familiar with this particular home and decided together we would like to move here as we can no longer look after ourselves.

Despite this cooperative decision-making on self-care, rarely did spouses enter the personal care home together. Generally the more frail member was admitted first and it could be several months before the partner would be placed.

Seven residents (23.3%) made the decision to enter the personal care home independently. As one woman, who became physically unable to live on her own stated: "I had no place else to go. My husband had died. Meanwhile I sold my home. I couldn't take care of myself." One resident followed the advice of her pastor about going into a personal care home, while one resident could not remember who made the decision to enter the personal care home.

Within the institutional environment the residents had more control over decisions in the areas of activities and ambulation, than in the areas of grooming, medication and diet. The theme related to resident self-care was: the healthier and more independent the resident, the more authority the resident had over decisions. The more dependent the resident was on nursing care for achieving outcomes, the less authority and control the resident had over decisions. Some residents were very perceptive of who had more control over certain decisions.

> Mealtimes, when to get up and so on, these are determined by the home, the administrator here. Often things such as when I go for a walk or whether I want to participate in planned activities are my decisions.

In all cases the more independent residents saw themselves as active and exhibited much more control over routine activities. Due to their health status they had power and authority over their decisions which were not generally options for the more disabled.

> Mealtimes are on a regular routine. Anything else, such as when I go to bed or get up or grooming or going outside, I determine all that. I take care of myself entirely except I don't make my own bed anymore because of muscle tightness in my shoulders.

Three residents (10%) described their health as poor. One resident who was unable to walk reflects a much more dependent state, and with it loss of control over the decision-making process.

> Resident - I can't decide my routine activities. They come and get me.
>
> I - Would you rather decide for yourself when you would like your hair combed?
>
> Resident - It doesn't really matter.

Residents exhibited the primary decision-maker role in the areas of ambulation and activities. For the disabled residents, these decisions required careful appraisal to evaluate choices and to regulate resources to achieve effective outcomes.

> I go to group exercises almost everyday. I feel this is necessary to prevent stiffening of the muscles. I find this is a good thing. Whenever I do not feel strong enough or well enough to go for exercises, I simply do not go. This is optional.

One factor frequently mentioned that affected options under activities for almost all residents was the weather. Few wished to venture out in the winter and a common comment was: "I have been out very few times this winter, as it is too cold."

Grooming was one area that identified the differences in decision-making for the healthy versus the nonhealthy. Other then bathing which was on a fixed schedule, the independent residents made autonomous decisions about their care. The more dependent ones had to rely on the availability of staff to complete their grooming. The majority of residents (N=21, 70%) accepted the notion that they were the ones who needed to adapt to the schedule rather than attempt to make changes.

> I need assistance in grooming and bathing and combing because I cannot lift my arms up that high. Also need help with dressing. This is done on a regular basis by the nursing staff. They determine when it is done and basically it's convenient with me.

Many residents (N=18, 60%) expressed a desire for more control and individualization of care under the area of grooming.

> Baths are taken at a regular time, once a week. Sometimes I would like to have it three times a week, but I do not want to impose on the nursing staff. It is alright the way it is.

All residents perceive medication dispensing as a nursing responsibility. Not one participant desired to have control over self-medication. Concerns were expressed by the residents in regards to forgetting medication or physical disabilities such as poor vision.

> If I take anything wrong, I'm sure it wouldn't agree with me... I'm not sure I could remember if I get the right one. I might mix them up.

The second area in which health workers were identified as the primary decision-makers was diet. Only two participants (7%) were on special diets. The majority (N=26, 87%) found the meals and the mealtimes adequate.

They stated that if they wanted anything special, they asked family members.

> I don't have any special meal requests because once a week my daughter takes me out to eat and them I can eat whatever I want.

There is almost 100% acceptance of institutional control over diet and medication. The data did not identify a passive compliance, but rather a desire to have the facility manage these specific areas of daily living. This finding is an interesting contrast to the findings under grooming and activities. In these areas many residents expressed a desire for more control and individualization of care. The contrasts suggest that the self-care concept within an institutional environment is multi-dimensional (i.e. self-care may be desirable in one area of their lives but relinquished in another).

6.2.2 The Institutional Environment

The second component of institutions facilitating self-care, the institutional environment, had an affect on resident decision-making. At times the resident perceived that he/she had made an independent decision, yet the impact of the environment could be identified: "I just do what I'm supposed to do. Nobody tells me what I'm supposed to do." Or as another respondent stated: "Yes, I have adapted to the routine and would not change it."

Also, the institutional environment had an affect on activities.

> I used to do quite a lot. Originally when I came here there was nothing to do, so I decided to start painting again. But now I haven't done any for quite a long time cause it was still in the old home. They were short of space so they stopped the painting. They wanted the room. So I haven't done any more since.

6.2.3 Psychosocial Components of Care

The third section, psychological components of care was identified as facilitated by friends within the institution, friends from outside the home and family. Many participants (N=19, 64%) mentioned that they had friends inside the personal care home. Here institutionalization seemed to offer some important psychosocial supports for residents who cited the loss of old friends outside of the home through death or illness.

> I have lots of friends here in the home who I enjoy visiting. Many of my friends outside the home have either died or are mostly elderly and can't get out easily. But I speak to them often on the phone.

As a resident became increasingly dependent, one method used to cope with this change of status was to lower aspirations to match diminished capabilities.

> I used to go for two weeks holidays in Saskatchewan to visit my son, but I gave that up. I had to climb the stairs of the plane and there was a terrible cold wind and it was more then I could take. The pilot came down to assist me up the last steps. So that was the last trip for me. I'm not going to take any more chances.

One frequently saw the resident's awareness that diminished capabilities had the potential to cause embarrassing situations which lowered their available options.

> I used to go to church occasionally, but I no longer do this because sometimes I need to use the bathroom immediately and this is not always convenient. So it is better to stay here.

One resident decided she would like massage on a regular basis, as she had been receiving it prior to admission to the personal care home. The primary decision-maker was the resident, but the supportive role necessary to implement and maintain this decision was fulfilled by her daughter, not the nursing staff. Families frequently played the crucial supportive role in aiding the resident to maintain a reasonably independent life style, especially in the area of activities.

> I feel like a canary in a cage. I am unable to go out on my own. If I want to go out, I would have to ask my children and they would take me if it is possible. The staff would be willing to take me out but they are very busy due to expanding the hospital ... Maybe there will be more time once all the new residents have moved in.

6.2.4 Supportive Components of Care

Two patterns emerged about resident perceptions of the supportive components of care. The notion of the primary decision-making role of residents to control disability and dependence was supported. It appeared crucial to all residents that they avoid unnecessary dependence in achieving outcomes.

> I would like to do things on my own for as long as possible for my own sake as well as not burdening the staff with extra work.

However, the supportive role of the nurse in maintaining this primary resident role was not identified by the residents. "If they have been doing it, I haven't caught on." Rather the residents appeared to identify a relationship between the need for support from nursing and dependence: "I don't have a great deal of interaction with the staff because I am fairly independent." The participants view the supportive role of nursing necessary for the more dependent residents or in time of health crisis.

> The nurses care about me, particularly when I am ill or when anyone else is ill, the staff do come and take care of them and look after them.

When families are not available as support systems the more dependent resident had fewer decision-making options. No residents perceived nursing as a source of increasing their potential options.

> Resident - I'd like to get out more, but I lost my sun glasses and the sun bothers my eyes.
>
> I - Who would you ask to take you to buy some?
>
> Resident - Nobody around here to take me.
>
> I - Would your sister take you?
>
> Resident - She doesn't drive anymore.
>
> I - What about the staff?

Resident - Nobody around here that would do that?
I - Maybe they could find a volunteer?
Resident - Yeah, that would be all right.

In summary, the kind of decisions that participants had control over differed according to the activity, their support systems and their dependency levels. Residents described themselves as the primary decision-maker of self-care in the areas of ambulation and activities. Health workers were described as the main decision-makers in the areas of diet and medication. Decisions about grooming were related to the dependency level of the participant, with self-control and authority diminished for the more frail individuals. Age peers within the personal care home offered important psychosocial supports. Nursing was identified as supportive during times of need and in assisting with the more dependent residents. Few identified nursing as encouraging independence but rather identified themselves as the prime motivators in the reduction and control of disability and dependence.

6.3 EVALUATION OF OUTCOMES OF SELF-CARE

Outcomes is the third dimension in Chang's framework and will be examined in relation to her three components within the dimension. The dependent variable was the outcomes of care, defined as self-reported competence and knowledge, satisfaction and adherence. Residents revealed that their primary source of knowledge about their health status and their care was from the physician. Knowledge about their medication and treatments varied, and education was a factor in understanding of their medication and treatments. All residents were on medication. However, not one resident desired decision control in this area. Perceptions about health status and the institutional environment were important factors in satisfaction. Residents expressed high levels of satisfaction with the care they received. Adherence to care plan was affected by the institutional environment, resident support systems and resident dependency levels. Residents expressed involvement in their care in the areas of ambulation and activities, but expressed adaptation to ward routines was necessary in the areas of grooming, medication and diet.

6.3.1 Resident Competence and Knowledge

This component of evaluation included the self-reported competence and knowledge obtained by residents within the areas of medication, treatments and diet. Generally, the residents displayed some understanding of the examined areas of competence. However, knowledge tended to be general, such as, "I am on a heart pill," rather then more technical, such as, "I take Digoxin .025mg a day". Some of the original questions, such as: "Could you explain the treatment to me," did not apply to the participants. Therefore, the findings are limited to self-reported knowledge of medication, diet and treatments, as it was not possible to tap technical competence.

The primary source of information about care was the doctor (N=4, 13%). The extent of this source of information varied from: "The doctor explained what it was [the medication]" to "The doctor explained only when I asked about it." Only two residents (7%) identified nursing as a source of information about medication or diet. However, the majority of residents (N=24, 80%) identified that they did not receive information from anyone.

> I take 3 capsules in the evening and 4 capsules and one pill in the morning. Nobody has explained to me what this is for. I don't know. The nurse brings it and I take it.

Resident understanding of their medication, diet and treatment varied, with level of education being a factor. One resident, with no formal education, exhibited a lack of understanding of her health status and her treatment.

> I got troubles, but I don't know the troubles. I take lots of pills for it. I don't know them.

In contrast, a resident who had a degree was able to describe her medication in more depth.

> Resident - I take a heart pill under the tongue called Nitroglycerin.
>
> I - Anything else?

> Resident - Yes, I've got Parkinson's Disease. I shake but the shaking is really minimal now that I am on medication for it.

Residents whose education was some grade school or more (N=27, 90%) had some idea of the purpose of their medication and gave fairly knowledgeable accounts.

> I am getting several kinds of medication. One tablet is for my heart. One is for the blood, to keep the blood thinned and one is to keep the stool soft. I don't know the other ones.

However, some residents did exhibit a lack of knowledge about their medication.

> I don't know what they are [the medication]. In the morning I take 8 pills ... they are all different colors ... if I don't take them I get shaky and nervous.

Residents did not appear frustrated about this lack of information, especially if they had a sense of trust in their doctor.

> The doctor has not explained what the medication was for. Neither did the nurses, but I am not concerned about this ... I have had my doctor for years.

Another pattern that emerged in the area of medication, was the large amount of medication the residents were taking. All participants were on medication, and it ranged from 2-12 pills a day. One alert lady eloquently describes what was a common scenario for many residents.

> I take 1/2 green pill for my stomach. I had an operation years ago and the veins don't open very good. I take calcium pills, a stool softener and pain pills ... I take Gravol for my upset stomach and a nerve pill - valium.

Few residents (N=2, 7%) identified requiring special treatments or special diets. Those on a special diet exhibited limited understanding.

> I - Do you know what you can eat on your diabetic diet?
>
> Resident - I get a piece of apple pie on my tray.
>
> I - Is this on your diet?
>
> Resident - Yes, I guess so, they give it to me.

Overall residents displayed a lack of knowledge and understanding about their medication, treatment and diet. The majority of residents stated they did not receive any information. This finding is of concern since within the sample, the average number of medical diagnoses per resident was five. This finding supports the work of Hulka et al. (1976) that suggests that health professionals do not identify clearly the critical points of knowledge and information residents must understand to maintain and control chronic disease.

6.3.2 Satisfaction with Care

Satisfaction referred to self-reports of "feeling good." Expectations about their health, perceptions of their health in comparison to their peers within the institution, health status, and expectations about their resident role emerged as important variables affecting resident satisfaction.

One theme that affected satisfaction was expectations about what their health should be in relation to their age.

> In comparison with my age, I would say my health is fair. In some cases, my health is not nearly as good. It would depend on who you compared it with. Age 87 is old you know.

A second theme was relating their health to others within the institution.

> Good [her health]. There are a number of others here that are deaf or are ill or can't walk. I am fairly well off.

These two themes support the literature (Chang et al., 1984) that expectations about health and comparing one's health with age peers are significant in dealing with satisfaction.

As with self-care, residents are cognizant of their diminishing capabilities. Often they exhibited how changes in health status bring about lower aspirations, which in turn, affected their perception of satisfaction.

> One has to be satisfied with how things are. I need to wear special underpants because of lack of control of my stool. This is something I am not happy with. But I can't change it, therefore I need to adjust to it.

Satisfaction with care was obtained as a global rating and as specific ratings. Satisfaction with care was acknowledged by almost all respondents. Only three residents (10%) identified some dissatisfaction with care. Global comments on satisfaction ranged from "no complaints; definitely yes; happy;" to "everything is perfect."

However; the pattern of resident expectations of the resident role emerged as a significant factor in their self-reports of satisfaction with care.

> Everything is perfect. I am very adaptable. When you are unable to do your own cooking and look after certain needs that you have, what more can you ask for than to be cared for in the way you are here.

These expectations of their role exhibited little active involvement in their care, and depicted a more passive role.

> I am very happy with the care I get here. If there is anything I do not feel is adequate, I close my eyes to that.

Satisfaction with nursing staff was described by some residents collectively: "All the nurses here care for me." Other residents identified differences in the quality of nursing care.

> This varies. Some do come in and ask how I am doing and they are helpful. Others hurry about and don't take the time or don't show a personal interest. Some come immediately. Then there are some that seem to have time but don't care or they'll say just a minute and will keep me waiting for 1/2 hour.

The majority of residents (N=27, 90%) expressed the staff do care in times of need or crisis. With more specific probing their perceptions seemed to be that on a day-to-day basis a more personal touch would have been more beneficial.

> I feel there has to be a relationship of trust established between staff and residents. It is important for staff to know the residents and the residents to know the staff.

In summary, the respondents contextualized their rating of satisfaction with regard to their age and comparison with their age peers within the institution. Residents also perceived the outcome of satisfaction with care positively. However, the impact of attitudes, perceptions of role, health, and environment on satisfaction was identified, which is consistent with Chang's conceptual framework.

6.3.3 Adherence

Adherence encompasses a wide variety of behaviors. Adherence, in Chang's framework, refers to a mutually agreed upon plan of care. The resident role in adherence varied within the area of grooming, based on the dependency level of the resident. Here if the resident required help, such as in bathing, the nursing staff made the decision and the resident was expected to adhere.

> Resident - Sometimes I would like a bath three times a week but I do not want to impose on the nursing staff. There is a regular time and I adapt to that.
>
> I - You would like more baths?
>
> Resident - Yes, but I'm not sure if they have the staff?
>
> I - Did you ask them?
>
> Resident - I don't know the rules. I wash myself everyday, so its not necessary.

It appears in this example, that the resident was well aware of the 'rules' but found it wiser to rely on her own limited capabilities rather than take the risk of demanding more care.

Acceptance of ward routines did not necessarily imply passive compliance to health professional decision-making. Residents frequently found some advantages to routines, such as specific times for grooming and medication dispensing.

> Routine activities are done at certain times of the day and I am happy with this arrangement. I know when certain things are done and I follow this routine because I have been here long enough to know what is expected.

Clearly, adherence to care plan within the institutional environment is restrictive in practice.

> I used to take it [medication] on my own, but when I moved in here, the nurses explained that all prescribed pills are given to us [the residents] by the staff. I am comfortable with that arrangement.

Attempts by dependent residents to gain more control over their activities, generally met with failure.

> I find it very pleasant to have a bath. I would like to have it perhaps two times a week. I did ask the nursing staff when I first came in. They suggested they might be able to change it. But they haven't done so. There are a lot of people that need this kind of care and it is quite a bit of work to get a person through the bathing routine. I am satisfied that perhaps it can only be done once a week.

Other participants found that as their dependency needs increased, nursing staff assumed the added responsibilities with virtually no input from them.

> Resident - I take too long to shave.
>
> I - Did you ask them to shave you?

> Resident - I don't think so. I think they just decided.
>
> I - That's okay with you?
>
> Resident - That's okay.

Most residents felt that the nursing staff would try and accommodate them if they requested changes, but few tested this assumption.

> I - Who do you ask when you want special meal requests?
>
> Resident - I ask the nurse that's assigned to me that day or ask the kitchen staff and I would likely receive it.
>
> I - Have you ever asked for special meal requests?
>
> Resident - No.

The few residents (N=3, 10%) that have attempted to bring about changes in diet met with a similar success rate as those attempting to introduce changes in grooming activities.

> I - If you have any meal requests who do you inform?
>
> Resident - The kitchen. They got a dietician there and I ask her.
>
> I - She makes the changes if you want them.
>
> Resident - Yes. But they don't keep it. Maybe a week and then the same thing all over again.

Perhaps residents place few demands on the staff due to their perceptions of the reality of caring for the elderly in a personal care home environment.

> There are many residents who are either senile or have a handicap of one type or another and cannot always be responsible for what they do nor are they able to do many things for themselves because their reasoning ability has been affected. It must be more difficult to work in a home like this then to work in a regular hospital where people come and go. The nursing care is very good and the nurses are considerate.

No resident interviewed wanted responsibility for their medication. One respondent, a long standing diabetic was happy to relinquish control over taking her own medication. As one resident stated: "I don't want the responsibility of looking after getting the correct pills at the right time." Given the large amount of medication many of the residents were given , this would appear a prudent and realistic decision. One resident stated he felt comfortable in taking his own medication, but added that: "Given there is such a change of nurses its better to leave it with them so things don't get mixed up." This suggests that residents perceive the difficulties inherit in self-medication within a personal care home and are willing to relinquish control in this area.

Most study participants stated that they rarely required non-prescription medication for minor ailments. "I have a headache, sooner or later it will go away." When non-prescription drugs were desired the resident felt comfortable in asking the nurse. Only one resident admitted to having non-prescription medication in her room.

When activities of daily living, particularly in the areas of grooming and diet, conflicted with ward routine, the resident was expected to adhere to ward routines. Regular mealtimes seemed acceptable to residents, as very few expressed a desire for changes or special requests, although some suggest the effort to try to introduce variety was not worth the energy required. All residents view medication dispensing as a nursing duty and seem relieved not to have control over this area.

6.3.4 Findings Relative to Hypotheses

The data obtained from the interviews do not support hypothesis one. The information suggests support in part for the second hypothesis. The investigator was unable to test hypothesis three.

Hypothesis one states: resident involvement in the decision-making process of their care will be related to their knowledge and competence in applying their expected outcomes of care. No relationship was identified between decision-making and residents being more knowledgeable about their care. Participants did not express a desire to have more access to information and did not identify nursing as assisting them in gaining information. This does not support the self-care framework, which suggests that the more knowledgeable a resident is in their care, the more active they will be in the decision-making process, therefore hypothesis one is rejected. The relationship appeared to be between the level of education of the resident and the knowledge and competence of the resident.

Hypothesis two stated that resident participation in their plan of care will be related to satisfaction with their care. Residents active in the development of their plan of care were satisfied with their care. However, satisfaction appeared to be related to health status rather than involvement in their care plan. The healthier residents had more control over participation which led to satisfaction. A positive relationship between satisfaction and involvement in plan of care existed only for the more independent residents.

Hypothesis three states that resident involvement in the development of their care plan, with the support from nursing, will be related to adherence to the plan of care. Adherence to care plan was clearly related to the dependency level of the resident. The more independent the resident, the more involvement he/she had in their own care. The more dependent resident had less control over their care. In the areas of activities and ambulation the more independent residents developed much of their care plan, with support from families increasing resident options. In the areas of diet and medication, all residents were expected to adhere to the institutional routines. In the area of grooming, adherence varied with dependency levels.

Examination of the resident records revealed no variance in the independent variable of self-care. There was no evidence of support from nursing for the more independent residents. Therefore, the data suggests that there is a relationship between independence and resident adherence to their plan of care. Another explanation for the lack of variance in the independent variable may be that the measures did not adequately tap the process of self-care.

The rejection of hypothesis one, qualification of hypothesis two and the inability to test hypothesis three suggests that the self-care framework differs in the institutional environment from self-care practised in chronic care at the primary health level. Clearly, the institutional environment was an important factor in self-care. Support for the framework was identified in that the residents perceive themselves as the primary decision-makers. Unfortunately, nursing was not perceived as supplementing/supporting this continuous primary role of residents to control disability and dependence. Rather, nurses were perceived as being supportive with the more dependent residents, in which the resident had to relinquish the primary decision-making role to the nursing staff.

6.3.5 Summary and Conclusion

The interviews with the residents produced rich and valuable data. The information revealed self-care was a complex but important process in achieving resident defined outcomes. Self-care was affected by the dependency level of the resident, the institutional environment, the support systems and resident expectations. Remaining independent as long as possible was clearly identified as the most valued outcome by the participants.

Power over choices was affected by health status. The healthier and more independent the resident, the more control he/she had over decisions about care. Given that only the most competent residents were interviewed, the findings suggest that the majority of personal care home residents have limited self-control over their plan of care. Satisfaction with health status was related to age and comparison with the other residents within the institution. Other residents within the personal care home offer important psychosocial supports.

Adherence occurred in the areas of grooming, activities and ambulation, but not in the areas of medication and diet. However, residents viewed loss of self-control in these areas as acceptable and no participant requested management of their own medication. The large amount of medication residents were taking suggests an area of concern to health professionals. Lack of understanding and knowledge about medication may be a factor in relinquishing control in this area. Attempts to introduce changes in diet or grooming were generally unsuccessful, despite residents stating they felt nursing would support their decisions.

Nursing staff were not identified as aiding in preventing dependency; were not seen as a potential resource for creating more self-care options; or as a major source of information. Residents perceive nursing as generally caring for the residents in times of crisis or assisting with the more dependent residents in their daily care. These findings suggest the resident sees a relationship between nursing and dependency.

Although nursing was not identified as increasing decision-making options, family members were crucial for this supportive role. Many residents would have had difficulty going to outdoor activities, or enjoying special diet requests, if it were not for family. The inability of nursing to play this supportive role was not perceived as negative. Rather residents were quick to identify the problems of caring for the frail elderly and the demands that such work places on nursing staff.

Focussing on resident strengths should not be underestimated. Throughout the interviews examples of resident strengths were identified, with adaptability being one of their key survival strategies. Residents talked about loss of friends, loss of capabilities, loss of home, busy families and busy staff. Yet, they consistently found strengths and satisfaction in what remained within their lives. As one resident stated: "Nobody wants to be here, but we must be. We need care 24 hours a day. It is a nice place. I plan on living here comfortably until I die".

Chapter VII

DISCUSSION

The design of the research study facilitated the collection of rich and varied data. The study was explorative-descriptive, which means the study belongs to the "context of discovery" rather than the "context of verification" (Glaser & Strauss, 1965). The discussion is organized around the major categories identified in the findings chapters.

7.1 CHART REVIEW

The first purpose of the chart review was to gain demographic and personal information. Demographic items such as age, sex, religion, marital status and diagnosis were documented. Inadequate record keeping was discovered in items such as, education level, which was missing in 80% (N=24) of the participants records; 20% (N=6) of charts failed to identify the reason for admission to the personal care home; 33.3% (N=10) of charts were missing information where residents lived prior to admission and 20% (N=6) made no mention of whether the resident received visitors. There is a lack of charting of specific demographics or background information that refers to the resident's past life.

The second purpose for examining the resident records was to explore briefly to what extent nursing notes reflect the self-reported factors identified by the residents. The charting focussed on nursings' perceptions of the residents and the recording of nursing interventions (i.e. what the nurse does). As well there was no acknowledgment of the supportive role of nursing in assisting resident self-care. The literature (Elbeik, 1986; Ryden, 1985; Simpson, 1985) suggests that nurses and residents have different perceptions of care. The present study supports the above authors' work, as even though the residents perceived themselves to be the primary decision-makers, this perception is not reflected in the charting. The nurses charting represents subjective evaluation of the residents, such as "appears confused" or "appears depressed," and is often based on their manageability within a ward setting. There were no indications of residents receiving information or education about their illness or aspects of the aging process.

One of the assumptions the investigator made in observing charting behavior, was the use of the nursing process as a guideline for nursing charting. The nursing process which refers specifically to assessment, planning, implementation and evaluation, was developed in the 1960s and is a cornerstone of nursing education and practice. In this study, the use of the nursing process was either inadequately developed or not used at all. Nursing assessments were frequently stated in simple and limited terms such as "appears depressed", with no explanation given for the statement. Planning, and evaluation were rarely noted.

The personal care home has identified the importance of resident outcomes as witnessed by the outcome form. A form defining the problem and expected outcome within specific time frames is consistent with the expected behavior identified in hypothesis three. However, awareness of the need to document outcomes and its actual use in writing revealed inconsistencies, vagueness and no evaluative component. Rarely were expected outcomes identified, and the collaborative nature between staff and resident was not mentioned. When, on occasion, outcomes were stated, no mention was given as to whether or not the outcome had been achieved.

Possibly such problems reveal a lack of understanding among the nursing staff about outcomes. Similar charting patterns were identified in the nursing care plans, which often contained limited information and vague goals. Further, the charting of comments such as "confused due to the aging process," may be exhibiting a lack of knowledge and/or poor assessment skills.

Another factor identified in the exploration of resident records was duplication of information. For example, information present on the medical history was also frequently written on the nursing history form. It is acknowledged that finding time to do thorough charting is often difficult but reevaluation of current nursing record keeping may lead to more effective charting.

7.2 RESIDENT INTERVIEWS

The purpose of the interview was to explore the institutionalized resident's self-report of participation in decision-making and competence in care, knowledge and information about care, satisfaction with the care and individual adherence to the care plan. A second purpose of the the interview was to collect data on the dependent and independent variables. Finally, the interview permitted the resident to share their perceptions of the supportive component of nursing care and self-care.

7.2.1 Individual Characteristics

The conceptual framework and relevant literature in the field identify individual characteristics as important in residents' perceived health and quality of care. Kane and Kane (1978) state a disproportionate number of personal care home residents are female, and are either widowed or have never been married. This was reflected in the present study population, as 76.6% were female with 63.3% of participants widowed, 16.7% never been married and 16.7% married. The researchers go on to state that personal care home residents suffer from multiple chronic conditions. A review of the respondents records supports this statement as the average number of medical diagnoses per resident was five. Linn and Linn's (1980) study of objective and self-assessed health of 286 elderly living in the community found the elderly averaged three medical diagnosis per participant. The authors demographics when compared to the study sample suggests that the institutionalized have more diagnosed chronic conditions.

Few residents acknowledged all their diseases when asked to describe their health. The present research supports the findings of Ferraro (1980), who found older individuals, despite physiological disorders, tend to express a more positive view of their own health. Few residents (N=3) described their health as poor. One method identified used by the old-old participants to deal with increasing physiological disorders, was to lower aspirations to match diminished capabilities. Another technique was avoidance of potentially embarrassing situations due to physical disabilities such as incontinence, rather then a negative description of their health.

Advanced age is another characteristic of personal care home residents and at the personal care home the mean age was 87 years. Much of the current literature on the elderly person's perceptions of health care deals with individuals over 65 years of age, who live in a community setting (Chang, 1984; Locker & Dunt, 1978).

As a group, this sample had little formal education, which is reflective of the elderly at large (Statistics Canada, 1981). Sixty-seven percent had less than grade eight education. The study suggests that this factor is important when dealing with resident expectations and perceptions of self-care. The findings did suggest for this cohort group, that the more educated residents were able to express a better understanding of their care, than the less educated residents. However, the small sample size discourages generalizability. Only two residents had an academic degree and both of them expressed an understanding of their care. Interestingly, both of them also expressed some dissatisfaction with their care. The study was cross sectional, and therefore failed to acknowledge possible cohort differences in education which may have affected perceptions of health care.

7.2.2 Long-term Institutions Facilitating Self-Care

Decision control by the resident is the main thrust of the self-care framework. According to Schaefer (1974), the nature of decision-making is the art of choice following deliberation and judgment. To make a decision, three conditions must be fulfilled: freedom, rationality, and voluntary participation. A person must be free to make a choice and therefore, have authority over that choice. The person must also be able to deliberate about alternatives to arrive at a judgment. And finally, the individual must make the choice, which is the art of volition. The extent to which these three conditions were present for self-care in the personal care home depended on the participants' health status, their support systems and the institutional environment.

7.2.2.1 Resident participation in decision-making

The study found that residents perceive themselves as the primary decision-makers. This is in concurrence with Ryden's (1985) research involving 113 cognitively well residents. In examining resident and staff perceptions she found residents saw themselves as the main decision-makers. However, the caregivers (N=137) saw themselves as the predominant decision-makers.

Within the personal care home residents had the main decision control, in particular areas such as ambulation and activities. This autonomy in decision control was directly related to health status and was significantly affected by the environment. The more independent the resident, the more decision-making control he/she had over their care. For the more frail elderly there was a shift in decision control from the resident to nursing staff. This generally resulted in a more passive role for the resident in their care.

All respondents completely relinquished decision control in the areas of medication and diet. On closer examination and using Schaefer's three conditions certain themes emerged within the area of medication. First, individuals upon admission to the home were informed that "nurses give out the medication," regardless of the individual's past history. This immediately eliminates freedom of choice. Second, all participants were on medication, some taking as many as twelve pills a day. Understandably this created a concern for the residents about making mistakes in taking their medication. Interestingly, not one resident questioned the need for so much medication. Given the above factors the rational choice, from the resident's perception, was to relinquish medication control to nursing.

Although the reasons for lack of control were not tapped, numerous medications, frequent doses, lack of knowledge about their medication and physical disabilities may have been significant factors. There is clear evidence that adherence is adversely affected when multiple medications are prescribed or drugs are given in frequent divided doses (Blackwell, 1976). Added to these difficulties, is the increasing awareness about the different effects drugs have on the elderly as opposed to a young adult. What are the risks of self-medication of responsible doses as compared to the risks of taking 12 pills/day? How do such risks from self-medication compare to the risks of feeling powerless? Are caregivers responding in terms of what is necessary for the mentally impaired, rather than individualizing care for the cognitively intact residents who comprised the subjects of the study? These questions suggest the need for scrutiny in the area of medication and its use.

The majority of residents were not on special diets and followed the meal schedules developed by the institution. Few voiced concerns about meals or meal scheduling. The facility did have kitchen areas which residents were free to use. Few residents seemed to use this option and stated they were satisfied with not having to make decisions about meals. In fact, similar to medication dispensing, some respondents appreciated not having the responsibility. Resident identification of lack of decision control in the areas of medication and diet suggests direction to target interventions that might be more productive in increasing self-care.

7.2.2.2 Supportive components of care

The importance of support systems prior to admission were recognized in two areas. Residents who had resided in the home the shortest period of time (1:5 years) mean age was 89 while residents who had been in the home for the longest period of time (16 years or over) mean age was 71. Second, the residents who had been living in the home for the shortest period of time were either widowed or married (N=16, 53.3%). The residents who had resided in the home for the longest period of time (N=4, 13.3%) were either single or divorced. Prior to admission they had been either in a mental institution, lived alone or lived with siblings. Those respondents (N=3) who lived with their children prior to admission tended to be the eldest age group (Mean=90 years). The findings suggest support systems for the elderly are valuable in keeping individuals in the community.

The personal care home, becomes the support system for the frail elderly, once community supports are no longer available. Both Chang (1980) and Orem (1985) view nursing in a supportive/ supplemental role in caring for clients unable to maintain self-care. The residents in this study did not perceive nursing as fulfilling that role. Rather the relationship appeared to be between the need for support from nursing and dependence. Attempts by residents to gain more control over self-care occurred occasionally in the area of grooming, but with limited success. The emphasis of nursing care in this study has been on passivity of the resident and cooperation with nursing tasks. Unless care providers consider the goals of resident self-care as important, self-care will not evolve as a product of the relationship with a resident.

Identifying dependent behaviors in nursing is beyond the scope of this study. However,the study did identify certain themes about resident's perceptions of nursing care. Residents perceive the caregivers as busy, focussing on tasks, necessary for the more dependent residents and available in time of health crisis. As one resident stated: "The nurses need schedules or they would never get their work done". Few residents identified nursing as supportive in prevention of illness or promotion of health.

Nursing care plans were placed over each resident's bed in an attempt to give individualized care. Although attempts to focus on the resident plan of care is to be applauded, the residents' perceptions suggest this has not been achieved in many areas of their lives, despite the availability of the care plan. This finding may reflect a need for information on the part of administrative staff and caregivers of the research findings that link perceived self-control with morale (Chang, 1979; Ryden, 1985).

7.2.2.3 Psychosocial components of care

Reasons for admission varied, but the data suggest that social reasons such as lack of support systems to keep the individual in the community, were important. Prior to admission to the personal care home 50% (N=15) of respondents acknowledged family involvement in their decision to enter the home. This decision was often precipitated by some health crisis which resulted in a change in health status for the resident.

Once the resident was within the personal care home, family support remained valuable in increasing resident self-care options. The majority (66.6%) of the sample had family support. This support was especially evident in the area of activities. If residents desired to leave the institution for an outing, it was family members who made it possible.

7.2.2.4 Institutional Environment

Clearly, the institutional environment has a tremendous effect on residents' perceptions. Comments such as, "I have adapted to the routine," or "I have been here long enough to know what is expected," reflect that impact. Kahana (1973) and Moos and Ingra (1981) found that within the institutional setting, social environment factors such as the degree of support and cohesion among residents and staff and the extent to which residents are encouraged to exercise responsibility and self-direction are important to resident well-being. Kahn et al.(1977) found in their examination of quality of life and care in twenty long term care facilities a lack of opportunities for residents to come and go from the facility. Whall (1987) suggests that self-esteem is related to the environmental situation. The problem of autonomy is further intensified by the fact that many residents suffer from marked physical and mental impairments.

In the present study, fixed schedules and a focus on nursing tasks were identified as negative aspects of institutionalization. Equally, supportive friends within the home, relinquishing control over mealtimes and medication dispensing and awareness of nurses available during illness were viewed as positive and comforting aspects within the institutional environment. Such positive aspects however, do not negate the central point of institutionalization, that it is a major life event that requires tremendous personal adaptation.

7.2.3 Evaluation of Outcomes of Self-Care

Nelson (1978) in analyzing a cluster of nursing studies that focussed on the development of outcome measures, summarized some key points of the studies. In general, psychosocial criteria were more sensitive to measurement than physiological variables; patient health status was highly predictive of outcome status, such as adherence to treatment plan; and that the institutional variables and patient characteristics were related to outcomes. The findings in this study were in concurrence with Nelson's study.

7.2.3.1 Knowledge and Competence

Residents stated that they received limited information about their medication, treatment and diet. The majority of residents identified that they did not receive information from anyone. When they did receive information, it generally came from the doctor. Only two residents stated that they received information from nursing staff.

Two points of caution in the residents interpretation of lack of knowledge need to be identified. First, the low level of education of the majority of participants may be a factor in understanding aspects of their care. The better educated the resident, the more knowledgeable they tended to be about their treatment plan. The second point is that residents may have received information about their treatment plan, but had "forgotten" who had given them the information. The fact that over half of the residents could give some form of description of what their medication was for, even if they did not know the name, suggests the possibility of someone previously informing them. This ability to describe their medication to some degree may also be a reflection of the adult education principle, where adults tend to learn better from experience then from information simply given to them.

Although the study was unable to answer the question regarding receiving and keeping of information, it does alert health professionals to the need to develop specific techniques in delivering knowledge and information. The present study suggests that giving information and instructions once only, may be insufficient with clients of advanced age, multiple conditions and numerous medications. Health professionals need to be aware of the principles of acquisition of new information, and with the advanced age group techniques, such as feedback and repetition are recommended.

Given these areas of caution, it must be remembered that the majority of residents stated they did not receive information about their health status and treatment plans. The compliant acceptance on the part of the resident of the treatment plan is no indicator of their understanding, but rather an indicator of their acceptance of professional dominance.

7.2.3.2 Satisfaction

Similar to the findings of Ferraro (1980) on the self-ratings of health among the old-old, the elderly in the present study contextualized their rating of health with regard to their age and in reference to their peers within the personal care home. Also in concurrence with Ferraro's (1980) and Linn and Linn (1981) findings, the participants tended to have a more positive view of their own health despite numerous physiological disorders and disabilities.

Work by Linn and Greenfield (1982) on satisfaction among patients with debilitating chronic disease found that patients who were more depressed and rated their general health poorer, were significantly less satisfied with their care. In the present study, 90% of residents (N=27) expressed satisfaction with their care. Fillenbaum (1979) explains the difference in findings according to the effects of the institution. His study on social context and self-assessments of health among the elderly suggests that criteria that are used for assessing the community elderly may be inappropriate in evaluating the concerns of the institutionalized elderly. A pattern of resident expectations of the resident role frequently emerged as in their self-reports of satisfaction with care. The residents perceived that once they had "adapted" to the environment, then they were satisfied with their care.

Another explanation may be related to the age of the residents. Locker and Dunt (1978) in the review of consumer satisfaction with medical care discovered age was one factor consistently associated with satisfaction: older patients tended to report more favorably. This contextualizing their rating of satisfaction with regard to their age, reference to peers and expectations of the resident role urges caution in using resident satisfaction alone as a measure of quality of care outcome.

7.2.3.3 Adherence to Care Plan

Adherence to the care plan within the personal care home was synonymous with compliance. Compliance implies that the caregiver is the decision-maker and the resident is the person to follow orders or comply. The pre-printed forms for writing individual care plans and outcomes acknowledge the importance of involving the resident in their care planning. The documentation on these forms was inconsistent and did not reflect an evaluation of a resident's capacity for self-care, nor did it reflect collaborative efforts between residents and staff on the care plan and outcomes.

Blackwell (1976) states that involvement in the information exchange is the most important factor in information retention. Blackwell's argument suggests that individual knowledge and individual adherence are closely linked through the process of involvement.

Situations where residents attempted self-care, such as changing bathing routines, was generally unsuccessful. The expectation was that the resident "adapted" to the situation, that is a bath once a week, not that the caregivers assisted in changing the system to conform to resident needs and preferences.

Interestingly, most residents stated that nursing staff would try to accommodate any changes they requested. With further probing, the investigator discovered this was largely an untested assumption on their part. As stated earlier in resident self-care, a person must be free to make a choice and therefore, have authority over the choice. Is it possible that the resident does not want to test an assumption that would be in conflict with their perceptions of themselves as the main decision-maker? Ryden (1985), in her study of environmental support for autonomy in the institutionalized elderly, found that caregivers (N=137) stated they preferred more resident control, but that they still wanted to retain a considerable share in the decision-making about daily activities. The actual interactive and/or collaborative effort between residents and staff needs to be further scrutinized.

7.2.4 Methodological Concerns

Five issues emerged during the study that should be acknowledged, in regards to methodology: the consent form, the length of the interview, the selection of the sample, the use of a translator and the therapeutic function of the interview. First, out of 33 potential participants, 30 volunteered to be part of this study. The relative ease of obtaining consent is consistent with the interpretation by Strain and Chappell (1982). The researchers found it was easier to obtain consent from participants in an institutionally based adult day care and day hospital programs, then those living independently in the community and not part of the service bureaucracy. Despite being informed that the study was being conducted by a university student and was unrelated to the personal care home, one wonders if those integrated into the bureaucracy often accept unquestioningly another professional and another series of questions to answer.

Another concern with use of a written consent form is that it may not be appropriate ethically with the elderly population. The problems of some respondents perceiving the act of signing a consent form as more undesirable then being interviewed was also reported by Singer (1978). The purpose of the consent may be misinterpreted and cause a great deal of stress to elderly respondents. Comments such as "I'm not good at tests," or "I hope I can give you the right answers," suggests anxiety with written consent forms. Three residents refused to sign the consent form until completion of the interview. One resident was so stressed after reading the consent form that she requested the presence of her son during the interview. Such resistance or anxiety implies the use of verbal consent with the elderly may be more appropriate then the written consent form.

Second, was the concern prior to data collection about the fatigue factor of a lengthy interview with the elderly. The reality in the present study was that all but one respondent wished to continue the conversation after the interview was completed. Frequent comments were, "it is important to know how we feel," or "I have never been asked my opinion before". The willingness of the participants, their enthusiasm, their availability and their rich backgrounds offer many potential avenues for future researchers.

Third, was the selection process of cognitively well residents by the charge nurses. Why were only 33% of all the nursing home residents deemed well enough to answer the questions? The capacity to make complex judgments was not the intent of the research, but rather the capability to make decisions about some aspects of their daily activities and care and to be able to articulate these activities. One of the most likely explanations is the view of caregivers that residents have only limited capability for decision-making. This low percentage of deemed cognitively intact residents within the home is consistent with Ryden's (1985) experience. She found that caregivers saw most residents as not capable of making decisions about their daily care. The reality that the personal care home population is indeed comprised of an increasing number of severely mentally impaired residents means that this perception is consistently reinforced. Perhaps this increase in the mentally impaired contributes to caregivers attributing incompetence to many residents who in fact have the capacity for making many decisions about daily activities.

Fourth, the use of a translator was instrumental in obtaining volunteers and in gaining rich and valuable data. Many of the German speaking residents expressed satisfaction in having the interview done in their native tongue. Having the self-care concepts under the six broad headings of grooming, ambulation, diet, medication, activities and satisfaction with care, with specific questions under each heading, led to structure and consistency in the interview process. The availability of the investigator during the

German speaking interviews also allowed for feedback in understanding the concepts that needed to be probed.

Finally, throughout the interviews with the residents, the investigator was aware of the therapeutic function of the interview. The respondents expressed an interest in the research, answered the questions with careful thought and attention, and expressed pleasure at being able to "help someone," or "hopefully make things better for other residents". Closing the interview was the most difficult aspect of the data collection. Many residents expressed a desire for the conversation to continue or for the investigator and/or translator to return at a later date. Although tapping this behavior was beyond the scope of this thesis, such behavior suggests that loneliness, depression and lack of sense of purpose are aspects of these residents' lives. This therapeutic function of the interview exhibits further the importance of focussing on the psychosocial needs of the institutionalized elderly, not only on their physical needs.

7.3 CONCLUSION AND RECOMMENDATIONS

The current profile of a personal care home resident has changed over the last decade. Residents are of a more advanced age, have multiple health problems of a chronic nature and more are likely to experience mental deterioriation. The demographics of this study were consistent with other researchers.

It would appear that despite acknowledgment of the importance of quality of care criteria specific to the long term environment, traditional, hospital based approaches based on medical diagnosis and physical care are still the organizational pattern for the personal care home. Specifically, in this study, the residents were unable to identify active encouragement of a collaborative approach between nurses and residents. Currently nursing is perceived as necessary only when one is "ill," or "more dependent". The study was also unable to identify a collaborative/ supportive approach within the nursing documentation. If the raison d'etre for a personal care home is to offer nursing support to those individuals unable to do self-care, then the development of policies which assist residents in preserving their independence should be a priority.

The nurses charting in this study appeared inconsistent, and exhibited a lack of understanding about outcomes and goals, and information related to resident perceptions was almost non-existent. Inservice provided to nursing personnel should address the following areas:

1. Review of basic concepts and principles of aging.

2. Review of the nursing process, with particular focus on evaluation.
3. Review of The Manitoba Association of Registered Nurses generic standards on outcome charting.
4. The development of a model or framework based on resident independence, with a supportive role from nursing, to guide nursing care and nursing documentation.
5. The reality of the personal care home environment to create a set of iatrogenic problems, such as dependency, depression and social isolation.

This study demonstrated that residents perceive themselves as the primary decision-maker in their care However, factors influencing this decision control were identified. The most influential factor was health status. The more physically independent the individual, the more decision control he/she displayed. To maintain the image of primary decision-maker, the more frail elderly exhibited certain survival strategies, such as diminishing expectations, avoiding potentially embarrassing situations and passive acceptance of change in status.

Another influential factor affecting decision-control was the institutional environment. Residents did not directly perceive the correlation between decision control and environment, but comments such as "I am adaptable," or "I know what is expected of me," recognize environmental control. The third influencing factor was that the availability of family supports increased resident decision-making options, specifically in the areas of activities and at times, in the area of grooming. The interest in leaving the facility may reflect a need for nursing to be aware of those specific residents who lack support systems. Perhaps nursing could assist in increasing resident options by the active use of volunteers.

Nursing personnel were viewed positively and were seen as enhancing the quality of care for the ill and the mentally impaired. Despite this positive view, a small number of residents expressed the desire for more collaborative efforts on the part of the nursing staff. The following factors were identified as influencing the collaborative process between residents and nursing personnel:

1. Residents expectations about the role of nursing.
2. The knowledge and information residents received about their care.
3. Nursings' focus on tasks, rather than individual care plans.
4. The demands of the cognitively unwell and more frail elderly on nursings' time.

Although residents perceive nurses as willing to collaborate, the study found few residents had tested this perception. Unfortunately, requests for changes in care were most often ignored. Support from administration to focus on individual care and resident decision-making would enhance the collaborative interaction. While they have less direct interpersonal interaction with residents than do the caregivers, their leadership and teaching functions give them the potential for exerting a broad influence on the interpersonal environment which residents experience.

Most residents stated that they did not receive information about their medication, treatment or diet. Exactly how accurate this perception was is not clear. The fact that 66.6% of residents had less than grade eight education may have been a significant factor in understanding received information. Nursing as a profession has defined one of its major roles as that of health teaching. The current study suggests that this is not occurring within the personal care home environment, despite the chronic nature of many of the residents' illnesses and the high use of medication.

Although satisfaction with care has been considered an important outcome in the quality of care literature (Scherer, Farrell, Sinha, 1985), this study suggests satisfaction is a complex concept that involves factors including resident expectations, age, and health status. The majority of residents (N=27) stated they were satisfied with the care they received once they had adapted to the institutional environment. This suggests that adaptability is an important survival technique, but perhaps at the risk of increasing dependency and powerlessness. Adherence to the care plan within a personal care home is synonymous with compliance. Active involvement of the resident in planning and implementing their care plan was not identified.

7.4 IMPLICATIONS OF THE STUDY

7.4.1 Implications for Nursing Practice

The study, using the theoretical framework of self-care, identified a number of weaknesses in nursing care of the elderly. Some of the difficulties have been identified in other studies as well. Therefore, the implications for nursing practice are congruent with previous research (Barton et al., 1980; Miller, 1985; Ryden, 1985). Perhaps the most important implication is the need for nurses to develop an awareness and sensitivity to the fact that residents perceive themselves as the primary decision-makers. Moreover, nurses need to be supportive of the resident's self-care role. Collaboration is based on the appreciation and recognition of the residents role within the personal care home environment. The acknowledgment and support of resident decision-making where appropriate, could contribute significantly to an improvement in his/her health status. The development of policies which assist residents in preserving their independence, and the inclusion of residents in the formalized process of care would enhance the quality of care that residents are currently receiving.

As well as being aware of resident perceptions, nurses need to recognize the tremendous impact the personal care home environment has on resident decision-making and resident outcomes. The literature (Kahn et al. 1977; Moos & Igra, 1980) and the findings of this study have substantiated this phenomenon. This fact establishes the need for nurses to recognize the differences between compliant behavior due to professional dominance versus cooperative behavior due to self-initiated decisions about treatment plans. Identification of medication, diet and to some extent grooming as areas residents exerted the least self-determination gives some specific direction to attempts to increase resident perceived control. The findings suggest that the impact of institutionalization on resident, spouse and family are rarely acknowleged by the personal care home. Support for residents and families, such as individual or group counselling could alleviate many of the stresses and strains experienced during the adjustment stage.

The aged succeed in reaching old age because of their strengths and their ability to cope with stressors and changes throughout their long lives. Nursing needs to be aware and supportive of focussing on resident strengths and coping strategies. Similar to previous research (Golander, 1987) this study identified resident survival strategies. These included a process of lowering aspirations to match diminished capabilities, finding supportive friends within the home and avoiding unnecessary dependence for as long as possible.

7.4.2 Implications for Nursing Education

Most registered nurses currently working in long term care did not have specific gerontological content in their nursing program, and few have had further education in gerontology beyond what has been provided as inservice education. Nursing assistants, who represent the bulk of caregivers, have minimal preparation for providing care to the elderly. The findings of this study stress the need for increased education about gerontology for the nonprofessional staff working with the elderly. There is also a need for experienced professional staff, such as clinical nurse specialists who can act as resource people to long term care staff. Professionally educated staff, who have a strong background in gerontology would be able to educate caregivers about the self-care needs of chronic care individuals.

The study also demonstrated that nursing process, outcomes, and individual care plans continue to be poorly understood concepts by many nurses, especially in the areas of planning and evaluating. This study supports the literature (Scherer et al., 1985) that nurses chart nursing interventions, but rarely acknowledge patient involvement or patient outcomes in the plan of care. Nurse educators need to ensure their students understand these concepts. Moreover, nurse administrators need to be supportive of this practice and ensure inservice and upgrading in areas of weakness.

The use of nursing conceptual models has guided curriculum development and at times has also been used within practice settings. Long term care facilities have rarely used conceptual models to guide their nursing care. This study demonstrated that mechanisms to involve resident input (setting of goals, outcomes, and individual care plans) were in place but tended to be of limited value or inaccurate in their application. Use of a conceptual framework, such as self-care, would give support to the philosophy of the personal care home and offer guidance and direction to the nursing care.

The literature (Miller, 1985) and the findings in this study exhibit nursings' lack of awareness about staff dependency fostering behavior. In long term care, the thrust of education on the supportive role of the nurse assisting the client in achieving outcomes, needs to be stressed.

7.4.3 Implications for Theoretical Orientation

The usefulness and appropriateness of the conceptual framework will be discussed in detail. The investigator's intention is to demonstrate how the components of Chang's, conceptual framework aided in providing a means to data identification and collection and where the components were incompatible with the data collected. As previously noted, Chang's (1980) self-care framework was adapted to the institutional environment. These refinements will be discussed.

7.4.3.1 Individual Layperson Characteristics

Examination of demographics were supportive of Chang's model in that they have a powerful effect on outcomes. Although the study examined only residents' self-reported levels of participation and decision-making, certain demographics seemed important in achieving outcomes. For example, the study raises the question about the relationship between education and achieving an outcome of knowledge and competence.

Health status was also identified as important in residents perceiving positive outcomes. In terms of attitudes and expectations, the study revealed that residents expected to "adapt" to the routines and schedules. Despite this compliant behavior, residents still perceive themselves as the main decision-makers. This suggests the effect of a cultural background, based on independence, self-reliance and care for family. As well, half of the respondents immigrated to Canada, which might suggest that adaptation to environment is important to this group.

Both Orem and Chang identify universal demands (i.e. behavior that helps people meet basic human needs), and health deviation demands (i.e. behavior that arises from illness, injury or life cycle) within their models. All participants in this study were experiencing difficulties in meeting universal self-care demands or in Barofsky's (1978) terms, regulatory demands. As well, especially for the frail elderly, they were experiencing health-deviation or again in Barofsky's terminology, were in an illness form of self-care. The findings of this study suggest that despite these deficits, residents still perceive themselves as the prime motivators of meeting their care demands. Remaining independent was the most valued outcome of the residents. To encourage and maintain the development of self-care for those experiencing universal self-care deficits and health deviation appears to require receptive health care providers.

Orem (1985), which Chang's model uses in part views the provider role in the application of self-care as a complementary relationship between nurse and resident. According to Orem, the complementary relationship is a core concept. Nurses act to help patients assume responsibility for their health-related self-care by: (1) making up for existent health-related deficiencies of the residents' capabilities for self-care and, (2) supplying the necessary conditions for the residents to maintain or increase their capabilities of self-care (Orem, 1985 p. 11). Chang's supportive/supplemental role of nursing was not identified by the residents. Perceptions of nursing care seemed to be that the nurses work hard, are always busy and generally care for the more frail elderly and the mentally impaired, as they demand more of the nursing staff's time.

7.4.3.2 Long term Institutions Facilitating Self-Care

Although the study examined only the residents perceptions and did not use objective measures, their comments suggested the powerful influence of the environment. The findings were in concurrence with the changes made to the original framework. The relationship between self-care and the institutional environment appears multi-dimensional. The self-care concept is directly affected by factors such as health status or level of independence of the resident, availability of support systems and the rules and regulations of the home. All four components of the second dimension emerged as important in the study. As well, the framework offered guidance in identifying areas of weakness in facilitating self-care.

The psychosocial component of care was perceived by the residents as coming from family and friends, both inside and outside of the personal care home. Perceptions of the supportive components from nursing tended to be limited to the knowledge that there were staff to care for them in times of crisis and/or failing health. The supportive component of the facility, in terms of increasing resident decision-making options, gaining more control over their environment or bringing about changes in the environment, were not identified. This challenges Chang's view that nursing supplies the necessary conditions for the resident to maintain or increase their capabilities of self-care. Perhaps use of Orem's words "complementary relationship of care," would better identify nursings' role, than "supportive components of care." Her terms suggest a less dependent state and identifies the resident's active involvement.

Resident participation in decision-making did occur, but tended to be limited to the specific areas of grooming and activities, with health status being an important variable in all areas. No resident participation was identified in the areas of medication and diet. Residents stated they did not want control over these areas of their lives. Although the reasons for this behavior are beyond the scope of the thesis, their perceptions suggest the complex relationship between self-care, individual characteristics and the environment.

Perceptions of the institutional environment did not reflect only the negative effects of institutionalization. True, residents found they had to adapt to rigid routines and schedules and some staff were more caring then others, or the meals were not always exactly what they wanted. The other side of the coin was routines, such as tea and cake served at two o'clock was something nice to look forward to, there was comfort in knowing that caring staff were available twenty-four hours a day, and that many of your close friends were within the home.

7.4.3.3 Evaluation of Outcomes

The findings of the study are in concurrence with Chang's view of the value of intermediate outcomes in dealing with the elderly. However, two of her components, satisfaction with care and adherence with care under the dimension of evaluating the outcomes of self care were difficult to apply to the personal care home environment.

Technical competence was not examined in this study. Individual knowledge was explored only through resident perceptions. Their responses suggest that they are not receiving the necessary information and knowledge from health professionals to obtain self-care skills. The framework gave guidance in identifying resident lack of knowledge about their treatment regimen.

Satisfaction with care emerged as a complex phenomenon within the personal care home. Almost all residents (N=27) stated that they were satisfied with their care. However, statements such as: "Now that I have adapted to the routine, I am satisfied," displays how individual characteristics and the environment affect the outcome of satisfaction. During the resident interviews two factors emerged that question the validity of satisfaction as a measure of quality of care.

First, although not specifically examined, the investigator sensed a therapeutic function of the interview. Are areas such as, loneliness, depression and lack of purpose, endemic within a personal care home, and if so, what is the relationship with satisfaction? Second, is there a relationship between satisfaction and compliance? The findings suggest a complex relationship not accurately acknowleged in Chang's framework. Perhaps for the institutionalized elderly stated satisfaction is less of an accurate evaluative outcome than perceptions about value and worth.

The resident responses to self-care suggests two questions. First, if self-care stems from the learner's perceived needs and preferences (Levin, 1978) then were the residents in this study practicing self-care? Second, does the relinquishing of decision-making control by and large reflect the professional expectation of the resident adapting to the system? Residents stated they have not witnessed efforts on the part of the health professionals to educate them about their illnesses, medication, and treatment. Nurses, as the primary care givers need to be aware of the subtle differences between supportive behavior to maintain self-care and compliant behavior because the resident has no options. Perhaps a further refinement to this intermediate outcome would be "individual involvement in care plan". Words such as adherence and compliance continue to suggest professional dominance, which is in conflict with self-care.

The findings are in concurrence with Orem, that the self-care framework aids nursing in keeping the complementary relationship between staff and residents as the prime concept in a nurse's development of insights about nursing and its practice. Chang's model with the refinements suggested in this section, offers valuable guidance and direction to nursing practice with the institutionalized elderly.

7.4.4 Implications and Recommendations for Nursing Research

Nursing in a long term care setting has received little investigative attention. An organized and systematic approach needs to be adopted in order to contribute effectively to the present knowledge base. Based on the data collected in this study, the following implications and recommendations for nursing research are suggested:

1. The design of this study contributed to the richness of the data collected. This design was conducive to investigation of the subject matter. There are other areas of resident perception which would benefit from the utilization of this design structure, such as, cognitively well residents' perceptions of the less cognitively well residents and the effects of the relationship on the resident's morale or lifestyle.
2. Further research of the modified components identified in the theoretical framework of the study, utilizing a larger institutionalized sample.
3. Factors influencing collaboration between nurses and residents were identified. A more sophisticated analysis, such as a observational-operant design would be of value in identifying particular factors that affect collaboration.

4. The impact of nursing charting upon nursing practice needs to be statistically supported. Although briefly explored in this study, an indepth investigation into the relationship between charting and influence upon nursing practice warrants scrutiny.
5. The coping strategies of the institutionalized elderly were briefly identified in this study. A more detailed ethnographic approach would assist in the analysis of this phenomenon. It would be of value to ascertain whether specific strategies can be identified that assist the elderly in dealing with losses.
6. Research on the extent to which passive, conforming behavior is a response to institutionalization or a personality characteristic of those residents that existed prior to admission to a personal care home.
7. Research on the relationship between medication use in the personal home care environment and resident self-control.
8. Further research in the area of resident decision-making, with particular focus on residents with cognitive impairment, such as memory loss and diminished judgment.
9. Research on the frail elderly in the personal care home and their sense of self-control.

10. Research on spousal separation, when one of the partners is admitted to a personal care home in advance of the other.
11. Factors influencing communication between health care professionals and the elderly of information and knowledge about treatment and prevention/promotion.

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Appendix A

CHART REVIEW

Code Number _______

<u>Demographic Information</u>

1. Sex M ____ F ____
2. Age at last birthday __________
3. Marital Status _____________
4. Religion ____________
5. Main language spoken _________________
6. Education level completed
    - less than high school ________
    - high school ________
    - college _______
    - university _______
7. Length of residency in the Personal Care Home _____________________
8. Last residency before admission to the Personal Care Home:
    - own home ______
    - hospital _______
    - own apartment ______
    - other, specify ________
    - living with children _____

9. With whom did the resident live before admission to the Personal Care Home?

lived on own ______ lived with child ____

lived with spouse ______ other, specify ____

10. Does the resident receive visitors to the Personal Care Home? __________

11. If the answer is yes, who visits:

family member ______ neighbour ____

friend ______ other,specify ____

minister _____

12. How often does the resident receive visitors?

13. Reason for admission to the Personal Care Home.

<u>Written Care Plan</u>

1. Are resident perceptions of their care written in the resident's record?
2. Where are they written? Nursing notes on the chart? Resident's kardex? Somewhere else?
3. Are resident expected outcomes written in the resident records?
4. Where are they written? Nursing notes on the chart? Resident's kardex? Somewhere else?
5. Does the charting of outcomes reflect resident involvement in plan of care? If so, describe.

Appendix B

INTERVIEW GUIDE

Code Number _______

1. Could you please tell me the reason for your admission to the personal care home?
2. Who made the decision for you to come into the home?
3. Could you tell me something about your health?

I would like to discuss some aspects of your care with you.

Grooming

1. Do you require assistance in grooming? (bathing, combing hair, brushing teeth, shaving)
2. Who determines when you do your personal grooming? You? Nursing staff? Other?
3. Are the times you do your care convenient?
4. If not, how would you change the times?
5. Are you able to bath as often as you wish?

Ambulation

1. Is exercise, such as walking, part of your daily plan of care?
2. Do you require assistance in walking or getting exercise?

3. Are you currently doing any specific treatment exercises? (e.g. physiotherapy 3 times a week)
4. Did you request the treatment?
5. Can you please tell me why you are taking the treatment?
6. Do you feel that you get all the exercise you want? You need?
7. If you felt that you received too much exercise, or not enough exercise, how would you go about changing it?

<u>Diet</u>

1. Are you on a special diet at the moment? Why?
2. If you are, who suggested this diet? You? Doctor? Nursing Staff? Dietician? Family?
3. Could you describe your special diet to me? (Probes: purpose, content, length of time on diet)
4. If you have any meal requests, who do you inform? Nursing staff? Kitchen staff? Other?
5. Do you require assistance in eating? If so, who assists you?

<u>Medication</u>

1. Are you currently taking prescribed medication?
2. Could you tell me something about the prescribed medication? (Probes: purpose, route, dose, side effects)

3. Did the nurses or the doctor tell you why you need this medication?
4. Who gives the medication? You? Nurse? Family? Other?
5. If you are not currently giving your own prescription drugs, would you feel comfortable about doing it? If not, why?
6. Do you take non-prescription drugs when you feel you need them (for example, when you have a cold or constipation), or do you request medication from the nurse or doctor?
7. Do you require any medical treatments, such as dressing changes, ointments applied?
8. If so, do you do them yourself? If not, could you please tell me why?
9. Do you know why you need this treatment? If so, who explained the the treatment to you?

<u>Activities</u>

1. How many times a week do you usually go outside the personal care home?
2. Do you get out as often as you wish? If not, why?
3. If you wished to go out more, how would you do this?
4. When you go out, do you go alone or with someone else? Family? Friends? Staff? Other?
5. Do you feel you attend as many activities within the personal care home, as you would like?

6. If not, how would you change this?

Satisfaction with Care

7. Do you think the staff show a personal interest in you?
8. Do you think the staff care about you?
9. If you require assistance from a nurse, does help come within a reasonable time?
10. Do you feel you are encouraged to do as much for yourself as possible? By nursing staff? By family? Other?
11. Do you feel that being in a personal care home has affected your interaction with others, such as family and friends? Do you see them less often? More often?
12. Compared to others your age, would you say your health is poor, fair, good, very good?
13. During the course of an average day, who determines most of your routine activities (for example, when you do your grooming, when you go outside of the home)? Yourself? Your family? Nusing staff? Other?
14. Are you happy with that arrangement or would you desire more say in over your daily activities?
15. In general, how satisfied are you with your care?
16. Are there any other concerns about your care, that you wish to tell me?

Appendix C

PROTOCOL FOR APPROACHING THE RESIDENT

"Hello, my name is Cheryl Walker. I am a student in the Master of Nursing Program at the University of Manitoba. I understand you have told the charge nurse that you are willing to participate in this study. The purpose of the study is to evaluate how much say you have in your daily care and how satisfied you are with your care. The information obtained from the study may be helpful in improving the care of residents living in personal care homes, but will have no immediate benefits to you as an individual volunteer. It is hoped that the results of the study can contribute to a better understanding of residents needs and concerns about their care in a personal care home.

Participation in this study involves answering questions about your daily care. For example; Do you require assistance in walking? It will take approximately one hour of your time and may be divided into two 1/2 hour sessions if you become tired.

The study involves meeting with myself, and if the interview occurs in German, then it will involve myself and a German speaking translator. Also I will be looking at your chart to gather some background information, such as age and last residence before coming to the personal care home. If you are interested in participating in the study, I will discuss the consent form with you, have you sign it and then decide on a mutally agreed time to meet for the interview. Do you have any questions at this time? Thank you for your time".

Appendix D

CONSENT FORM FOR RESIDENT

The major purpose of this study is to determine what things make you feel satisfied with your care and how much of your care you do. Although this research will not directly benefit you, it is hoped that the information from the interview will improve nursings' understanding of the needs of older people living in personal care homes. The study is being done by a graduate student, Cheryl Walker, School of Nursing, University of Manitoba. It is being supervised by Cynthia Cameron, Assistant Professor at the School of Nursing, University of Manitoba.

If you decide to participate in this study, I would like to ask you questions, in an interview format, about your participation in daily care. For example, do you get all the exercise you feel you need? I would also like to ask you your thoughts on the care you are currently receiving. The interview will take about one hour of your time. If this seems too long for you, the interview can be scheduled for two 1/2 hour periods. Also, the interview will be done in the language of your choice, either English or German. If done in German, a translator will be required.

I would like to use a tape-recorder during the interview, and also to tape the translator if you cannot speak English. If the presence of the tape-recorder makes you uncomfortable in any way, it will not be used. The tape will not be identifiable with you and the tape will be erased upon completion of the study. All tapes and field notes will be locked in a filing cabinet in the investigator's office.

There is no obligation to participate in this study. Those who choose to be volunteers for the study may drop out at any time. Withdrawal from the study will in no way affect present or future care provided by the staff in the personal care home. Participants may also refuse to answer any questions, or ask any questions of the investigator at anytime during the interview. I will also be looking at your records for information about the reason for admission to the personal care home, and some background information, such as how long you have lived in the personal care home.

Any information that is obtained in connection with this study will be identified by a number and your name will remain anonymous. Specific answers given to me or the translator, will remain confidential and will be discussed only with my research committee. The need for confidentiality has been explained to and will be observed by the translator. The written report of this study will not refer to specific residents, but will refer to residents as a group. No individual resident will be identified in the final report. A copy of this consent form will be provided to you. When the information is analyzed by the investigator, a brief summary of the final results will be made available to participants in the study who would like this information.

Date	Signature of Respondent
Date	Signature of Investigator Cheryl Walker Home phone 261-0495 University phone 261-5839
Date	Signature of Translator

Appendix E

PRIOR PLACE OF RESIDENCY IN RELATION TO LENGTH OF RESIDENCY

Length of Residency in a Personal Care Home	House	Child Home	Hospital	Other
1 - 5 yrs	9	3	2	3
6 - 10 yrs	5	0	1	1
11 - 15 yrs	0	0	1	1
16 - over	1	1	1	1

Appendix F

PRIOR RESIDENCY

Length of Residency	Alone	Spouse	Relatives	Institution	Child
1 - 5 yrs	7	4	1	1	4
6 - 10 yrs	3	4	0	0	0
11 -15 yrs	1	0	0	1	0
16 - over	2	0	2	0	0

Appendix G

RELIGION OF THE RESIDENT IN RELATION TO LANGUAGE

	Menn.	United	Roman Catholic	Other
German	13	1	0	1
English	5	5	4	1

Appendix H

LENGTH OF RESIDENCY IN RELATION TO LANGUAGE

Length of Residency in a Personal Care Home	German	English
1 - 5 yrs	10	7
6 -10 yrs	4	3
11 - 15 yrs	1	1
16 -over	0	4

Appendix I

LENGTH OF RESIDENCY IN RELATION TO MARITAL STATUS

Length of Residency	Widowed	Married	Single	Divorced
1 -5 yrs	13	3	1	0
6 -10 yrs	5	1	1	0
11 -15 yrs	1	1	0	3
16 - over	0	0	0	1