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DISTRICT NURSING CLIENTS:
PERCEPTIONS OF PARTICIPATION IN NURSING CARE

A thesis presented
in partial fulfillment of the requirements
for the degree of
Master of Arts
in
Nursing at
Massey University
Palmerston North, New Zealand

WILMA AUDREY YOUNG
1989

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I apologize to readers who may be inconvenienced by these typographical errors. Please amend body of text as follows:

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ABSTRACT

Research on participation in nursing care is sparse in New Zealand, particularly in the district nursing field. No studies were found on participation from the perspective of the New Zealand client of district nursing care. This study initiates steps to fill this gap by examining the question "What are the perceptions of district nursing clients toward participation in their care?". An exploratory descriptive study using a multiple triangulation design provided a background data base and revealed rich, meaningful qualitative information. Thirty eight district nursing clients were interviewed seeking quantitative data which were statistically analyzed and qualitative data which were analyzed using analytic description technique. The district nurse/client relationship studied here provided evidence supporting Kim's (1983a) theoretical framework of collaborative decision making, particularly that the nurse controls the "client's propensity to participate" through "allowance" or "sanctioning" of participation (p.279). This research discovered that from the client's perspective the district nurse guides the client/nurse relationship, encouraging the client's participation through discussion. Client and nurse cooperated and worked together to achieve a mutual goal of selfcare and independence. Study clients acquiesced to the nurse's guidance as a result of preconceived patient/nurse role attitudes and deference to the nurse's professional expertise. A continuum of participation was conceptualized with four perceptions of participation evident in this study: 'Withdrawal' of those who did not wish to participate; 'Acquiescence' or supporting the status quo by consenting without comment; a mid-point of 'Cooperation and Working Together'; and, 'Taking more Control' of care.

DEDICATION

I dedicate this thesis to the people who participated in the research - the clients. Without their participation and co-operation I would have nothing. My thanks.

I also thank the District Nurses who indirectly assisted in this research by nursing the clients I interviewed. I add my admiration to those of a grateful caregiver below.

TRIBUTE TO NURSES

Sir. - I would like to pay tribute to a wonderful group of people, who I feel may be taken for granted in the normal course of events. I refer to the district nurses, who undoubtedly ease the burden of spouses and families of patients who wish to remain in their homes rather than be hospitalised.

My husband passed away recently after a short but very trying illness, during which he needed a great deal of care, and without these dedicated people I could never have coped with nursing him.

They came in pairs, three times a day, armed with linen, towels and all the necessary equipment, and never once did we see anything but kindness and caring. everything was done without complaint, and always with a smile.

I will always be grateful for their help, as they enabled me to keep John at home with his family which was his last wish.

I hope you will publish this letter, as I believe many people have no idea this service is available, or how extensive it is.

Moir Glasgow
Palmerston North.

Letter to the Editor. Evening Standard, Palmerston North, New Zealand. Monday, October 3, 1988

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It is my pleasure to acknowledge those who helped this thesis to materialize. With sincere gratitude

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As a Canadian, the two years I have spent in New Zealand have been, for me, an ethnological exploration of the New Zealand way of life. To all those who helped that process - Merci beaucoup, I am very grateful.

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CHAPTER 1: INTRODUCTION

SECTION I: OVERVIEW

What affects health and the quality of life most is not what is done by the physician, dentist, nurse, or other clinical provider. The greatest potential for improving health is through changes in what people "do and don't do to and for themselves".

Victor Fuchs (1975, p.55)

Active participation of the individual in health care is essential. As Fuchs' statement succinctly states, participation has considerable benefits for clients, reducing disease symptoms and medication side effects, decreasing the risks of end-organ damage and morbidity, and increasing the quality of life. Individual participation in health care can reduce anxiety and stress and enhance treatment outcomes (Kim, 1983a). Providers benefit by reduced utilization and costs, and improved services to those requiring more direct or acute care (Given, Given, & Coyle, 1984). Vital as it is, achieving and maintaining active participation of clients in their health care presents a substantial challenge to providers of health care.

Viewing patients as responsible, intelligent, active participants with important contributions to make in their health care is not consistently practiced. Indeed the literature review that follows in Chapter 2 presents overwhelming evidence that the present day health care system falls short in that regard. A traditional viewpoint prevails that the doctor or nurse controls the relationship with the patient expected to be a passive recipient of care complying with the professional's goals. The values, priorities, or goals of the patient play little part in decision making regarding his or her care. Quite understandably, patients frequently do not commit themselves to the professional's goals of treatment (Hayes-Bautista, 1976).

In addressing this issue, a relationship of collaboration and participation between health care provider and client which has

been successful in promoting health is advocated by physicians and nurses (Eisenthal, Emery, Lazare, & Udin, 1979; Kasch, 1986) and by clients or consumers of health care (Bergman, 1986).

Nurses have long recognized that the understanding, cooperation, and participation of the patient in mutual planning of care is imperative. Nursing professional standards of care emphasize client involvement and shared decision making, but research is scarce on how this participative, collaborative relationship is achieved (Conway-Rutkowski, 1982a ,b; Kasch, 1986). In particular, the client's perceptions are inadequately known (Kim, 1983a; Roberts, 1982). An essential antecedent is to develop knowledge of clients' attitudes and perceptions as they relate to participation in care (Rieder, 1982). Therefore the present study proposes to initiate steps to fill this gap in one area of client care - District Nursing.

Participation in District Nursing Care

Active participation of clients is reflected in nursing standards and philosophy of care in New Zealand (NZNA, 1981, 1985). Encouraging participation in decision making about health care and mutual setting of goals is a function of the professional nurse providing home care (Chick, 1983; NZNA, 1974, 1978; Powell, 1986). The Palmerston North Hospital Board, for example, specifies that one of the standards expected of a District Nurse is "consultation with the patient and significant others" shown by involving "the patient in his own care and planning of objectives".¹

¹ Palmerston North Hospital Board Nursing Staff Appraisal, District Nurse Standards, Standard 1b.

Statement of the Purpose

Beliefs, values, and assumptions about participation are practiced, but are not based on specific New Zealand research. Nursing care in the community is presumed to be influenced by philosophies and values encouraging participation (Chang, 1980; Kim, 1983a; Pybus, 1983). These presumptions have not been closely examined in New Zealand from the client's viewpoint; therefore, using a triangulated approach it is the intent of this study to:

- initiate research on participation in individual health care in the New Zealand community;
- contribute to a base of knowledge about district nursing clients and their participation in nursing care;
- seek greater understanding of the range and depth of the meaning of participation to the individual human experience;
- describe an emic point of view of the phenomenon participation; that is, from the perspective of those experiencing it.

Study Question

This study proposes to examine the participation of New Zealand district nursing clients through the perceptions of the client. It expects to answer the question

"What are the perceptions of district nursing clients toward participation in their care?"

Definitions

For the purposes of this study:

Participation is defined as a reciprocal relationship composed of receiving information, having choices, making decisions, planning, and negotiating; it includes elements of one's perceived self-ability to participate and experiencing a feeling of control over care.

Perception is defined as an individual's unique world view from their own perspective (King, 1968).

The Structure to Follow

Section II will explain the relationship of participation to nursing theory and examine the theory used to structure this study. The following Chapters describe the approach used to explore the topic of district nursing client's participation in nursing care. Chapter 2 presents a literature review of participation theory and client/nurse/physician relationships organized within the framework of Kim's (1983a) model. Chapter 3 describes the methodology of the research carried out for this thesis. Analysis, results, and interpretations follow in Chapter 4. Conclusions and implications sum up the thesis in Chapter 5.

SECTION II: THEORETICAL FOUNDATIONS

This section will briefly place participation in the context of nursing theory, and as the theoretical base for the present research. The participation theory guiding this research will be described in detail.

Nursing Theory and Participation

Nursing theory is concerned with differentiating nursing from other disciplines and activities (Stevens, 1979). It is a way of looking at the world from a uniquely nursing perspective. While nursing theorists have distinctly different perspectives of the world, there are certain elements common to all contemporary theories, models, and frameworks of nursing. These commonplaces, commonalities, or areas of agreement are discussed by Stevens (1979), Flaskerud & Halloran (1980), and Meleis (1985) extensively.

One area of agreement for all theorists is that the domain of nursing should include the situation and interplay of nurse, patient, society, and health. The view of how these concepts interrelate is particular to each theorist and some have argued that other elements should be included or excluded in this domain, but there is general agreement of these domain concepts (Meleis, 1985). Meleis (1985) proposes that nursing theory explains nursing in a manner like the following:

The nurse interacts (interaction) with a human being in a health/illness situation (nursing client) who is an integral part of his sociocultural context (environment) and who is in some sort of transition or is anticipating a transition (transition); the nurse/patient interactions are organized around some purpose (nursing process) and the nurse uses some actions (nursing therapeutics) to enhance, bring about, or facilitate health (health). (p.184).

Stevens (1979) maintains that nearly all nursing theories focus on "the nursing act, the patient, or the relationship between patient and nursing act (i.e. the interaction phenomenon

itself)" (p. 12). Within the domain of nursing the notion of some type of interaction to describe the dynamics between concepts is common to all nursing theorists. Contemporary theorists contend or imply this is a reciprocal exchange (Cox, 1982; Kim, 1983b; Kogan & Betrus, 1984; MacElveen-Hoehn, 1983; Meleis, 1985; Stevens, 1979). It is here argued that the interaction which occurs between the human elements of the nursing domain must be achieved through the process of participation, for the relationship cannot be mutual (reciprocal) unless both parties join in or take part (participate). Therefore the concept of participation is a fundamental sub-concept of contemporary theories, models, or frameworks of nursing. As such participation need not be associated with one particular model of nursing, but is applicable within all.

Participation: Theoretical Base for This Study

A theoretical framework for collaborative decision making in nursing practice was proposed by Kim (1983a) in which the term collaboration is used to encompass the process of participation. Basing her framework on the assumptions that the nursing care situation requires many decisions influencing health and that clients have resources to be active participants in decision making, she presumed their participation may have effects on the outcomes of nursing care.

Kim (1983a) establishes that there are three concepts relevant to the concept of collaboration that require rethinking; client/professional relationships, the sick role, and the theory of participation. The first two will be discussed extensively in Chapter 2, with both professional and lay viewpoints given, along with participation theory.

The theory of participation establishes that control and influence in varying degrees of decision making (equal

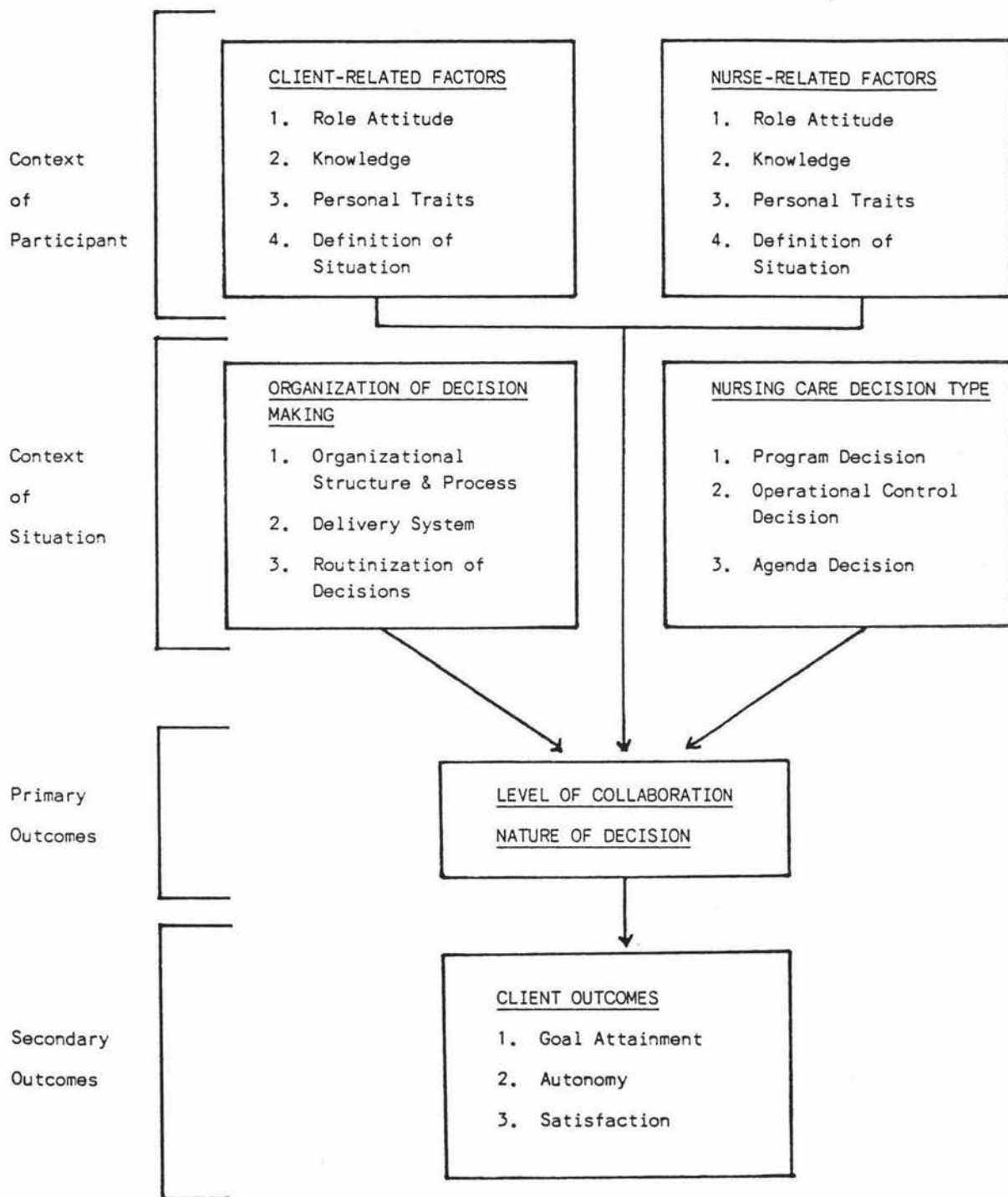
representing the ideal) enhances positive outcomes. In rethinking the concept of participation Kim (1983a) makes the same point as Stevens (1979) who argues that the nature of participation in nursing has not been seriously examined, yet token concession has been made to the idea of patient participation in nursing care planning and delivery. She charges that patient participation is incorrectly conceptualized in cases where patients are assumed to have equal status (professional) or equal knowledge with the nurse. Stevens (1979) believes it is foolish to treat the patients as though they are peer professionals; if they were, they would have no need of nursings' expert knowledge. Patients come to nursing to seek professional knowledge and judgment. The relationship between them should be a partnership, but a partnership of unequals, where each has a "separate and different expertise from the other" (p.260). The nurse is an expert in nursing and the patient is an expert on him or herself.

Only a theory which reflects this distinction can constitute the partnership between nurse and patient. Stevens (1979) explains under the umbrella of 'participation', the nurse commonly tries to teach the patient nursing expertise, rather than using the patients' self expertise, and then expects the patient to agree to a plan of care based on his/her inadequate judgment of the situation from the nurse's perspectives. Balch (1974) describes just such a process in an insightful analysis of her own nursing practice. Misusing participation in this way is a misunderstanding of the concept of participation and under-utilizes the patient's contribution as a partner in the process.

Kim (1983a)² proposes a theoretical framework for the process of collaborative decision making which encompasses seven variable components: client, nurse, organization, decision type, level of collaboration in decision making, nature of the decision, and client outcomes (See Figure 1: 1). Two contexts - who is involved

² This following section explains Kim's (1983a) theory in detail therefore continual citation is redundant.

Figure 1.1 A Theoretical Framework for Collaborative Decision Making in Nursing Practice.



in making the decision, client and nurse, and in what type of situation, organization and decision type, in which clients participate in decision making modify and influence degree of involvement. These four "independent and interdependent variable components (client, nurse, organization, and decision type) influence participation in decision making by "sanctioning, through which clients may be 'allowed' or 'prevented' to collaborate in the process, and by promoting mechanisms through which clients may be 'enhanced' or 'detracted' to participate in decision making (p.277).

Kim theorises that client's propensity to participate in nursing care decision making is influenced by:

1) Clients' role expectations and attitudes --Internalization of expected roles formed by social interpretations and experience in the role shape the degree and ways in which clients expect to "have any voice in nursing care decision making" (p.278).

2) Client's knowledge-- A dependent role is often assumed in situations requiring expert, technical knowledge when clients perceive themselves to be inadequate in knowledge requirements. Level of knowledge will affect tendency to participate.

3) Client's personal traits-- Some clients, because of personal characteristics (locus of control, health beliefs, self efficacy etc.), normal coping patterns, or other traits are more likely to participate in decision making.

4) Client's definition of the situation--

Client's perceptions and definitions of situations in which decision making takes place vary in terms of the degree of freedom of choice, the degree of sanctioning present for certain behaviors, and the attribution of responsibilities. Such perceptions and definitions are interpreted by individuals as situational constraints within which they may be "permitted" to influence outcomes of the situations. Since cognitive science theories postulate that a person's actual behaviors are

often modified by such perceptions, we can postulate that clients may participate in nursing care decision making only to the extent that they believe they have control over the outcomes. (p.278)

The nurse has more power and control in the nursing care decision making situation than the client. The nurse's characteristics influence the degree of "allowance" for client participation similar to the client's.

- 1) Nurse's role expectations and attitudes - The nursing role is internalized through social, experiential, and professional expectations which shape attitudes and behaviors. The nurse's attitudes toward client collaboration in decision making and expectations held toward patient behavior influence the degree of participation allowed.
- 2) Nurse's knowledge - High levels of expert knowledge may be perceived as a greater difference between clients' and nurses' knowledge levels. The nurse may view this a need to have control.
- 3) Nurse's personal traits - The nurse's behaviors are influenced by same personal characteristics as the client.
- 4) Nurse's definition of the situation - Nurses' perceptions vary in the perceived amount of inherent power and attribution of responsibilities. Therefore nursing behaviors influencing degree of allowing client participation in decision making are modified by specific expectations of exercise of power in decision making.

Since patients' goals and knowledge are known to differ from nurses' goals and knowledge (Brands, 1983; Chang, 1978; Elbeck, 1986; Gardner & Wheeler, 1981, 1987; Whiting, 1959), and propensity to participate is faced with "allowance" to participate Kim suggests that reconciliation between these disparities occurs through negotiating. According to Kim (1983b) negotiating entails

"a reciprocal, dynamic exchange between the nurse and the client in an effort to arrive at a mutually acceptable solution through a balanced use of expert knowledge, power, human sensitivity, and understanding" (p.143).

Decisions are made within the context of the organization and organizational factors such as when, where, and under what conditions decision making occurs. The type of decision is relevant to different kinds of client outcomes. Three different outcomes are postulated by Kim's model. They are the level of collaboration, the nature of the decision, and client outcomes. The former two are immediate, primary outcomes of process while client outcomes are a consequence of these two. Kim views the level of collaboration in nurse/client relationships as a continuum, where the lowest level is complete domination of decision making by the nurse and the highest level as equal joint decision making between client and nurse. Client outcomes such as goal achievement, perceptions of satisfaction, autonomy, and control, or improved health status and/or recovery are dependent on the variable level of collaboration.

Preliminary study in North America based on this theory showed that while nurses believe in collaborative decision making, circumstantial factors often interfere with implementing this belief. One such study found that "elderly clients receiving nursing care at home from visiting nurses ... have a desire for a greater level of participation than they perceived had been granted to them by nurses" (p.282).

Kim suggests that her theory is operationally feasible and useful for further empirical study. It will help to fill the areas where nursing knowledge is deficient about participation and collaboration. She raises numerous research questions which sparked the present investigation into district nursing client's participation in nursing care. The research being reported here is based on Kim's (1983a) theoretical framework of collaborative decision making in nursing practice.

CHAPTER 2: LITERATURE REVIEW OF THE CONCEPT OF PARTICIPATION

While the topic of this thesis is District Nursing clients' participation in care, a brief prologue to the concept of participation in its broader context in events affecting one's whole life and social environment is indicated. The people participating in this study are not just consumers of health care; they are citizens, mothers, fathers, schoolchildren, employers, workers, housewives, grandparents employed, retired...and so on. They are individuals engaged in the fabric of living, and their lifelong participation patterns in living continue in their interactions with the health care system. Government, education, leisure, social relations, work, health, sickness, living conditions - these and others are the basic concerns which one must participate in and have some control over in order to influence one's destiny and lifestyle.

SECTION I: PARTICIPATION AS A CITIZEN AND WORKER

Decision making and consensus are key issues of participation as a citizen in governing the workings of community living. Who makes the decisions? How they are arrived at? Who has input into them? Will powerful persons make them all? Questions such as these are of vital importance to people's lives, yet as modern society grew and expanded, people yielded their decision making powers to others. Yielding to chiefs, royalty, their elected representatives - in short, to their leaders, chosen or otherwise - to people who were interested in, and possessed characteristics and abilities to participate in democracy, politics, and government.

Beliefs, assumptions, and values about participation in contemporary society often reflect John Stuart Mill's classic theory cited in Abrahamsson (1977):

1) Only if all citizens participate in the political decision-making process can political decisions be guaranteed to reflect the interest of the mass of people.

2) Participation educates those who participate, thereby making them permanently able to defend their own interests.

3) Participation develops the individual's personality, making the citizen aware that he is part of total society, and making him feel he is responsible not only to himself but to society at large. (p.202)

Pateman (1983) in reviewing classic theorists points out that a classic view of democracy defined participation as "a fundamental means of political education. Citizens learned how to participate by being active in a wide variety of social institutions..." (p. 109). But Stromberg (1978) points out that "even under the best of conditions, most people tend to avoid participation and involvement." (p.35).

If participation is defined in terms of social learning, it can be explained how those most likely to participate (white, male, and middle-class) seem to have the necessary qualities to participate as active citizens, while those least likely to participate (female; non white, different culture; low-skilled, low-status working class) do not possess the necessary qualities (Pateman, 1983). Those least likely to participate are also least likely to have had the opportunities to learn how to participate, or to have developed feelings of competency or efficacy in effective participation.

Pateman (1983) identifies another group of non/participants as those who feel competent in participation but may not think it is worth the effort, since participation benefits those who are well off already. That is, perceptions of relative power are the crucial determinant, making participation worthwhile only when one feels it can make a difference.

Participation, as a concept, argues Pateman (1970) must be participation in something. As a citizen and in industry she

defines participation as full involvement in decision making with equal power to determine the outcome of decisions. Partial participation is influencing a decision without equal power to decide outcomes. Pseudo-participation is one way information passing or discussion for therapeutic or persuasive reasons where one party dominates.

With another viewpoint, Stromberg (1978), defining participation as "Taking part in or influencing the events or issues that affect one's existence" considered that participation could be measured along a continuum, with one end of the scale representing participation in its most passive form (inert), and the other end as the most active form (full authority). Stromberg (1978) contends that passive participation in which one remains inactive with a lack of opposition when some type of action or decision is called for is participating. By doing nothing the individual is indirectly supporting the status quo, therefore is doing something. He hypothesized that there was a positive relationship between client satisfaction and participation, assuming that a satisfied client would remain passive, however no relationship between satisfaction and participation was found.

Decision Making and Control in the Workplace

Participation in the workplace has been extensively studied both from worker and management point of view (Bernstein, 1976; Butteriss, 1971; Guest & Fatchett, 1974; Heller, Drenth, Pieter, Koopman, & Rus, 1977; Nightingale, 1981; Norton, 1976; OECD, 1976). Although vague as a definition, basically the idea of participation in the workplace is that people who are managed should have some say about the decisions that affect them (Guest & Fatchett, 1974). Abrahamsson (1977) defines participation as "the involvement of employees in decision-making on different levels in an organization" (p.186) since the key issues of participation in the workplace are control and decision making.

A major omission in theory on participation in the workplace

is the conventional consideration of work and where it takes place (Pateman, 1983). The worker is thought of as a man who goes out from the home to work. Although constituting a major part of the workforce, women's work in the home, and women's work in the workforce is devalued (also Gamarnikow, 1978). In a type of patriarchal exploitation women's contributions are ignored or considered incidental as possible participants. Pateman (1983, 1970) considers this relationship to be pseudo-participation or non/participation.

Participation in the workplace is believed to influence job satisfaction and productivity (Guest & Fatchett, 1974; French, Kay, & Meyer, 1966). Norton's (1976) study showed that participation in decision making was significantly correlated with satisfaction with work itself. However, O'Brien (1983) found no evidence that employee participation increased job satisfaction or affected productivity in his study. He proposed that participation in decision making is only satisfactory to the worker when decisions made are meaningful to the employee; when desired job changes result; or when wage level rises equal to skill-level and responsibility growth.

O'Brien (1983) also suggested that "collaborative decision making can often be a powerful way of reducing productivity" (p.85). Modified by the type of supportive relationships between the worker and management, French, Kay, & Meyer (1966) found that experimental participation can have "strong negative effects on subsequent performance improvement" under conditions where there was perceived high threat in the present situation with a usual level of low participation" (p.18). It appears that as time and experience with participation has increased the worker has come to expect and want more from their participation.

The style, structure, and size of the organization influences participatory levels and positive feelings of employees in decision making and control (Nightingale, 1981). Authoritarian supervisory style combined but inconsistent with formal decision-making rights of subordinates was indicated as a major problem in

Nightingale's (1981) study. Conflict surfaced when people were prevented from participating in decision making, when they believed it was their right. In conjunction, Abrahamsson (1977) maintains that "participation rate declines steeply with increasing organizational size....The larger the organization, the less chances there are for establishing direct interaction between all members" (p.205).

— Active participation of everyone in the workplace, however, is not considered necessary nor is it considered feasible as a citizen. Citizens and workers are sometimes reluctant to voice their opinions personally and may defer that to another. Difficulties are encountered in putting various forms of participation into practice in the workplace (OECD, 1976, p.15).

In summary, participation as a citizen or worker means being involved, influencing events, having control, and making decisions in varying degrees. Participation must be meaningful, and is associated with rewards and power. Beliefs and assumptions about participation are not always put into practice, although they exert major influences on all areas of participation in one's life. Such values extend to participation in health care.

SECTION II:

PROFESSIONAL AND CONSUMER RELATIONSHIPS IN HEALTH CARE

Relationships between professional and consumer in health care are complicated and multifaceted (Daniels & Kochar, 1979; DiMatteo & DiNicola, 1982; Friedman & DiMatteo, 1982; Fuchs, 1974; Graner, 1986; Reeder, 1972; Stimson & Webb, 1975). As doctors dominate within the health services field, their power and control has the most influence on these relationships. It is the doctor/patient interaction that is often examined in the following literature review.

A nurse/client relationship proposed by Kim (1983a) theorizes that client/professional relationships, the sick role, and participation theory require examination and rethinking. Kim's (1983a) model proposes that the context of the participant in which the role attitudes, knowledge, personal traits, and definition of the situation for both client and nurse, and the context of the situation influence outcomes of decision making and care (see Chapter 1 for complete explanation). The following literature review and discussion of the theory underlying these relationships is organized within Kim's (1983a) framework to provide a background for the research reported in this thesis.

Context of Participant

Definition of the Situation

The emerging philosophy of participation in health care is egalitarian. Participation is the keynote of a world-wide consumer health care movement partly resulting from a better educated and more aware public who

"are no longer willing to be blind recipients of whatever treatment the doctors, nurses and others decide to give them. They want to know what is wrong with them, what alternatives for care exist and to take part in the decision-making process" (Bergman, 1986, p.111).

People believing in this philosophy contend that clients are active participants in their health care with access to essential knowledge enabling them to exercise control over elements affecting their health. Health care professionals are regarded as consultants or facilitators in a collaborative relationship, viewed as a therapeutic alliance to achieve care of self (Boettcher, 1978; Chang, 1980; Gartner & Reissman, 1974; Given, Given, & Coyle, 1984; Kogan & Betrus, 1984).

This philosophy is not necessarily echoed by all those delivering health services. Research has found that while both concerned citizens and health professionals want to exert control over management and operation of health services, they have different perceptions of the degrees and "ideal" amounts of involvement (Caporael-Katz, 1983; New, Holton, May, & Hesler, 1977) and the scope of responsibilities (Gentry, Veney, Kaluzny, Sprague, & Coulter, 1974; Kane & Kane, 1974; Thompson, 1980). For example, citizens in the New, Holton, May, & Hesler (1977) study, perceived themselves as having control over political and organizational health care delivery, and participating in clinical aspects with professionals as advocates. On the other hand, professionals in the study, saw themselves retaining complete control over clinical aspects, participating in organizational matters while allowing citizens minimal participation, but preferring to leave the political arena to the citizens.

Power Relationships

Since the degree of participation and equality of decision making is known to be subject to power relationships (Bailey, Theile, Ware, & Helsel-DeWert, 1985; Partridge & White, 1972; Salber, 1975; Sparer, Dines, & Smith, 1970; Warner, 1981), an explanation of power is needed. Power is a major influence on role attitudes.

Assumptions that patients will take on a passive/dependent role that must be 'guided or led' permeate doctor/ patient

relationships. Patients (and nurses) rank very low in medicine's status hierarchy (Caporael-Katz, 1983; Oakley, 1979; Roberts, 1981). The source of these assumptions lie in social power relationships (Rodin & Janis, 1979, 1982). Power is thought of as the ability to make people do things that they might not otherwise do, or stop them from doing things they might do; it may be termed potency or mastery and its standard is effectiveness in determining or influencing behavior in others (Kalish & Kalish, 1981). Six sources of power have been identified: expert, informational, legitimate, coercive, reward, and referent.

Expert power is the base of power for medical professionals. This power set derives from the special body of knowledge held by medicine; knowledge too specialized to be communicated to the public who were unable to make intelligent judgments about it (Jordan, 1983; Sommerville, 1988; Stone, 1979). Expert and informational power is exercised by controlling the flow of specialized knowledge and information from expert to uninitiated. Legitimate power derives from superior knowledge, genuine skill, and experience (Rodin & Janis, 1982; Stone, 1979).

Expert, informational, and legitimate power invest medicine with authority viewed as "the right to expect and command obedience" (Kalish & Kalish, 1983, p. 213). Haug & Lavin (1980), though, define authority as the right to direct interactions in therapeutic encounters, rejecting the notion of commanding obedience and demanding compliance.

Coercive power is a function of authority based on force while reward power is based on inducement (Kalish & Kalish, 1983). Both are attempts to gain voluntary compliance through using commands, manipulation, direct force, or threats in the former case, or influence through use of persuasion, ingratiation, or rewards for obeying in the latter case. Rewards can be tangible or intangible benefits such as praise, warmth, time, or availability (Rodin & Janis, 1982).

Referent power is based on acquiring power as a significant reference person (Janis, 1983; Rodin & Janis, 1978, 1982). This

equal power set relies on motivation, acceptance, encouragement, benevolence, and change, beginning with disclosure of expectations and hidden agendas, establishing cohesiveness and trust, free exchange of information, and teaching vigilant decision making.

Paternalism and Dominance.

Expert, informational, legitimate, coercive, and reward power maintain the balance of power in favour of the dominant. Their use can be illustrated by the paternalistic example of father and child. Patronization may characterize this relationship, with expectations of blind trust that things are done "for your own good" (Ehrenreich & English, 1979). Father "knowing best", with the right to make decisions, directs and controls the child's actions through coercion, commands, and expectations of obedience. The child tries to influence decisions through manipulation, persuasion, force, and disobedience. The resemblance to government/citizen, management/worker, physician/patient, relationships in preceding models is evident. Continued failure to influence or induce more powerful persons in positions of unbalanced power may lead to the dysfunctional reactions of alienation (Seeman, 1959), powerlessness (Rodin & Janis, 1979), and learned helplessness (Taylor 1979).

Unbalanced power relationships are characterised by domination, although the dominated are not always powerless. The subordinate either makes a commitment to, or alienates from, the directives or goals set by more powerful personages (Edel, 1985). Commitment to another's goals leads us to the central issue of doctor/patient/nurse relationships--that of complying with medical orders, following doctor's recommendations, or agreeing to recommendations for needed improvements in one's health. It will be shown in the following pages that the issue of compliance is largely the result of a one-sided authoritarian viewpoint of doctor/patient/nurse relationships.

Language influences the issue as well (Edel, 1985). Different

associations and connotations may foster negative power-based relationships. Reeder (1972) remarks that being a patient/client delivers power into the hands of the professional, while being a consumer implies caveat emptor; negotiations and bargaining are subordinate stances but the purchaser of services dominates. A concern for terminology is consciousness raising in that while appearing trivial, it focusses attention on "something far more fundamental-- citizen participation in health care" (Reeder, 1972, p.410).

SECTION III:
INDIVIDUAL ROLE ATTITUDES AND
CLIENT/PROFESSIONAL RELATIONSHIPS IN HEALTH CARE

Individual participation in health care can be classified within the various elements that constitute its whole. As reviewed in the literature so far participation has meant having or exercising control through being involved in and influencing decision making. Knowing or learning how to participate requires knowledge and education. Participating or not participating may depend on the use of power. Participation is a dynamic give and take relationship described in various ways as consultation, negotiation, alliance, or similar ideas. Associated with rewards and meaningful behavior participation enhances personal growth as a citizen, a worker, and a consumer.

Individual participation in health care will be discussed here classified within Kim's (1983a) framework of context of the participant and situation under the major elements of role attitudes and control, knowledge/information, decision making, and negotiation relationships. Organizational structure and process, and the delivery system of care as they influence participation are examined.

Context of the Participant

Role Attitudes and Control

The issue described as compliance/noncompliance in medical literature arises directly out of the unequal power relationship between doctor and patient and the question of control. Indeed, the negative implications of the word compliance have been much discussed (Edel, 1985), and adherence is proposed as an alternative. The distinction is ambiguous since both words have come to mean 'do what the doctor orders'; 'failing to adhere' carries the same connotations as 'noncompliance'- that of 'bad'

Szasz and Hollender (1956) discuss the gratifying nature of the first two models, which satisfy needs for mastery and superiority, but demand that the physician detach from identifying the patient as a person. The second model allows the physician to mold patients into a like image of himself, seeing the patient as potentially like himself, in total agreement with the same aim..

Parsons (1972) also, expects the patient will adopt the physician's aims. "Therapeutically, recovery is defined for him [the sick person] as a job to be done in cooperation with those who are technically qualified to help him." (p.114, emphasis added in the first case). Expectations of sick role and sick role behavior were first postulated by Parsons in 1951 (Parsons, 1972). Norms of behavior for the role of being sick are 1) the sick person is not responsible for the illness but is obligated to seek help; 2) illness is legitimate and exempts the sick person from normal roles and tasks; 3) being ill is undesirable, the sick person is obliged to try to get well and must cooperate with others to achieve this; and, 4) the sick person is obligated to seek competent and professional help and to try to prevent threatened illness (p.107). The sick person takes a dependent role, needing help, described as the secondary gain of conditional legitimation bought at the price of acknowledging that "illness itself is an undesirable state, to be recovered from as expeditiously as possible". In order not to tempt the well to fall ill, illness has to be regarded as "deviant behavior" (Parsons, 1972, p.108). If the patient is believed to not be working actively to get well, the legitimacy of the sick role is doubted, and questions raised that the patient is "malingering" (p.113).

Szasz & Hollender's (1956) and Parsons' (1972) theories sum up the prevailing thought on doctor/patient relationships from the medical viewpoint. Treatment is imposed by the physician who demands willing compliance. If compliance is not forthcoming, a power struggle ensues and moral judgments of 'good' or 'bad' patients are made. This mode of thought has ended with power and control firmly in the hands of the physician, in spite of the

small cadre of medical practitioners who attempt to practice in the mutual-participation mode (Bloom, 1963; Eisenthal & Lazare, 1977; Eisenthal, Emery, Lazare, & Udin, 1979; Kleinman, 1980; Kleinman, Eisenberg, & Good, 1978; Stone, 1979).

The following theories propose a reciprocal relationship. The role theory model proposed by Dracup & Meleis (1982) focuses on the premise that the sick or at risk role is incorporated into self concept, and when reinforced by significant others and other reference groups leads to compliance. The cognitive model recognizes that patients are intelligent beings capable of rational decision making and supports information giving, teaching and knowledge sharing (Daniels & Kochar, 1979). The health transaction model moves on to encompass the whole relationship between expert and client in mutual participation and equal power sharing, utilizing the professional as an expert advisor, working together on a common goal, with shared responsibility for compliance. The professional should fully assess the patients' expectations of role, difficulties, and outcomes, then share professional expectations with the patient (Stone, 1979).

Clearly perceptions of the patient role differs widely. Perhaps the clue lies in Suchman's (1972a) statement that patients experience illness while doctors seek and treat disease. Mechanic (1972) adds that patients use a commonsense model of health and coping with disease which does not conform to the physician's model. From this perspective "to stop medication or cancel a follow-up visit when he is feeling well, is logical" (p.126). Problems of noncompliance result from lack of understanding between participants (Kleinman, 1980). Patients are less satisfied with care when they want their illness dealt with but only the disease is treated. To treat both illness and disease together a negotiation transaction between the patient/doctor explanatory models of sickness must be assessed and made explicit. The practitioner "actively negotiates with the patient, as a therapeutic ally, about treatments and expected outcomes" openly comparing models, pointing out discrepancies, and seeking

conflicts in goals (Kleinman, Eisenberg, & Good, 1978, p.257). This type of relationship is not the norm in the sickness care system, especially in hospitals.

The Context of the Situation

The Hospital: Patient Role Attitudes

The circumstances in which the participants interact in participative decision making are influenced by organizational structure and process, by the delivery system, and by external organizational factors (Kim, 1983a). Role attitudes and client/professional relationships are strongly influenced by the bureaucratic organization of a hospital. Certainly health care system professionals retain power and control in institutional settings (Glogow, 1973). Taylor (1979) affirms that hospitals, organized for staff convenience, socialize the patient's behaviour to accommodate to staff directions. The "patient becomes concerned with doing precisely as he or she is told... following all instructions literally in an effort to increase his or her chances of recovering" (Taylor, 1979, p.161).

In hospital the patient is rarely invited to participate in decision making about their own care and it is difficult for them to retain control. Loss of control or "specifically, the absence of information regarding one's condition and treatment, and the inability to take steps or make a contribution in one's own behalf" can result in anxiety, helplessness, and depression (Clark A., 1976; Glogow, 1973; Taylor, 1979, p.180). "Reactance" to loss of control and freedom may also result in anger, frequent complaints and demands, especially of "the right to know" (Taylor, 1979, p.162).

Trying to fit the expected patient role is fraught with conflict and fears. In a study first reported in the early 1950's, Tagliacozzo & Mauksch (1972) found hospital patients experience conflict over obeying doctor's orders explicitly or pleasing the

nurse. The fear that disobedience would result in deterioration of their condition is opposed by patient's desire to be liked by the nurses and to not be a bother, besides their fear of reprisals for good and bad behavior (also Glowgow, 1973; Marram, 1973a).

Patients thought they had no rights, especially if their illness was not visible. Beliefs that nurses are too busy with sicker patients, doctors are not to be bothered, essential needs might not be tended, being "at their mercy", and reluctance to complain about care were common (Tagliacozzo & Mauksch, 1972, p.166; also Nehring & Geach, 1973). Indeed, Kratz (1978) indicates that when patients do not improve and treatment is ineffective, they are perceived as taking up a needed hospital bed. Doctors and nurses like patients who get better quickly; a major cause of patient unpopularity was being hospitalized for more than three months (Kratz, 1978, p. 27, citing Stockwell).

Fears that no one would be there when really needed, that doctors knew conditions but wouldn't tell patients, or that one needed to be vigilant of one's safety preoccupied hospital patient's thoughts (Tagliacozzo & Mauksch, 1972). Thirty years later these fears are reaffirmed by desires for frequent observation and perceived availability of staff, desires for explanations, competence and efficiency offered in a friendly, kind, helpful, and concerned manner (Brink, 1986b).

Socialized expectations forbid expressions of such fears and conflicts, never-the-less doctors and nurses must continuously prove themselves to patients (Tagliacozzo & Mauksch, 1972). Stimson (1974) in an eloquent description of how patients are disenfranchised asserts that the patient's expectations of the doctor enable the patient to evaluate actions and instructions and to make decisions about recommendations. Patients also expect that spontaneous and willing services will be given by dedicated and reliable nurses, and kind physicians will be trustworthy and thorough. In return, patients will be cooperative and good, so they could get care when they really needed it (Tagliacozzo & Mauksch, 1972).

Nurse Role Attitudes and Control

In seeking professionalism nurses have acquired some less favorable practices of professionals related to the use of power and control (Corless, 1979; Davies, 1976). Assumption of authority, of the "right to determine what service is needed or how it should be performed" and putting professional interests first were explicated by Marram (1973b, p.153). Nursing's power base, however, does not emanate from the same firm foundation as medical power. Rather nursing's authority is based on personal power, invested power, and delegated power (Field 1980).

Marram (1973a) found that superior/peer approval and influence were more influential on nurses than patients' evaluations. Although nurses said patients' evaluations were the most important, they did not allow this to influence them. Some have ascribed this to the hierarchal structure of the health care system, where doctors/nurses/patients have taken on the roles of man/wife/child. As the children, patients have the least power and influence. Indeed nurses may do more to maintain these rigid hierarchal power structures than patients or physicians (Chapman, 1983; Cohen, 1979, Davies, 1976; Davis, 1981).

Flaskerud, Halloran, Janken, Lund, & Zetterlund (1979) note that rather than developing close caring relationship with patients, nurses practice in an avoiding, distancing manner in hospitals. Nurses are taught to develop empathy for successful nursing care, but empathy is practiced by maintaining an objective distance between nurse and patient. Bemoaning their inability to change the system nurses say they are too busy to give nursing care, for reasons such as inadequate staffing. But their first priority is that the system run smoothly and the job gets done. Avoiding direct patient contact nurses spend time on indirect care and paperwork, performing the delegated tasks of doctors, organizational policy, and support departments such as X-Ray or diet kitchen. (Flaskerud, Halloran, Janken, Lund, & Zetterlund, 1979; Marram, 1973b). Nursing actions that can cause patient

dependency and extinguish independent behavior through reinforcement of dependent behaviors may be fostered to 'save bother' (Damant, 1981; Fielding, 1979; Miller, 1984). Punitive beliefs and nonsupportive behaviors also hinder patient/nurse relationships (Webb, 1986). Studies have found that nurses do not understand their patient's concerns and problems or their education needs (Tilley, Gregor, & Theissen, 1987; Roberts, 1982). Roberts (1982) quotes an informant in her study who said "nurses only see the surface things, They never ask about the things underneath, and those are the real problems" (p.489).

Nurses who do develop close relationships with patients are rewarded by being promoted, away from direct patient care (Chapman, 1983). Bedside nursing does not provide professional elitist status (Marram, 1973b).

Nurses and nursing, too, have expectations that "good" hospital patients are cooperative, helpful, happy, tidy, and uncomplaining, while "bad" patients are uncooperative, noisy, belligerent, complaining, and demanding as described by Glogow (1973). Nurses help to socialize model patients to keep quiet and mind their own business, to offer no disturbance; carry out doctor's orders to the letter without embarrassing questions; to not ask for extra attention; and to sleep or be quiet all night.

Exertion of control over patients in the hospital is covert (Marram, 1973b; Tagliacozzo & Mauksch, 1972). Through the use of manipulation, ingratiation, helplessness, effacement, or other indirect control/influence methods hospital wards run the way nurses want (Kalish & Kalish, 1981). A nursing expert recently summed this up with the sentence "I defy you to make anything happen on a hospital ward that the nurses do not want to happen".³

Although nurses like to believe they interact with patients in a different manner than doctors, they are just as likely to manipulate, influence, and abuse authority to control patient's

³ Dr. Patricia Benner, personal words. Workshop on "Excellence and Power in Clinical Nursing Practice", August 18, 1988, Massey University, N.Z.

behavior. Professionalism has taught some nurses they also "know best"; challenges to this threaten loss of control of the little power they hold (Caporalet-Katz, 1983; Larkin, 1987).

Despite such damning evidence, nurses are critically examining the nurse/patient relationship beginning with admitting that neglect and violation of patients' rights have occurred (Storch & Stinson, 1979). Nurses are making efforts to change traditional roles, offering innovative nursing care in the form of collaborative relationships based on active participation of the patient (to be discussed in more detail later), in fact "putting the patient on the team" (Zawacki & Patterson, 1984).

Client Personal Traits and Perceptions of Control

A recent study shows that perceptions of having control over ones' care while in hospital affects physical and psychological well-being, notably reducing anxiety and stress (Dennis, 1987). Elements of control defined in Dennis's (1987) study included knowing and fulfilling the patient role, involvement in decision making, and directing interpersonal and environmental factors. Clients did want to have control, gaining this by having information about diagnosis, treatment, and lifestyle implications of their illness enabling them to make informed decisions. Conversely Dennis (1987) also found that stress levels increased for a few study participants who did not want, and could not cope with decision making or control if this was imposed on them.

Professionals must accept the patients' right to reject advice but yielding to patients' needs for control and desire for independence may allow permanent damage of bodily integrity (Burckhardt, 1987; Hanks, 1984). Kinnaid, Yoham, & Kieval (1982) report that the process of gaining patient participation includes realistic expectations of the patients' right to make choices and decisions. Negotiating to allow for "changes within limits" in recommended treatment plans increases self esteem and sense of independence for some patients, and may actually increase overall

acceptance of treatment (also Armstrong, 1987; Gull, 1987; Raymond, 1984).

Littlefield & Adams (1987) imparted that women delivering in an alternative birthing unit were significantly more likely to perceive themselves to be participating and their care as satisfactory than those delivering in conventional units. But Nelson (1982) found that attempts by people to maintain or gain control over some aspects of hospital care during delivery "appear to have only minimal effects on what happens to them" (p.151). Choices and decisions planned prior to hospital admission were overridden and usurped by physicians and hospital staff with or without the agreement and collusion of clients.

In contrast Rieder (1982) found that patients who planned and anticipated their admissions to hospitals for surgery perceived themselves more in control, powerful, and active in self-care agency than those who had unexpected admissions. "Participation in care was determined by the degree to which subjects sought information and solved problems in relation to their care" (Rieder, 1982, p.102). The key element showing participation in care found in Rieder's (1982) study is personal control. Three types of patient role were found by Rieder (1982); a dependency role, with decision making behaviors showing loss of control; a reactance role, displayed by frequent complaints; and a self-care role with assertive information seeking and decision making behavior. Rieder (1982) suggests that the patient role is in the process of evolving from the traditional role of passive recipient to one of active participant in care.

Control in the Home Setting: Patients and Nurses

This thesis focuses on the patient and the nurse in the home setting where the philosophy that the health care provider is a guest in the client's home presumably maintains the balance of control in the client's favour (Cary, 1988; Pringle, 1982; Twomey, 1986). There was some evidence found by Kratz (1978) that (for

both clients and nurses) values and behaviors learned through experience in the health care system - in hospital, previous encounters with health professionals etc.- carry over into the home setting. That is, nurses' expectations of the patient, patients' adoptions of the sick role, or expectations of the nurse are not altered by the setting.

Elderly clients in the home were found to retain control through decision making over daily activities and care in a Canadian study by Pringle (1982). Caregivers perceived themselves as making few decisions for elderly family members, but both clients and caregivers believed "they had a great deal of control over the help patients received" (p. xiv). On the contrary Kratz's (1978) major British study of district nurses and their patients found that rather than retaining control, the patients became "non-persons ... those who are present during an interaction but do not take the role either of performer or audience" (p. 116; also discussed in Taylor, 1979 re hospital patients). Nurse and carer talked about them and over them, but not with them. Interaction with the patient was governed by certain rules enforcing normal behaviour allowing no maudlin questions about health or recovery. Any participation in care, planning, or decision making noted occurred between the caretaker and the nurse in this study (Kratz, 1978).

Elderly home clients were able to "distinguish between high and low levels of care, and are more satisfied with high technical care, a high psychosocial environment, and high patient participation in a study done by Chang, Uman, Linn, Ware, & Kane (1984). They advised that older women could be expected to respond positively to participation in goal identification and decision making about their own care.

Perceptions of control vary with the individual. Having control alone is not enough to ensure active participation in care; other elements are necessary to fulfill the interaction.

Participation and Knowledge

If the nurse/patient relationship is to be an active participative alliance focussing on client autonomy and individuality the issue becomes one of how clients can assume responsibility for health care and care of self. Learning how to participate is necessary, and in the health care relationship, having, seeking, or learning the necessary information to make intelligent, informed decisions is crucial (Lenz, 1984). Nevertheless uninformed decisions made without access to all necessary information is more the norm in present day health care professional/patient relationships (Roter, 1977).

Knowledge alone, informing or giving information is not enough to ensure active participation of clients in their health care and adherence to medical treatment (Carey, 1984; Conway-Rutkowski, 1987a; Roter, 1977; Spelman, 1984). Information seeking and question asking behaviors of clients yield the same conclusions (Gosch & Fox, 1981; Sands & Holman, 1985) while having knowledge about a disease may or may not increase treatment cessation (Given, Given, & Coyle, 1985; Kerr, 1985; Swain & Steckle, 1981). Pre-operative teaching is known to enhance post-operative recovery measured by functional recovery (Fortin & Kirouac, 1976), however it is not clear how much patients perceive and accept the teaching role of the nurse (Tilley, Gregor, & Theissen, 1987).

A role of facilitator of learning and self care is suggested as more appropriate and more successful (Carey, 1984; Connelly, 1987; Conway-Rutkowski, 1982b; Gartner & Riessman, 1974; Raymond, 1984; Rover, 1987; Tagliacozzo, Luskin, Lashof, & Ima, 1974). Facilitating self management helps to develop abilities to solve problems and make effective decisions thus helping the person to move from potential to actual control (Armstrong, 1987; Gartner & Riessman, 1974; Raymond, 1984; Rodin & Janis, 1982).

Learning specific skills (eg. self monitoring of blood sugar, blood pressure, or exercise routines) to manage aspects of disease

has had mixed effects on promoting adherence (Kerr, 1985; Spelman, 1984), better results being obtained when this intervention is combined with personal treatment from involved professionals (Conway-Rutkowski, 1982a; Del Fante, 1985).

Green, Kreuter, Deeds, & Partridge (1980) refer to overwhelming evidence that cognitive and behavioral changes are directly related to active participation of the learner. Basing education on the premise that communication is a reciprocal process, strategies to promote an active patient role in interaction are necessary for both provider and receiver (Becker & Rosenstock, 1984; Roter, 1977) since moving out of traditional roles creates dissonance. Roter (1977) noted that when participants were not prepared for and not comfortable in roles of active participation dissatisfaction, anger, and anxiety is increased, rather than satisfaction. Davis (1980) reported a hospital study based on a staff/patient interaction framework of information exchange, open agendas and expectations, shared staff decisions, and a philosophy that it was advantageous for patients to take an active, informed role in their care. Open knowledge strategies were used to gain patients co-operation with an end goal of self care. Davis (1980) concluded that legitimation by all staff of the participation role was required before any significant participation of the patient in his care could occur.

Organization of Decision Making and Participation

The literature reviewed thus far on participation indicates that control and decision making are defined as the key elements of participation. Control is often dependent on information and knowledge acquisition and dissemination, and informed decisions are based on adequate information. Making decisions must include an information seeking element (Lenz, 1984). Moughton (1982) conceptualizes the process of decision making and planning as a complex open systems model of four phases of deliberation, judgement, choice, and evaluation with constant feedback in and

between phases. Collection of information and conditions for action are explored in the deliberation phase. In the judgement phase analysis of alternatives and consequences are examined to choose the most effective action. The choice phase occurs when one option is chosen (Moughton, 1982).

Chang, Uman, Linn, Ware, & Kane (1984) identify that patient participation in self care must be assisted by knowledge acquisition in order to plan care. The decision making model used in their study has the phases of "identifying goals, seeking clarification of data, evaluating options, selecting an option, and implementing the course of action selected" (Chang, 1980, p.47). Chang and colleagues (1984) found that patient participation in planning care and decision making was related to global satisfaction.

Choices, Goal Setting, and Planning

To be effective decision making is followed by taking some action and this is often described in the literature as making choices, planning, goal setting, mutual goal setting, contingency planning or contracting.

Latham & Yukl (1975a,b) have shown that participative goal setting results in better performance for employees, enhancing production more than in conditions of no goal setting or assigned goals. Goal attainment was higher in the participative group even though participative goals were set higher, and performance differences were found that related to goal difficulty. Client involvement in goal-setting at a psychiatric hospital resulted in greater client satisfaction and goal attainment, but less than 21% of the study informants reported being involved in setting goals (Willer & Miller (1976).

Latham & Yukl (1975a) inferred that acceptance of the goals was increased by participating in goal setting but this was a mixed effect depending on the interrelationships in the situation.

They suggested formulation of a contingency model would result in more goal-setting effectiveness. CURN (1982) and Galano (1982), after literature reviews, concluded that increased treatment effectiveness and goal achievement, as well as greater client and professional satisfaction resulted from client participation in goal setting. Using a formalized goal setting instrument and plan, Galano's (1982) study found moderately significant indications (when analyzed against interrelationships and results) that participative goal-setting procedures are potentially valuable clinical tools. Client satisfaction was not related to the level of participation in goal setting. The key variable found by Galano (1982) was client participation in goal setting.

Hefferin (1979) found that progress toward attainment of goals and patient/nurse satisfaction increased when goal setting statements were written. Patients were encouraged to identify and develop their own health goals whether related to medical treatment or not.

Written goal setting contracts set out behavioral objectives agreed upon by client and professional, giving self determined rewards for obtaining objectives, and changing frequently as goals are achieved or renegotiated (Cameron & Gregor, 1987). Contracts have been effective for short-term cases (Cameron & Gregor, 1987) but have hidden inherent problems associated with perceptions and expectations of both parties (Zangari & Duffy, 1980). The contract may be viewed by patients or nurses as a tool of authority to manipulate or control behavior, it may not be explicit enough, or re-assessed often enough. When used effectively, the contracts' major effect may be the encouragement of patients and professionals participation in planning as partners (Sloan & Schommer, 1982).

Outcomes: Level of Collaboration

The Nature of the Participative Relationship

The notion of a negotiated relationship between health professional and patient alters the meaning and changes the nature of adhering to a treatment plan. In shifting responsibility for health outcomes to the individual a consensually agreed upon plan that the individual has a part in shaping is undoubtedly a major influence in improving the problem of poor participation in one's own health care.

Swain & Steckel (1981) found that a contingency contracting negotiation process of sharing information, increased personal staff attention, mutual goal setting, skill training, incentives for goal achievement, social support, and active decision making by clients promoted adherence to a hypertensive regime. Diastolic blood pressure decreased and health status was improved through patient participation in planning and goal setting. All clients in this study adhered to the written contract they had agreed on with the nurse.

Eisenthal, Emery, Lazare, & Udin (1979) found the negotiated clinician-patient interaction; seeking patient participation in treatment planning; patient's feelings of having control over organizational and administrative procedures; and the patient "getting the plan he wanted" (p.397) increased adherence to treatment (also Starfield, Wray, Hess, Gross, Birk, & D'Lugoff, 1981).

Kasch (1986) identifies such a relationship as collaborative adding the key element of joint decision making to mutual goal setting and implementing a negotiated plan of action. Collaboration enhances patient identity in the realms of self esteem, autonomy, and efficacy. Boettcher (1978) speaks of nurse-client collaboration as a dynamic equilibrium with constant feedback in a mutual exchange of assessment, setting goals, negotiating differences, setting mutual goals, forming an

alliance, assigning tasks, and evaluation of goal achievement.

Rather than studying participation in care as a causal function of individual traits and characteristics (and defining it as adherence or compliance as it has been in medically oriented research), Schulman (1977, 1979) proposed a framework of "Patient-Centered Care" (PCC) and "Active Patient Orientation" (APO) where health care services were oriented to the patient. The following components must be built into the treatment process.

1. Attitudes and expectations communicated to patients by health professionals are supportive of patient's motivations and abilities to contribute to the treatment process (within the medical facility) and to understand and carry out treatment recommendations, with active participation reinforced through such means as praise, graphic display of clinical progress.

2. Illness-management is conducted as a collaborative process between patient and health professional, involving two-way communication and joint decision-making; patient input is actively encouraged through direct solicitation of information/opinions and responsiveness to questions.

3. Medical resources are provided in such a way as to insure their usefulness to the patient; that is, explanations are full and clear; instructions are explicitly operationalized; skill training and technical aids are made available to assist self-care activities.
(Schulman, 1979, p.268)

Testing of active patient orientation in two hypertensive clinics and linking it to treatment outcomes showed that patients understood their treatment, followed through on recommendations, took more responsibility for their care, used health resources more effectively, and more often achieved controlled levels of hypertension when they were actively involved in treatment. Patients in this study, followed and counselled by either physicians, nurse researchers, or nurse clinicians wanted to participate more, both in and out of the medical setting but were hampered by their perceptions of the conventional patient role (Schulman, 1979).

The literature review thus far has developed the concept of

participation through the context of the participant in roles of citizen, worker, health care consumer, patient, and nurse. Both the patient and the nurse bring role attitudes influenced by power and control, personal traits, and the organization of health care delivery to the participative relationship. Participation has been discussed through its major sub-components: control, knowledge or information acquisition, and decision making. The nature of the participation relationship between client and provider was reviewed giving the traditional viewpoint of doctor/patient/nurse relationships, and discussing the evolution of a new relationship. The new relationship is based on assumptions that the client is responsible for personal health care and is a willing active partner in treatment and achievement of goals. Health professionals take on a new role of expert consultant or facilitator in a therapeutic alliance to achieve mutual goals.

SECTION IV

NEW ZEALAND: PARTICIPATION IN HEALTH CARE

The concept of participation in health care is well established and has been widely discussed and researched in overseas countries such as North America and Great Britain. However, this present research is sited in New Zealand and it is widely believed that overseas research cannot be directly applied in New Zealand since social and contextual factors are different.

If this belief is true it leads to a number of questions regarding research on participation in New Zealand. Do New Zealand consumers of health care also demand to participate - to receive more information, to have choices, and to make decisions - in their individual care? Do New Zealand patients or clients participate in their care and if so, how do they? What does participation in health care mean to New Zealanders? Do views about participation differ in New Zealand? In short, participation in health care in New Zealand is a different entity than participation in health care in other countries, until proven otherwise.

Literature Review of Relevant New Zealand Research

Citizenship and Workforce Participation

Participation in citizenship in New Zealand is noted for some significant historical points. New Zealand was the first country in the world to legislate franchisement of women and the rights of trade unions. Registration of nurses (Shaw, 1988) and women lawyers occurred first in New Zealand.

Participation in the workplace is defined by McLennan (1978) as directly influencing the decisions that affect people at their jobs and having influence over how things are done. In acknowledging the difficulties worker participation poses for workers and management, McLennan (1978) refers to typical New

Zealand attitudes of "leave it to the government" (p.22), authoritarian orientation, and a "national habit of confrontation" between union and management (p.15). He suggests change in the form of collaborative planning. The N.Z. Employers Federation (1977) views involvement as a way of increasing job satisfaction and productivity and of improving management-labour relations with emphasis placed on employees exercising more control over work environment and production. They note that overseas study shows that few workers want to participate directly while McLennan (1978) mentions that it will take time and skill learning before workers and management can participate. Such comments allude to a perspective that participation, decision making, and control in the workplace is in the process of evolving in New Zealand.

Definition of the Situation: Consumer Participation in Health Care

Fostered by government and concerned health professionals, the current trend in New Zealand is toward encouraging community involvement and participation in the health care system - in planning, decision making, and policy making (Boddy, 1985; Davey & Dwyer, 1984; Fraser, 1981; Hospital and Specialist Service Committee, 1987; Powell, 1986; Slinger, 1987; Wright-St.Clair, 1983). New Zealand nurses have been much involved in advocating primary care as a strategy and philosophy for affirmative action towards "Health for all" (NZNA, 1988; Powell, 1986; Shaw, 1986a,b, Takarangi, 1986, 1987). Primary care is based on seeking the involvement of individuals and groups in their care and sharing decision making and responsibility between professional and client. "Self-care, self-reliance and self-responsibility are key words" (Powell, 1986, p.21).

However Davey & Dwyer (1984) point out that critics have suspiciously seen encouragement of participation in care as a management tool or as a move to reduce government responsibility for care. There is a tendency in policy makers to identify community participation as self-help. They may see this as a way

to encourage "families or self defined groups to meet their own goals in their own ways" and to use families, volunteers, and voluntary agencies to provide services in the wider community (Davey & Dwyer, 1984, p.12). Such a one-sided view of participation may result in abdication of governmental obligations without providing support in turn.

Also, feelings of policy makers are ambivalent towards self help movements; they create controversy. While self help groups are applauded for encouraging self-reliance, independence, and support they also ask difficult questions, they advocate 'causes', and want changes. And self help groups may oppose or conflict with professional interests (Davey & Dwyer, 1984, p.22). It seems there may be some basis for criticism of participation schemes which do not allow decision making to occur but use the same empowering words as 'catch phrases'.

Parslow (1983) comments that "lip service" paid to the concept of consumer participation is quite common in New Zealand where planning is sometimes completed before the public is invited to make written submissions. Decision making can thus occur with only token participation of the community, while appearing to occur with community input. A research survey reported by Reinken, deLacey, & Salmond (1979) was the result of a community health project planned and executed by consumers utilizing professionals as experts. Showing awareness of such tokenism the project exhorted the powerful "to give up some of their power and help search for ways to enable groups and individuals to make for themselves many of the decisions that affect their lives" (Reinken, deLacey, & Salmond, 1979. p.4).

Therefore it can be concluded that similar controversy and power struggles between professionals and consumers for participation in health care control and decision making exists in New Zealand as overseas despite official government sanction of consumer participation (also Davis, 1981).

Role Attitude and Client Professional Expectations

Relationships between doctor/patient/nurse are much the same as revealed in overseas research, with both the conventional unequal power relationship (described by Coney, 1988; Consedine, 1984; Davis, 1981; Stoller, 1963) and new power sharing relationship (Butterfield, 1978; Davey & Dwyer, 1984; Fursdon, 1985; McDonald, 1988; NZNA, 1988) represented in New Zealand. One aspect of the doctor/patient relationship not found in overseas review is discussion of the "priestly role" of the doctor using mystique and authority to reassure patients and command compliance (O'Hagan, 1988; Scott, 1983).

Expectations of compliance and 'victim blaming' are evident in Kellaway & McCrae's (1979) study of medication noncompliance. Scriven (1987) discusses the expectations of health care professionals that patients are not competent to administer self-medication in hospital but are blamed for non-instant compliance to medication prescriptions the minute they are discharged. This study found that self medication in a surgical ward led to patients developing a sense of control and a desire to learn about medication use while a reduction in medication error and workload for nurses occurred. Concern has been expressed as well about the modern tendency to focus on individual responsibility for one's own health in a 'victim blaming' fashion rather than acknowledging the culture and environment which fosters destructive lifestyles and health habits (deLacey, 1984; Fraser, 1988; Reinken, deLacey, & Salmond, 1979).

Expectations of the sick role in hospital and shocked helpless reactions to sudden depersonalization are eloquently described by Anne Clark (1976). Davis (1981) states that "research in New Zealand suggests that hospitals are extraordinarily insensitive to the basic human requirements of their clients" (p.132). Indeed Wright-St. Clair (1983) believes that good health can finally be restored only when hospital patients return home. Allowing that the illness role is culturally defined and that

variations exist --in essential character, expectations of the sick role in New Zealand does not differ from overseas expectations.

Nurse Role Attitudes

Hospital bureaucracy and hierarchal organizational structures have fostered rigid barriers and role definitions in New Zealand too (Committee of Inquiry, 1988; Consedine, 1984; Davis, 1981; Moulson, 1983; Shaw, 1988). Jealous guarding of professional rights, privileges, and power continues (Coney, 1988; Committee of Inquiry, 1988; Moulson, 1983; Rennie, 1988). Moulson (1983) cites a study showing a strong positive relationship between length of service and need for power and influence in full-time nurses.

Butterfield (1982) concludes there is a strong professional conviction that nurses know better than clients, and philosophy otherwise is merely a 'pious professional cliché'. Only 1% of the nurses in her study assisted patients with goal setting, while 1.5% set goals for the patient which were not met. Information seeking by 17% of patients resulted in decision making behaviors by 3% of patients. Another 3% of nurses set up decisions for patients to make, but 2% made decisions for the patient without consultation.

The philosophy of 'nurses knowing best' is illustrated by the semantic nuances used in Mathias's (1981) pilot study of patients with urinary incontinence where she states that patients may not be interested in or accept "the need for collaboration with nurses or the need for being or becoming active participants in their own self-care" (emphasis added, p.2). The report further states "after considerable deliberation it was considered that the lack of control that nurses have over other variables substantially reduced the effect of patient participation" (emphasis added, p.3).

Nurses (and doctors, Lichter & Davidson, 1981; O'Hagan, 1984) practice in New Zealand hospitals too, in avoiding, distancing manner (Thompson, Kinross, & Chick, 1977), delegating unwelcome

tasks to less well-trained staff (Christensen, 1984). Thompson, Kinross, & Chick (1977) document inadequate communication and flow of information revealing that pressures to appear 'busy' predominate. In their study the nurses withdrew from emotional verbal or nonverbal contact with patients. Thompson, Kinross, & Chick (1977) ask "Why should nurses need protecting from the emotional problems of patients?" (p.86).

Describing the feelings and needs of patients, Judge Cartwright, head of a Committee of Inquiry (1988) writes

A patient who enters hospital for examination or treatment will usually be nervous and feel out of her depth. She may be surprised by how little information is offered about her diagnosis and management. Frequently she will ask very few questions of the nursing or medical staff. Occasionally she will be outraged when she learns that treatment or procedures have been undertaken without her knowledge or consent. Overwhelmingly, however, she will trust the medical, nursing, and administrative staff to have one over-riding goal: Her health and welfare.

(Committee of Inquiry, 1988, p.127)

In her report Judge Cartwright unquestionably reveals that expectations of altruism and professional peer review are not enough to protect patients or their rights. The report recommends legislated systems of professional review with primary aims of protection of patients rights (Committee of Inquiry, 1988). By documenting in Court practices which hither-to were swept away as heresy this inquiry will provoke far-reaching implications for health professional/client relationships.

The New Zealand inquiry (Committee of Inquiry, 1988) specifically revealed the subordinate nature of nursing to medicine, and the nature of the nurse/patient relationship. Rather than acting as patient advocates (a role nurses claim) Judge Cartwright declares "Nurse have been conditioned to protect patients by stealth. They cannot therefore be effective advocates who will act bravely and independently" (p.173). Nurses at this hospital claimed they were helpless and had no responsibility or authority to influence research on the patients they cared for.

They betrayed this in continuing to perform a ordered research protocol for 30 months after the investigator lost interest in the project (Coney, p.212; Committee of Inquiry, 1988, p.140). During the Inquiry itself, nurses refused to give testimony in public, instead choosing to speak in secret behind closed doors. Judge Cartwright has a firm basis for her statement.

Such lack of control also reflects the degree of institutional power held by the hierarchy at this hospital. Consedine (1984), calling it institutionalization, comments on similar findings at another hospital which lead to insensitive, uncaring, even harsh behavior of nurses toward patients. At the same time these inquiries expose the willing collusion of nurses in supporting bureaucratic control generally (also Davis, 1981, p.132).

In response to the Cartwright report New Zealand people are examining their roles in the health care system. Already influential physicians such as Professor Scott (1988) are recommending "we will have to learn to function as partners in a team which involves the patient, rather than seeing ourselves as leaders who are guardians of some precious core of knowledge which should be restricted to the priesthood of medicine" (p.656). Coney (1988) affirms that consumers want " a new relationship with doctors, one where there was an equal partnership, a collaborative relationship where consumers could have real choices and exercise real control over their bodies and health care" (p.263). Nurses are strongly championing the central philosophical concepts of primary care which affirm that health is a fundamental human right; primary care is social justice; people have a right to participate individually and collectively in planning and implementing their health care; and (going beyond regional boundaries) world peace and quality of life are consequences of health promotion and protection (Takarangi, 1987). The New Zealand Nurses Association (1988) is specifically addressing the rights of powerless members of society. As Davis understates the current situation, health professionals are "'trying to come to grips'

with changes in public attitude, but currently 'there is a bit of a mismatch'" (Coney, 1988, p.263).

It seems that "core understandings which seem to be quite central to the functioning of health activities...[are] quite stable across different societies"(Davis, 1981, p.76). With evidence suggesting that the patterns of New Zealand health care are similar to other western societies this researcher concludes the patterns can be assumed to approximate overseas research.

Participation in the Home Setting, New Zealand

Study of the district nursing role and the district nursing client in New Zealand is sparse. A major exploratory study was done in Christchurch looking at the recipients of district nursing services and the services provided to them (Higgins, 1983; Malcolm & Higgins, 1983). This descriptive study focussed on nursing tasks and requirements of the patients. Other studies have looked at integrating the district nurse and public health nurse roles into one role by exploring functions and tasks (Kinross, Takarangi, Nevatt, & White, 1983; MacInnes & Glover, 1985). Research on consumer attitudes to para-medical care yielded the information that the public was satisfied with public health, district, and Plunket nurse services, and that doctor's services would be improved by employing nurses (Dixon et al, 1975).

The above studies did not examine participation or collaboration in care. Kinross, Nevatt, & Boddy's (1987) study on the viability of combining the district/public health role does analyze aspects of the nurse's practice including her solicitation of patient's participation and the patient's participation. The project nurse perceived the focus of her client contact as "doing to" themes while outcome of her practice was "working with" the client. She practiced in a consultative, discussant manner with any number of other people- other professionals, family, friends, neighbors, chemists, home help, for the benefit of her client. "The nurse often involved others, including the clients

themselves, in care....[using a] collaborative approach" (p.146). Her initial discussant approach logically led to "participative outcome themes" (p.147).

Bathing of district nursing clients was described by Ridley (1974) and James, Rabuka, & Muslim (1982) with a philosophy of self care and independence detected in the latter study, although the question used to ascertain this variable was slanted towards giving a positive answer. Health care in the client's home is influenced by expectations that the client will "manage", will make his or her own "arrangements", and will provide his or her own resources in New Zealand and overseas (Fraser, 1981; Kratz, 1978, p.28; Pybus, 1987; Roberts, 1975, p.118).

It is evident from the literature review that client participation associated with district nursing has not been previously researched in New Zealand.

Summary

This chapter has explored the background and theory of participation, role attitudes, and client/professional relationships through a literature review. Chapter 3 discusses the methodology for the present research.

CHAPTER 3: METHODOLOGY

Study Question

This study proposes to examine the participation of New Zealand district nursing clients through the perceptions of the client. It expects to answer the question

"What are the perceptions of district nursing clients toward participation in their care?"

Rationale for Choice of Research Design

The study question posed problems in methods of conceptualizing. While the concept of participation is well established and has been studied overseas, it has not been studied in New Zealand, particularly in relation to district nursing clients. There is some evidence that overseas research does not always 'fit' the New Zealand population. Two major questions thus arise: What does participation mean - what are its relevant elements to the New Zealand district nursing client? Are the relevant elements identified in overseas research applicable to the district nursing client?

With such a situation the research design had to be exploratory in nature. Overseas literature furnished a definition of the concept of participation which may or may not 'fit'; the definition required exploration in this study's population.

A multiple triangulation research design making use of the known elements of participation and exploring the unknown meaning to the particular study population was chosen as the most appropriate fit of design to problem.

Definitions

It is intended first to describe an emic point of view of the phenomenon participation; that is, trying to understand it from the perspective of those experiencing it. In order to achieve this goal the study will seek understanding of the meaning of participation to the individual using a qualitative approach. With such an approach participation will be defined by the client, elucidating this definition through descriptions of thoughts and feelings about the phenomenon. That is, perceptions of participation in one's care, whatever the form, will be considered the true evidence of its existence and described as such.

Secondly, this research proposes to describe participation in district nursing care quantitatively through its known sub-elements. A literature review identified that one participates (shares in or takes part) through several sub-elements; those common to the studies reviewed are encompassed in the following definition.

For the purposes of this study:

Participation is defined as a reciprocal relationship composed of receiving information, having choices, making decisions, planning, and negotiating; it includes elements of one's perceived self-ability to participate and experiencing a feeling of control over care.

Perception is defined as an individual's unique world view from their own perspective (King, 1968).

Triangulation and Multiple Triangulation

It is often recognized that the complex nature of nursing's concern - human health and behaviour - is not adequately addressed by restrictive research methods. The enigmatic puzzle of human behaviour needs to be approached from multiple angles, from different theoretical perspectives, and with diverse methods of collecting and analyzing data to reach meaningful but scientific explanations. Research designed with triangulated methodology helps to solve this problem (Campbell & Fiske, 1959; Denzin, 1970b).

Data Collection Triangulation

Data collection was planned in this study to be conducted by personal interviews seeking qualitative data to complement, enhance, and expand on questions asked using a structured questionnaire (Appendix A). Data collection methods should be sensitive to the problem being studied, and be acceptable and accurate within the setting. They should 'fit' or suit the study.

A combination of questionnaire and interview is a common method of data collection when conducting research. Multiple approaches augment the information collected and provide a means of cross-checking data, as well as revealing different sorts of knowledge (Denzin, 1970a). For example, using just the structured questionnaire when interviewing clients for this study would have yielded only controlled data - answers which were structured by the questions. Seeking qualitative explanations as well as answers revealed different meanings, connotations, values, and understandings which resulted in revelation of a new definition of participation for this study's population. Triangulation, as used in this study, consisted of collecting specifically focussed data structured by the questionnaire, and collecting expanded explanatory information describing the perceptions of clients towards participation. This method of data collection resulted in

achieving a comprehensiveness which would not have been achieved by one approach alone (Goodwin & Goodwin, 1984).

Across Method Triangulation

The data collection methods of this study were discussed above but their relationship to differing philosophies and schools of thought about research was not emphasized. Methodological triangulation was accomplished in this study with the "across different paradigms method" (Mitchell, 1986, p.21). Two opposing approaches which have evolved from seemingly different scientific paradigms and philosophies are termed qualitative or quantitative methods of research. Because different types of knowledge are revealed by quantitative and qualitative paradigms, combining them may lead to an expanded understanding of the concept under study (Denzin, 1970a; Goodwin & Goodwin, 1984; Hinds & Young, 1987; Mitchell, 1986; Sandelowski, 1986).

Quantitative research strives for objectivity and gives restricted, specific information, often numerical statistical data (Gray & Rudy, 1981; Tinkle & Beaton, 1983). Its aims are to produce reliable and valid data using context free rigorous techniques, and it is generally hypothesis testing and predictive.

The strength of the scientific research method is in reductionism - in its ability to reduce and refine, to precisely and scrupulously define the variable under study. Its weakness is also reductionism - refining and reducing the variable, stripping it of contextual meaning, and moving it further and further from the whole, from its holistic meaning (Kaptchuk & Croucher, 1986). The scientific method reduces, quantifies, and measures exactly to allow generalizations across populations.

Qualitative data, on the other hand, reveals rich, broad, subjective information confined to the study at hand because each experience is unique. It is exploratory and hypothesis generating. Qualitative information expands and amplifies the variable under study, giving breadth and depth. Rather than aiming to be value

free, it is context rich. Qualitative research augments meaning.

In recent years some authors (Bennett, 1984; Field & Morse, 1985; Goodwin & Goodwin, 1984; Hinds & Young, 1987; Mitchell, 1986; Sandelwoski, 1986; Swanson & Chenitz, 1982; Tripp-Reimer, 1985) have proposed that perhaps these two approaches are not as dissimilar as believed but are complementary methods of research, each contributing its own type of knowledge to the research process. These researchers suggest that mixing qualitative and quantitative methodologies in a single study will "tend to correct, clarify, expand, and stimulate each other and... triangulate into truth" (Hinds & Young, 1987, p. 195).

Multiple triangulation in an integrated research design is also termed convergent validity where the aim is to give a complementary picture of the problem being studied. Quantitative and qualitative paradigms alone are incomplete; each is blind to certain information (Kuhn, 1970) and each has its "unique strengths and weaknesses" (Denzin, 1970a, p.309). Combining and overlapping the two contributes to convergent representation of the whole concept, thus cross-validating the findings (Denzin, 1970a; Goodwin & Goodwin, 1984).

Recognizing and convinced of the philosophy that using multiple techniques gives a more exact, more meaningful, more powerful, and more holistic conception of the phenomenon being studied, a triangulation of qualitative and quantitative methods of data collection and analysis was chosen to act multi-dimensionally in a complementary manner in this study. In order to tap the types of knowledge which each method unfolds, data collection methods suited to each paradigm were blended in multiple triangulation fashion. Structured, but open-ended interviews yielded data that was analyzed quantitatively and qualitatively (described in detail in data analysis section).

A method of qualitative analysis was chosen focussing on understanding the meaning of participation from the subject's perspective.

Three premises underlie the qualitative philosophical

viewpoint used here. They are

1. Human beings act towards things on the basis of the meaning these things have for them.
2. The meaning of things in life is developed from interactions a person has with others.
3. People handle and modify meaning through an interpretive process.

(Wilson, 1985, p.398)

Problems of Multiple Triangulation

Problems encountered by this researcher were similar to those outlined by Mitchell (1986). This study had a small scope and was conducted by a single researcher limited by both time and money constraints and demands upon the investigator of knowledge and ability to work within and integrate both paradigms.

Numerous questions arise when analyzing data in multiple triangulation studies that requires much fore-thought. A decision must be made about how much weight each technique should carry in the research report. Following the conviction that it was necessary to understand participation through the perceptions of the subjects and from their perspective, the decision was made in this report to place emphasis on qualitative accounts when analyzing and reporting the research. The quantitative data would be used to enhance validity and generalizability and help to establish a ground base of knowledge about district nursing clients.

Research Design

The research design planned for this study was to conduct personal interviews with clients in their homes using a structured questionnaire (see Appendix A). Qualitative information and personal meanings would be explored during the interview by encouraging clients to explain and clarify their answers and to

discuss their own views. Interviews lasted from 30 minutes up to 2 hours, depending on the loquacity of the client.

Selection of Participants

Random selection of participants for this study began by defining a population or sampling frame, in this case, the total number of district nursing clients in the Palmerston North City Community Health District. The master computer list of community health clients was used in a systematic sampling design to randomly select a final study sample of 45 clients.

Interviews

The planned approach to clients was to send a letter (see Appendix A) one week before the anticipated visit, explaining that the researcher wished to interview them and would visit them on a certain day. The investigator's telephone number was given to allow clients to refuse, ask questions, or make a different appointment. It was planned to interview 8-10 clients per day in series of 3 days/week interviewing per fortnight, allowing for analysis in the interim week. Interviews were conducted over a period of two months.

Problems with this plan soon surfaced. Clients were concerned about the time of visit, feeling they wanted to know what time of day the researcher was coming. Originally the researcher had considered telephoning clients as well as a letter, but was concerned at the ethics of appearing to press clients to participate in the study and making them feel obligated to do so or as a violation of confidentiality. Never-the-less it seemed that clients preferred to be telephoned first, as a matter of courtesy; they could make an appointment and ask questions during the phone call. The process of interviewing also proceeded more efficiently for the investigator by telephoning first.

The Interview Plan

The interview proceeded by visiting client's homes, explaining the study and asking permission to interview the person before entering. An explanation of the project and verbal assurance was given that refusal to participate fully or withdrawal at any time would not result in any penalty or affect their nursing care. Clients were told their confidentiality would be protected and that no one but the researcher would know who they were. Any data or tapes would be destroyed on completion of the project. An introductory letter (Appendix A) was produced and clients' questions answered before beginning the interview. To complete the process of reassurance on conclusion, a letter was sent to clients thanking them for participating in the research project, briefly outlining the results, and informing them that their data had been destroyed (see Appendix D).

Consent forms (Appendix A) were available for clients and researcher to sign if a tape recorder would be used during the interview. It was planned to tape record interviews for the second part of the questionnaire if it seemed fruitful, i.e. the client was informative and willing to talk. Clients preferred to give verbal permission to tape.

A consistent method of interviewing was designed incorporating the suggestions of Denzin (1970a), Kornhauser & Sheatsley (1976), Marriner (1981), Swanson-Kauffman (1986), Verhonick & Seaman (1978), Waltz, Strickland, & Lenz (1984), and Whyte (1984). Each client would be asked all the questions in the structured questionnaire (Appendix A). Discussion, expansion, and volunteering of information was encouraged. Explanatory phrases, encouraging words, phrases, and gestures were devised and placed within the questionnaire, along with instructions. This was done so that the researcher would not forget or be distracted from asking or discussing all the questions and giving necessary information. It was possible to format the questionnaire in this fashion because the researcher would be the only person using and

handling the questionnaires, and the only interviewer.

A number of probes which might be used during the interview to seek clarification were devised. Probes and clarifying questions, as well as the communication technique of summarizing and repeating statements back to the informant validates the information collected and verifies that the interviewer has understood the informant correctly. The technique of validating themes emerging in the data was seen to be successful as it lead to expanded definition, clarification, and constant validation of themes. A brief composite example follows

Researcher: The nurse consults me about my nursing care.
 Client: No, not consult, we talk about it sometimes.
 Researcher: Some people have said they discuss their care.
 Client: Yes, we 'discuss' it, she tells me what to do, I 'co-operate' with her because she knows what she's doing, but I want to know why.....she listens to what I have to say.....makes me feel.....I like the way....

Establishing Rapport and Trust

One of the difficulties encountered during the interviews were suspicions of the researcher's motives. Study participants demonstrated their suspicions to the researcher in evasive answers, reluctance to express an opinion, and fears that the researcher was trying to "find out" information or was seeking complaints. Frequent assurances that "their nurse was just wonderful" or that "I just can't do without..." were made. Participants "didn't want to complain" and would not express negative feelings. Instead of no, clients would say "I don't know" or "I'm not sure". At the end of interviews, clients showed their relief that I had not asked them to disclose something they didn't want to tell me. It was then that they would say "Oh once or twice...; or one time, in all the years....." and share a negative experience. The last question requesting dislikes was presented in

global terms, what was it they disliked about the whole experience of being ill and needing a district nurse. Beyond that, the questionnaire was constructed so that clients were not asked for any negative comments with the following reflections found in the literature foremost in the mind.

Nunnally (1970) pointed out that research was often reacted to as if it was 'nosy', people felt twinges of anxiety. Gosch & Fox (1981) reported that questions considered threatening or invasive produced reluctant, evasive answers. Diers (1979) in discussing measures of patient satisfaction concluded that these "may be measures of how much the patient trusts the interviewer, and therefore, is willing to tell the interviewer about" (p.89). Butterfield (1982) also found that clients evaded answers and avoided complaining in her study.

Some time was spent during each interview establishing 'just who the researcher was' and 'what she was doing there'. Establishing rapport and some element of trust with each client interviewed, and conducting the interview itself was an experience requiring much energy from the researcher. Not surprisingly, exhaustion resulted at the end of each interviewing day.

Ethical Considerations

Permission to conduct research was sought from the Palmerston North Hospital Board and the ethical committee reviewed approved the study proposal (see letter Appendix A). Community Health Services management staff also reviewed and approved the study proposal, assisting with pre-testing the questionnaire by peer review. The Nursing Education and Research Foundation of New Zealand also reviewed the study proposal and assisted with a small grant for the study (see letter Appendix A).

Protection of the anonymity of the informants is considered to be of premier importance since the size of the district nursing population may allow certain informants to be recognized through diagnosis or length of time as a client. Therefore qualitative

descriptions of the clients' diagnoses requiring nursing care were limited, specific diagnoses were not used, nor was exact length of time as a client given. A systematic disguise is used here when reporting, where considered necessary to protect anonymity. Strict confidentiality was practiced by the researcher at all times.

The questionnaire was not coded in any manner which would identify the informant being kept anonymous. Data was transcribed directly from cassette tapes by a typist, or entered into a locked computer file by the researcher. No identifying marks accompanied the cassettes or the computer files. They were coded by number in order for the researcher to validate data and to set up the file for statistical analysis.

Names and addresses, kept in a separate location, and original data was destroyed as soon as the research has been reported by erasure of tapes and burning written documents. Pooled data, analysis, and computer files was retained by the researcher.

Validity and Reliability

Reliability

When constructing a measurement instrument such as a questionnaire, major issues are establishing its validity and reliability. Reliability alludes to the stability and constancy of a measuring instrument and the extent to which repetition yields similar data. It also refers to the extent to which a measure will produce equivalent information when administered by different people (Diers, 1979). Reliability is also a measure of accuracy-the internal consistency - or the ability of a test to accurately reflect the true measures of the trait or attribute to be investigated (Polit & Hungler, 1983).

The questionnaire used here was constructed for this research, thus there has been no previous opportunity to test its external reliability. Internal reliability, or the consistency achieved amongst informants in the study was secured by a

consistent method of interviewing and a common understanding amongst informants of the concept under study. That is, repetition of the questionnaire to the broad cross-section of clients in this study yielded similar results between individuals. External reliability will need to be established by subsequent research to ascertain if similar results are obtained in another population.

Validity

Ensuring the scale measures the critical attribute is also a question of validity (Brink & Wood, 1983; Diers, 1979; Nunnally, 1970; Polit & Hungler, 1983; Shaw & Wright, 1967; Thorndike, 1982). Face validity was established for this questionnaire by peer and staff review and multiple instances of consultation during development. When developing the questionnaire used here, the concept of participation was carefully examined through an extensive literature review and common, recurring elements of participation are included in the developed questionnaire for content validity.

Collecting qualitative data also provides for learning personalized or new meanings of the concept which are not documented in the literature. Across-method triangulation provides validity and reliability for both paradigms of research by contributing convergent validity to the concept.

Validity and Reliability in Qualitative Research

Validity and reliability are addressed in different ways in qualitative research and some proponents argue that the issue of validity and reliability does not apply to qualitative methods.

However rigour in qualitative research is appropriate and truth value or credibility are achieved when

it presents such faithful descriptions or interpretations of a human experience that people having that experience would immediately recognize it from those descriptions or interpretations as their own. A study is also credible when other people ...can recognize the experience when confronted with it after having only read about it in a study.

(Sandelowski, 1986, citing Guba & Lincoln, p.30)

Credibility is threatened by 'going native' and enhanced by the researcher's descriptions, interpretations and awareness of their own and the subject's influences on the study.

Applicability or fittingness relates to the external validity of quantitative research. Sandelowski (1986) argues that generalizability in quantitative research is an illusion because the controlled conditions are artificial and don't exist in that situation again. Rather fittingness is achieved when findings of qualitative research will fit into other contexts and situations beyond the study itself and when "its audience views findings as meaningful and applicable in terms of their own experience" (p.32, citing Guba & Lincoln).

Auditability relates to the consistency of findings and is achieved when the "decision trail" of the researcher is able to be clearly followed from beginning to end of the study. Another researcher should arrive at similar or comparable conclusions with the same situation, data, and perspective when results are auditable Sandelowski (1986, p.33, citing Guba & Lincoln).

Neutrality or confirmability is the "criterion of neutrality" or freedom from bias in qualitative research. it is achieved when the consistency, truth value, and applicability are established.

Paying attention to the basic issues of validity and reliability will increase the credibility and plausibility of the results of the research. Quantitatively, validity and reliability should be addressed when designing the study and should be built into the research design. On the other hand, in qualitative research validity and reliability are displayed by data analysis.

Validity was addressed in this study by maintaining stability

in interviewing questions and technique throughout the series of interviews. As themes emerged from the qualitative data they were validated with subsequent participants and with other people who were not part of the sample. Convergent validity and cross validity of the data obtained within the interviews strengthened themes and brought out meanings that were not incorporated in the structured questionnaire (see chapter 4). Reliability was displayed in the consistency of the questionnaire's responses over the broad range of participants in the study. Quantitative techniques of study design enhanced the generalizability of findings. Qualitative description here demonstrates truth value and fittingness. Independent evaluators of the qualitative description have agreed that the description of participation reached in this study is the way things are saying "You're right, right on target".

Quantitative Analysis

Quantitative analysis was accomplished by coding and categorizing demographic data and answers to structured questions (see Appendix A for coding scheme) for use in the SPSSx computer analysis program. Although advised by statistical and computer experts to code and categorize expected data before collecting it, it proved a difficult task to forecast all possibilities. Coding and categorization was found to be much quicker and easier after the data collection, because the categories came out of the data obtained. Whyte (1984, p117) also noted this contradiction.

When using a newly developed questionnaire and in an exploratory study appropriate statistical procedures are frequency tables of univariate data and correlations and contingency tables of bivariate data. "Bivariate descriptive statistics describe the degree and magnitude of relationships between two variables" (Polit & Hungler, 1983, p.496). These statistical tests display relationships among variables based on less rigorous assumptions than higher-order tests. Chi square statistic describes the

expected frequency or proportions in crosstabulated groups. The simple statistics used in this study are explained in chapter 4 along with analysis and tables showing data and making conclusions.

Qualitative Analysis

Qualitative analysis proceeded in this study in a process of "analytic description" (Wilson, 1985, p.339). The purpose of the analysis was to discover What is happening?; What is going on here?; What is important?; and/or How does it vary? Analytic description "generating novel categories" out of and in to "descriptive narratives" (Wilson, 1985, p.401) is the intent of this analysis.

Analysis began by becoming very familiar with the data, reading and rereading it, then starting to search the data for descriptive expressions, themes, commonalities, or differences. For example Table 3:1 shows the sorting for some of the data of the theme self care/independence. The descriptive expression "look after yourself" frequently occurred throughout the interviews and was an important concept but more than one idea was being described by the phrase. When viewed in the context of the client's situation, the meaning of the phrase varied. Once combined and analyzed with other data collected, the phrase, "look after yourself" sorted into two major categories "trying to look after yourself" and "looking after yourself" with a common goal or overall theme of self care and independence. During analysis, terms, phrases, and themes grounded in the data were employed as they were used or synonyms devised to describe interactions and demonstrate the commonness of the concepts.

Validation and verification of the themes with the data, with other persons, or with the participants was the second step, but also continued throughout the data collection and analysis. Frequencies were counted as to whether themes are supported or rejected by the emerging data. The next step involved summarizing

Excerpt from theme categories: Self care/independence -
'looking after yourself', 'trying to look after yourself'

Self care and independence

Looking after myself and looking after my health. Caring for self.

Self supporting and self independent.

Self care.

Rather manage on own.

Feel its really important to manage on my own.

Yes. I manage things, manage my money, manage home help, plan what is needed and tel her; run my own place so I see that they are done.

Look after own diabetes. A bit independent. Like to do things myself. I watch my blood sugar very closely; learned from the sisters and read up about it.

Learned how to look after own BS.

Lets us do things our own way.

Do all that I can. Very important to be independent, get to depend on other people if you don't do for yourself. Has been caring for husband for a while by self. If I was sick it would be a different thing.

Looking after yourself

You know better than anybody else what your body needs or what it doesn't need. Its between your body and the medical side, so you know what is better I mean they only know what you tell them and if you can diagnose something yourself without being an expert on it. (Validated summary - you feel there are lots of times when you know what is better for you because you are the person it is happening to).

My personal problems - have to keep an eye on them and pamper myself and not take things for granted.

Learnt how to care for self a long time ago.

Care for self as needed and to teach to care for self. Treat him as normal and encourage normal activities. Some times have to be cruel to be kind. Engineered idea and made up ideas for control of urine -- tried different things and came up with a way that others use now. Teaching him to care for self -- eg. recognizing urine infection by self.

Look after self, do what you can for self. Just straight out commonsense, you just do the things as you see they need to be. You have also got to be independent to know what best to get myself back on the road to recovery.

Yes, want to be independent but good to be just a phone call away from the nurses.

Yes. Made me independent because I wanted to be.

Suggestions made to me but I'm so 'pigheaded' I go my own way.

Yes I am accustomed to running my own life.

Did own dressings after nurse showed how to. Arranged home aide and meals on wheels by self. Couldn't manage otherwise.

Trying to Look after Yourself

Just couldn't manage colostomy so wife had to do it. Nurses taught her.

(Family say) difficult to help her, needs lots of care. Family wants to help them be self sufficient and keep them in their own home.

Did not want or plan nurse to pour her pills or to give them to her. Gave own drugs for years then doctor made DN give morning and night pills. Threat to my dignity; feel angry and powerless.

Try to give own shower. Did what I was told -- co-operated with what nurse said.

I suppose so. I can run my own life with a certain amount of help. Manages and organizes problems for self. I make the decisions about what I need, and gone out and got it myself. Sends out washing, deliveries to home/ home help/ MOHs.

Yes I would love to more for myself but I can't.

Wash myself and they do the rest.

They were a great help, but picked up myself how to help her.

Dry myself and look after myself. Now pretty well looked after, had trouble getting help but saw consultant.

Give and take. See yourself as doing what you can.

Does major part of care for self. Managing for self. Making decisions about what is needed. (Goal is self care for a lot of these informants, and compromise seems to be accepting as little care as needed).

Help wash self and talk. They do it to me.

Very important to look after self and need DN to help; have no family here and occasionally need someone.

I live on my own and can't be too long out of action.

I think do, cause otherwise you find yourself going down. You must help yourself; you have to move around and get yourself going. (Doing laundry and hanging it out before I came, wanted to get it done before HA came to do it).

(Helping yourself, directing care, having control, saying what he needs making decisions, examples given with much vocal agreement and given by examples) Wanted to do these but nurse wouldn't let them.

Wanted to get help and couldn't seem to get what was needed. Then finally daughter made arrangements for them.

I have my own ideas about my care. If they said any thing I didn't agree with I would say so. (Again the idea of monitoring or watching what's done).

Do it my own way and then show nurse.

theme by theme, using descriptive and illustrative quotes to support the materializing premises. Validation of this summary with the data, with frequency details, again with the participants and against any negative information in the data was the last step before the final description was written. Each negative case of the essential characteristic of participation was described.

Authorities on qualitative research or analysis of data were consulted to arrive at the plan of analysis used in this study (Cantanzaro, 1988; Field & Morse, 1985; Leininger, 1984; Munhall & Oiler, 1986; Parse, Coyne, & Smith, 1985; Paterson & Zderad, 1976; Polit & Hungler, 1983; Wilson, 1985). Analysis of this data was conducted alone, validated on occasion by informants, thesis supervisor, and other persons.

Chapter 3 has presented the methodology plan for this study. A multiple triangulation research design utilized both qualitative and quantitative techniques of data collection and analysis to answer the study question. Analysis, interpretation, and report of the results follow in Chapter 4.

CHAPTER 4: ANALYSIS, RESULTS, AND INTERPRETATION

Data collected from study clients is analyzed and interpreted in this chapter. Results are presented in both quantitative and qualitative fashion integrating the two methods to explain district nursing client's participation in care as discovered in this study. Background data and tables are presented in the first section to compare study participants to the whole district nursing population for this exploratory research. The meaning of the concept of participation to study clients is presented in the second section illustrated by qualitative quotations and by statistical data. Data are compared and validated by references to other research.

SECTION 1: CONTEXT OF THE PARTICIPANT

Study Participants

The clients for this study were selected from the master computer list of patients of the Community Health Services of the Palmerston North Hospital Board. Thirty eight people agreed to and were interviewed for this study; they were 16 men and 22 women. Those who agreed to partake in this study were a cross section of district nursing patients (based on cases encountered during the researcher's working experience as a district nurse). The majority were able to communicate with the researcher or their caregiver in their own way. Caregivers and client were interviewed together, if possible (in cases where the client had a caregiver), to reduce chances of the researcher misinterpreting answers.

Five people refused interviews: two people refusing personally, one was "too painful, too big an effort at the moment" and the other because he had "permanent problems and does not require district nurses...takes care of things in his own way."; the families of three people refused interviews for the client, two were seriously ill and the other was unable to speak.

Description of Participants

Age and Sex

Table 4: 1 shows the age and sex distribution of the study informants, ages ranging from 8 to 90 years. The majority (n =27, 71%) were over 60 years, 8 being over 85. Males dominated the under 60 group constituting 9 of the total 11. Females predominated in the over 60 group, making up 52.7% of clients over 60; the over 85 group was all female. The only age group with a more balanced mixture of female (15.8%) and male (13.1%) was the 75-84 year group. This study shows an overall pattern of more females requiring district nursing services, predominating in the aging population.

TABLE 4: 1
AGE AND SEX DISTRIBUTION OF STUDY CLIENTS

Age group Years	Number			Percentage & %			Cum.% Total
	Male	Female	Total	Male	Female	Total	
0-25	4	0	4	10.5	0	10.5	10.5
26-40	2	0	2	5.3	0	5.3	15.8
41-60	3	2	5	7.9	5.3	13.1	28.9
61-74	2	6	8	5.2	15.8	21.1	50.0
75-84	5	6	11	13.1	15.8	28.9	78.9
85 and over	0	8	8	0	21.1	21.1	100.0
Cum. Totals	16	22	38	42.0	58.0	100.0%	

A study of Christchurch district nursing patients had more patients 65 and over (80.8%) and more females (68.8%) than the present study (Malcolm & Higgins, 1983). New Zealand Department of Statistics (1985) census information shows a similar pattern of female/male distribution in the population reflecting the greater life expectancy of females with more women in the 'very old' (over 80) group.

Age and sex are demographic variables affecting the need for district nursing care which can distinctly alter the focus of the nurse's practice (Twomey, 1986). The Kinross, Nevatt, & Boddy (1987) report found that one portion of the project nurse's area (which had no clients over the age of 55) infrequently required district nursing attention. The Social Advisory Council (1984) states "People in the over-80 age group are heavy users of health and hospital services, and the growth in their numbers has important consequences for health planning" (p.16).

Living Arrangements

Table 4: 2 shows living arrangements of male and female clients by age. Most study participants that lived alone (n= 13) were female (n= 11) in the older age group. The oldest person living alone was a 88 year old woman. It is thought that elderly and disabled people living alone are at risk of increased vulnerability to other problems such as becoming socially isolated. Never-the-less elderly people living alone are not as isolated as thought, and studies have found that daily contact with a relative or neighbor is common (Bowman, 1980; Pybus, 1987). Clients in this study who lived alone followed this pattern; neighbors and shopkeepers were perceived as helpful daily contacts especially for those who had no family or family living elsewhere.

Seventeen (44.7%) study informants lived with spouses, 3 of the 4 mid-age (26-60 years) males having children at home as well.

In the older age groups clients were cared for by spouses, but in 4 cases the client cared for a spouse, despite requiring district nurses for themselves. Other studies have found that while both may have a significant degree of limitation, it is often possible for spouses to help and support each other with little outside assistance (Social Advisory Council, 1984).

TABLE 4: 2
LIVING ARRANGEMENTS BY AGE AND SEX

Age	With Family	With Spouse	Lives Alone		
0-25	xxxx			4	
26-40		xx		2	
41-60	x	xx	oo	5	Male = x Female = o
61-74	oo	oo x	oo x	8	
75-84		ooo xxxx	ooo x	11	
85 & over	o	ooo	oooo	8	
Total %	n8= 21.1%	n17= 44.7%	n13= 34.2%	n38= 100%	

Of those living with family, 5 males who were younger (8-60) lived with parents and siblings, or with mother alone; one lived with a son. Three women (7.9%) who were older (61-85 and over) lived with a daughter or female relative. This contrasts with 22% of those over 60 in the general population, both male and female who live with a relative (Social Advisory Council, 1984) or friends (Bowman, 1980).

Clients' Perspectives: Treatments, Illness, Needs

This study inquires about the use and purpose of district nursing services from the client's perspective. Higgins (1983), Kinross, Nevatt, & Boddy (1987), and Malcolm & Higgins (1983) have studied these elements from the nurse's point of view giving a clear picture of the types of district nursing clients and the reasons they require the services of the nurse. The client's perspective of the nature of their illness or disability and of relationships between nurse and client may be distinctly different than the professional's.

Nature of illness or disability

Clients of district nurses were asked in this study to describe their perceptions of the nature of their illness or disability. The researcher noted if they first had described their problem as a medical diagnosis (76.3%, n= 29), or as a loss of functioning or problem to themselves (23.7% n= 9). A number of participants perceived themselves as having more than one condition. Information was classified as - one condition n= 38 (100%); two conditions n= 22 (52%); three or more conditions, n= 11 (28.9%). A list of the conditions disclosed follows in Table 4: 3 categorized under three headings: acute, chronic, and inability to cope. The number beside each condition is the frequency of naming each condition.

Clients named their conditions as they came to mind, sometimes speaking of a medically diagnosed condition first and the reason for district nursing visits last. For example participants might say they had a "bad heart" but the district nurse was visiting them because they had a fall; or that their operation (with or without complications) was the reason they needed the district nurse, but added as an afterthought that the operation was for cancer. Therefore to avoid making assumptions regarding the primary diagnosis the researcher categorized by order of naming when coding.

A total of 72 conditions were noted in 38 clients, an average of 1.9 conditions each. Clients having more than one condition often said they had equal disabilities or more distress from the second or third conditions mentioned. Sometimes it was the combination of conditions that required the district nurse. For example a condition of advancing age was complicated by a fall and a fracture for five study participants or a client might have complications of pressure sores from a condition which restricted mobility.

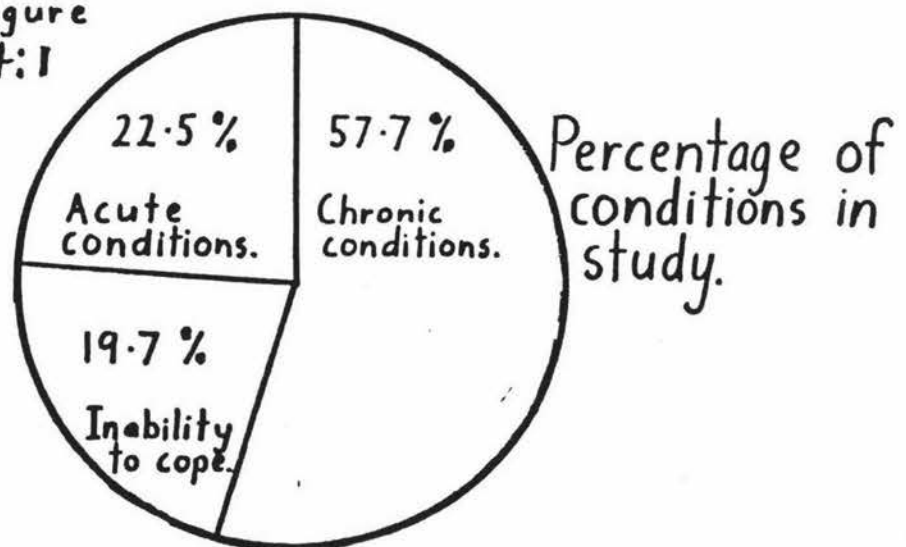
The most common condition found in study participants was an accidental injury or fracture, 12.7% (n= 9), followed by client

diagnosed advancing age and poor memory, 9.9% (n= 7). Figure 4: 1 shows client's chronic conditions dominated the study. Although the classification system differs in Malcolm & Higgin's (1983) study diagnoses of musculoskeletal disorders (18.9%) and arthritis (15.4%) were most common while frailty and agedness were ranked fifth at 11.2%.

TABLE 4: 3
FREQUENCY OF CONDITIONS IN STUDY CLIENTS

<u>Acute:</u>	9 accidental injury/fractures	
	5 operation/complications/infections	
n= 16	2 operation	
<u>Chronic:</u>	5 Stroke	5 Heart conditions
	5 Cancer	4 Arthritis
	2 Depression	2 Multiple
	2 Amputation	Sclerosis
	2 Blind	2 Alzhiemers
	2 Leg Ulcers	2 Diabetes/
	1 Diabetes	complication
	1 Epilepsy	2 Spina Bifida
	1 Constipation	1 Alcoholism
	1 Retardation	1 Hypertension
n= 42	1 Autoimmune disease	
<u>Inability to cope:</u>	7 Advancing age/poor memory	
	4 Falls	
n= 14	3 Bereavement	

Figure
4:1



Frequency of visits

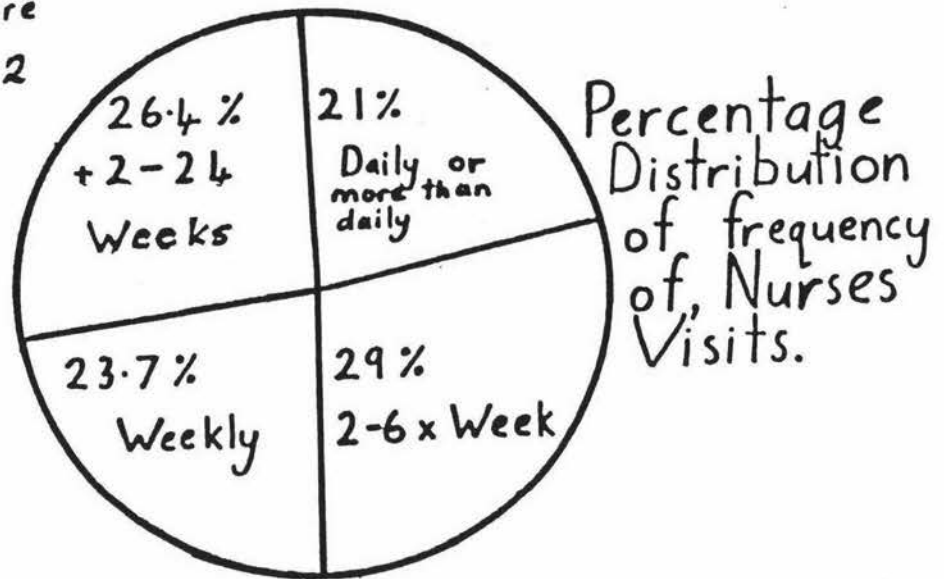
Clients who received visits 2-4 times daily or daily made up 21% of district nurse's total visits (see Figure 4: 2). The highest single reason to visit was weekly visits for hygiene for primary (one), secondary (two), or tertiary (three or more) reasons (see Table 4: 4).

The clients in this study received more daily or more than daily visits from the district nurse, but fewer weekly visits than either the Kinross, Nevatt, & Boddy (1987) or Malcolm & Higgins (1983) studies. This is explained by differences in the number of weekly hygiene visits. Fewer hygiene visits were made in this study ($n = 19$, 24.6%, see Table 4: 4) compared to 66.8% in the Malcolm & Higgins (1983) study. This present investigation reveals a different focus of practice (although classification categories were dissimilar) than the Kinross, Nevatt, & Boddy (1987) study where 75% of the clients were classified as 'supervision' visits while 20.7% ($n=16$) in this study were visited for supervision.

TABLE 4: 4

FREQUENCY OF DISTRICT NURSES VISITS: COMBINED PRIMARY, SECONDARY, AND TERTIARY REASONS FOR VISIT.

COMBINED PRIMARY, SECONDARY, AND TERTIARY REASONS FOR VISIT									
	Hygiene	Dressings	Super- vision	Total nursing care	Teaching	Supplies	Medi- cations	Coun- selling	Arranging other care
VISIT FREQUENCY									
more than daily	4	1		4		2			
daily	1	4	1						1
5 x week	1				1				1
4 x week		4	3			1			
2 x week	3	3	3			2			
weekly	7	1	5				4	1	
up to 4 weeks	1	1	1		1	1			1
4 to 12 weeks	2	3	3			2			
12 to 24 weeks		1				1			1
column total	19	18	16	4	2	9	4	1	4

Figure
4: 2Service Needs

District nurses frequently have a "gatekeeper" role in access to other services and in relief of caregivers (Pybus, 1987; The Society for Research on Women in New Zealand, 1976). That is, district nurses assess the need for these services and make arrangements for provision either personally or through referral. Patients and caregivers (Koopman-Boyden, 1981; The Society for Research on Women in New Zealand, 1976) and social services advisors (Flowers, 1987; Social Advisory Council, 1984; Social Monitoring Group, 1985) in New Zealand believe that not enough help is offered and that treatment services should be expanded.

Available services from the Palmerston North Hospital Board, those available from Department of Health or from Social Services, and private or voluntary help were included in this study. Participants were asked if they received other assistance besides the district nurse and these answers were classified by the service. Table 4: 5 shows the breakdown of number of people in the study receiving each service, as well as those receiving services not on the original list (see Questionnaire, Appendix A).

TABLE 4: 5
SERVICES RECEIVED BY STUDY CLIENTS
IN ADDITION TO THE DISTRICT NURSE

Service	Number		Total
	Male	Female	
Home help	4	15	19
Volunteer help	4	7	11
Volunteer support group	9	4	11
Private help	1	9	10
Meals on wheels		9	9
Alternative/ Intermittent care	4	5	9
Social worker	4	3	7
Other nursing help	4	1	5
Occupational therapy	2	2	4
Physiotherapy		3	3
Practice nurse		2	2
Counselling	1	1	2
Public health nurse		1	1
<u>Added by clients:</u>			
Supplies/equipment	4	3	7
Disabled camp	1	1	2
Speech therapy	1		1
Orthotic clinic	1		1
			104

Alternative and Intermittent Care are programs funded by hospital boards or social services to relieve caregiver's by providing alternative care, eg. hospital, rest home, for patients several weeks of the year. 'Other nurses' were identified by clients as diabetic nurse, psychiatric nurse, ostomy nurse, and nurse aide. Practice nurses work for doctors' private practices, hired by the doctor but salary subsidized by the government. Supplies were perceived as critical necessities by study clients, sometimes available only from the hospital board, or if available at the chemist, very expensive. Examples were sterile dressing supplies, ostomy equipment or catheter supplies for self care. This category does not include supplies used directly by the district nurse in nursing care which are categorized under district nursing treatments.

A number of clients received more than one service besides the district nurse; 34 people received 104 services, an average of 3 services each for those using additional services. These services were predominantly used by people over 61 (80%).

Home help (19), volunteer help (11), volunteer support group (11), and private help (10) were the most used services (see Table 4: 5). Chronically ill, disabled people, or elderly in the community sometimes prefer to pay for private help using public services as little as possible. They often receive the majority of their help from family, neighbors, or volunteers (Social Advisory Council, 1984). Volunteer help here refers to help from outside the home which does not include living with caregivers.

The source of home help was not distinguished in this study, i.e from hospital board or social welfare. Private help used was most often for household chores, gardening, cutting lawns, sometimes for cooking meals (hospital home aides do not cook meals for patients in most cases) or for 'granny sitting', and in one case for nursing care. Private help may be paid by the client personally or sometimes by Accident Compensation if injury is accidental.

Social workers are involved since they are 'gatekeepers' to a long term level of services while hospital board additional services are usually short term. Means tested financial assistance for needs such as continuing home help, major equipment (beds, wheelchairs, structural changes in home, etc.), or alternative care can be obtained from social welfare. Therefore these public services, initially assessed by the district nurse, can be funded through the hospital board or referred to social services.

Client Attitudes and Expectations: What Does the District Nurse Do?

Social Contact and Personal Attention

Some participants in this study viewed the nurse as a social

contact and friend.⁴ They said "I like to have her visit, she's always so cheery." "It breaks the day." The nurse shows "genuine concern for me, they are very caring." "She is always so friendly and helpful, nothing is ever a trouble." One person felt "the nurse is like a friend...relates to you as a person." Several showed sincere affection for "their" district nurse. One woman tried to do what her nurse wanted because she was "such a dear little thing". James, Rabuka, & Muslim's (1982) study clients also thought the nurse's visits broke their loneliness.

Clients recognized the difference between a professional manner and a caring friendly manner and believed there was a place for each in their relationship with the nurse. They were pleased with individualized and personal care. One client said "She is Nurse until the job is over, then she becomes an individual." Another client explained that he most liked "the homely attitude...being on first name terms; they sit and talk about different things - its not all officialdom and I'm the nurse, I'm the expert attitude." A woman clarified that it was important to her to be seen as an individual (not as a disease) so she wanted nurses to call her by her first name.

It was possible for clients in this study to develop long term relationships with district nurses since each nurse is responsible for a geographical area and may care for the same clients for a number of years. Findings of friendship and feelings of support may relate to having the time to develop such relationships. Pringle (1982) found that home care clients and their caregivers did not recognize nurses as giving support or psychosocial care in a Canadian study when they did not know their nurse well. Nurse's visits to the same patient were not consistent in Pringle's (1982) study, having a negative effect on the nurse/client relationship.

⁴ The researcher apologizes to male nurses who may be offended, but to the clients who participated in this study the nurse was a woman and was addressed as she.

Source of Support

Most of the study participants were aware that they could call on the nurse for assistance, advice, or support anytime saying "If I need her, I just have to call." The district nurse provided support through confidence boosting and encouragement. Clients depended on the nurse; making actual use of the nurse did not matter but 'knowing she was there' if they needed her did matter. One participant thought the nurse "boosted his moral courage", he felt strongly supported by this while others said the nurse "gave me confidence" and "reassured me". "I have faith in them, they are dedicated to their work". An older woman living alone explained that the nurse helped relieve her worries about being alone saying "they are taking some responsibility for me...it pretty much lies on my shoulders."

American studies by Gardner & Wheeler (1981, 1987) found that although rank priorities differed, patients perceived support given by nurses as: moral support; showing interest in the patient; response to friendship; and providing physical care and comfort.

Support of Caregivers

When people require assistance with personal care, mobility, activities of daily living, or home health care, they are often able to continue living in the community because of help available from informal support networks. Most frequently this help comes from relatives, the pattern being generally that one family member assumes responsibility for care. This caretaking role is most often assumed by women - the spouse, daughter, or daughter-in-law of the person needing care - in New Zealand and overseas (Bass & Noelker, 1987; Davis, 1980; Dixon & Caradoc-Davies, 1987; Koopman-Boyden, 1981; Pringle, 1982; Social Advisory Council, 1984).

Goldstein, Regnery, & Wellin (1981) found a philosophy in the USA which was echoed by the caregivers in this study.

Nearly all caretakers express their determination to maintain the patient at home as long as possible....The general attitude seems to be: whatever the physical, psychic, and other costs of caretaking, they are the price one pays to avoid institutionalizing the patient.
(p.27)

Persons living with a caregiver differ from those who live alone in New Zealand in their needs for community support (Higgins, 1983; Koopman-Boyden, 1981; Malcolm & Higgins, 1983; The Society for Research on Women in New Zealand, 1976). Too often, formal health and social services provide less support than needed by tending to rely on caregivers to provide it (Campbell, 1987; Social Advisory Council, 1984). Thus caregivers become fatigued and exhausted from the strain of giving constant care and require relief from stress and responsibility (Campbell, 1987; Davis, 1980; Dixon & Caradoc-Davies, 1987; Foxall, Ekberg, & Griffith, 1985). The Alternative and Intermittent Care programs provide occasional relief but ongoing daily support for caregivers of some study clients came from the district nurse.

Caregivers of study clients needed the district nurse's support. One caregiver said "I just don't know where I'd be without their help" and another "It was a great day for me when Sister... walked into my home." "You just don't know how beneficial it is until you use them [nurses]." Others just plainly said "we need her" or "we can't do without her support". Moira Glasgow (1988) wrote "I could never have coped" without the help of the district nurses. The following summary explains what caregivers in this study needed and expected from district nurses.

Caregivers wanted the "best" for their loved one(s), and "depended" on the district nurse to help them plan and execute care; to "suggest" helpful ways of coping; to "warn" and prepare them for what was coming; to "accept" and "support" their decisions; and to "work together. ...explain and teach as we go along."

The Society for Research on Women in New Zealand (1976) also found that regular visits by the district nurse with help for routine and difficult nursing care, served not only as support and

encouragement but as friendship and a morale booster. Martinson (1977) in USA found that support given by home care nurses was "emotional and psychological"; it was essential to caregivers that someone who 'understood' was available to talk and answer questions, to instil confidence, to encourage, and to teach nursing care.

Treatments and Service

The treatments or services given by the district nurse as perceived by the client were categorized into eight major categories. Both the major categories and items fitting into each category follow in Table 4: 6.

TABLE 4: 6
TREATMENTS/SERVICES FROM DISTRICT NURSE

Hygiene	bathe, shower, dress, bowel/bladder care.
Dressings	acute wound care; chronic ulcers/pressure sore care; sterile techniques- catheterization etc.
Supervision	following more acute reasons for care; support to caregivers; bereavement/coping; advancing age/coping; Hypertension, Diabetes monitoring etc.
Total Nursing Care	bathing, bed bath, sponging, pressure cares, dressing, transfers, repositioning etc.
Teaching	dressings; nursing care to caregiver; colostomy urostomy, tracheostomy.
Supplies	equipment, beds, walkers, crutches, canes, commodes etc.; linen; bath boards; ostomy; incontinent needs- catheter equipment, pads, kanga pants, rubber drawsheets etc.
Medications	pills; injections; supervision.
Counselling	psych; diabetic.
Arranging other care; referrals	Physio; occupational therapy; Meals on Wheels; Home Help; Alternative/Intermittant care; Accident Compensation; Social Welfare; Filling forms; private care etc; monitoring/reporting to physician.

What is nursing care?**Hygiene -- 'Giving a Bath'**

As Table 4: 7 shows, hygiene reasons were the primary reason for 12 nursing visits (31.6%) and most of these were for bathing and showering. District nursing is associated with bathing patients in both nurse's and client's perceptions but some study clients questioned whether bathing is "really nursing care". To illustrate, study participants who received bathing or showering (hygiene) as their only service from the district nurse often said "I'm only getting a bath (or shower)" and did not recognize this as nursing care. In fact they described their needs as trivial, "hardly worth mentioning".

However, it must be clarified that baths or showers are often given by auxiliary staff- enrolled nurses, nurse aides, or by nursing students in Palmerston North. This confounds the issue, but may also explain it, leading to speculation (grounded in the data obtained) that if the district nurse does not value and perform the task herself, but sends someone else to do it, the patient may learn from this that it is not nursing care and not highly valued.

In this study one client carefully explained "its not the regular nurse that gives shower, I don't need nursing care". The reason for having the bath or shower altered perceptions of whether it was nursing care or not. Six clients who were being bathed because they were "getting old" and likely to slip or fall did not perceive a bath as nursing care while thirteen clients receiving a bath combined with illness, immobility, or other needs did perceive it as nursing care.

Complaints about district nursing services centred around bathing and auxiliary staff. Six people were unhappy about certain aspects of this. Some focussed on time, saying they "never seem to have enough time", one lady said they just "shoot off before I'm done". Another complained "they're always sending someone

different, you never know where you are." One client wanted to "have a bath more often, once a week is not enough."

Despite the fact that patients want and need physical care from nurses, bathing and physical care is often relegated to the realm of 'tasks' delegated to auxiliary personnel in New Zealand and overseas (Borwell, 1980; Christensen, 1984; Davis, 1970; Kratz, 1981; Ridley, 1974; Schulman, 1972). Kratz (1978), in England, discusses the values that district nurses place on care they give, proposing that nurses do not highly value care given to those who are "not getting better" and where there is no clear identifiable purpose for visiting (p.77). Bond (1984), in New Zealand, talks of devalued care given to the elderly; this care is considered low status with low expectations of entitlement by both client and professional. But McGilloway (1976), in the U.S.A., points out that the skills of the professional nurse are most required to protect and respect integrity of the individual thus sensitivity in performing tasks which are intimate and private and allowed to no other is essential. Helplessness and dependency places the patient in a vulnerable position which may not be recognized by unqualified persons performing task-oriented care.

District nurses perceived giving a bath as nursing care when it was combined with "comprehensive observations of the emotional, mental, and general physical condition" of patients and the nurse "provided general support and encouragement to their principal supporters" during the bath. (Higgins, 1983, p.16).

Teaching

Hygiene, dressings, and supervision were both high primary and secondary reasons for district nursing visits (Table 4: 7). Doing dressings and giving total nursing care were definitely perceived as nursing care, as was teaching for the two clients who identified this as a secondary reason for visits (specifically diabetic teaching and how to care for the needs of a bedfast patient).

Never-the-less, overall, participants in this study did not perceive a teaching role for nurses. The researcher, however, took note of numerous instances described by clients where the nurse had taught them. For example teaching clients how to do their own dressings or how to cope with and take care of their colostomy, urostomy, or tracheostomy, where initial teaching was done in hospital, but ongoing coping and troubleshooting was taught and assisted by the district nurse. The nurse taught practical skills like how to transfer to and from the bed, wheelchair, or bathtub when incapacitated or what one could do for this or that problem to almost every client in this study.

While clients acknowledged and appreciated the nurse's contribution, saying the nurse did this or that, or 'gave them useful instructions' (n= 23) they did not identify it as teaching. Instead it appeared to be part of their expectations of the nurse's normal role. In other words they 'took it for granted' that the nurse should teach certain things and did not consider this as formal teaching.

Perceptions by clients that the nurse does not have a teaching role were shown in a Canadian study (Tilley, Gregor, & Thiessen, 1987). However helping the patient to interpret their illness experience and to integrate implications of that into their lifestyle was a perceived nursing function (Tilley, Gregor, & Thiessen, 1987).

Other services

Some of the care needed by themselves was extremely distasteful to a few of the clients in this study. Several clients commented on this aspect of nursing care saying "I wouldn't (or couldn't) want to do some of the things they do!" "I couldn't look at it! I hated the thing but the nurse..." "There's never a look or a sign..... They're [nurses] just marvelous about it...." It was very important to these clients that the nurse coped with something that was intolerable for them and that gradually she was

able to help them accept and cope with the intolerable. In particular some of these situations were associated with altered body functions and image eg. colostomy, tracheostomy, or cancer. For others, loss of independence and loss of ability to care for their own physical needs was an intolerable situation.

Providing needed supplies and supervision (Table 4: 7) were perceived as being helpful and necessary; those receiving supervision appreciated having someone "checking on them" but did not always identify this as nursing care. Half the participants (three out of six) being supervised for primary, secondary, or tertiary reasons did not think they participated in care because they did not perceive themselves as receiving nursing care. A person receiving counselling said "Oh, I'm not getting nursing care." Another client having medications administered and blood pressure monitoring said "I haven't got nursing care really".

Arranging for other care (n= 6, Table 4: 7) was frequently not perceived as care from the district nurse, and participants were often not aware that the nurse had done, or could do, anything in this regard. An elderly woman (and her husband, 90+ years) "wanted to get help and couldn't seem to get what was needed....daughter finally made arrangements for them but they were unable to arrange their own help." They had not told the district nurse what they needed.

Expectations of the nurse's role

Expectations of the nurse's role differed. Two young men (both under 25) and three elderly clients believed "The doctor directed the whole thing, made decisions and the nurse followed orders. She just carries out treatment started" by doctors or the hospital.

It was quite clear that clients in this study perceived nursing care as approximating hospital nursing care, as they did in Kratz's (1978) major British study. Participants sometimes simultaneously related incidents of hospital and district nurses

together. One man said "I learned in the hospital that the way to get on with nurses is to work in with them, do as you're told. If you're too strong, you don't get as good care."

Data confirmed that a traditional view of the nurse's role was perceived by the clients in this study. Fifteen clients who vocalized specific expectations of what the nurse should do identified the nurse's professional advice, knowledge, experience, and observation as the foremost expectation. Physical nursing care and tasks, including sterile procedures (n= 6) and providing caring and support (n= 3) were the other specific expectations mentioned.

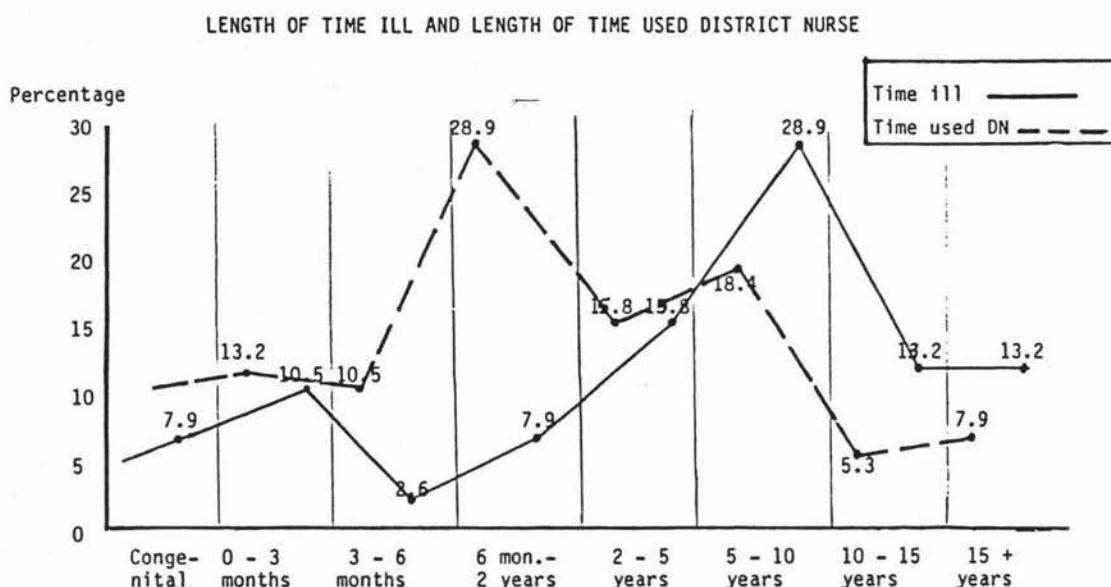
Assumption of new functions by nurses has also received slow acceptance by American community clients (Brands, 1983; Shamansky & Germain, 1987). Brands (1983) found that more than 50% of her study population believed in a traditional role for the nurse in contrast to a transitional, or an expanded non/traditional role of primary care giver.

Client's Knowledge and Personal Traits

Independence and self care

Some clients in this study were ill for long periods and had tried to cope for some years before they started to get help from the district nurse. Help was kept to a minimum at first, perhaps a weekly bath, but as the condition worsened they reluctantly realized they had to accept more help. Figure 4: 3 shows the percentages of length of time ill compared with the length of time participants used district nurses' services. The congenital category (see Figure 4: 3) refers to illness or disability present at birth. The graph (Figure 4: 3) portrays a shift of several years duration, between the length of time ill and the length of use of district nursing, for example 28.9% of the clients had been ill for five to ten years, but only 18.4% had used district nursing services for five to ten years.

FIGURE 4: 3



Study clients wanted to care for themselves as much and as long as possible, 24 (63.2%) referred to self care as their direct goal, 28 (73.7%) participated in their nursing care, and 34 (89.5%) wanted to participate in their nursing care. The qualitative pattern shown by study participants is one self reliance and trying to maintain independence; their compromise is accepting as little help or care as possible.

An 86 year old client who was blind with one amputated leg explained "I am accustomed to running my own life. I manage things- manage my money- manage the home help- plan what's needed and tell her. I am running my own place so I see that things are done. To me its really important to manage on my own."

Another elderly woman was washing and hanging clothes outdoors when the researcher arrived. She said "I just want to get this done before the home help arrives [to do it]" and later said

"you must help yourself...have to move around and get yourself going, otherwise you find yourself going down". This lady's mobility was restricted, so much so that the researcher had concluded she wasn't home, when in reality she couldn't reach the door in time.

A study informant who couldn't "get around much anymore" (in fact, was housebound) pointed out "I can run my own life with a certain amount of help. I manage and organize problems for myself, make the decisions about what I need, and then make the arrangements for myself."

Trying to "look after yourself" for the elderly

As elderly clients in this study had gradually lost some functioning, family and neighbors urged them to get help with some things like bathing but they usually resisted this pressure for a time. Twelve clients only began to get district nursing help after a fall, or for fear of falls (31.6%). Along with the belief that "nurses were too busy" a few study informants thought they didn't want to be "bothered being a nuisance to them [nurses]". They preferred "not to be helpless" and tried to do as "much as I can for myself". One 80 year old woman who had fallen and fractured a bone after eye surgery, expressed the overall impression with her statement:

I do all that I can. Its very important to be independent. You get to depend on other people if you don't do for yourself. I have been caring for my husband by myself. If I was sick it would be a different thing.

Overseas studies have found that sick role expectations of chronically ill and older people are mainly influenced by the ability or capacity of the person to perform usual roles within the limits of their disease. Kassebaum and Baumann (1972) found that the aging, chronically ill person, believing symptomology and loss of function is due to aging, doesn't define him or herself as ill, consequently does not adopt a sick role or seek help.

Perceptions of health status have been found to be the principal contributor to feelings about abilities to cope with the activities of daily living and to feelings about the future, whether positive or negative, certain or uncertain, in both the very elderly and the chronically ill (King, Figge & Harman, 1986; Melanson & Downe-Wamboldt, 1987).

Covering up and keeping up, sometimes for years, is common amongst the chronically ill (Reif, 1973; Wiener, 1975). Hiding visible signs like canes or walkers, using strategies to conceal and normalize behavior, or reducing social contacts and engagements puts off the time when the person has to become more dependent and enlist some help (Wiener, 1975).

Study participants frequently said "we manage... I can cope... I do what I can for myself... I care for myself... or I look after myself." One 80 year old man, determined to continue to take care of himself and his wheelchair bound wife, was outraged when his daughter "went over my head" and asked for meals on wheels and home help for them. "I didn't want those things, she had no business doing that. I can cook, and clean my own house."

Other study clients accepted family, friends, and neighbors advice as evidence of failing functions, but kept on till they "couldn't manage anymore".

Barstow (1974) describes a similar tradition of self reliance in America which is only overcome when symptoms become "urgent, incapacitating, or painful" and evidence is overwhelming that one must seek help (p. 138). In an elderly client population which highly valued independent behavior in Minnesota, patients valued self control of diet and bodily functions, self decision-making, and nursing discussion/consultation with themselves and their families (Smith, Buck, Colligan, Kerndt, & Sollie, 1980).

Trying to look after yourself for the chronically ill

The pain associated with some chronic illnesses and the uncertainty of one's ability "to manage" aspects of care worried

some study clients. Along with the desire to 'look after themselves' they had other difficulties to cope with as illustrated by Armstrong (1987), Gull (1987), Locker (1983), Reif (1973), Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Weiner (1984), and Wiener (1975).

The chronically ill have to maintain a constant vigilance over the course of their disease, managing it, watching for signs and symptoms, side effects, and preventing crises. Relaxing this continual watch can be disastrous!

A diabetic client in this study injured his feet accidentally. He has required dressings to his feet for a year but since his diabetes hampered healing his feet show no signs of healing. He also suffered other complications of diabetes. Two other clients in this study had amputated legs resulting from diabetic complications.

Analysis: Quantitative Data

The purpose of this study is to discover the meaning of participation to district nursing clients. For this reason correlations will be confined to these data. The SPSSx computer program was used to calculate Pearson product-moment correlations between parametric variables.

Correlation coefficients and probabilities for the question (see Questionnaire, Appendix A) "Would you say you participate in your nursing care?" with each variable of age, sex, services used, frequency of visits, the length of time ill, and the length of time using district nursing follow in Table 4: 8.

Spearman's rho and Kendall's tau rank correlations were calculated for the question "Would you say you participate in your nursing care?" with the nonparametric variables: primary (1), secondary (2), and tertiary (3 or more) reasons for the visit, one, two, and three or more conditions, mobility, and living

arrangements. These correlations and significance levels are set out in Table 4: 8.

Those with tertiary (three or more) reasons for the visit from the district nurse ($n = 13$) show a .4859 or .5350 correlation (Table 4: 8) with participation that can be cautiously interpreted as significant with $df = 36$ at the .05 level. Having three or more conditions also has a moderate correlation, .4209 or .4867 with participation, but significance level of .06 is not rigorous enough to refute that the results may be due to chance (Table 4: 8).

Moderately significant results between "Would you say you participate in your nursing care?" correlated with Tertiary reasons for the visit and Three or more conditions indicate that there is a relationship between participation level and having more illnesses and/or district nursing needs. Because these clients were a subpopulation within the study population, their reduced numbers do not justify a firm conclusion of significant relationships. However these are identified as areas likely to reward further exploration. None of the other variables appear to warrant further exploration.

TABLE 4: 8

CORRELATION COEFFICIENTS OF PARTICIPATION
 "WOULD YOU SAY YOU PARTICIPATE IN YOUR NURSING CARE?"

Variable	Participation correlation probability	Variable	Participation correlation significance	Participation correlation significance
Age	r= .2093 p= .104	Primary reason for visit	-.0554 .354	sig. -.0617 .356
Sex	r= .1771 p= .144	Secondary reasons for visit	.2547 .077	sig. .2848 .079
Service needs	r= -.2155 p= .097	Tertiary reasons for visit	.4859 .032*	sig. .5360 .030*
Time ill	r= .0045 p= .489	One condition	.1004 .237	sig. .1178 .241
Time use D. Nurse	r= .0948 p= .286	Two conditions	-.0552 .384	sig. -.0646 .388
Visit frequency	r= -.0202 p= .452	Three or more conditions	.4209 .062	sig. .4867 .064
		Mobility	.0866 .280	sig. .0960 .283
		Live with someone	-.1081 .241	sig. -.1154 .245
Variable	Pearson Product- moment Correlation	Variable	Kendall Tau Correlation	Spearman Rho Correlation

* Significant at .05 level

r= correlation
 p= probability
 sig.= significance

SECTION 2: CLIENT DEFINITION OF THE SITUATION

Quantitative Analysis: Elements of Participation

Elements of participation identified in a literature review were incorporated into the questionnaire in Question 12 (see Appendix A). These elements (see Figure 4: 4) are displayed by the questions:

- a) The district nurse gives me useful instructions for looking after myself.
- b) The district nurse consults me about my nursing care.
- c) I am given a choice of treatments which suit me best.
- d) I feel involved in making decisions about my care.
- e) The nurse encourages me to participate in my care.
- f) I planned my care with the district nurse.
- g) The nurse listens to my opinions about my care.
- h) I know I can improve my condition with different treatments.
- i) I feel that my participation is important to the nurse.

Each of these elements were analyzed against the answers to question 11b (see Questionnaire, Appendix A) "Would you say you participate in your nursing care?" (Table 4: 9) and the answers to question 13 (see Questionnaire, Appendix A) "Is it important to you that you participate in your care?" (Table 4: 11) Using the SPSSx computer program Chi square statistics were calculated on 2x2 contingency tables of each element's (questions a to i, above) agree/disagree answers against participation or desire to participate yes/no answers. Significance level was set at .05 with 1 df. Chi square is based on assumptions that the expected value has roughly the same proportions in each column of a cross

FIGURE 4: 4

AGREEMENT FREQUENCY DISTRIBUTION: ELEMENTS OF PARTICIPATION

Elements of Participation

I KNOW I CAN IMPROVE MY CONDITION WITH DIFFERENT TREATMENTS	(9)	XXXXXXXXXXXXX 23.7%
I PLANNED MY CARE WITH THE DISTRICT NURSE	(14)	XXXXXXXXXXXXXXXXXXXXX 36.8%
I AM GIVEN A CHOICE OF TREATMENTS WHICH SUIT ME BEST	(19)	XXXXXXXXXXXXXXXXXXXXXXXXXXXXX 50.0%
THE DISTRICT NURSE CONSULTS ME ABOUT MY NURSING CARE	(22)	XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX 57.9%
I FEEL INVOLVED IN MAKING DECISIONS ABOUT MY CARE	(23)	XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX 60.5%
I FEEL MY PARTICIPATION IS IMPORTANT TO THE NURSE	(24)	XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX 63.2%
THE DISTRICT NURSE GIVES ME USEFUL INSTRUCTIONS	(25)	XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX 65.8%
THE NURSE LISTENS TO MY OPINIONS ABOUT MY CARE	(28)	XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX 73.7%
THE NURSE ENCOURAGES ME TO PARTICIPATE IN MY CARE	(30)	XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX 78.9%
Number		0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30 32 34 36 38
		Frequency

tab table. An expected frequency of cells below 5 (shown on Tables as E. F. < 5) of 25% was accepted as tolerable since it is not possible to attain the desired 20% or less in a 2 x 2 table. Therefore the significant findings observed here are cautiously interpreted, as the expected frequency results raise some doubt about assumptions of Chi square.

Would you say that you participate in your nursing care?

Figure 4: 4 shows the rank agreement frequency distribution of the different elements of participation investigated in this study. Study participants were asked to agree or disagree with each statement (Question 12a to 12i) in terms of their relationship with their nurse, so that the frequency distribution shows how often the element was perceived as being executed by clients in the study.

The lowest ranking element (Figure 4: 4) 'I know I can improve my condition with different treatments' was expected to be low (see Appendix B). It was reasoned that if one participated in their care they would have already suggested using the treatments which they thought would improve their condition, or that people would not participate in a treatment they thought was wrong for them. The low frequency ranking (Figure 4: 4) of 'I planned my care with the district nurse' was unexpected.

The mid-frequency ranking elements (Figure 4: 4) 'I feel involved in making decisions about my care', 'The district nurse consults me about my nursing care', and 'I am given a choice of treatments which suit me best' also were unexpected results. These elements, along with 'planning care' were identified as the most important elements of participation by the literature review of participation theory as a citizen, in the workplace, and in the health care system.

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
a) The nurse gives me useful instructions for looking after myself	agree	19	6	25	65.8%
	disagree	9	4	13	34.2%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.00376	1	0.9511	3.421	1 of 4 (25%)	
0.20211	1	0.6530		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
d) I feel involved in making decisions about my care.	agree	19	4	23	60.5%
	disagree	9	6	15	39.5%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
1.36934	1	0.2419	3.947	1 of 4 (25%)	
2.39329	1	0.1219		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
g) Nurse listens to my opinions about my care.	agree	24	4	28	73.7%
	disagree	4	6	10	26.3%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
5.75065	1	0.0164	2.632	1 of 4 (25%)	
7.94122	1	0.0048		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
b) The nurse consults me about my nursing care.	agree	18	4	22	57.9%
	disagree	10	6	16	42.1%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.92571	1	0.3360	4.211	1 of 4 (25%)	
1.78279	1	0.1818		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
e) Nurse encourages me to participate in my care.	agree	26	4	30	78.9%
	disagree	2	6	8	21.1%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
9.41009	1	0.0022	2.015	1 of 4 (25%)	
12.38619	1	0.0004		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
h) I know I can improve my condition with different treatments.	agree	7	2	9	23.7%
	disagree	21	8	29	76.3%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.00000	1	1.0000	2.368	1 of 4 (25%)	
0.10192	1	0.7495		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
c) I am given a choice of treatments which suit me best.	agree	17	2	19	50.0%
	disagree	11	8	19	50.0%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
3.39286	1	0.0655	5.000	none	
4.88571	1	0.0271		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
f) I planned my care with the nurse.	agree	13	1	14	36.8%
	disagree	15	9	24	63.2%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
2.78255	1	0.0953	3.684	1 of 4 (25%)	
4.20230	1	0.0404		(before Yates Correction)	

Would you say you participate in your nursing care?		agree		disagree	ROW TOTAL
i) My participation is important to the nurse.	agree	21	3	24	63.2%
	disagree	7	7	14	36.8%
	COLUMN TOTAL	28	10	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
4.62438	1	0.0315	3.684	1 of 4 (25%)	
6.41250	1	0.0113		(before Yates Correction)	

* significant at .05 level or less.

TABLE 4: 9

CROSSTABULATION OF PARTICIPATION BY ELEMENTS OF PARTICIPATION

Significant Elements of Participation

Three elements with the highest frequency ranking (Figure 4: 4) were shown in this study to be significant elements of participation (Table 4: 9). 'The nurse encourages me to participate in my care' is significant at .002. 'The nurse listens to my opinions about my care' is significant at .016. and the statement that I feel my participation is important to the nurse was significant at .03.

Is it important to you that you participate in your nursing care?

The contingency table showing the chi square statistic and significance of the two participation questions (questions 11b and 13, Questionnaire, Appendix A) 'Would you say you participate in your nursing care?' and 'Is it important to you that you participate?' follows in Table 4: 10.

TABLE 4: 10

CROSSTABULATION OF PARTICIPATION BY DESIRE TO PARTICIPATE

		Is it important to you that you participate in your care?		ROW TOTAL
		agree	disagree	
Would you say you participate in your nursing care?	COUNT	28	0	28
	EXPECTED VALUE	25.1	2.9	73.7%
	RESIDUAL	2.9	-2.9	
		6	4	10
disagree		8.9	1.1	26.3%
		-2.9	2.9	
COLUMN TOTAL		34	4	38
		89.5%	10.5%	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5
8.63083	1	0.0033	1.053	2 of 4 (50%)
12.51765	1	0.0004	(before Yates Correction)	

Table 4: 10 shows that 34 of 38 participants in the study desired to participate in their nursing care while 28 out of 38 actually perceived that they did so. Four out of 38 people (10.5%) did not participate and did not desire to participate; whereas 6 out of 38 people (15.8%) wanted to participate but did not perceive themselves as doing so.

A problem was encountered in interpreting the significance of the results shown in Table 4: 10 since the cells with $E.F. < 5$ are 2 or 50%. Consultation with a statistician has revealed that these results can likely be cautiously considered to be significant despite cells with lower E.F. being more than 25%. Participation and the desire to participate show a significant difference (.003) which is unlikely to be due to chance.

Crosstabulation tables of question 13 'Is it important to you that you participate in your care?' (see Questionnaire Appendix A) with the elements of participation, questions 12a - i (see Questionnaire Appendix A) are displayed in Table 4: 11. The desire to participate ('Is it important to you that you participate in your care?') related to 'The nurse encourages me to participate in my care.' shows significance at the 0.0006 level despite the E. F. Other elements of participation in Table 4: 11 do not show significant results.

Client's Quantitative Definition of Participation

'Nurse encouragement' is the element most associated by study clients with participation in frequency ranking and in statistical significance analysis. The frequency distribution, Figure 4: 4 demonstrates that the elements of participation chosen most often by clients in the study are 'the nurse encourages me to participate in my care' (n= 30), 'the nurse listens to my opinions about my care' (n= 28), and 'the nurse gives me useful instructions for looking after myself' (n= 25), followed by 'my participation is important to the nurse' (n= 24).

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
a) The nurse gives me useful instructions for looking after myself.	agree	23	2	25	65.8%
	disagree	11	2	13	34.2%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.02149	1	0.8834	1.368	2 of 4 (50%)	
0.49520	1	0.4816		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
d) I feel involved in making decisions about my care.	agree	21	2	23	60.5%
	disagree	13	2	15	39.5%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.00000	1	1.0000	1.579	2 of 4 (50%)	
0.20733	1	0.6489		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
g) Nurse listens to my opinions about my care.	agree	26	2	28	73.7%
	disagree	8	2	10	26.3%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.28839	1	0.5913	1.053	2 of 4 (50%)	
1.293282	1	0.2554		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
b) The nurse consults me about my nursing care.	agree	21	1	22	57.9%
	disagree	13	3	16	42.1%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.76283	1	0.3824	1.684	2 of 4 (50%)	
1.98446	1	0.1589		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
e) Nurse encourages me to participate in my care.	agree	30	0	0	78.9%
	disagree	4	4	8	21.1%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
11.87616	1	0.0006	0.842	2 of 4 (50%)	
16.76471	1	0.0000		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
h) I know I can improve my condition with different treatments.	agree	9	0	9	23.7%
	disagree	25	4	29	76.3%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.30939	1	0.5781	0.947	2 of 4 (50%)	
1.38742	1	0.2388		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
c) I am given a choice of treatments which suit me best.	agree	18	1	19	50.0%
	disagree	16	3	19	50.0%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.27941	1	0.5971	2.000	2 of 4 (50%)	
1.11765	1	0.2904		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
f) I planned my care with the nurse.	agree	13	1	14	36.8%
	disagree	21	3	24	63.2%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
0.00000	1	1.0000	1.474	2 of 4 (50%)	
0.26943	1	0.6037		(before Yates Correction)	

Is it important to you that you participate in your care?					
		agree		disagree	ROW TOTAL
i) My participation is important to the nurse.	agree	23	1	24	63.2%
	disagree	11	3	14	36.8%
	COLUMN TOTAL	34	4	38	100%
Chi Square	D.F.	Significance	Min. E.F.	Cells with E.F. < 5	
1.26484	1	0.2607	1.474	2 of 4 (50%)	
2.79744	1	0.0944		(before Yates Correction)	

* significant at .05 level or less.

TABLE 4: 11

CROSSTABULATION OF DESIRE TO PARTICIPATE BY ELEMENTS OF PARTICIPATION

The first three of these elements (Figure 4: 4 - 12e, 12g, 12a) are of 'patient response to the nurse' type of questions. They are actions initiated by the nurse which the client responds to. The questions which relate to client-initiated and client-taking actions: making decisions (12d), consulting (12b), having choices (12c), or planning (12f) were less frequently executed. For example having or making choices about treatments was perceived by only half of study clients, while planning care with the nurse was realized by only 36.8% (n=14) of the clients. Decision making and consulting ranked mid frequency at 23 (60.5%) and 22 (57.9%) respectively.

Perceptions of participating in nursing care were significantly related to nurse encouragement (12e), nurse listens (12g), and my participation is important to the nurse (12i) (Table 4: 9).

The desire to participate is significantly related to nurse encouragement (12e) (Table 4: 11).

The significant quantitative definition of participation revealed by clients in this study follows.

Participation in district nursing care consists of being encouraged by the nurse to take part in my care; the nurse listens to my opinions and gives me useful instructions for looking after myself.

The above definition will be expanded on qualitatively in the next part to arrive at a triangulated description of the meaning of participation to the clients in this study.

Qualitative Analysis: What does Participation Mean To You?

When asked for their definition clients in this study defined participation as a process. Participation meant to "take part in", to "help", to "join in", or to "be involved". As discussed earlier in this chapter, study clients valued an overwhelming goal of self

care and independence. Within this goal four different perceptions of the concept of participation were displayed.

The majority of clients viewed participating in nursing care as co-operation and working together, as "doing what you can for yourself".

The second perception of participation, acquiescence, is accompanied by a 'watching and waiting' dimension and is described as "helping the nurse".

Other clients viewed participation as taking more control of themselves; it was acquiring "knowledge to look after yourself" because "Its my life; I had to put up with it".

A few viewed their nursing care as one-sided, as "doing something the nurse wanted them to do" or as the nurse doing it all, while they stipulated that they did not participate.

These perceptions of participation will be discussed in detail in the following sections classified under the themes and dimensions revealed by qualitative analysis of data.

Participation as Co-operating/ Working Together

A process of negotiation or consultation was described as "co-operating" and manifested as "working together" by study clients. "The nurse helps in ways the family don't know how to do...until she tells us and explains, we don't have a clue what to do." The negotiation relationship is not one sided, both nurse and client contribute.

There are special little points that have to be told to the nurse in order to get the best care... We run over important points for the nurse, how to transfer and important places to care for. Most accept the advice ...some not as happy to receive advice about care.

Clients favoured being involved in decision making (n =23, 60.5%), but did not desire to make the decision alone. They preferred a situation in which "I listen to her suggestions, but make up my own mind" similar to the following anecdote.

She is a most understanding person....never forces her opinions on me, just suggests something and leaves it at that. Eventually I'll say "What is the next move Sister?" and she'll say "I've been waiting for you to say that". But she left it for me to say it to her.

Although frequency data shows that only 12 clients (31.6%) view themselves as making decisions together with the nurse, qualitative data and analysis reveals that this finding relates more with reluctance to make decisions or appearing to be "dominant" than to having a co-operative relationship with the nurse. Clients wanted to 'discuss' their care with the nurse even though they may defer the decision making to the nurse. Some clients believed it was

the nurse's job to advise about care. I don't think it's mine - the nurse knows certain things - areas of knowledge I don't have, and has access to equipment and supplies I don't have. On the other hand, Nurse asks you to try, but gives you information to go on if it doesn't work.

As well, in most cases clients preferred to 'discuss' their care with the nurse before they made their decision alone. That is, they pictured the final decision being made by themselves (n= 27, 71.1%) after a discussion with the nurse.

Semantics

Semantic meanings of the words co-operation and participation may be colloquial and related to culture. Moulson (1984) in New Zealand states that "co-operation means participation in decision making" and goes on to say that co-operative forms of action are more rewarding than "power-ridden forms" (p.103). Her submission that ambivalence towards participation can result from perceived threats in the situation of participating and taking control is a useful aid to understanding the meaning of participation to New Zealanders.

Boettcher (1978) in America adds another word to the discussion, saying rather than referring to clients as co-operative, the word used should be collaborative. "Co-operation implies that the person did as he was told. Collaboration attests to a client's strengths and his right to become an active participant in decision making" (p.15). MacElveen-Hoehn (1983) also American, equates the words co-operation and collaboration using them interchangeably, defining co-operation as "acting jointly for ...mutual profit or common benefit" (p.516). She uses co-operation as a concept to describe a negotiated participative relationship which emphasizes strengths and mutual respect between client and nurses.

Clients in this study defined and used the word co-operation to describe a participative relationship which the researcher has considered to be equivalent to the concepts of participation and collaboration.

The argument regarding semantic differences is also extended to the word discuss, discussion, and consults. The statement 'The district nurse consults me about my nursing care' was rejected semantically by clients. "No, not consults", more a "discussion"- the nurse "discusses" care, she "advises" or "suggests" and "explains" and helps them "to make up their mind about what's needed". One client attested to this "there's not much point in her coming here and saying you have to do this or that. I do what I can. They don't dictate to me, they advise."

Kinross, Nevatt & Boddy (1987), N.Z., depict the district/public health nurse in their study as 'doing with', practicing collaboratively using a "discussant" approach "which logically leads to ...participative outcome[s]" (p.147). They use the word discuss in the sense of 'talking things over', as did the clients in this study. However, that definition is Webster's definition of the word 'consult'. In this study clients did not perceive that the nurse 'consult[ed] me about my nursing care'

(57.9%) as much as they perceived 'the nurse listen[ed] to my opinions about my care' (73.7%).

It is here proposed that clients in this study do not use the word consult because its association with professionals implies a use of power and expertise which they do not wish to assume. Rationale for this argument proceeds along these lines. One 'consults' a lawyer or doctor for advice. One goes to a 'consultant' for specialist medical care, and needs a 'consult' to see an orthodontist or psychologist. One 'consults' with one's colleagues; university professors and doctors 'consult' one another. A client might 'consult' a nurse for her advice and professional expertise, but the nurse does not 'consult' the client, she 'listens to their opinions'. Clients have no special area of expertise to consult - instead they 'discuss'.⁵

Clients' Personal Traits: Achieving Co-operation

Co-operation was achieved through several dimensions by study clients. Their overall value of self care and independence was influenced by limitations of disease and mobility. The dimensions in which clients perceived reaching this goal were 'looking after yourself' and 'trying to look after yourself' using the strategy of 'managing' under circumstances when they couldn't 'get around much anymore'.

"Can't get around much anymore"

In the qualitative perceptions of study clients, the degree of participation was related to the ability to move about. Mobility restrictions affected perceptions of what clients could do for themselves. Study clients were 21.1% (n= 8) wheelchair or bedbound; 50.0% (n= 19) restricted to using a cane, walker, needed

⁵ This rationale is put forward as an argument of how clients participating in this study appear to see it; it does not reflect the opinion of the writer.

assistance to walk, or confined by pain; and 28.9% (n= 11) not restricted. Thus 71.1% of the clients in this study had their mobility restricted in varying degrees.

Table 4: 12 shows perceptions of participating in care classified by mobility.

Table 4: 12
Perceptions of participating in care by mobility

	Not Restricted		restricted		bed/wheelchair bound	
Participate YES	n= 10	26.3%	n= 11	28.9%	n= 7	18.4%
NO	n= 1	2.6%	n= 8	21.1	n= 1	2.6%
	n= 11	28.9%	n= 19	50.0%	n= 8	21.1%

'Looking after myself'

The majority of those not restricted in mobility (n= 10) participated in their nursing care. These clients thought "they didn't need much really" or that they (or caregiver) "did it all". Some clients who were not restricted focussed on the physical aspects of participating in care: "do things for self", "looking after myself", "I'm able to do anything I need", with a goal to be "self supporting and self independent." The one case of non/participation in this category was mentally but not physically restricted.

'Trying to look after myself'

Those who were partially restricted perceived themselves as participating or not participating in the greatest numbers. Continuing to value an overall goal of caring for themselves, their abilities to cope with activities of daily living were influenced by perceptions expressed as "can't get around much anymore". They coped by making less demands on themselves, by doing less, and by settling for what they could "manage to do", in short by narrowing the boundaries of their life. A stroke victim in this study described his life as reduced to "spending my days reliving my youth, my former glory" while another said "I'm doing nothing, just sitting around." Bowman (1980) reached similar conclusions when he learned that clients who moved to inner-city locations, which increased proximity to services, was done to compensate for increasing "role-losses attendant on old age" (p.i).

Some clients communicated this difference by saying "trying to look after myself", "do major part of care for self", "working together" or "helping the nurse". Thus the prevailing philosophy of "I do what I can for myself" is underscored by a qualification of within my limits. A composite vignette of the perceptions of participating in ones' care with restricted mobility follows.

I move slowly and carefully around the house getting ready. Don't want to fall. The nurse comes today. I hang clean towels in the bathroom struggling to get my walker through the door. I put my underclothes to warm in the airing cupboard and lay out my clothes. I'm finished. I am looking forward to seeing her, she's always so bright and cheerful. Now I just have to wait.

Trying to look after yourself with partial restrictions in mobility seemed to be a transition stage in definition of participation for these study informants. This leads to conjecture that as loss of mobility increases, it is compensated for by altering perspectives. Prevented by loss of some abilities in

achieving their primary value and goal of independence and self care, clients moved to different viewpoints of participation. Instead of 'doing it yourself', as their circumstances altered they described participation as 'doing some of it yourself' or 'helping someone else to do it'. Moving beyond the viewpoint of participation as doing physical aspects of care, clients with restricted mobility began to see it as 'assisting with' or 'directing their care'. One participant defined this as a "give and take...you see yourself as doing what you can."

Seven of the most immobilized clients, bed/wheelchair bound, perceived that they participated in their care. The one negative reply was given by a man who wanted to participate but perceived himself as not being allowed to participate. Completely shifting from the definition of participation as the ability to move about or assisting with physical aspects of their own care, the immobile defined participation along other dimensions. As one lady phrased it "I can only see and talk; the only thing I can do is tell them what to do."

Immobile clients frequently expressed aloud their dependence by saying things such as "what they do for me I couldn't do for myself. I can't survive without them". But at the same time they were vocal about their need for control of their care and their desires to be independent of mind. These clients controlled their care by directing it; by planning what they could; by teaching the nurses how to give their care in the way that worked best for them; by making decisions; or by telling the nurse what they needed.

One immobile client in this study, a quadriplegic, had no control over his body but maintained total control of his care by directing it, through his wife who acted as advocate, support, and primary caregiver. Another client in this study was immobile and severely restricted, both physically and mentally, completely unaware of surroundings. His wife became the client in this situation, acting more vigilantly on his behalf than she might have on her own, she wanted "him to have the best, not to have to

put up with anything he might not like". She worked hard at achieving this goal with the nurse.

Participation as Acquiescence/Watching and Waiting

The second perception of participation discovered in this study is acquiescence with a dimension of 'watching and waiting'. It was described as "helping the nurse" by study clients.

Clients' Role Expectations and Attitude

The clients who envisioned participation as 'helping' the nurse had different reasons for this viewpoint. In some cases it related to the client's expectations of the patient and nurse roles. Eighteen of the study clients thought it was nurse's job to make the decisions about nursing care. Twenty seven thought they should make decisions about their care alone but only twelve saw themselves making decisions together with the nurse.

Those who believed it was the nurse's job to decide about their nursing care thought that they should

more or less do what she asks you. We realize she's got a certain knowledge we haven't got. You'd listen to her.... its no use going... if you don't hearken

The nurse was deemed an expert and, as such, should be attended to for "if you appeal to them for help, you must take their advice". Clients held expectations that the nurse

knew what needed to be done. I don't expect to have a lot of say. They are there to do their job and they know what they are doing....what they are supposed to and not supposed to do.

Watching and Waiting

Despite these assurances that study participants viewed the nurse as an expert, there was an element of reserve displayed in an attitude of "watching and waiting". This was shown by study participants in three ways, either as uncertainty, as needing time to establish rapport and trust between client and nurse, or as acquiescence.

Uncertainty

Uncertainty is described by short collective sketches.

I'm not sure what she wants of me, what she wants me to do. I have to be a good patient. I want to co-operate with you because I want to get well. What does she want?

Should I suggest something? I hesitate. What would a good patient do? I wait and watch.

I don't know what to expect, but I know if she is not what I expect.

What is she coming for? Coming to spy! Put me in a home! I don't need nursing. I don't want her here, I'll have to be careful. I'll just wait and see.

Clients who were uncertain, who didn't quite know what to expect of the relationship between themselves and the nurse were new to the district nurse/client relationship or had a new nurse. 'Watching and waiting' ensued until they knew what to expect.

Other clients accepted the nurse on her credentials but reserved judgment relating this back to previous experiences "if she makes suggestions, I follow them, but I want to know why". Some of the clients thought the nurse should make the decisions but saw a conflict between what they thought should happen and what did happen. This conflict is evident in following snippet.

A middle aged woman had experienced a long series of difficult operations from numerous complications of cancer and an operation to correct a congenital defect.

She had stayed for long periods in the hospital and vividly described her feelings of helplessness leading to treatment for depression (also described by Clark, A. 1976). Her view of the district nurse was inextricably intertwined with hospital nurses. She attributed her problems to a mistake made by a nurse and an intern and showed her reactance and confusion by saying "I wish to God I'd spoken up....it would never have happened if I had..." Emphasizing that she was "guided by what they [nurses] say, its their job and they've been trained", she added "but you should often question what they do."

These clients also were watching the nurse and waiting before giving their trust to the nurse.

Establishing Rapport and Trust

Some clients were suspicious of the district nurse's motives. "I didn't know she was coming till she arrived" and "I didn't think she needed to be here" were comments heard. One said "well, she [district nurse] didn't try to talk me into anything I didn't want to do." The nurse/client relationship under suspicion may be a question of how much the client trusts the nurse and how safe they think an honest answer will be. To use a New Zealand colloquialism clients 'sussed' out the situation first. They knew that establishing "rapport with the nurses is important" to their care. One long-term client knows several ways in which her nursing care can be facilitated but she doesn't always share this with the nurses that care for her. She explains why:

They need to ask how you do it. Some are pigheaded, and want to do it their own way...nurses who asked found out there was an easier way. I would tell them the best way to do it, they soon realized this. Others wouldn't ask and then I couldn't do anything about it.

Thomson, Kinross, and Chick (1977) discovered that half the patients in their study waited to be approached by the nurse before requesting a service. Patients may not mention needs until they were assured the nurse was interested in them (citing Elder).

Acquiescence

An attitude of watching and waiting prevails throughout study participants - a vigilance dimension which continues until clients know what to expect from the nurse or the relationship is terminated. Clients have certain expectations of nurses; while unvocalized, they are aware if these expectations are not met. "I have my own ideas about my care. If they said anything I didn't agree with I would say so." Participants watched their nurse and waited for what they expected, prepared to take action only if their expectations were not met. Several participants expressed their thoughts saying "I'd leave it to them....they're professionals ...until such time, until I think they're not doing a good job...then I'd say something" or "so far has given us good instructions" "She's so capable, really..." "Nurse is so reasonable, they don't ask you to do anything unreasonablethen it might be different."

Participation by acquiescence, by accepting the status quo, was commonly found in informants. Clients were willing to 'go along' with the nurse's suggestions, so long as it seemed rational and reasonable to them, they "agreed to what was happening."

In the United States, Stromberg (1978) theorized that accepting the status quo by doing nothing was a form of participation and not mere apathy. Daniels & Kochar (1979) reaffirm that patients "need to believe it is valid and reasonable to participate"(p.238) thus therapeutic goals and activities must hold personal relevance.

Page (1987) discovered vigilance-harmonizing behaviors in women's health protection practices which defined vigilance as "a state of alert watchfulness" over one's health and harmonizing as "balancing, compensating, stabilizing...categories which keep the role of vigilance in check" (p.45). Janis (1983) in America, postulates a coping pattern of vigilance in health protection. The

watching and waiting dimension detected in this study's clients serves to corroborate Page's (1987) vigilance-harmonizing theory. "Watching and waiting" can be viewed as vigilant behavior for the purpose of self protection in clients receiving health care from district nurses.

Participation as Taking More Control

Planning care and having choices about treatments were not general perceptions. Clients thought nursing care "just happened, not really planned" or that "over the years have come to a routine that suits us both." This was an area where "they left that up to nurses...did what they said." and "followed instructions", because "really, I was improving all the time" or "the nurse knew best."

Those who agreed they should plan care (n =14, 36,8%) and have choices (n= 19, 50%) tended to value taking more control or responsibility for themselves. This was vocalized by one participant as "I want to know what's going wrong...want to find out as much as I can...want to know more and I have to ask. I need a feeling of control." An 83 year old woman said "I'm not a dummy to be pushed around...I like to think for myself...I'm so pigheaded I go my own way". Others stated "They can only recommend, act in conjunction with the patient...its up to me." and "After all, its me that has to live with it."

Some families taught clients to take control and practice self care.

The world is made for normal people and disabled are not catered for. We told him if he wants to be crippled, we'll get him a wheelchair, otherwise he has look after himself.

Knowledge was also recognized as critical to the participative relationship, some participants had "feelings of not getting enough information" and others felt that sickness was "outside their experience" and they needed "to have a certain base of knowledge before [could] evaluate care." Knowledge was the key

to taking control for some "If you learn enough you can care for yourself. Her [the nurse's] job is to give you professional advice." "Once I learned how I could do it myself, and didn't need her."

Discouragement of Participation:

The Issue of "Allowance" or "Sanctioning"

While encouragement of participation in care by the nurse was the most frequently chosen element in this study, particular instances of discouragement were brought out by clients who sometimes did not perceive an encouraging environment for their participation with individual nurses. The following excerpt portrays the nurse's encouragement of client participation.

Nurse didn't make it seem so. She leaves it up to me, just suggests on those things she knows about, when she knows what to do...[in the end] I'm the person who knows what I can do.

Those who spoke of difficulties explicitly indicated that these were isolated instances, not wanting the researcher to think they were "complaining" about their care. Some clients considered that the nurse had assumed responsibility inappropriately; when asked if it was the nurse's job to make decisions, a woman said "she thinks so". Clients indicated that the nurse hadn't assessed their situation in depth instead "just told me what she thought was necessary"; or, "only one nurse in all the years asked what he did after getting up". Another didn't feel understood "I don't speak up about what I want... scared of being jumped on."

Several spoke of "personality clashes" when they described instances of disagreement between themselves and individual nurses. Some nurses did not place high priorities on soliciting patient participation "some asked, others didn't; it was important to some" while others demanded too much of their clients "almost forcing you to become independent".

Clients were wary of seeming "too demanding" trying to "manage" and "only ask for little things they need, otherwise don't ask for more help". Some felt 'trapped' saying "it doesn't matter whether I like care or not, I have to have it". "I can't do without it."

Of the clients who did not believe they participated in their nursing care (n =10), two thought that they "weren't allowed to participate" and had lost control of their care. One felt victimized and depersonalized "as though I'm just a disease, not a person; they take away my dignity and I feel just like a number. I feel angry and powerless." The other was unable to obtain what "was wanted" from the nurse and services provided. Both situations displayed deteriorating communication patterns with preconceptions and misconceptions evident, resulting in increasingly rigid bargaining and demands from both client and nurse.

Hayes-Bautista (1976) described similar relationships which sometimes lead to termination of relationships. Inadequate assessment and poor communication patterns remains the primary cause of communication breakdown in client/nurse participation relationships. A participant in this study had difficulty with some nurses "its just an inability to communicate, to relax attitude[s]; [they] use a formal approach....they can be very good at their job...but that's only half the battle."

McDonald (1988) asserts the importance of assessing "what the individual already knows, believes and thinks it is important to know" (p.25). A district nurse illustrated her expert knowledge by saying⁶

Difficult patients don't remain difficult long. I have always found that there is a reason for them to be difficult. If they remain difficult its because they are trying to be bulldozed into something, that you haven't given time to look into it....and sort it out between you.

⁶ Personal interview with Evelyn Wood, Palmerston North, New Zealand, June 29, 1988.

Non/Participation: Withdrawal and Dependency

The last theme discovered in this study was a passive client/nurse relationship of withdrawal and dependency. The client perceives the nurse as 'doing it all' and themselves as being 'done to'. This was expressed as doing "something they wanted you to do" or "by doing what they told me."

Withdrawal

Four clients in this study did not participate and did not want to participate in this study. They had voluntarily withdrawn from looking after themselves. All were women over 74 (2 were 90); and had 'passed responsibility' for their care over to caregivers. These clients thought it was time others looked after them, they chose to be dependant because they "couldn't manage anymore". A case study presented below illustrates

A 90 year old lady lived in her own home with her very deaf husband. They were unable to care for themselves or cope with activities of daily living. They could 'get around' but required one of their eight children with them constantly. Four daughters shared this responsibility staying a week at a time, leaving their husbands or family in their own home. They chose to look after their parents in this way because "that way the 'oldies' could stay in their own home where surroundings were familiar". Their mother appreciated and loved their care, telling her husband "Aren't we lucky to have such good daughters to look after us?" It became a family responsibility to care for them; the family believed they had earned their rest.

Lack of desire to participate is a phenomenon noted by other researchers. This has been attributed to threat or conflict inherent in decision making situations (French, Kay, & Meyer, 1966; Moulson, 1984); to lack of enabling factors or latent dissonance (Roter, 1977); or is related to expectations of the "good" patient role (Eisenthal & Lazare, 1977; Glogow, 1973;

Tagliacozzo & Mauksch, 1972). Apathy may also account for lack of participation in the elderly from lack of positive meaning to life (Putnam, 1987; Twomey, 1986). Particularly in the very elderly withdrawal from participating may be viewed as disengagement, or a preparation for dying but Bergsma (1986) theorizes that withdrawal is "saying goodbye." Saying goodbye is contemplating and savouring past experiences; it is not loss, but "a form of completion, of fulfillment" of life, the final completion of life plans (p.110). 'Passing responsibility' over to others willingly was a realistic way of coping with inability to "manage" for four clients in this study; it enabled them to achieve their goal of continuing to live in their own homes and fostered feelings of self esteem and being cared about, as well as relieving self or family anxiety over their welfare.

Dependency

Six clients in this study wanted to participate in their care but did not perceive themselves as doing so. As discussed earlier, 3 didn't participate because they didn't perceive themselves as getting nursing care and 2 thought they "weren't allowed to participate".

Study clients who saw themselves as "totally dependent on the nurses - can't do without them" generally wanted to participate in their care but one person assumed a dependent passive role in which she did not participate.

She 'passed responsibility' for her nursing care over to the nurse believing that the way to be a good patient was to be passive, and do "what the nurse tells me." One would "be very ungrateful if they didn't appreciate care. Some patients give them trouble even when they do their best for you." At the same time she "wanted to participate in her care", she had perceptions of herself as helpless and unable to participate "How can I? I can't do anything for myself...[have to just] leave it up to the nurse." She also believed she should defer to the nurse's expert knowledge." After all she knows what she is doing."

Thus one (2.6%) of thirty eight district nursing clients did not feel able to cope with participating in care. Overseas, Rieder (1982) found a role related to helplessness with perceptions of loss of control assumed by one third of patients in her study of hospitalized patients' participation in care. Dennis (1987) in USA, discovered a few patients who could not cope with making decisions or having control of their care. In New Zealand, Nevatt (1981) suggests that not everyone may "be comfortable with, or desirous of, the degree of autonomy inherent in and required by the selfcare approach" (p.90). However, Pringle (1982) in Canada found the elderly home care patients in her study exerted "a great deal of control over daily activities and care", even those who did not perceive themselves as making decisions had cognitive control (p.156).

In this client's case, long term illness and chronic pain had reinforced dependent behaviors which were partially satisfactory to her as she complained that the nurse "wanted her to do too much for herself" while she wanted the nurse to "do more for her". Dependency may be fostered by nurses or patients, both deriving satisfactions from this relationship (Damant, 1981, Fielding, 1979; Miller, 1984). Problems do arise, however, when the patient and nurse disagree about goals of their relationship and treatment.

Overseas research on client's perceptions of nursing practice has revealed that nurse's beliefs about client needs and client's perceptions of what they need do not coincide (Brands, 1983; Chang, 1978; Elbeck, 1986; Gardner & Wheeler, 1981, 1987; Whiting, 1959). In these nursing models nursing takes on a 'watching over' dimension while client models preferred a 'doing for' dimension. The watching over dimension fits one of this study's clients recognition of the context within which nursing care takes place.

Decision making depends on what sort of care. If you're really sick and unable to make the right decisions for health care, then the nurse should make them.

Butterfield (1978) states that New Zealand nurses must learn to accept patient goals that do not coincide with nurse's conceptions; nurses need to internalize the right of the patient to take responsibility for self care including the right to refuse recommendations and treatment (also McDonald, 1988). Patients should be assisted to attain their own reasonable goals with the nurse acting as facilitator toward that goal (Butterfield, 1978) .

Here it is contended that clients whose goals are not self care, but dependency, do not 'fit' this nursing model of self-care; never-the-less the philosophy of the 'right to choose' should remain foremost. The philosophy should prevail whether it is believed that dependency is a well-earned reward or a dysfunctional reaction. Participation is a two way process in which both client and nurse contribute, the outcome is influenced through negotiating the goals of each party. If the goal of one is dependency and the goal of the other is self-care, consensus might be reached of a mutual goal of 'dependency within limits' or another satisfactory (to both parties) solution.

Discordant goals of participation in nursing care were rarely found in this study. Overall, clients wanted to participate and perceived themselves as doing so. Exploring the reasons and values of those who did not participate, shed light on the meaning of participation to the clients in this research.

Summary

Data results, analysis, and interpretation have been presented in this chapter. Findings, discussion, and implications will be reached in the following chapter.

CHAPTER 5: CONCLUSIONS

Findings and Discussion

Methodology Fit

The purpose of this exploratory study was to examine the participation of New Zealand district nursing clients through the perceptions of the client. It expected to answer the question

"What are the perceptions of district nursing clients toward participation in their care?"

To answer this question a research design utilizing multiple triangulation was the most suitable 'fit' of design to question. Methods of data collection and analysis of data emanated from two differing paradigms of research.

Interviews were conducted which collected clients qualitative perceptions about participation by asking "what does participation mean to you?". Qualitative data were analyzed using the technique of analytic description. Structured questions, based on an extensive literature review, along with background information were also asked during the interview (See Appendix A, Questionnaire). These formed the quantitative data collection which were statistically analyzed. The structured questions about elements of participation served another purpose during interviews - that of stimulating further thought and developing the informants' description of their personal meaning of participation.

Both quantitative and qualitative data validated the other by helping to enlighten, expand, and clarify to form a more comprehensive picture of participation. Using either method alone would have resulted in learning less about participation, or in understanding in a different way. Quantitative results were shaped by the structured questionnaire, which focussed on

previously known elements of participation. Qualitative data and analysis extended beyond to broaden meanings of the concept.

This present research using triangulation showed that participation in nursing care is perceived differently by the New Zealand district nursing client, i.e. from participation as described in the literature. This can be illustrated through the — definitions of participation discovered in this study.

Study Definitions of Participation

The previous operational definition which directed the questions asked in the structured questionnaire is given first. A literature review identified that one participates (shares in or takes part) through several sub-elements; those common to the studies reviewed are encompassed in the following definition.

Participation is defined as a reciprocal relationship composed of receiving information, having choices, making decisions, planning, and negotiating; it includes elements of one's perceived self-ability to participate and experiencing a feeling of control over care.

The significant quantitative definition of participation (from analysis of the structured questionnaire data) revealed by clients in this study is

Participation in district nursing care consists of being encouraged by the nurse to take part in my care; the nurse listens to my opinions and gives me useful instructions for looking after myself.

The qualitative definition of the meaning of participation to clients in this study (based on analytic description analysis of client interviews) is revealed through the primary values and goal of independence and self care. Within this goal four perceptions of participation were displayed.

Participating in nursing care as co-operation and working together, as "doing what you can for yourself".

Participating in nursing care as acquiescence accompanied by a 'watching and waiting' dimension.

Participation in nursing care as taking more control of oneself, as acquiring "knowledge to look after yourself".

Non/participation in nursing care as withdrawal or dependency described as "doing something the nurse wanted them to do" or as the nurse doing it all.

The definition that emerges from the perceptions of the clients in this study is

Participation in district nursing care is a process of co-operation achieved by discussion and working together, in which the nurse encourages, listens, and gives useful instructions to achieve a goal of looking after one's self.

The definitions of participation developed in this study are clearly enhanced by the use of triangulated methodologies as they disclose different types of knowledge and understanding of participation in nursing care. The quantitative definition is focussed on role expectations and attitudes, and 'allowance' or 'sanctioning' (Context of the Participant in Kim's (1983a) model) while the qualitative definition is focussed on the process of participating. Together they give a more comprehensive picture of participation in nursing care as perceived by the district nursing clients in this study. Relating these findings to the model guiding this research will show how the quantitative and qualitative definitions of participation fit together.

Relating the Study's Findings to Kim's Model

Context of the Participant

Who are they?

Background data analysis shows that clients who participated in this study were a representative cross-section of New Zealand district nursing clients ranging in age from 8 to 90 years, with females outnumbering males 22 to 16. Clients fluctuated from those who were completely independent to those who were totally dependent on others for care. They varied in need and length of time as a district nursing client from one or two visits for surgical dressings or arranging other care, to total nursing care of many years' duration. Many were restricted by varying amounts of difficulties in walking, speaking, and carrying out activities of daily living. Some were restricted by limited mental abilities.

Clients lived alone, with spouses, parents, children, other relatives, or with friends. They were employed, retired, students, or housewives....and they came from varied social backgrounds and cultures. As citizens and workers - members of society - clients brought beliefs, values, and patterns of participation into their interactions with the district nurse.

Does the Model 'Fit'?

Conceptually, this study is based on a model for collaborative decision making hypothesized by Kim (1983a) which is explained in detail in Chapter 1. She proposed that role expectations and attitudes, knowledge, personal traits, and definition of the situation (for the client and the nurse) influenced the propensity to participate and the "allowance" to participate in collaborative decision making. Since this research did not study nurse-related factors, the discussion is focussed on client-related factors.

Quantitative results (see Figure 4: 4, Tables 4: 9 and 4: 11) from the client's perspective support Kim's (1983a) proposition that the nurse influences "the degree of allowance for client's participation". The significant findings that 'the nurse encourages me to participate in my care' for those who did participate and for those who desired to participate in their care are highly relevant in the light of Kim's (1983a) theory. These results show that the district nurse leads or guides the relationship for the clients involved in this study.

Responses to nurse-induced actions were significant (these are: nurse encouragement of participation, nurse listens to patient, and nurse gives useful instructions). The client-induced actions of making decisions, consulting, having choices, and planning were executed by more or less 50% of the clients. Client induced actions did not dominate in frequency of execution (Figure 4: 4) or show statistical significance (Tables 4: 9 and 4: 11).

These findings were unexpected since the extensive literature review, in the main, emphasized decision making and control as critical aspects of participation as a citizen, a worker, and a health care consumer (e.g Abrahamsson, 1977; Dennis, 1987; Pateman, 1970, 1983; Rieder, 1982; and others). Those who espoused differing conceptions (eg. Conway-Rutkowski, 1982a, b; Janis, 1983; Kim, 1983a; Kinnaird, Yoham, & Kieval, 1982; Schulman, 1977, 1979; and others) emphasized a negotiative relationship of consulting, choices, planning, and mutual goal setting.

Although these unexpected results may be due to a small sample size, qualitative analysis does help to explain them as a matter of semantics and cultural differences, and of reluctance to assume power and control. New Zealand district nursing clients do not perceive that they 'consult' with the nurse, rather they 'discuss'; they do not have 'choices' or 'plan care', instead they 'cooperate' and 'work together'. The district nurse/client relationship is one of negotiation between individuals but study clients termed it discussion and cooperation, preferring to take an overt stance of less power and control than the nurse.

Client Role Attitudes and Expectations

Expectations of their own and the nurse's role were found to influence the degree of participation exhibited by clients; expectations were clearly vocalized in some instances, covert in others. Clients expected themselves and the nurse to play traditional roles often associated with hospital nurse and patient roles (described in detail in Chapter 2).

Study clients anticipated that the nurse would guide or lead the relationship and participation was influenced by the direction which the client perceived the nurse was giving, i.e., through encouragement or discouragement of their participation.. This is demonstrated by the 79% of clients who perceived that the nurse encouraged them to participate in their care and the 66% of clients who thought their participation was important to the nurse.

Clients determined what the nurse wanted by 'watching and waiting' until they knew what expectations of themselves were. They also 'watched and waited' to determine if the nurse met their expectations of a 'Nurse'. 'Watching and waiting' was a vigilant behavior of being alert on behalf of one's own welfare. Clients would "go along" with the nurse as long as it seemed reasonable, but unusual or unexpected requests or behavior were questioned.

Client Knowledge

Clients in this study deferred to the nurse's expert knowledge and expertise in nursing care and perceived that as an expected course of action. Clients were direct in stating they needed the nurse for her knowledge, upholding Stevens (1979) and Kim (1983a) in their contention that clients come to nurses to seek professional knowledge and judgment. Study informants identified that once they had gained the knowledge they lacked, they no longer needed the nurse.

Client Personal Traits

Some clients in this study took more control of their care and the situation with the nurse as a result of personal traits and belief in self direction. These clients had expectations of being in control and making decisions alone based on professional advice from the nurse. They sought knowledge which would allow them to look after themselves and were strongly oriented to self care and independence.

Clients perceiving themselves as taking more control in their care were allied to the philosophy of participation discussed in Chapter 2. That is, clients are believed to be active participants in their health care seeking access to essential knowledge enabling them to exercise control over elements affecting their health. Nurses are regarded as consultants or facilitators in a collaborative relationship, viewed as a therapeutic alliance to achieve care of self.

These district nursing clients displayed a widespread belief in self reliance. In fact, self care and independence was the foremost goal of all clients in this study but achievement was influenced by limitations of disease and mobility. Even the four clients who had withdrawn valued this goal but just could not 'manage' it. The dimensions in which clients perceived themselves reaching this goal were 'looking after yourself' and 'trying to look after yourself' using the strategy of 'managing' under circumstances when they couldn't 'get around much anymore'.

Perceptions of participation altered with the level of mobility. Those who were unrestricted in mobility tended to perceive participation as physically 'looking after themselves', but as mobility restrictions increased, the perceptions of how one participated varied. The effort of physically 'looking after oneself' gradually changed to mental control, or directing care as the client became more immobilized. Severely immobilized clients continued to perceive themselves as doing what they could 'to look after themselves'.

Client's Definition of the Situation

The elements and themes discovered by this research support Kim's (1983a) proposal that clients will "participate in nursing care only to the extent that they have control over outcomes" (p. 278). Statistical results, the 'watching and waiting' dimension, and perceptions of participation as 'acquiescence' indicated that the client looks to the nurse for "allowance" or "sanction" in the relationship.

Difficulties with individual nurses were described by clients as constraining situations influencing their degree of participation. A client in the study acutely revealed her awareness of nurse "allowance" or "sanctioning" by saying "if the nurse didn't ask, then I couldn't do anything about it." Other informants who described difficulties with individual nurses illustrated situations where the nurse exerted autocratic control and client participation was illusory.

Context of the Situation

While Kim's (1983a) model shows that organizational factors impinge on the level of collaboration, this study assessed perceptions of the client. Perceptions of organizational factors affecting the participative relationship between client and nurse were limited to constraints of delivery of care, specifically limits to services available and what was needed, and time factors. Some clients were not able to get services they required from the hospital board and they hired private help as well.

Volunteer help, privately paid help, and volunteer support groups were commonly used services in this study. It is likely that Locker's (1983) findings are relevant in New Zealand too.

Buying help on the open market may be preferable to the help given by a formal service because the buyer can retain control over what is provided and can choose to employ whosoever is willing to offer the right kind of help at the right time and does not compromise their

independence. Those who do not have the means to buy help must put up with formal services which operate according to their own timetable and provide the help they think is needed, or call on relatives and friends and tolerate feeling and being a burden on others.

Locker (1983, p.195-196)

The time available for each client became an issue of complaint to some clients when auxiliary personnel gave baths or showers. Although clients recognized constraints of time affecting care, they did not perceive it as a matter of complaint otherwise.

Context of the situation and organizational factors specifically requires research as neither were addressed in this study, nor have they been addressed elsewhere in New Zealand.

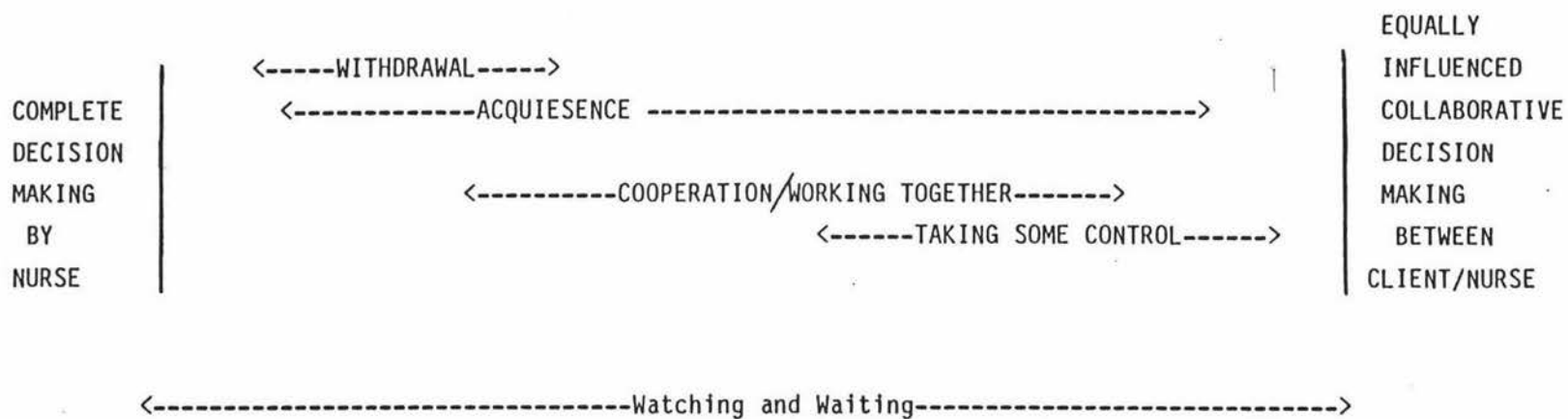
Primary Outcomes: Level of Collaboration

Kim (1983a) theorized that the level of collaboration could be viewed as a continuum "on which the lowest collaboration is expressed as complete domination of decision making by the nurse and the highest level of collaboration is expressed as an equally influencing joint decision making" (p. 280). Despite results that indicated decision making was not a prominent issue in the client/nurse relationships displayed in this study (see Table 4:4), a continuum of participation was found.

Continuum of Participation

Client/nurse participation relationships were conceptualized in four ways on a dynamic continuum (Figure 5: 1). Points on the continuum were not fixed, but altered as the relationship varied between client and nurse. End points on the continuum of complete decision making by the nurse or equally influenced collaborative decision making between client and nurse were not reached by any study clients.

FIGURE 5: 1



CONTINUUM OF PARTICIPATION

(Young, 1989)

The majority of clients in this study were centered on a continuum mid-point of cooperation and working together, with some clients moving toward taking more control (see Figure 5: 1). Acquiescence and 'watching and waiting' occurred for most of the clients at some period in the nurse/client relationship before some moved on to cooperating and working together or to taking more control.

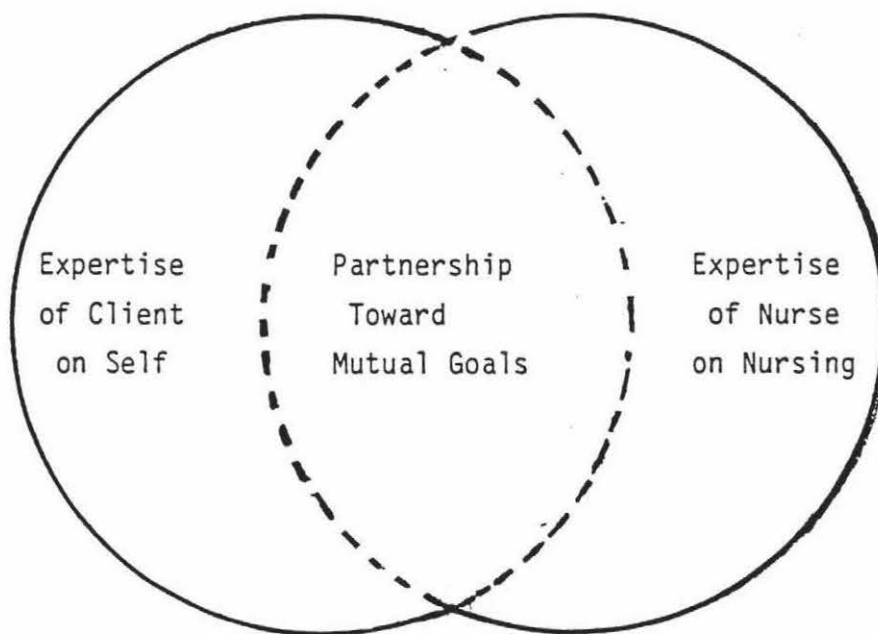
Watching and waiting continued throughout the entire nurse/client association, as clients looked to the nurse for cues to role attitudes and expectations for this particular relationship. That is, previous role attitudes and expectations brought to this situation could be altered by the interactions which occurred between the nurse and client in this circumstance.

Acquiescence (supporting the status quo by consenting without comment) transpired under circumstances when the client was watching and waiting to determine role attitudes and expectations, and also when the client concurred with the treatment given by the nurse. Acquiescence also continued throughout the entire nurse/client relationship and was encompassed in the withdrawal stance.

The point closest to complete decision making by the nurse is occupied by the four clients in this study who chose voluntary withdrawal from participation, passing responsibility for their care over to others. That is, they did not refuse to participate, but nominated someone else to participate for them, as a realistic way of coping with inability to 'manage'. The withdrawal stance is distinguished from the end point of complete decision making by the nurse because these clients expected others to be their advocates and make decisions for them. The withdrawal phase then included an element of acquiescence to the others' decisions when these others carried out the watching and waiting responsibility.

FIGURE 5: 2

NURSE/CLIENT PARTICIPATION RELATIONSHIP



(Young, 1989)

The Nature of the Client/Nurse Participation Relationship

Figure 5: 2 pictures the client/nurse participation relationship conceptualized in this study, illustrating that the boundaries existing between the expertise of the nurse on nursing and the expertise of the client on self overlap to create a partnership towards mutual goals. Boundaries are not fixed, but are flexible and variable, dynamically moving as circumstances change in the relationship. Participation is conceived of as a two-way process to which both client and nurse contribute, the outcome influenced through negotiating the goals of each party. Figure 5: 2 is a simple diagram showing that the participation level of the client or nurse may alter depending on what is required in the negotiated partnership toward mutual goals.

Cooperation and Working Together

The client/nurse participation relationship in this study was perceived by clients as cooperating and working together. It is demonstrated in the following definition of participation.

Participation in district nursing care is a process of co-operation achieved by discussion and working together, in which the nurse encourages, listens, and gives useful instructions to achieve a goal of looking after one's self.

In the perceptions of the clients who participated in this study the goal of self care and independence was the objective of the partnership between themselves and the nurse. The participative, "working together" relationship is not one-sided but mutual, both client and nurse contribute. While the nurse 'led' or 'guided' the nursing care situation, clients perceived themselves as doing what they could to look after themselves, assisted by the nurse. In this study, as in Saunders & McCorkle's (1987) research, clients perceived their own efforts to be merged

with efforts of the nurse working together toward a common goal.

In the participative relationship found here, the client's ideas about their treatment are legitimized and given credibility when the nurse encourages participation, listens to the client, and gives useful instructions. These have been identified as key components in the client taking a part in shaping an consensually agreed upon plan of care (Eisenthal, Emery, Lazare, & Udin, 1979).

Discussion of treatments and issues increased client beliefs that they did what they could to look after themselves. Client perceptions that the nurse encouraged participation and that their participation was important to the nurse reflect the skill of the district nurse in fostering client self esteem and efficacy. Kasch (1986) even suggests that

patients may be more likely to collaborate with care givers who are skilled at using talk to create a positive self image for the patient (i.e. increase patient's perceptions that they are liked and respected by the nurse and/or they have positive qualities that are valued by the nurse).
(p. 46)

Clients and caregivers in this study remarked on the feelings of support and friendship, genuine concern, caring, and affection they felt for and received from the district nurse. Such feelings may have a direct effect on client's beliefs of maintaining self care and independence despite varying and sometimes severe degrees of immobility. Positive feelings may encourage participation and cooperation; they certainly enhance a 'working together' aspect.

Feelings of psychosocial support and friendship which developed in client/caregiver/nurse relationships found in this study are postulated to be the result of long-term association. The organizational structure was such that nurses were responsible for a geographical area for long periods perhaps caring for the same people for years (in several instances). Such long-term association provided an opportunity to develop rapport and trust and a successful working relationship between individuals.

In contrast, Pringle (1982), in Canada, found that patients and caregivers in her study did not recognize nurses as a source of psychosocial support. The most common complaint made in her study was of "lack of continuity of nurse and visiting times"; patients frequently did not know who their nurse was, which nurse was coming, or when the nurse would arrive (p.216).

Summary

The New Zealand district nurse/client relationship studied here provided evidence supporting Kim's (1983a) theoretical framework of collaborative decision making, particularly that the nurse controls the "client's propensity to participate" through "allowance" or "sanctioning" of participation (p.279). From the perspective of the clients this research discovered that the district nurse guides the client/nurse relationship, encouraging the client's participation through discussion. Client and nurse cooperated and worked together to achieve a mutual goal of selfcare and independence. Study clients acquiesced to the nurse's guidance as a result of preconceived patient/nurse role attitudes and deference to the nurse's professional knowledge.

Four distinct perceptions of participation were discovered in this study: 'Withdrawal' of those who did not wish to participate personally, but chose someone else to participate for them; 'Acquiescence' or supporting the status quo by consenting without comment; a mid-point of 'Cooperation and Working Together' which the majority of clients perceived themselves as occupying; and, 'Taking more Control' of care for a minority of study clients.

Implications

It was the intent of this study to:

- initiate research on participation in individual health care in the New Zealand community;

- contribute to a base of knowledge about district nursing clients and their participation in nursing care;
- seek greater understanding of the range and depth of the meaning of participation to the individual human experience;
- describe an emic point of view of the phenomenon participation; that is, from the perspective of those experiencing it.

In fulfilling the study's intent it is anticipated that valuable informative knowledge about district nursing clients will be contributed to provide "detailed descriptive data that can be used by practicing nurses to help them understand patient's behaviours" (Field & Morse, 1985).

Little research has been conducted in New Zealand on community care and even less on home nursing care. This present research added to demographic data about district nursing clients, in addition to beginning a base of knowledge about their perceptions of participation in care. To the author's knowledge it is the first research in New Zealand on participation in care from the client's perspective.

Establishing a base of knowledge was believed to be essential considering the present emphasis in New Zealand towards community based care. The planned introduction of Area Health Boards will make community participation obligatory and nurses need to be prepared with research in order to take their place in this process. The knowledge acquired in this study can assist nursing practice and provide guidelines for encouraging participation in home nursing care.

It was discovered that the crucial element of participation for the district nursing clients studied here was the nurse's encouragement of participation; decision making and control were not found to be significant elements. Based on these findings, the implications for nurses are that an alteration in the theoretical approach to clients may be indicated. Rather than expecting clients to take responsibility for self care in the

client/nurse relationship (Butterfield, 1978, 1982), nurses need to be more aware that clients may have a different conception of self care. Nurses also must recognize their greater responsibility in the participative relationship. Active client participation in care may depend on the nurse's attitude and approach toward participation.

Another implication arising from the data in this study concerns the organization of nursing care and the apparent satisfaction of clients who have learned to know their nurse well. Nursing care is often organized to suit nurses and little credence has been given to client's wishes in that respect (see Chapter 2). The author has heard nurses state "it is better for the patient not to have the same nurse constantly" yet the clients in this study preferred and desired to have continuity of nurses. Indeed it was an issue of complaint when nurses changed frequently. It appears from the results found here that serious consideration should be given to aiming at developing closer relationships between client and nurse by providing continuity of nurses.

Implications of this study for nursing education include developing objectives for curriculum which recognize the nature of the partnership between client and nurse. Curriculum must teach the skills which will draw out and fully utilize the client's self expertise and the professional expertise of the nurse in the participative relationship described here as cooperation and working together.

Suggestions for Further Research

The work achieved in this study is only a beginning. Throughout the text, areas were identified which warranted further research. Indeed, the subject matter of this thesis requires further research in every area studied as participation in nursing care is, as yet, a poorly understood phenomenon. Participation theory as a citizen, as a worker, or as a health care consumer did not anticipate the results found in this study. As perceived by

the district nursing clients studied here, participation in nursing care differed in definition and attitude from previous research and the literature review.

Based on the findings in this study, there is evidently a discrepancy between participation theory models and reality in the district nursing care setting which points to a gap in knowledge which must be filled by research. Participation is an important component of nursing and research to support nursing practice must continue.

APPENDIX A:

Questionnaire

Consent Form

Coding Scheme

Letters

QUESTIONNAIRE: INTRODUCTION AT DOOR

Hello, my name is Wilma Young. Are you Mr. Or Mrs. ? Did you receive my letter?" (If yes, go on. If No, explain what was in letter by reading it out.)

I've come to see you today to ask you a few questions for research. I would like to come in and talk to you now." (If yes, proceed. If no make a convenient time or find out why they've said no.)

If they just don't want to be bothered I might say something like the below to persuade them

"This will only take 20-30 minutes of your time."

"The information you give me is very important to get an accurate account of the situation."

At the door or inside, show letter.

This letter from Community Health Services will introduce me."

"I'll just go over a few points before I ask you any questions. Every precaution has been taken for you to remain anonymous. I know who you are, but any answers you give me will be confidential and the form I fill out will not identify you in any way, even to me. This is done so that you can reply as freely as you wish. Answering my questions involves no risk to you and your answers will be used only for the purpose of research."

You are free to refuse to answer any specific question if you wish, and you can stop the interview at any point.

"Do you have any questions or concerns at this point?" (I will have consent forms available if the person is concerned about this, and will leave a copy with them, otherwise try to answer to their satisfaction. e.g. how I got their name or chose them?)

"I have a questionnaire form here that I would like to fill out. Are you comfortable and ready to begin? I will have to take notes while we talk"

All the questions will be asked of all the informants.

Any of the questions may be answered along with a prior question, but I will say

"You've mentioned this before, but I'll just ask it again to confirm what you said."

QUESTIONNAIRE

Introduction:

"As I said in my letter, I am doing a research project on district nursing clients. I'm going to ask you some background questions to find out who uses district nursing services and the ways they use the service.

"I understand you are a patient of the district nurses. Would you tell me....."

1. How often does the district nurse visit you at present? _____

2. What treatment/s (if any) or services do you receive from the district nurses?

3. How long have you used district nursing services?

4. How long have you been ill or disabled with this present condition?

5. How would you describe the nature of your illness or disability?

5a) (If gives answer in terms of disease, ask:)

How does this affect what you do?

5b) (If gives answer in terms of functioning, ask:)

What is the name of your illness? (Note which one is given first)

6. How easily do you get about indoors?

Not restricted _____ Restricted to _____

Bedridden _____ Wheelchair bound _____

Other _____ (please describe)

Need help with walking _____

7. What age group are you? 0-25 _____ 26-40 _____ 41-60 _____

61-74 _____ 75-84 _____ 85 or over _____

8. (Male _____ or Female _____)

9. Do you live alone? _____ with spouse? _____ with family? _____

With others? _____ (please describe)

10. Do you receive other assistance besides the district nurse at present? (Please tick all that apply to you.)

Social worker _____ Public Health Nurse _____ Practice Nurse _____

Other nursing help _____ (please describe)

Occupational Therapy _____ Physiotherapy _____ Counselling _____

Home Aid _____ Meals on Wheels _____ Privately Paid Help _____

Volunteer help _____ Volunteer support group _____

Alternative/Intermittent Care Programme _____

"That takes care of the factual part of the questionnaire. In this next part I am interested in your opinions related to the care you receive. There are no right or wrong answers, only your viewpoint is important."

If the person is eager to talk and articulate; or has difficulty speaking (impediment); or the circumstances seem appropriate----- At this point, say

I may not be able to take notes quickly enough, during the next part. Would you mind if I used a tape recorder to keep track of your answers? I would be able to pay more attention to our conversation then.

You would not be identified at all on the recording and it would be erased as soon as the research project ended.

If person agrees to use of the tape recorder ask if they would like to sign consent form or give verbal consent. Switch it on and say

"This man or woman has given their consent to the use of a tape recorder. Would you just say "Yes, I give consent." (Indicating the informant).

Introduction:

"I will begin the second part of the interview with this question."

(Alternate words to use if person doesn't understand participate:

Take part, share in, assist with.)

11. "My special focus is on discovering how much you participate in your care. Words like participation mean different things to different people. Would you tell me what participation means to you?"

11a) "Give me an example of participation."

11b) Would you say you participate in your nursing care?

11c) Can you describe how you participate in your nursing care?

Now I am going to make some statements to you and I would like you to give your reactions to these statements. Remember I want to find out your personal opinion.

(Classify reactions as agree or disagree, and take down their comments about each statement.)

	disagree	agree
12a) The district nurse gives me useful instructions for looking after myself.	_____	_____

Comments: (Why? Reasons for reaction?)

12b) The district nurse consults me about my nursing care.

Comments: (Why? Reasons for reaction?)

12c) I am given a choice of treatments which suit me best.

Comments: (Why? Reasons for reaction?)

12d) I feel involved in making decisions about my care.

Comments: (Why? Reasons for reaction?)

12e) The nurse encourages me to participate in my care.

Comments: (Why? Reasons for reaction?)

disagree

agree

12f) I planned my care with the district nurse. _____

Comments: (Why? Reasons for reaction?)

12g) The nurse listens to my opinions about my care. _____

Comments: (Why? Reasons for reaction?)

12h) I know I can improve my condition with different treatments. _____

Comments: (Why? Reasons for reaction?)

12i) I feel that my participation is important to the nurse. _____

Comments: (Why? Reasons for reaction?)

Introduction:

"Thank you very much for your help so far. Now I just have a few more questions to ask.

13. Is it important to you that you participate in your care?

Comments: (Why? Reasons for reaction?)

14. Is it the nurse's job to decide about your care?

(Why? In what areas?)

15. Are there things that you can best decide alone or together with the nurse?

Comments: (Why? Reasons for reaction?)

16. What is one thing you like about your nursing care?

Comments: (Why? Reasons for reaction?)

17. What is one thing you dislike about your nursing care?

Comments: (Why? Reasons for reaction?)

That completes the questions I have to ask. We've discussed a lot of things but I wonder if you have anything to add. (Pause for answer.) Perhaps you have some questions? (Pause, and wait.)

THANK YOU VERY MUCH FOR YOUR CO-OPERATION, HELP, AND PARTICIPATION.
Your information will be of much assistance to me.

Massey University
Department of Nursing Studies
Palmerston North, N.Z.

INFORMED CONSENT FORM

TITLE: District Nursing Clients: Participation in Care

RESEARCHER: Wilma A. Young, R.N., Reg.Comp. Nurse, BScN. Phone 258-538

This nursing research project will study the viewpoints of district nursing patients and how they participate in their nursing care. Personal tape recorded interviews will be necessary for this research. Each interview will last about 30 minutes. During the interview you will be asked to talk about your illness and your care and what it means to you personally. Your viewpoint will help nurses to plan better nursing care and understand what patients want to do for themselves.

Your tape recording will be kept completely confidential and your identity will remain unknown to everyone except the researcher. At the end of the research project the tape will be erased. Any quotations used from your tape will be completely anonymous in the final report.

I _____ agree to the use of
(print name)

a TAPE RECORDER for the purpose of RESEARCH. I understand the information contained on the tape will be used for research purposes only and will be erased at the end of the research project.

I understand my PARTICIPATION is VOLUNTARY. I may withdraw at any time and I may refuse to answer any specific questions during the interviews without jeopardy.

This research project has been explained to me by Wilma Young and any questions have been answered to my satisfaction.

Participant's
Signature _____

Researcher's
Signature _____

CODING SCHEME FOR DATA FILE
DISTRICT NURSING CLIENTS: PARTICIPATION IN CARE

Variable	Coding Scheme
Identification	Number on questionnaire, 2 digits
Question # 1	0= more often than daily 1= daily 2= 5x week 3= 4x week 4= 2x week 5= weekly 6= up to 4 weeks 7= 4 to 12 weeks 8= 12 to 24 weeks
Question # 2	
3 columns sort into	
1. Primary	
2. Secondary	
3. Third or more	
reasons for treatments/services	0= Hygiene (dress, bathe, shower, bowels/bladder) 1= Dressings (acute/surgical; chronic/ulcers etc. sterile techniques, catherizations etc.) 2= Supervision (following more acute care; support to c a r e g i v e r ; bereavement/coping; advancing age/coping BP; Diabetes) 3= Total Nursing Care (bathing, bed, sponging, pressure cares, dressing, t r a n s f e r s , repositioning etc.) 4= Teaching (dressings; nursing care to caregiver; colostomy/urostomy, tracheostomy) 5= Supplies (equipment, beds, walkers, commodes etc.; catheter; dressings; ostomy) 6= Medications (pills; injections) 7= Counselling (psych; diabetic) 8= Arranging other care: (Physiotherapy; Meals on Wheels; Home Help; Occupational Therapy; Alternative Care; Intermittent care; Accident Compensation Social Welfare; Filling forms; Private care)

Question # 3

- 1= up to 3 months
- 2= 3 to 6 months
- 3= over 6 months to 2 years
- 4= over 2 years to 5 years
- 5= over 5 years to 10 years
- 6= over 10 years to 15 years
- 7= over 15 years

Question # 4

- 0= congenital/since childhood
- 1= up to 3 months
- 2= 3 to 6 months
- 3= over 6 months to 2 years
- 4= over 2 years to 5 years
- 5= over 5 years to 10 years
- 6= over 10 years to 15 years
- 7= over 15 years

Question # 5

3 columns

sort into

1. Principle

2. Secondary

3. Third or more

reason for illness

Acute

- 0= operation
- 1= operation/ chronic cond.
- 2= operation/complications
- 3= operation/infections
- 4= accidental injury/fractures

Chronic

- 5= Psych/Depression
- 6= Multiple Sclerosis
- 7= Diabetes
- 8= Epilepsy
- 9= Stroke
- 10= Alzhiemers
- 11= Blind
- 12= Cancer
- 13= Arthritis
- 14= Hypertension
- 15= Heart conditions
- 16= Alcoholism
- 17= Amputation
- 18= Diabetes/complication
- 19= Constipation

Congenital

- 20= Retardation
- 21= Spina Bifida
- 22= Congenital Hip
- 23= Autoimmunune disease
- Inability to Cope
- 24= Bereavement
- 25= Falls
- 26= Advancing age/poor memory
- 27= Can't cope/nerves
- 28= No illness/disability
- 29= Leg Ulcers

Question # 5a

1= disease first

Question # 5b

1= functioning first

- Question # 6
- 0= not restricted
 - 1= restricted to
 - 2= bedridden
 - 3= wheelchair bound
 - 4= other
 - 5= need help with walking
- Question # 7
- 0= 0-25
 - 1= 26-40
 - 2= 41-60
 - 3= 61-74
 - 4= 75-84
 - 5= 85 or over
- Question # 8
- 0= male
 - 1= female
- Question # 9
- 0= live alone
 - 1= with spouse
 - 2= with family
 - 3= with others
- Question # 10
- 0= 1 service
 - 1= 2 "
 - 2= 3 "
 - 3= 4 "
 - 4= 5 or over
- Question # 11b
- 0= yes
 - 1= no
- Question # 12a
to 12i
- 0= agree
 - 1= disagree
 - 2= N/A
 - 3= don't know
- Question # 13
- 0= agree
 - 1= disagree
 - 2= N/A
 - 3= don't know
- Question # 14
- 0= agree
 - 1= disagree
 - 2= N/A
 - 3= don't know
- Question # 15
- 0= agree
 - 1= disagree
 - 2= N/A
 - 3= don't know
- a) alone
- b) together

LETTERS

Massey University
Department of Nursing Studies
Palmerston North, N.Z.

RESEARCHER: Wilma A. Young, R.N., Reg.Comp.N., BScN. Phone 258-538

Dear Mr. or Mrs. _____,

I am a nurse who is seeking to improve the care you receive from district nurses. I would like your help with this by answering some questions in a short interview for the purposes of research. As a client of the district nursing service, your views of the service are essential. If you are satisfied or dissatisfied with your participation in the care you receive, it is important we know this.

The Palmerston North Hospital Board Ethics Committee and the Community Health Services have reviewed and approved this research project.

I will call at your home on (day), (date) to give the interview. If you are not going to be home on this date, you may telephone me at 258-538 to arrange another date. Any questions or concerns you have will be answered when I visit.

Thank you very much for your co-operation and your help. I am looking forward to meeting you.

Sincerely yours,

Wilma A. Young

PALMERSTON NORTH HOSPITAL BOARD

COMMUNITY HEALTH SERVICES

PRIVATE BAG
PALMERSTON NORTH HOSPITAL
NEW ZEALAND

108-112 RUAHINE STREET
PALMERSTON NORTH
TELEPHONE 65-045

29 April 1988

Eileen Day
Supervisor District Nurses
Community Health Services
Palmerston North Hospital Board
PALMERSTON NORTH

TO WHOM IT MAY CONCERN

This letter will introduce Wilma Young, Registered Nurse and Massey University post-graduate student. She is carrying out a research project involving district nursing patients.

Her research project has the approval of the Palmerston North Hospital Board Ethics Committee and of the Community Health Services.

You can be assured that any information you choose to share with her will remain strictly confidential.

Yours faithfully,

Mrs Eileen Day

EILEEN DAY
Supervisor, Community Health Services

Massey University
Department of Nursing Studies
Palmerston North, N.Z.

RESEARCHER: Wilma A. Young, R.N., Reg.Comp.N., BScN. Phone 258-538

November 3, 1988

Dear ,

I am writing to thank you for your help with the research project on district nursing clients. If you recall, I asked you to answer some questions in a short interview in May or June, 1988. As a client of the district nursing service, sharing your viewpoint on participating in the care you receive was important.

I have almost finished writing the research project and realized that without your help, I would not have been able to do any research. For this reason I am dedicating my thesis to the people who helped me by giving interviews.

The key elements that I discovered in this research were:

The majority of district nursing clients believe that

1. the nurse encourages them to participate in their nursing care;
2. the nurse listens to their opinions; and
3. the nurse gives them useful instructions for looking after themselves.

The overwhelming majority (34 out of 38) preferred to 'look after themselves' and 'managed' to do that in various ways despite varying degrees of disability, assisted by the nurse.

I want you to know that I have kept all information shared between us confidential. Any quotations used in the written material are disguised so that no one will know your identity. I will destroy the list containing names and addresses immediately these letters are mailed.

Again thank you very much for your co-operation and your help. The finished thesis, in which you assisted, will be available in Massey University library in a few months. It is called District Nursing Clients: Participation in Care

Sincerely yours,

Wilma A. Young

PALMERSTON NORTH HOSPITAL

mjg

Telephones (063) 69-169 — (063) 69-159 Telex N.Z. 30009

PRIVATE BAG PALMERSTON NORTH NEW ZEALAND

Address reply to officer
whose official title
appears below signature.

12 January 1988

Miss Wilma A. Young
R.D. 4,
PALMERSTON NORTH

Dear Miss Young

At a recent Ethics Committee Meeting your proposed research project to study District Nursing Clients: Participation in Care, was considered. I am pleased to say that the Ethics Committee were happy for this project to proceed as outlined in your proposal.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'K. J. Davey', with a stylized flourish at the end.

K. J. DAVEY
SECRETARY
THE ETHICS COMMITTEE

APPENDIX B: Questionnaire Development

DEVELOPMENT OF THE QUESTIONNAIRE

This is a brief report on the development of the final questionnaire used in this research project (found in Appendix A). The questionnaire was revised several times in various stages of development and was changed radically following the results of a pilot study. The Likert scale developed for this research and used in the pilot study was discarded and the second part of the questionnaire was rewritten.

The research plan was revised considerably, although the original intent to use multiple triangulation methodology was retained throughout revisions. From an original plan to use both mailed questionnaires and conduct a small number of indepth interviews, the final plan (discussed in detail, Chapter 3) evolved as conducting a series of personal interviews using the questionnaire, seeking both quantitative and qualitative data, during the interview. Thus questionnaire development occurred in two major stages: developing the first questionnaire (discussed in detail in Appendix C: Pilot Study) and then revision to the final questionnaire. Therefore, this report and the report in Appendix C fit together into a complete report of questionnaire development.

The Questionnaire

Since little is known about the perceptions of New Zealand district nursing clients toward participation, background information and a data base should be established in order to answer the study question

"What are the perceptions of district nursing clients toward participation in their care?"

The questionnaire (Appendix A) was developed using questionnaires from other studies as a guide for construction and format (Brown, Yelsma, & Keller, 1981; Elbeck, 1986; Heller et al,

1977; Roberts, 1975; Schulman, 1979; Willer & Miller, 1976). Structured questions about demographic and background information are followed by qualitative agree/disagree questions measuring responses to elements of participation as identified by a literature review. Advantages, disadvantages, and strategies of questionnaires are discussed in the pilot study (Appendix C), as well as the background issues of measurement and questionnaire construction.

Rationale for Questions

Demographic Information

Questions 1-6 (see Questionnaire, Appendix A) inquire about the use and purpose of district nursing services from the client's perspective. The client's perspective of the nature of their illness or disability may be distinctly different than the professional's. To illustrate the importance of seeking the client's perspective and demonstrate that diagnosis and treatment can differ in the perspectives of client and nurse, an example is given. From the nurse's perspective a district nursing client with Multiple Sclerosis is immobile except for use of the left arm and very limited use of the right arm; hand and finger movement intermittent. She is unable to move without someone's help and totally dependent on others for activities of daily living. The district nurse visits to shower her twice a week, support her husband, arrange for his relief as necessary, provide home help, and teach techniques of nursing care as necessary. In a pretest, completing the questionnaire developed for this study, the client described her condition as "unable to walk" and herself as "wheelchair bound"; the services she received from the district nurse as "showers twice a week". She is certain that she participates in her care. There is a distinct difference in severity, need, and requirements between these two perspectives. The client views her or his situation differently than the nurse

and her or his perspective needs to be explored.

While questions 2 and 3 (see Questionnaire, Appendix A) help to describe what the district nurse does for the client personally, questions 9 and 10 (see Questionnaire, Appendix A) aim to show what other requirements are needed by the client, and what arrangements were made by the nurse. Support services requirements are known to increase by the degree of severity of disability. (Dowland, Jack, & Hyslop, 1982; Jack, Dowland, Dourado & Hyslop, 1981; The Society for Research on Women in New Zealand, 1976).

Persons living with a caregiver differ from those who live alone in New Zealand in their needs for formal and informal community support, (Higgins, 1983; Malcolm & Higgins, 1983). Needs differ considerably if the person lives in a family situation or alone (The Society for Research on Women in New Zealand, 1976). Question # 9 (see Questionnaire, Appendix A) is included to determine if this also has an effect on participation in care.

Age (Question 7, see Questionnaire, Appendix A)) is a demographic variable distinctly affecting the need for District nursing care and which can alter the focus of the nurse's practice. Question # 8 (see Questionnaire, Appendix A) asks the client's sex, a variable which has some effect on the need for care and willingness to help (Jack, Dowland, & Hyslop, 1982; The Society for Research on Women in New Zealand, 1976).

Participation in Care

A wise strategy advocated by Nunnally (1970) for test construction is to compose the most homogeneous test possible based on the known nature of an attribute. Thorndike (1982) advises that an accumulation of research will relate "various self-descriptive and behavioral indices" to one another to provide a clear "picture of the nature and generality of the construct" (p.13). Thus a literature review is the first step in devising questions.

Question 11 (see Questionnaire, Appendix A) seeks the meaning

of participation to the client helping this definition to emerge by asking for examples; it also asks Do you participate in your care? This question was placed before the questions containing the known elements of participation so that definitive answers would not be influenced by statements 'giving the answer'.

Questions 12 a - i (see Questionnaire, Appendix A) ask for agree or disagree responses to statements which include the elements identified in the literature as part of the concept of participation. Explanatory qualitative information is sought to reveal and explore the informant's usual manner of participation; desire for control of the care they receive; self-perceived ability to participate; and values placed on participation.

Question 12h (see Questionnaire, Appendix A) is intended to explore an element identified in the literature as a reason for non adherence. People are offered or recommended to have treatments which have no meaning for them, or which are not cognizant of their personal goals. Often they simply do not comply, or they alter the treatment to suit themselves. This question ascertains if such a situation arises in district nursing care. It also serves as a test of validity of the participation question; i.e. if people perceived themselves to be participating they would be getting the treatments they wanted; their answer to this question would be disagreement.

Question 12e and 12i (see Questionnaire, Appendix A) ask directly about participation and the nurse's encouragement of it, and the client's perceptions of participation's importance to the nurse. The importance of participation to the client is sought in question 13 (see Questionnaire, Appendix A).

Questions 14, and 15 (see Questionnaire, Appendix A) explore decision making further, asking whether it is the nurse's job or the client's job to make the decisions, or should they make them together?

Likes and dislikes are questioned in number 16 and 17 (see Questionnaire, Appendix A), questions which yielded much information about client's perceptions of nursing care. These

questions gave the informant an opportunity to bring up areas which had not been previously questioned and to tell the researcher anything they thought had been omitted from the questionnaire.

Selection of participants for the study, the planned approach to informants, plans for conducting interviews, ethical issues, and methods of analysis are delineated in the methodology section of Chapter 3. Concerns of validity and reliability are also discussed in that section. This section describes the method and rationale for using the particular questions in the final questionnaire.

APPENDIX C: Pilot Study

THE MAILED QUESTIONNAIRE

A literature review and statement of the study problem are detailed elsewhere in this thesis (Chapter 1, 2, and 3). This section describes the mailed questionnaire as used in the pilot study. The final questionnaire formation is discussed in Appendix B and final Questionnaire itself is in Appendix A.

A mailed questionnaire approach was originally planned to be used in the major study to obtain a basic measure of New Zealand District Nursing client's attitudes toward participation. The planned research design combines the mailed questionnaires with indepth interviews which will draw out the perceptions of the informants giving depth, meaning, and a holistic perspective to the concept of participation, expanding and amplifying the data.

Questionnaire Construction

The decision to use a mailed questionnaire approach to data collection in this study was made primarily for practical reasons of limited time. Mailed questionnaires are quicker and easier to administer and can acquire much data within a short time frame (Brophy, 1981; Diers 1979; Marriner, 1981).

Disadvantages of mailed questionnaires include a low response rate, responses can't be verified and respondents may omit or misunderstand items (Brophy, 1981; Marriner, 1981). Queries are raised whether those who answer are representative of the sample or differ in some major way from those who don't answer. But Marriner (1981) suggests that disadvantages of mailed questionnaires can be overcome with various strategies which were incorporated into the design of this questionnaire.

The questionnaire developed for this study consists of structured questions about demographic and background information followed by a Likert scale and a open-ended question seeking client perceptions. In constructing the Likert scale for this study it was thought desirable for the scale to be as brief and

uncomplicated as possible, in keeping with the conviction that the whole questionnaire should remain short and simple, easy to read, easy to complete, and attractive. The study sample is expected to be non-homogeneous, with participant's ages scattered throughout the life span (although the majority are expected to be elderly); with diverse levels of education and intelligence; with widely disparate social and cultural backgrounds; and with any possible degree of disability. A dissimilar sample such as this requires sacrificing some comprehensiveness for brevity to provide clarity and understanding for all participants.

Likert Scales

A Likert scale (Likert, 1977; Seiler & Hough, 1977) was developed for this study to measure attitudes towards participation in care of district nursing clients. Likert scales are easy to construct, reliable, adaptable, and produce meaningful results (Nunnally, 1970).

During analysis the Likert scale score will be correlated with other scale items. Tables, graphs, and correlations explaining quantitative data will be formulated and carried out by computer, using the SPSSx package. The product-moment correlation coefficient known as the Pearson r formula which describes the degree of relationship between two variables will be used to compute correlations.

Report on the Development of the Questionnaire

The questionnaire was developed and then revised numerous times over a period of two months of evaluation and discussion with faculty, graduate students, public health and district nurses, and patients including a peer review. Based on that peer review, the questionnaire was revised again, particularly in relation to the 4-point Likert scale.

Following revision of the questionnaire and prior to the

pilot study, consultation with Professors and Senior Lecturers with the Computer and Statistical Departments at Massey University, experienced experts in questionnaire construction, administration, coding, and analysis, produced some very useful suggestions for analysis and for revision of the questionnaire.

Pilot Study Report

A pilot study was considered necessary to test the feasibility of the mailed questionnaire developed for the planned study; to refine and revise the questionnaire as necessary; and to test the planned analysis. In particular the questionnaire was to be tested for clarity of meaning and understanding to the participants and reveal areas subject to misinterpretation. It was also a good opportunity to give the researcher experience with all aspects of the planned research and to establish the appropriateness, efficiency, reliability, and validity of the questionnaire (Van Ort, 1981). The same assumptions, research question, design, setting, and subjects (i.e drawn from the same population) should be used, for the purpose of the pilot study is to correct preliminary problems and prevent subsequent problems in the major study.

Methodology of the Pilot Study

A sample of ten active district nursing clients was selected in a stratified random manner from the total list of district nursing clients entered into the Palmerston North Community Health Services computer. The computer list contained no obvious bias. Ten questionnaires were sent to the randomly selected sample in plain brown envelopes. Each envelope contained a white self-addressed and stamped return envelope, stamped Confidential; the questionnaire; and an accompanying letter of explanation requesting participation in the pilot study. Anonymity was assured and built into the research plan with questionnaires not being

coded for identification in any manner. A date of return was specified in the cover letter which explained that this was a pilot study. It asked for the respondent's suggestions for improvement, as well as offering other necessary information.

Analysis of the Results

Results of the pilot study were discouraging. Three out of ten questionnaires were returned. One questionnaire had demographic data completed but the Likert scale was blank with a "Nil" answer to question 12. One questionnaire was returned completely blank; another was returned blank with the notation that the questionnaire had been sent to someone who was deceased. While a low 30% rate of return can be expected from mailed questionnaires, the returns indicated problems. Some of these problems had been anticipated and planned for, but others were unforeseen. Some careful scrutiny was necessary. (Abbott, 1981).

The Sampling Procedure.

Although the sampling procedure was chosen for objectivity and non-bias, this method was unsuitable for the particular computer list used since factors unknown to the researcher handicapped the plan. On discussion and investigation with department supervisory staff it was discovered that the only way to ensure that the client was active was by actually checking each chart for that information. The computer list had been in use for two years but first entries could not be relied on to be kept up to date regarding discharges and deaths.

The method of choosing the sample also posed another problem which had been anticipated. There was the possibility of sending the questionnaire to people who were unable (either mentally or physically) to answer it and provision had been made for that event by asking for the return of the questionnaire explaining that information. This method relied on the co-operation of a

caretaker to account for unanswered questionnaires. However there may be other reasons for non-response.

Likert Scale Problem

It was not possible to test the developed questionnaire in any way. Never-the-less, the fact that the one participant that did answer chose not to complete the Likert scale indicates problems. The researcher can only speculate about reasons for this and for non-participation in the study.

Comments of a New Zealander regarding another questionnaire she was sent indicate the mailed questionnaire approach has shortcomings. " The questionnaire just arrived, without any explanation or introduction. I was rather annoyed. The questionnaire was poorly written and I thought it was an invasion of privacy, questions were invasive. But if someone had introduced the questionnaire I would have filled it out for the interviewer."

Nunnally (1970) and Shaw & Wright (1967) pointed out that research was often reacted to as if it was 'nosy'. People felt they were asked about personal, embarrassing matters, had twinges of anxiety that their shortcomings would be exposed, or of being treated as a set of statistics, or compared with others. Thorndike (1982) hypothesized that while researchers want frank and truthful answers, subjects might not choose to be truthful, may not have enough self insight to give this, or did not understand the question being asked.

Nehring & Geach (1973) first tried a questionnaire approach with little success, eventually coming to the conclusion that written forms would not produce the information they wanted. In fact, in some cases the forms created fear, anxiety, and dissatisfaction. Frank answers could not be relied on since the patient would write one answer down and give an opposite answer verbally, and misinterpretation was common. Gosch & Fox (1981) and Smyth (1981) reported that questions considered threatening or invasive produced reluctant, evasive answers in a personal

interview approach as well.

It appears that people are very reluctant to express negative feelings or experiences about their care (Nehring & Geach, 1973; Taylor, 1979) and this factor may provide a clue to non-response in this study since parallels are apparent in this study. While conducting the pre-test to this study, a client who completed the questionnaire wrote down a positive experience, but told the researcher about a negative experience of participation in conversation about the questionnaire.

A primary feature of a Likert scale is that it requires an equal number of positively and negatively worded statements. The negatively worded statements in this study may have been too emphatically or forcefully worded putting off those who might have responded. Later discussion with district nursing staff revealed that patients receiving the pilot study questionnaire were disturbed. The questionnaire aroused their suspicions that the researcher was attempting to solicit complaints about the district nurses. Misinterpretation and misunderstanding is possible for those who are not aware of the principles of construction behind a Likert scale. Instructions for completing the Likert scale may also cause confusion.

Conclusions

Investigation of the results of the pilot study has indicated possible errors in study design, particularly in the sampling method and the Likert scale. Much of the evaluation is conjecture since so little information was collected. Regardless, results were discouraging enough for the researcher to abandon the mailed questionnaire strategy. Conclusions that the Likert scale and mailed questionnaire approach was not acceptable to respondents were made. A different research design and method will be chosen to study the same population for the major research project.

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