

**NURSES PERCEPTIONS OF THEIR ROLE WORKING WITH
PEOPLE WITH SEVERE MENTAL HANDICAPS IN THE
COMMUNITY**

by

LORNA JEAN CHURCH

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Department of Nursing

The University of British Columbia

Vancouver, Canada

Date: August 22, 1994

Abstract

In British Columbia, people with mental handicaps are moving from institutions to living in the community and the British Columbia government has recently hired nurses to supervise the health care needs of these people. A body of knowledge on which to base the specific roles for nurses working with this client population is virtually non-existent. The purpose of this study was to explore and describe nurses' perceptions of their role in working with individuals with severe mental handicaps in the community.

This was a qualitative, descriptive study. Sampling was theoretical and twelve respondents were conveniently chosen. Data were collected through tape recorded, semi-structured interviews which were transcribed verbatim and analyzed using a process of inductive content analysis.

Three distinct categories of nurse functions (with subcategories) emerged from the data: Collaboration, support, and teaching/learning. Collaboration included activities where the nurses worked with others and was divided into components of consultation, liaison, and team participation. Support included activities related to maintaining the health of or meeting the needs of clients and maintaining caregivers in their roles; it was comprised of advocating, assessing, documenting, planning, providing direct care, and relationship

building. Teaching/learning encompassed activities related to teaching others and self-learning.

Collaboration and teaching/learning were stated to be major roles by all of the nurses. The support components deemed to be important were advocacy, assessment, planning and relationship building. Most nurses were doing case management activities and saw this as their future focus. Travelling and documenting consumed much time and observation; communication, time management, and interpersonal skills were important for each aspect of the nurse's role.

The most difficult part of the job for most nurses was advocating for clients while collaborating with caregivers at the same time. A major frustration was expressed when nurses identified the clients' health to be at risk but felt they were not listened to by caregivers.

Nurses with advanced educational qualifications and experience working with individuals with severe mental handicaps appeared to be the most comfortable in the collaborative and teaching roles. Ongoing inservice education and support are required for nurses working with this client population and it is realistic to consider a baccalaureate degree as a minimum requirement for this job.

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CHAPTER ONE: INTRODUCTION

This document reports on a research study that examined the nurse's role in working with people with severe mental handicaps in the community.

Chapter One provides an introduction to the problem and the research study.

Background to the Problem

In British Columbia we are now moving away from the large institutional model for mentally retarded citizens. Community placement opportunities are being created and retarded people trained for social and employment integration into the community
(VanderZalm, 1978).

This position statement, originated by William VanderZalm (then Minister of Human Resources in British Columbia), and cited in Adolph (1978), reflects the ideology of normalization for people with mental handicaps. This principle stresses the integration of people with mental handicaps into the mainstream of society. It is the principle of normalization which has guided the government of British Columbia to make a number of decisions with regard to people with mental handicaps, including the decision to provide community nursing services for those severely affected.

The concept of normalization originated in Denmark where the principle of letting people with mental handicaps obtain an existence as close to normal as possible was put into Danish law in 1959 (Wolfensberger,

1979). Bank-Mikkelsen was instrumental in making this change. Bank-Mikkelsen (1976) defines normalization as the right to normal living conditions; the right to the same environments and privileges as other citizens. The goal is to create a life for people with mental handicaps as close to that of normal society as possible. Bank-Mikkelsen (1976) states that, it would, in a way, be correct to say that the normalization principle is an ideology which aims at normalizing society to make society accept people with mental handicaps.

The principle of normalization has now been supported in many countries, including Canada, and today efforts are being made on a wide medical, educational and social front to humanize and normalize the lives of people with mental handicaps (National Institute on Mental Retardation [NIMR], 1981). A number of driving forces, including the impact of new ideologies in human services (basic human rights and normalization) are responsible for establishing a social trend of community living for people with mental handicaps.

In British Columbia, efforts to downsize the institutions began shortly after 1959 and became publicly apparent when Tranquille (the second largest institution for people with mental handicaps in the province) closed in 1985. The two remaining institutions are Glendale and Woodlands with a combined current population of approximately 200 adult residents. These

institutions are downsizing rapidly with an expected closure date of 1996 for both. Most of the residents will be placed, in clusters of three or four, into community group homes.

Three major issues which have an impact on nursing and clients with regard to community living are client health concerns, group home staff related issues, and the lack of a clearly defined role for the nurse. Concerns about client health are shared by many families, staff, and professionals in this field. The current residents of Glendale and Woodlands are people with severe mental handicaps. Many have multiple physical disabilities, such as cerebral palsy, epilepsy, and sensory disorders. These people have been in large institutions which have administered "custodial" care for most of their lives. These factors have major implications for the movement of this client population into community settings. The maintenance of client health is of great concern. Complex care plans are often required to address the many needs of these clients.

Downsizing efforts to date have been concentrated on those people with mild to moderate mental handicaps and very few physical disabilities. Although in recent years people with severe and multiple handicaps have been moving into the community, success of these placements has not yet been demonstrated. In a jointly written document Planning for the future: A proposal for services for people with mental handicaps, it is explained that

current programs are targeted to the social needs and daily living requirements of individuals (the Ministry of Social Services and Housing [MSSH] & Ministry of Health [MOH], 1991). This document states that while these are crucial aspects of community living, additional supports are required to ensure the ongoing health, safety, and security of all persons with mental handicaps.

Baker, Seltzer, and Seltzer (1977) identify staff related issues as the most crucial factor determining the success of community group homes. A number of staff-related issues have an impact on the care given in community settings. These issues include large turnover, lack of staff training for group home caregivers, and stress related to the job of providing care for people with mental handicaps. Staff training in group homes with clients with severe mental handicaps has been a difficult issue to address, particularly when complicated by staff changes. For example, I was once asked to do a lifting program for staff at a group home I had already visited. In three months, there had been a complete turnover of staff.

In an effort to address health care concerns of residents, the government has implemented community nursing services. The new community nurse positions are filled by nurses with previous work experience at Glendale and Woodlands and nurses from the Home Care component of the Continuing Care Division of the Ministry of Health. Either

way, the roles of these nurses have changed. Nurses who were caregivers and supervisors of care now focus on teaching other caregivers and overseeing health care needs of residents in group homes. The perspectives of such nurses can provide valuable information for the ongoing development and assessment of this new role.

Conceptualization of the Problem

Community living for people with severe mental handicaps is a new field. There is very little information found in the literature which discusses community living for people with mental handicaps. Many people with mild to moderate handicaps have been placed in the community successfully, but the future for those with severe handicaps is unclear. It is not normal for people to be looked after by nurses 24 hours a day. In an effort to be consistent with the normalization principle, community group homes have not been staffed by nurses. People with mild and moderate handicaps seem to have made this transition successfully, but it is a controversial issue related to those with severe mental and physical problems. Activities, including care and supervision of care, which have traditionally been performed by nurses, are now being delegated to non-professional staff working in these agencies. Studies suggest that community living has

resulted in a number of staff related issues as well. These include large turnover, stress, and training deficits.

Families, nurses, and others are concerned about the impact community living will have on the client's health. Some family members are terrified about sending their loved ones out to the present state of loosely monitored, unstructured, unsupervised settings when what is needed is daily support and professional assistance (C. Downing, written communication, January, 1992). Some nurses currently working at Woodlands feel an ethical conflict in sending people out to be cared for inadequately (E. Snow, personal communication, June, 1993). They feel it is their duty as client advocates to ensure that health care needs are met, and yet the clients are being discharged into community group homes where there is no access to professional assessment or planning for health promotion and maintenance. Most professionals in this field believe that nurses, with the required education and experience have a strong, positive influence in promoting and maintaining good health status for people with severe mental handicaps.

To address the many concerns about health, safety, and security of residents that have been raised, the British Columbia government implemented community positions for nurses in this field in June, 1993. There are proposed additions to these positions in 1994 and 1995. The roles for community nurses in this field, however, are new. There is very

little published material which describes roles for nurses working with individuals with severe mental handicaps. Until recently, most of these people were cared for in institutions where nurses performed traditional roles through functions such as giving medications, caring for basic hygiene, and maintaining a healthy physical environment (Jarvis, 1981). Although community living for citizens with mental handicaps has been implemented for some time now, nursing services to support these placements were not previously positioned in the community, so little is known about the nurse's role with individuals with severe mental handicaps in the community setting.

Problem Statement

British Columbians with severe mental handicaps are now moving from the institutions to community living. Families, nurses and others are concerned about the impact of this move on client health. To address these concerns, the British Columbia government has implemented community nurses in this field to supervise the health care needs of this population. This is a new endeavour for nurses and there is not yet a body of knowledge on which to base the specific roles for nurses working in the community with individuals with severe mental handicaps.

Purpose

The purpose of this study was to explore and describe nurses' perceptions of their role in working with individuals with severe mental handicaps in the community.

Research Question

What is the nurse's perception of his or her role in working with individuals with severe mental handicaps in community residential facilities?

Definitions of Terms

There are a number of terms used in this study for which definitions are provided.

1. "Community residential facility" refers to any type of facility outside the institutions where people with mental handicaps live. In British Columbia, the most common model for community living is a group home located in a residential setting with single family dwellings. There are usually three or four residents in each group home. People with mental handicaps also live in the community in families, foster homes, and individual care networks. Individual care networks are groups of families with one or two people with mental handicaps

living in each family's home. These families work together to provide services for their residents.

2. "People with mental handicaps" is a term currently used to describe the mentally retarded. Mental retardation is operationally defined as significantly low intelligence with deficits in adaptive behaviours manifested during the developmental period (American Association on Mental Deficiency [AAMD], 1983). Significantly low intelligence is measured as an intelligence quotient less than 70, adaptive behaviours are measured on a standardized scale, and the developmental period extends to the individual's 18th birthday. All three of these components must be present for a person to be mentally retarded.
3. "Nurse" refers, in this study, to professionals (licensed to practice by either the Registered Nurses Association of British Columbia, or the Registered Psychiatric Nurses Association of British Columbia) working with individuals with severe mental handicaps living in the community.
4. "Role" means functions performed by the individual. In this case, the role of the nurse refers to the functions the nurse carries out as part of the job.

5. "Severe mental handicap" is operationally defined as those individuals who are mentally retarded, with an intelligence quotient of less than 35. Often these individuals have many physical disabilities as well, and are referred to as individuals with multiple handicaps.

Assumptions

Some assumptions were made which were not being investigated in this study, but are directly pertinent to the investigation.

1. The nurses will openly and truthfully answer the trigger questions.
2. Nurses working in this field are able to identify the needs of their clients.
3. Nurses working in this field are able to discuss the nurse's role in terms of meeting client needs.

Limitations

I have a lot of experience working with people with mental handicaps, and have been involved with program development for the community nursing services. I have developed the roles for the nurses as I see them for this program. Even though bracketing was addressed, as the interviewer, I am aware that I was part of the context in this study and some bias existed because of that.

Significance of the Study

As the large government institutions for people with mental handicaps close, all services for these people, including nursing services, will be in the community. Therefore, it is important to delineate nursing's role in this arena of health care. As one of the characteristics of a profession is defining and delimiting its own roles, a nursing perspective for the ongoing development and assessment of nursing roles is important to the profession of nursing.

The findings of this study provide information to add to a body of knowledge for nurses working with individuals with severe mental handicaps in the community. They also point to additional research required in this field, as no inquiry was found from a nursing perspective. Potential significance to clients' health is also implicated by this study. Specific concerns raised and discussed by the nurses need to be addressed.

This study has implications for areas of nursing beyond the deinstitutionalization of people with mental handicaps. The move by government to place more health care services into the community will have a major impact on nurses in all fields. A nursing perspective of what nurses roles are in relation to individuals with severe mental handicaps can assist with the development and assessment of nursing roles in other areas such as community psychiatry, early surgical discharge, and continuing care.

Summary

This chapter has introduced the research study. Background information and conceptualization of the problem were discussed and the problem statement, purpose, and research question were presented. Definitions of terms were given and assumptions and limitations mentioned. The significance of this study was briefly presented and will be discussed in detail with the implications of the findings in the final chapter of this thesis.

CHAPTER TWO: REVIEW OF SELECTED LITERATURE

Review of the literature reflects a limited state of knowledge about individuals with severe mental handicaps living in the community, and most of the literature is narrative in nature, rather than research based. Lord & Pedlar (1991) state that they are unaware of any reports of longitudinal studies in the context of deinstitutionalization in Canada, other than their own which discusses the examination of life experiences four years after the closure of Tranquille. Knowledge of nursing services and perspectives of roles in this field is even more limited.

I have identified three major issues related to the research problem which will be discussed in the literature review. The first issue is a concern for the health of group home residents. Community nurses have now been hired to address this concern. The second is staffing issues which have been identified as the most crucial factor determining the success of community group homes (Baker, Seltzer, & Seltzer, 1977). The third issue is the role for the nurse in working with people with severe mental handicaps who live in the community. The literature review is divided into three sections, reflecting these major issues.

Health Concerns

In a document From institution to community: Family participation in community placement planning, the adequacy of medical care in the community is presented as a frequent concern voiced by families (MSSH, 1991). Keill (1991) in an article written for a local newspaper describes his daughter's experiences in a group home. In the past two and a half years since she was moved out of the institution, her encounters include a number of unexplained bruises, a severe drug reaction which put her in a catatonic state, and 35 days in the burn unit at Vancouver General Hospital as a result of taking a bath at the group home. Keill states that she is still suffering from the effects of the drug reaction and that he was never told what kind of medication she was given or anything about possible side-effects.

The literature found regarding health concerns for people with severe mental handicaps living in the community, however, is very limited and predominantly narrative. Most examples are newspaper articles like Mr. Keill's, written by parents or disgruntled staff and cannot be considered objective. They do, however, bring up a number of crucial issues related to resident health and safety, and therefore provide information which will be valuable in the study of nursing roles.

In an effort to identify and determine the relative frequency of serious incidents, Spangler, Gilman, and Laborde (1990), analyzed incident reports

in urban-based community group homes over a period of 18 months. Seven hundred and seventy persons with mental handicaps were evaluated to determine frequency and types of incidents. The authors do not discuss the degree of physical disability of the residents, but identify 62% of subjects having severe or profound mental handicaps. Prior to placement in group homes, 69% of the clients resided in institutions.

The identification of 3,075 incidents provides sufficient cause for concern. These 3,075 incidents involved 446 (or 58%) of the 770 clients participating in the study and those clients involved in incidents are demographically similar to the general population studied. For example, 62% had severe or profound mental handicaps. The 3,075 incidents represent only those incidents which were reported. Experience indicates that for each reported incident, there are probably others. Findings from this study indicate that medication errors, behavioural incidents, and medical emergencies comprised 86% of the incidents recorded. Medication errors represented the greatest number of incidents. Most (82%) of these medication errors included situations where dosages of medication were not given, medication records were not signed, or medications were administered incorrectly. Behavioural incidents included aggression towards others, self-injurious behaviours, property destruction, and other maladaptive behaviours. Psychiatric emergencies presented greater difficulty than their

actual numbers indicate due to a lack of resources available to deal with clients who have severe mental handicaps and who are also diagnosed with a psychiatric illness (dually-diagnosed).

The authors' discussion of this study points out that multiple medications, differing dosages, and administration schedules for various individuals, combined with high staff turnover make this a complex problem resistant to change (Spangler, Gilman, & Laborde, 1990). As many of the medications prescribed are psychotropic medications aimed at reducing psychiatric symptoms and maladaptive behaviours, medication errors often result in exacerbation of these conditions. Nurses are specifically trained in medication procedures. Most group home staff are not.

Merker and Wernsing (1984), physicians in the field of mental handicaps, state that individuals in this setting have specific acute and chronic medical problems including long-term use of medications. Many people with mental handicaps take anticonvulsants and psychotropic agents on a long-term basis. Often, group home staff complain that a resident is very sluggish or fatigued. This behaviour may have been tolerated in an institutional setting where the resident had few responsibilities, but is difficult in a group home where all individuals must work and interact. Psychotropic agents are often given in the institution to control behaviours which do not occur in a normalized group home setting. For these reasons,

medications must be reviewed and frequently changed. The nature of the drugs and possible side effects of withdrawal and dosage alterations create a very complicated process which may result in physiological deterioration if carried out too abruptly (Merker & Wernsing, 1984). Other specific problems include exposure to hepatitis B. Merker and Wernsing (1984) state that there is a 50 to 90 percent prevalence rate of hepatitis B serologic markers among people with mental handicaps who live in institutions. Although this is an American statistic, it is anticipated that the Canadian prevalence would be similar. As the hepatitis B virus is blood borne and may be transmitted through broken skin and mucous membranes, a carrier in a group home constitutes a potential risk for all other residents, staff, and family members.

Problems with sexuality and contraception are also unique for this group. Sexual abuse, public masturbation, and body exposure may have occurred in the institutions (Merker & Wernsing, 1984). The residents may have been sexually segregated and as relationships develop in the community, the teaching of sexually appropriate behaviours and contraception is often necessary. The individual's cognitive deficits may make this difficult.

Merker and Wernsing (1984) suggest that acute medical problems should be treated in the physician's office as the commotion of an emergency department will exacerbate behaviour problems. The most

frequent acute problems are skin infections (often a result of poor hygiene) and trauma caused by behavioural problems. This article, although narrative, is based on the knowledge of physicians experienced in the group home system, and provides useful information about client health care needs.

Gambert, Liebeskind, and Cameron (1987) state that as this population continues to grow older, they will be subject to unique physiological and psychological problems related to a lifetime of developmental disability, as well as all the usual age-related changes and illnesses. Lakin, Anderson, Hill, Bruininks, and Wright (1991) state that persons with mental handicaps are now more likely to survive into "old age", even though their average life expectancy is still less than that of the general population.

Bell and Bhate (1992) studied the prevalence of overweight and obesity in adults with mental handicaps living in the community. Their study measured the body mass index (BMI) of 183 adults in England. They found that 71% of males and 96% of females with Down's syndrome, and 49% of males and 63% of females with mental handicaps, but not Down's syndrome, were overweight or obese as compared with 40% males and 32% females from the normal population (Bell & Bhate, 1992). The prevalence of obesity was more significant. This study identified 19% of

males and 35% of females as obese, compared to 6% and 8% for the normal population.

Bell and Bhate (1992) state that there is overwhelming evidence of overweight and obesity being hazardous to health and often associated with increased mortality and morbidity. Obesity is also associated with coronary heart disease, hypertension, gallstones, diabetes, gout, decreased lung function, and osteoarthritis (Royal College of Physicians, 1993). The BMI is a widely used method to calculate overweight and obesity, but validity in individuals with mental handicaps and reliability is not discussed by Bell and Bhate. The subjects included all cooperative clients for two day centres which appear to be conveniently selected. Although the survey is on a small population, a significant health concern is identified.

It seems, in an effort to be consistent with the concept of normalization, we have moved away from the medical model of the institutions to a social model which excludes the health aspects of community residents. At a meeting in New Westminster, B.C., people with group home complaints were told by Terry Pyper, assistant deputy minister in the Social Services Ministry, that the new and improved operational plan for deinstitutionalization is addressing a lot of the concerns raised by families (Royal City Record, January 23, 1991). This includes the concern that health status is not being monitored and appropriate care is not being given.

The plan includes the introduction of nurses in community roles. Nursing services which are guided by a comprehensive nursing model will encompass both health and social needs, providing a more consistent and comprehensive approach to care.

A number of concerns regarding the health of people with mental handicaps living in group homes have been raised. Parents are concerned about accidents, and there have been many documented medications errors. Incidents related to maladaptive behaviours which are difficult to deal with, hepatitis B exposure, and problems with sexuality and contraception have specific significance for people with severe mental handicaps. Health hazards related to obesity and long-term medication usage are also important.

Staff Related Issues

The three most serious problems of community residential facilities are inadequate funding, staff training, and staff maintenance (O'Connor & Sitkei, 1975). Although staff related issues are identified as critical to the success of a group home (Baker, Seltzer, & Seltzer, 1977), these issues have, unfortunately, not been sufficiently addressed. In a comprehensive review of the literature, Heal, Sigelman, and Switzky (1978) did not include any references concerned specifically with staff issues and McCord (1981) found

very little inquiry into the work lives of group home staff. Since 1977, a small number of studies have investigated the issues of large turnover, stress, and training of group home staff.

George and Baumeister (1981) collected information from 21 randomly selected community residential facilities in Tennessee to study staff turnover. This study has many strengths. The group homes studied were randomly selected from a directory of all community residence facilities serving people with mental handicaps in Tennessee, and all staff and administrators employed by the 21 organizations used were included as subjects. Only those separations due to voluntary terminations and firings (controllable separations) were used to determine staff turnover. Scales used were supported by validation and reliability studies, and the data were compiled over a fiscal year. All of these factors help to maximize generalizability to similar communities.

The results of George and Baumeister's (1981) study indicated that large turnover in direct service employees was a significant problem which resulted in inconsistent, unstable relationships between service providers and residents. A total of 40 separations occurred from 55 full-time positions, representing an annual controllable turnover rate of 73 percent. Controllable turnover refers to that which cannot be attributed to uncontrollable factors such as illness and death. The major factors contributing to staff turnover

were lack of methods to orient, integrate, and maintain new staff members, low pay and wide variation for amount and kind of work to be accomplished, and a lack of training and support systems. Price (1984), also states that smaller units tend to make staff feel more isolated from colleagues and career structures.

George and Baumeister (1981) conclude that the turnover problem documented in this study is not unique to Tennessee, and that the findings provide empirical support to inferences made by others that staff withdrawal may be a national (and international) problem. George and Baumeister (1981) further state that if the findings in their study are representative of community residential facilities on the whole, then these are dysfunctional organizations, unlikely to fulfil their roles properly.

George and Baumeister (1981), however, do not consider the role that the residents play in a worker's decision to stay or leave the group home. Some staff, for example, find it very difficult to work with residents with severe mental handicaps and aggressive, disruptive behaviours. Other staff find it difficult to deal with inappropriate sexual behaviours, and many staff are unable to meet the physical demands of working with people who are extremely dependent. In relation to resident characteristics, the mental handicaps of the residents were not described in terms of degree and all but two of the residents were ambulatory. The findings may not be generalized,

therefore, to residents with severe and multiple handicaps in terms of this variable. The authors do not describe health care issues other than behaviour problems as a factor, and the study is clearly from the perspective of psychology rather than nursing.

Bersani and Heifetz (1985) investigated potential sources of stress and satisfaction as perceived by direct-care staff members in community residences for adults with mental handicaps. They focused on four relatively unexplored aspects of the work experiences of direct care staff in community residences for adults with mental handicaps. These aspects included the staff members' perceptions regarding sources of stress and satisfaction, the role that residents play in this, the relationship between perceptions of stress and satisfaction, and the relationship of various background characteristics including the degree of residents' mental handicaps.

This study clearly indicates that stress and satisfaction are two different entities for staff. Sources of stress included 31 items taken from resident-related and work-related sources of stress scales. Many of these items, such as resident behaviours, and lack of training and support for staff, have also been identified by people with whom this researcher has worked. Sources of satisfaction included 37 items from resident-related and work-related sources of satisfaction scales. This included resident-related

items such as independence in self-care skills, ability to walk about independently and regular participation in a daily program, and staff work-related items such as opportunities for personal growth, challenge, and recognition of work. Items were more highly rated, in terms of greater satisfaction for staff, when resident-related. Sources of job related stress and satisfaction were measured using a 7 point Likert-type scale. Test-retest reliability was determined for individual items and those with a reliability coefficient of less than .60 were deleted. The Hoppock Job Satisfaction Blank #5 was also administered. This instrument has demonstrated internal consistency and validity.

Bersani and Heifetz (1985) found no greater levels of staff stress or lower levels of staff satisfaction associated with residents with prior institutionalization or with more severe levels of mental handicaps. The subjects however, appear to be chosen by convenience which limits generalizability. The participants are also limited by the criteria of a minimum of three months experience in their current positions. George and Baumeister (1981) suggest that many direct service workers are already gone by three months (median length of service for relief workers was three months). Therefore, many workers experiencing high levels of stress and low levels of job satisfaction were likely not included in the study as they had already terminated their employment. The study is also limited because

levels of stress and satisfaction were rated in terms of potential sources of stress and satisfaction, so the amount of actual stress experienced by the staff overall and compared to other staff is unknown.

One potential source of stress identified by Bersani and Heifetz (1985) was lack of staff training. Savage (1984) suggests that group home staff should be given an induction course before going into the house and that regular inservice training should be built into the group home system. This does not appear to be happening, however (Savage, 1984). George and Baumeister (1981) found in their study of staff turnover that staff orientation, preservice, and inservice training was episodic at best and that job descriptions were provided to fewer than half of the employees.

Staff training in group homes was studied and analyzed by Schinke and Wong (1977). Following random assignment into experimental and control groups, staff in six Washington State group homes were given 12 hours of training in behaviour modification techniques. Schinke and Wong (1977) found that experimental home staff significantly increased their knowledge level, had better evaluations of their residents, indicated less decline in job satisfaction, and had significantly greater increases in the frequency and duration of positive staff and resident behaviour, as compared to the control group.

Although group homes were randomly assigned to experimental and control groups and 93% of full-time staff participated, the original sample appears to be conveniently chosen from Washington State group homes. All group home residents were people with mild or moderate mental handicaps and most were involved in full-time employment or day programs outside the group home. The behaviour modification techniques taught would likely be more effective with this group than with a group of people with severe, multiple handicaps because cognitive abilities would be higher.

Staff in all homes were reassessed following the training, but the length of time following the training was not specified. This may make a considerable difference to how the questions were answered, particularly in the assessment of knowledge. Four instruments were used to assess knowledge, attitude, job satisfaction, and naturalistic behaviour. These instruments used are described and interrater differences are addressed, but there is no discussion of reliability. This study adds to the current state of knowledge about staff related issues and supports the belief that group home staff benefit from training but again, presents a psychological, rather than a nursing perspective and addresses behavioural training only, not health related issues.

Staff related issues identified in the literature include large turnover and lack of staff training. One study identified a staff turnover rate of 73

percent. In another study, an experimental group of staff, for which training was provided, indicated less decline in job satisfaction, increased knowledge levels, better evaluations of residents, and increased frequency and duration of positive staff and resident behaviour, as compared to the control group. Levels of staff stress and satisfaction were explored in only one study, which found no greater levels of staff stress or lower levels of staff satisfaction associated with residents with prior institutionalization or with more severe levels of mental handicaps.

The Nurse's Role

There is also a lack of information in the literature about nursing services for clients with severe mental handicaps living in the community. The articles reviewed are for the most part narrative and describe what people believe the roles should be, the different models nurses may use to guide practice in this field, and the focus of practice for nurses working in similar fields.

Role theory in general, however, is substantially documented. Nye (1976) states that roles are homogeneous sets of behaviours which are normatively defined and expected from a given social position. Friedman (1981) suggests roles are refined by the individual and that one person may

carry out a number of roles related to their particular position. Role theory has been pulled into many fields of nursing.

Many people working in this field believe that nurses can provide services addressing health related needs for individuals with severe mental handicaps living in group homes in the community. The only evidence of nursing perspectives was found in articles published in Britain, where nursing in this field is a recognized specialty. Most of the British authors suggest that nurses staff the group homes as well as supervise care. Savage (1984) for example, suggests that to ensure appropriate care, group homes should be supervised by charge nurses and that at least two regular staff should be nurses in each group home.

Others discuss a more innovative role for nurses than staffing. Darbyshire (1988), editor of Mental Handicap Nursing, suggests that a branch of nursing which boasts of its interpersonal skills should be devising more creative ways of informing and discussing community living. This points to an educative, consultative role for nurses. Darbyshire (1989) later suggests that we can no longer justify a relationship based on professional dominance, and must move towards a partnership between individuals. This clearly identifies advocacy as another role for nurses. There is also a preventative role for nurses as suggested by Bell and Bhate (1992). They state that professional time spent on preventative measures will reduce

morbidity associated with obesity in the population and that community nurses can help.

Information looking at different models to guide nursing practice may give direction for specific nursing roles in this field. Massey (1988) states that the medical model loses its rationale in the community and that there is a new opportunity for nurses to dramatically widen their area of professional competence. Massey identifies more appropriate models for community living based on psychodynamic theory, family therapy, and learning theory, which imply that the person with a mental handicap is a whole person, basically healthy, who needs to achieve maximum independence. These ideas are consistent with many nursing models today. For example, the U.B.C. model for nursing views man as a behavioural system with biological and psychosocial needs. This model may be applied to people with mental handicaps. They are clients experiencing a critical period where coping behaviours continue to be influenced by loss that occurred years earlier (Campbell, 1987). This nursing model encompasses all the needs of people with mental handicaps including the biological needs which are of concern to a number of families and professionals, as well as the psychosocial needs which have been addressed with the social model of care.

Orem (1991) views the individual as a whole being, never isolated from his or her environment. Orem suggests that all humans have universal,

developmental, and health deviation care requisites. One universal requisite is the promotion of human functioning and development in social groups according to potential, limitations, and desire to be normal (Orem). People with mental handicaps may be appropriately cared for using this nursing model.

The provincial government has implemented community nursing services for people with mental handicaps. The Ministry of Social Services and Housing and the Ministry of Health (1991) state that these nursing services will be developed and that nurses will monitor and support the physical and medical well-being of all adults with mental handicaps in government funded resources as well as become the primary link to all facets of the health care system for these residents. Whether health promotion and illness prevention are included in this mandate is not clear.

This acknowledges the need for nurses to supervise physical and medical care in the community but does not recognize many of the other contributions nurses in this field believe they can make. Kirk (1983) states that, in Britain, it is clear that the ideology behind a community service is most important and that at present, nurses working with individuals with mental handicaps are playing an important role in this area. Blackwell (1979) states that in the United States, although nursing is challenged in this field to remain a primary resource for effective and creative professional

involvement, a qualified nurse is the most effective professional for home health assessment, general support, and basic developmental education. Blackwell (1979) suggests that the challenge further requires a definition of effective new roles for professional nursing. Bean (1981) states that many multidisciplinary community teams have evolved over the years, and that identifying the unique components of the nurse's role is a concern of many nurses working on these teams.

No information was found, from a nursing perspective, about what the role of a community nurse in this field is in British Columbia. The notion that nurses deal with physical and medical needs only, as proposed by the Ministry of Social Services and Housing and the Ministry of Health (1991), substantiates this. The proposed nursing positions are integrated into the Continuing Care Division of the Ministry of Health, which traditionally has been comprised of home care and long term care nurses. Registered Psychiatric Nurses and Registered Nurses with background, training, and expertise in this field are now included with the community nurse positions. They will contribute to an important body of information which will be useful in the ongoing development, and assessment of these nurses' roles.

Due to the lack of information on nursing's role with this specific population, literature on the focus of practice of community health nurses was reviewed. The Canadian Public Health Association (CPHA), in a 1990

document, discusses community health nursing and delineates the roles and activities of community health nurses. The CPHA defines community health nursing as an art and a science synthesizing knowledge from public health sciences and professional nursing theories. The focus of practice is health promotion, illness and injury prevention, health maintenance and community development (CPHA). This focus is consistent with nursing having a role in the health care of people with severe mental handicaps living in the community.

The American Nursing Association (ANA) states that health promotion, maintenance, education, management, coordination, and continuity of care are utilized in a holistic approach to the management of the health care of individuals, families, aggregates or groups and communities (Stanhope & Lancaster, 1992).

The CPHA identifies 12 activities for nurses which may be interpreted as specific roles. These activities include service provider, educator, consultant, facilitator, communicator, resource manager, team member, and researcher (CPHA, 1990). Many of the roles listed by CPHA are consistent with those identified in the American literature. The ANA identifies education, counselling, advocacy, and management of care as nursing activities. According to Anderson and McFarlane (1988), the American Public Health Association focuses on identifying high-risk groups and

working with resources to help them through a systematic process which includes assessment, planning, implementation, and evaluation. This approach is consistent with nursing services for people with severe mental handicaps living in the community. They would be identified as a high-risk group. A comprehensive and clearly written discussion of community nursing roles and the skills required for each, is offered by Spradley (1990).

These sources provide guidelines for beginning development of roles for nurses working in the community with individuals with severe mental handicaps. The nurses working in these new roles are also important resources. Information provided by these nurses will guide ongoing development and assessment of these roles.

Literature focussing on similar groups was also referenced. One article by Bremer (1987) discusses a needs assessment conducted in Oregon for the elderly. People that are old and people with severe mental handicaps have many similar health care needs. Bremer states that it appeared, that without professional monitoring of health status, the elderly person's functional level deteriorated and readmission to hospital was likely to occur. While this is probably related to the interventions used as a result of monitoring, Bremer points out that the monitoring is important. Hospital discharge coordinators cited the lack of in-home monitoring by nurses as the primary cause of hospital readmission (Bremer). Bremer identifies

nontechnical services (such as assessment, teaching, counselling, and referral services) as part of the professional role for community nurses.

Bean (1981) states that nursing intervention offers a total approach to the provision and coordination of services for developmentally disabled children living with their families. The needs of this group are very similar to those of people with severe mental handicaps living in group homes.

Children with developmental disabilities sometimes have severe mental handicaps, and often have conditions like cerebral palsy and epilepsy. Bean discusses basic components of the nurse's role in the care of the developmentally disabled child. These are assessing, planning and implementing nursing interventions, as well as evaluating and revising the nursing interventions (Bean). Bean also states that defining the specific functions of the nursing role is an evolving process and that the basic components may need to be redefined in a particular setting. Basic functions for nurses working with developmentally disabled children living with their families include teaching, supporting, coordinating, counselling, and advocating.

Although there was a lack of information in the literature about the nurse's role working with people with severe mental handicaps in the community, there were narrative articles reviewed which gave some direction to nursing practice in this field. Most of the British authors

suggested that nurses staff and supervise the group homes. Others suggested an educative, consultative role for nurses. One article clearly identified advocacy as a role for nurses and a preventative role was also discussed by professionals working in this field. Nursing models provided direction for using a holistic approach to practice, and the focus of practice of community health nurses and nurses working with elderly patients and children with developmental disabilities specified a number of functions for the nurse. These functions included providing service, educating, assessing, planning, consulting, facilitating, communicating, managing resources, counselling and researching.

Summary

This chapter has discussed the current state of knowledge about people with severe mental handicaps living in the community and nursing's role with these individuals. Literature examining health concerns, staffing issues, and the nurse's role was reviewed and described. Literature on the focus of practice for community health nurses and nurses working with groups similar to people with severe mental handicaps was discussed.

Although the literature regarding staff related issues and health concerns of individuals with severe mental handicaps living in the community is limited, there is enough evidence to identify significant issues. The state of

knowledge about how nursing can address these issues is largely speculative, but many experienced people in the field believe that nursing services will make a difference.

The government of British Columbia has hired nurses to work with people with severe mental handicaps living in the community. Although the roles of these nurses are not yet defined, and there is no information on which to base such a definition, these nurses will be expected to provide appropriate nursing services. The perspectives of these nurses, once established in these positions, will provide insight into what their roles are, or could be. This is necessary to prepare for the increasing services which will evolve as the institutions close.

CHAPTER THREE: METHODOLOGY

This chapter presents the methods used in the study to collect and analyze data. Following a brief overview of the research design, the selection criteria and procedure for selection of participants is presented. Data collection and analysis are discussed at length and the procedure used for data analysis is provided. This chapter is completed with a discussion of reliability and validity of the data and ethical consideration of subjects.

Research Design

This was a qualitative, descriptive study. Given that the purpose of this study was to increase understanding of the role for nurses working with people with severe mental handicaps in the community, a qualitative, descriptive method was used. Qualitative methods are used when there is little known about a subject of interest or when the research question pertains to understanding (Field & Morse, 1985). The major data collection techniques are interviews, participant observation, and field notes.

The research question to be answered in this study is: What is the nurse's perception of his or her role in working with individuals with severe mental handicaps in community residential facilities? Riemen (1986) states that the qualitative approach attempts to understand empirical matters from the

perspective of those being studied and rationalizes efforts to understand individuals by entering their fields of perception.

The qualitative, descriptive method involves gaining the perspective of people who are involved in the phenomenon of interest; in this instance the perspective of nurses working in the community with individuals with severe mental handicaps. It is appropriate to study nurses' perceptions of what their role is from a qualitative perspective in order to analyze the role of nurses in this field. The nurse who has experience working with individuals with severe mental handicaps who live in the community has the best perspective of what the role of a community nurse is in this field. Qualitative description simply communicates the insights into human experience (Oiler, 1986).

Selection Criteria

Respondents were chosen conveniently, from nurses who were able to speak about their role in working with people with severe mental handicaps in the community. As there is little known about the role of nurses working with individuals with severe mental handicaps in the community, a representative or random sample would be inappropriate (Oiler, 1986). The sample should include the best informants available. Participants were selected if they met the criteria of currently working as nurses (Registered Nurses or Registered Psychiatric Nurses) with clients who have severe mental handicaps living in the community, and were able to articulate in English what the role is for nurses in

this field. The nurses were working in either the Health Services for Community Living (HSCL) Program, which is a Continuing Care program described by the Ministry of Social Services and Housing and the Ministry of Health (1991), the In-School Support Program, or in the community as part of a transdisciplinary team.

Selection Procedure

Permission to conduct this study was received from the University of British Columbia Screening Committee for Research and Other Studies Involving Human Subjects. I then spoke with the supervisor of the In-School Support Program. She referred me to the chairperson of the Research Committee for the Vancouver Health Department, who requested a summary of the research proposal, information letter (Appendix 1), and consent form (Appendix 2) to be approved by the committee.

Once the Vancouver Health Department Research Committee approved the research proposal, the researcher contacted the coordinator of the In-School Support Program who discussed participation with the nurses, and distributed the information letter. The subjects contacted the researcher directly, and planning for the interviews was then set up between the subjects and researcher.

A similar process was carried out with Health Services for Community Living. The Program Manager of Health Services for Community Living was

contacted, and the research proposal summary and prospective participant letters were forwarded to her. She in turn discussed participation with the nurses who contacted me directly. A Mental Health Unit was contacted and the same process was carried out to include a nurse who was part of a transdisciplinary team.

Sandelowski (1986) states that sample size in qualitative study cannot be predetermined because of its dependence on the nature of the data and where the data take the investigator. For the purposes and time constraints of this thesis, however, it was predetermined that twelve subjects would participate.

Data Collection

Data were collected through semi-structured interviews. These are face-to-face verbal interchanges in which one person, the interviewer (researcher) attempts to elicit information from another, the respondent (subject), usually through direct questioning (Waltz, Strickland, & Lenz, 1991). Waltz et al. state that the interview is often the method of choice to collect research data because misinterpretation and inconsistency can often be identified at the time, communication can be clarified, and its diversity makes the interview a very useful tool.

In depth, semi-structured interviews were conducted by the researcher, with trigger questions to initiate responses from the subjects as necessary

(Appendix 3). Semi-structured interviewing is the most appropriate way of gathering data for a qualitative, descriptive study. The unstructured interview is flexible in that it allows the interviewer to respond to changes and is often used when the respondent's meanings are important in descriptive and exploratory research (Waltz et al). Waltz et al. suggest that with more structure in the interview, however, there is less likelihood of interviewer bias. With completely open-ended responses, the respondent may answer any way he or she wants. Waltz et al. state that the more structured the response alternatives are, the more reliable the interview. On the other hand, structure may focus the respondent to answer in a way that doesn't reflect the true response and validity may be compromised (Waltz et al). The use of semi-structured interviews therefore enhanced both reliability and validity.

The trigger questions used were semi-structured as well. Some examples of trigger questions included: Based on your experience in this field, what are your roles as a nurse in the community, working with people with severe mental handicaps? or, What kinds of things do you do working in the community with individuals with severe mental handicaps? According to Waltz et al. (1991) a semi-structured question contains elements of both closed-ended (structured response alternative) and open-ended (no response alternative) types of questions. The questions used in the study led subjects to provide general information about their roles working with individuals with severe mental handicaps living in the community. The questions were also designed to allow

the subjects to respond openly, by exploring their ideas and expanding on these. The purpose of qualitative description is to understand what the informants say and uncover the meaning. Semi-structured interviews and trigger questions facilitate this process.

The interviews were held at a site chosen by the participants. Ten of the interviews were held in the health unit where the nurse worked, in a private office or small meeting room. Two nurses came from the Okanagan area of the province for the interviews. Their interviews took place at a location of their choice. One of these interviews was in a common area at the British Columbia Institute of Technology, the other was in the Board Room of a MSS Regional Office.

A number of things were discussed with the subjects at the beginning of the interview. Subjects were told that participation was voluntary and that if now was not a good time for them the interview could be rescheduled. Subjects were told that if they were not comfortable with any part of the interview it would be erased and that they could withdraw from the study at any time. A brief description of how the interview would proceed was given. Subjects were also told that when they felt they had exhausted their descriptions, or when they felt they had nothing else to say on the subject the interview was finished. Consent forms were also signed at this time. Although there were no requests to erase information, a number of the nurses turned off

the tape recorder at points during the interview when they felt they had exhausted the subject, or needed a few moments to collect their thoughts.

The interviews were conducted with no major problems. Questions were asked by the researcher only when it was necessary to continue the flow of dialogue. The trigger questions were often rephrased to reflect the immediacy of the interactions. The respondents answered the questions openly and non-verbal behaviour was consistent with verbal responses.

It was anticipated that the information flow of the nurses would be quite rapid and according to Waltz et al. (1991) the more rapid the flow of information in an interview, then the more preferable is the use of a tape recorder. In order to improve reliability and validity data should be transcribed and coded as soon as possible after the interview (Waltz et al). Transcription of the interviews commenced soon after the interview was taped and field notes were completed immediately following. These field notes included nonverbal behaviours, setting specifics and any distractions or difficulties evidenced during the interviews. The coding for each interview was completed within a week.

Four transcriptions of interviews were shared with the thesis committee as a test for the interview process. Field notes were taken and then transcribed into an "interview process" for each interview. These described the non-verbal components of the interviews. Any distractions or difficulties during the interviews were also noted.

Data Analysis

The data were analyzed using a process of inductive content analysis. Content analysis involves the simplification of recorded language to a set of categories that represent the presence, frequency, intensity, or nature of selected characteristics (Markoff, Shapiro, & Weitman, 1977). Characteristics of the content to be measured are specified and rules for identifying, coding and recording these characteristics are applied. According to Fowler (1986), these are the two key processes involved in content analysis. Content analysis was used because it was the method most congruent with the purpose of the study. The content analysis was inductive because categories of data evolved during the analysis.

Waltz et al. (1991) state that content analysis has several features which make it a useful measurement technique for nursing research. Analysis is applied to recorded information and this allows for an exact replay of the original communication (Waltz et al). Content analysis also emphasizes the content of the communication, not the process or paralingual aspects and content is often emphasized in nursing research (Waltz et al). Detailed coding instructions or rules to examine the recorded information enhance objectivity and specified criteria are consistently applied in selecting and processing the data. These two characteristics make content analysis appropriate for drawing scientific conclusions (Waltz et al). The final feature identified by Waltz et al. is that content analysis has a wide variety of potential qualitative applications.

All of the above features are important in considering the use of content analysis for the qualitative study of exploring and describing the perceptions of nurses' roles in working with individuals with severe mental handicaps in the community. It is the content of interviews with the nurses that provided the information I needed, not the process, and I taped the interviews and transcribed them verbatim which allowed an exact replay of the original communication.

As well as useful features, there are many advantages of using content analysis as a technique for nursing measurement (Waltz et al., 1991). According to Waltz et al. major advantages include information that is easily accessible and inexpensive, characteristics that may be studied unobtrusively, information that can be made usable for scientific inference and categories that are generally developed after data are collected and so do not constrain or bias the data.

Procedure for Data Analysis

Content analysis involves a multistep procedure that is guided by the purpose of the investigation (Waltz et al., 1991). The purpose of the study was to explore and describe nurses' perceptions of their roles, so the content analysis procedure was guided by this. The procedure followed was suggested by Waltz et al.

Step 1

The first step in the procedure was to define the universe of the content or the totality of recorded information about which characteristics would be described or inferences drawn. The universe of content in this study was all the tape-recorded responses to interviews with nurses working with people with severe mental handicaps living in the community.

Step 2

Step two was to identify the characteristics or concepts to be measured which again was driven by the purpose of the investigation. This was the initial phase of partitioning or subdividing the content, and for this study, the concepts measured were those responses which identified specific roles or functions of the nurse.

Step 3

In step three, the unit of analysis to be employed was selected. I selected themes as the elements to be analyzed. These themes were sentences (or word groups) about the nurses' roles or functions. The use of themes or sentences requires very little inference, so unitizing reliability was enhanced. The themes were, in most situations, directly taken from the subjects' words. Significant phrases were highlighted as they occurred in the dialogue and themes were derived from the underlying meaning of these.

Step 4

Step four of the procedure was to develop a sampling plan. The entire universe was examined in the study, which is generally true when content analysis is being applied inductively (Waltz et al., 1991).

Step 5

In step five, a scheme for categorizing the content was developed. According to Waltz et al. (1991) this category system is the crux of content analysis. This was done inductively by deriving categories from the data. Clusters of similar data were identified then shuffled and sorted as described by Stern (1980). Clustered data was used as the basis for forming concepts and the categories moved from concrete to abstract.

According to Waltz et al. (1991) the categories for a given characteristic must be mutually exclusive and constructed so that each unit of content can be assigned unequivocally to one category. Criteria must be clear and explicit and it is generally recommended that the categories in content analysis be as close as possible to the original wording to minimize distortion in meaning (Waltz et al). The categories and subcategories derived from the study, in most cases were very close to the words used by the subjects. In some cases they were direct quotes or words frequently stated by the subjects.

Waltz et al. (1991) suggest four strategies for the nurse to help construct a categorical scheme for content analysis. These strategies were used in the study. The first strategy was to carefully read and listen to the available

material to develop a sense of language used and possible data divisions. I transcribed the interviews verbatim personally and became very familiar with the data during the process. I then read the interviews over completely, first just to get a general sense of the language, and then a second time to start to get a feel for individual categories which I jotted down.

The next strategy was to examine existing categorical schemes developed by other content analysts. I reviewed categories of nursing roles suggested in the literature for nurses working in fields similar to working with individuals with severe mental handicaps living in the community (Anderson & McFarlane, 1988; Bean, 1985; Canadian Public Health Association, 1990; Jarvis, 1985; Spradley, 1990; Stanhope & Lancaster, 1992).

The suggested categories in the literature formed the basis for some of the categories and subcategories used in the study. I also added subcategories which emerged from the interview data which were not reflected in the literature but were activities the nurses stated they spent a lot of time doing. These included "relationship building" and "documenting".

The third strategy for constructing the categorical scheme was to ask experts in the field to evaluate the relevance, clarity and completeness of the scheme (Waltz et al., 1991). This was done through the thesis committee who critiqued four of the interviews and evaluated the scheme. I also presented the category scheme to two other nurses working in the community with people with severe mental handicaps. I asked them to relate the information to their

jobs and both agreed with the categories used. These activities also address the final strategy for categorizing using the inductive approach which is to avoid premature closure and to avoid overly delayed closure by sharing the categories and collaborating with others.

Step 6

Step 6 of the content analysis procedure was to develop explicit coding and scoring instructions. I developed criteria for processing the content, trying to be as specific and complete as possible. I prepared a list of categories and criteria with accompanying key words and phrases to be used as a guide for analyzing the data (Appendix 4).

Step 7

The seventh step in the content analysis procedure was to pretest the categories and coding instructions. I applied the category scheme according to the explicit instructions to small portions of the first interview. Waltz et al. (1991) suggest at least two coders be asked to analyze the same material in order to assess interrater reliability and clarify discrepancies. Four interview transcriptions were forwarded to the thesis committee with the coding scheme to be pretested. As a result of this, categories were redefined.

Step 8

Step eight according to Waltz et al. (1991) refers to coder selection and training to assess interrater reliability which must be established before the

actual data analysis. I did the data analysis in the study so this step was not applicable.

Step 9

The final step in the content analysis procedure was to perform the analysis and code the data according to prescribed procedure. I coded the data from the interviews using the category scheme for the entire interview of each subject. The themes were quite easy to identify and words and phrases relating to activities, functions and skills used by the nurse in the job were pulled out of the text. One challenge was to differentiate what was essentially feelings, thoughts, and ideas. Occasionally one of the subjects got a little bit off track and started to talk about what they thought would be good skills or what they had thought the job would be. This information, although interesting, was not used because it did not relate directly to what the role was.

Most of the themes were coded quite quickly and fit into the categories and subcategories well. This was particularly true in the concrete components (assessing, planning, documenting, providing direct care). Some of the abstract themes were a little more difficult to code. For example, phoning behaviours needed to be carefully looked at in context. A telephone call could be for the purpose of relaying information which would put it in the subcategory of "liaison", or it could have been for the purpose of discussion "team participation", or giving advice "consultation". Most times, going back to the

text clarified this, but on a few occasions, this needed to be clarified at a follow-up interview.

Some of the categories on first glance seemed to overlap. The specific activities were different, however, when put into context of how the particular function was performed, or with whom, and the categories were mutually exclusive. For example, participating in meetings was coded "Collaboration: Subcategory team participation" if this was a team meeting. When the meeting was to do informal problem-solving it was coded "planning" or "teaching" if the nurse was providing information to the group either informally or formally in an effort to increase their knowledge.

Priorizing and using time efficiently when working with client needs was coded "planning". When this was done for the nurse him/herself to collaborate with others, it was coded "consultation". A visit with the client to the doctor's office was coded "Support: Subcategory relationship building" if it was used to let the client know the nurse was there for him/her. When an informal session on community living philosophy was required with the physician this was coded "teaching" or "planning" if the nurse worked with the client and physician at this time in a cooperative effort to meet the needs of the client.

Communication with health care professionals and community resources or agencies was coded "Collaboration". Communication with clients and caregivers was coded "relationship building" or "teaching" when specific knowledge was provided.

After coding each interview, I periodically went back to the previous interviews and recoded sections of data from them to increase intrarater reliability. After the first interview was analyzed using this procedure, interview process and field notes were examined and the categories were integrated into an exhaustive description for each interview. A follow-up interview with the same subject clarified and validated information. New information from the second interview was analyzed in the same manner as the first interview. A second subject was then added to the study. This second person was interviewed twice, as above, and data were analyzed by the same method. The data from the second respondent was then compared with data from the first.

A third respondent was then added to the study and more data was collected, analyzed, and compared with that of the previous respondents. This process, with repeated interviews to clarify and validate (for the first four subjects), and repeated analysis, continued until all twelve interviews were analyzed. Data gathering and analysis were done continuously and simultaneously throughout the study. Recurrent themes were grouped together and categorized according to the category scheme. An exhaustive description summary of the nurses' roles completed the data analysis.

Reliability and Validity

In content analysis both the consistency in identifying the units to be categorized (unitizing reliability) and the consistency in assigning units to

categories (interpretive reliability) are important (Waltz et al., 1991). According to Garvin, Kennedy, and Cissna (1988) adequate unitizing reliability is a prerequisite for adequate interpretive reliability.

Unitizing reliability refers to consistency in the identification of what is to be categorized across time and judges (Garvin et al., 1988). In general, the less inference required, the greater the specificity, the more exhaustive the coding system, and the greater the ability of the data to be examined repeatedly, the easier it is to establish unitizing reliability (Waltz et al., 1991). The use of themes in the study enhanced unitizing reliability as well as the use of words from the interview data as categories. Themes or phrases and sentences taken from the direct dialogue required very little inference. The criteria for coding and classifying data were clear and explicit, and examples and key words were given to increase unitizing reliability as well.

Interpretive reliability refers to the consistency with which data is categorized and meaning assigned to it (Garvin et al., 1988). It is the basis for intrarater and interrater reliability. Interpretive reliability encompasses the extent to which coders consistently use coding systems across all categories and the extent to which coders use a given category with consistency (Garvin et al., 1988). Interpretive reliability in the study was high because the coders were consistent in using the categories. The coding scheme for the study was clear and criteria was described with examples and key words and phrases

given. Consistency was demonstrated between the author, the two community nurses and thesis committee.

Unitizing and interpretive reliability are both important in establishing more traditional types of reliability such as stability reliability which is assessed by interrater and intrarater testing techniques (Waltz et al., 1991). Waltz et al. state that stability reliability is relevant for content analysis and requires clear delineation of units to be categorized and rules for assigning them to categories. These requirements were met in the study. Interrater reliability was improved by sharing interview data with the thesis committee for coding. Lynn (1985) states that the investigator working alone should periodically assess intrarater reliability because it tends to decline over time and fatigue, boredom, and concurrent experience may influence coding. Intrarater reliability was improved in the study when I periodically went back to recode previous data.

Krippendorff (1980) states that validity in content analysis refers to the degree to which analysis process variations correspond to variations outside the process and whether the real phenomena in the context of data is represented. The interviews were validated and clarified individually, face-to-face, following the analysis of the first four interviews. This was determined by the thesis committee to be sufficient to establish validity. The people having the experience were able to immediately recognize it from the descriptions as their own. This fulfilled the requirement of credibility which, according to Sandelowski (1986), is the criterion against which the truth value of qualitative

research is evaluated. Internal validity in the quantitative sense is generally inapplicable because there is no testing of subjects. The study will be given to other nurses in the field to read. Credibility will also be established if these other readers can recognize the experience.

The three major threats to validity in qualitative research are researcher bias, overweighting elite stories, and making the data look more congruent than they are (Sandelowski, 1986). These threats were managed through bracketing, checking for representativeness of the data as a whole, and using different data sources. Clear coding instructions increased the objectivity of decisions, data were not weighted, and frequency of responses was not tabulated. Credibility and fittingness were also achieved by these measures. Credibility and fittingness occur when findings can "fit" into contexts outside the study situation and findings are viewed as meaningful and applicable in terms of readers' own experiences (Sandelowski, 1986).

The study was shared with the thesis committee and the data analysis and findings will be forwarded to the Ministry Planning Committee. This fulfils the requirement of auditability which is when another researcher can clearly follow the decision trail used by the investigator of the study and arrive at the same or comparable conclusions. This is the criterion which relates to consistence of qualitative findings (Sandelowski, 1986). In order to achieve auditability, I described a clear decision trail. I also described and justified what

was actually done throughout the study and analysis, and why. This included how the data were transformed and categorized.

Another threat to validity is the researcher's inability to maintain distance from the experiences required to describe or interpret them in a meaningful way (Sandelowski, 1986). My own personal and theoretical bias on the generation and analysis of data was limited through the process of bracketing. I set aside in writing my own perspective of what the role of nurses in this field is, working in the community with people with severe mental handicaps, at the beginning of the study and tried not to impose this prior knowledge on the emerging data.

Once the trigger questions were developed and prior to the interviews taking place, I employed bracketing in an attempt to limit personal bias (Woods & Catanzaro, 1988). To increase the reliability of the study it was important to recognize that, as part of the interviewing process, I influenced the interview, regardless of what I intentionally said or did. Therefore, bracketing was done once, before the first interview of all the interviews commenced. I wrote down my own thoughts about what I think the roles for nurses are working with individuals with severe mental handicaps who live in the community.

As I was involved with the development of the service delivery plan for the HSCL program, I think it is also necessary to list the roles which were identified as a starting point for this program. These roles include assessment, planning, case management, client advocacy, consultation and support, direct

care, health teaching, liaison and monitoring. After completing this bracketing, I put the information aside and started to plan for the interviews.

According to Waltz et al. (1991) interpersonal factors in an interview may have an influence on data collected as well. One such factor is the relatedness to the interviewer of the subjects. For example, if the subject feels a common bond with the interviewer, Waltz et al. state that the flow of information will be enhanced. I have many years of experience working with people with severe mental handicaps and was involved with the planning of the HSCL program. All of the respondents were aware of this and information seemed to flow easily during the interviews.

Other interpersonal factors include a sense of trust by the respondent towards the interviewer, the interviewer's ability to listen and show attentiveness to the subject, and the congruence of the interviewer's non-verbal behaviours with what is being said during the interview (Waltz et al., 1991). Being aware of these factors, I tried very hard to actively listen to what the subjects were saying and establish congruence throughout the interviews.

According to Waltz et al. (1991) timing, duration, and scheduling also influence the interview. If the respondent is feeling rushed, or is in the middle of a busy day with other commitments, the information flow is impeded. Interviews were all scheduled by the subjects in an effort to control these variables. There were no time constraints. When the informants felt they had finished or exhausted their descriptions, the interviews ended. Most of the

interviews were about 40 minutes in length and all were scheduled at one hour so it is unlikely that the respondents were feeling rushed.

Ethical Considerations

In addition to the process outlined in the Selection Procedure, the rights of the research subjects were addressed in a number of ways. Prospective participants were identified and contacted by their supervisor. Each prospective participant received an information letter on UBC letterhead from the supervisor. The supervisor enquired if the nurse was interested in participating in the study and directed interested nurses to contact me directly.

Once initial contact had been made with me by the prospective participants, they were informed that they would be required to sign a consent form at the interview. They were also informed of the procedure, purpose of the study, and my interest to forward the findings to the Ministry Planning Committee. They were assured of privacy and confidentiality.

Subjects were told that they could withdraw from the study at anytime without jeopardizing their employment, and that participation was voluntary. Participants were also told that the interviews would be taped and that any responses could be deleted from the study at anytime if they were not comfortable with them.

The interviews took place in a room and location chosen by the subject. Consent forms were signed and interviews were taped. These tapes were only

shared with thesis committee members. The tapes were erased when the study was completed.

No risks related to participation in the study were identified so it was not necessary to inform subjects of risks as planned to protect their rights. The benefit of being able to give input at the early stages of the ongoing development and assessment of the roles for nurses, working with people with severe mental handicaps in the community, was discussed with each subject.

Summary

Chapter three discussed the research methods used in the study. The study design, selection criteria and procedures for the selection of participants were presented. Data collection and analysis were discussed at length and the procedure which was used for data analysis (content analysis) was provided. A discussion of reliability and validity followed, along with ethical considerations of subjects.

CHAPTER FOUR: FINDINGS

The purpose of this study was to explore and describe nurses' perceptions of their role in working with individuals with severe mental handicaps who live in the community. Twelve nurses working in the community with people with severe mental handicaps participated in in-depth interviews about their roles. These were recorded then transcribed verbatim and analyzed. This data provided a rich base for examining and describing the functions of community nurses working in this field. This chapter describes the demographics of the participants and presents the findings from the interviews.

Description of Participants

Twelve nurses, two male and ten female, participated in the interviews. The ages of the nurses ranged from 28 to 52 years, with the mean age being 42 years. Each nurse worked in one of three different government nursing programs which provided services for people with severe mental handicaps living in the community. Length of employment in the present position, educational qualifications, and experience working with individuals with severe mental handicaps varied among the nurses.

The length of time spent in their present jobs ranged from two months to two years at the time of the interviews. The average time was a little over seven months. Length of time varied according to the specific program

involved. Some nurses worked with children and others with adults; in addition to a severe mental handicap the client may also have a physical handicap, mental illness, or other complex health problem. Despite this, the clients as a group experienced similar needs.

Two nurses worked for the In-School Support Program. The In-School Support Program provides support services to enable the integration of children with special needs into the public school system (Bard, Jiminez & Tornack, 1993). Program planning for In-School Support commenced in 1989 and implementation was completed in 1991 (Bard, Jiminez & Tornack). The two nurses interviewed worked specifically with children who had mental handicaps and often physical handicaps as well. One of these nurses had been working in this program for two years, the other for one year.

One nurse worked in a Mental Health Centre as part of a transdisciplinary team providing services for adults of all ages with mental handicaps and concurrent mental illnesses. This program was first established in January, 1992 and this nurse had been working with dually diagnosed adults living in the community since this time. The remaining nine nurses who participated in the study were working in the Health Services for Community Living (HSCL) Program, which is part of the Continuing Care Division of the Ministry of Health. This program provides nursing and rehabilitation services for adults of all ages who, for the most part, have moved from the institutions and are now living in the community. Many of these people have severe mental handicaps and

complex health care needs. Two of these nurses were working with Vancouver Metropolitan Health Services and seven were with the Provincial Program. Nurses were first hired into this program in June, 1993.

Educational levels varied. All of the nurses interviewed in this study had a diploma in nursing (psychiatric or general) and all were registered in the province of British Columbia to practise nursing under the Nurses (Registered) Act (1979) or the Nurses (Registered Psychiatric) Act (1979). Eight were Registered Nurses (RNs) and six were Registered Psychiatric Nurses (RPNs). (Two were dual-trained and registered as both). The two nurses working in the In-School Support Program were RNs with degrees in nursing. The two nurses working in the Vancouver Metro HSCL Program were also RNs. One of these nurses had a BN, the other had a diploma in public health and was four courses short of a BSN.

The seven nurses working in the provincial HSCL program had varying educational qualifications. One was dually-trained (RN and RPN), had a BSN, and was well into a Masters (MSN) program. Another of these nurses was also dually-trained and working on a diploma in Advanced Psychiatric Nursing which leads to a degree in Health Sciences. Two of the provincial HSCL nurses were RNs and three were RPNs with a basic diploma only. The nurse working in the Mental Health Centre was an RPN with a diploma in working with people with mental handicaps (from the United Kingdom), and held a BA in psychology and

sociology. Some of the nurses had attended other courses, workshops, and conferences.

Previous experience working with people with mental handicaps also varied among the nurses. For example, the two nurses working in the In-School Support Program had very little experience in this field. Their experiences were from the fields of paediatrics, acute care, orthopaedics, and paramedics. This is understandable because, until recently, most people with severe mental handicaps lived in government institutions. Even when they required acute care services, staff were always sent with them to hospital to provide continuity of care. It is quite likely then, that nurses would not be exposed to people with severe mental handicaps during acute care employment. The In-School Support Program is part of the Preventive Community Health Division and as such hires only Registered Nurses (RNs), preferably with a baccalaureate degree in nursing (BSN). The institutions have been traditionally staffed primarily with Registered Psychiatric Nurses (RPNs), therefore it is not likely that nurses with experience in this field would have applied for these jobs (or would have met the eligibility criteria).

Previous experience of the nurses working in the HSCL Program varied depending on whether they were associated with the Vancouver Metropolitan or the Provincial Program. The two nurses working in the Vancouver program were doing a special pilot project to introduce the HSCL services through the Home Care program and had no experience working with people with severe

mental handicaps. It was decided that a pilot project would run and be evaluated prior to full implementation. These positions were therefore filled by two nurses from Home Care and their previous experiences were predominantly in Home Care and practice with the Victorian Order of Nurses.

All but one of the nurses working in the provincial HSCL Program had considerable experience in the field, ranging from ten to 25 years. Most of this was institutional experience, although one of these nurses had worked as a social worker and support team member, and another had supervised group homes. The nurse who did not have considerable experience in this field, had experience working in and managing community facilities for people with mental illness and multiple sclerosis. The nurse working in the Mental Health Centre had 20 years of experience working with people with severe mental handicaps in institutional settings. Ten nurses interviewed were working in Health Units in the Lower Mainland or the Fraser Valley. One HSCL nurse came from Vernon for the interview, and another came from Kelowna.

In summary, the mean age of participants was 42 years, educational levels varied from RPNs to BSNs, the average time spent in this job was seven months and previous experience with persons with severe mental handicaps ranged from no experience to 25 years.

The Role of the Nurse Working with People with Severe Mental Handicaps in the Community

Three distinct categories of information emerged from the data. These categories can be divided into major functions of the nurse in this setting. These functions or roles include collaboration, support and teaching/learning. Collaboration includes activities where the nurse worked jointly with others in a cooperative effort. Support refers to activities which were used to assist or sustain client health, as well as caregivers or others in their decisions or positions and teaching/learning includes all activities related to teaching others as well as self-learning. Figure 1 lists the three categories and the subcategories which emerged from the data collected in the study.

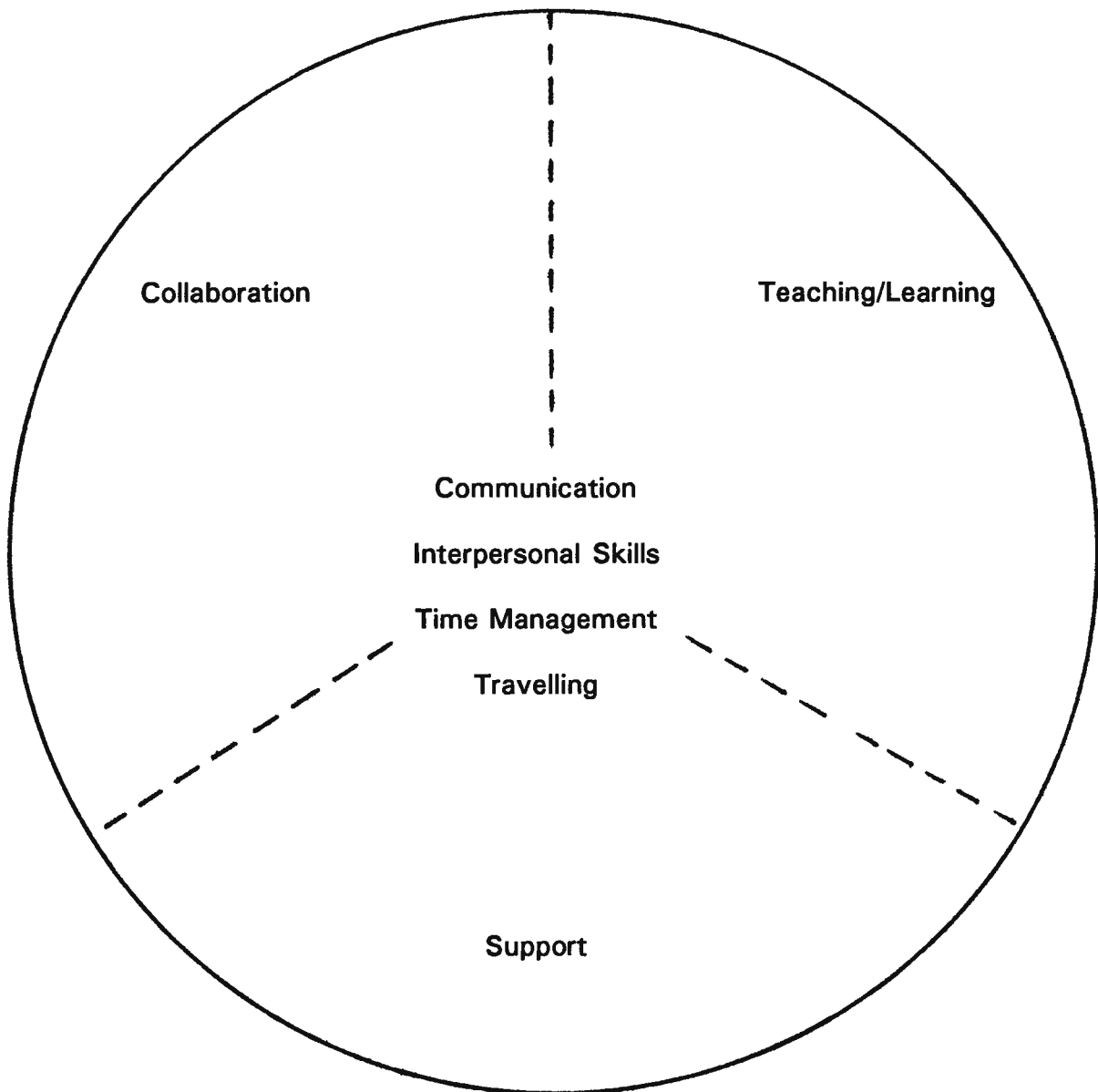
- 1. Collaborate**
 - a) consultation
 - b) liaison
 - c) team participation
- 2. Support**
 - a) advocating
 - b) assessing
 - c) documenting
 - d) planning
 - e) providing direct care
 - f) relationship building
- 3. Teaching/learning**
 - a) teaching others
 - b) self learning

Figure 1: Categories and Subcategories of the Nurse's Role

The functions are closely related to one another and many of the themes encompass more than one category. For example, the nurse must assess the client before a care plan can be developed. Collaboration with clients, caregivers, and others is necessary to complete a comprehensive assessment, particularly when the client is non-verbal. The functions coalesce to form a holistic sense or essence of the nurse's role in working with individuals with severe mental handicaps living in the community.

Figure 2 presents the holistic view of the role of the nurse working with people with severe mental handicaps who live in the community. Figure 2 also includes four activities which, although not classified as specific functions, were necessary to carry out the components of the job. Travelling, time management, communication, and interpersonal skills were threaded through each of the nursing roles identified.

No specific quantifiable data was collected about the relative importance and time spent on each individual function, so functions cannot be ranked in order of perceived importance or amount of time required. The information collected was to describe and explore roles only. The categories, therefore, are presented in alphabetical order. Despite the absence of researcher intent to identify role importance and time spent, participants spontaneously noted major roles, subcategories, and time spent with some activities. These will be noted in the presentation of findings.



Broken lines illustrate the flow through of themes.

Figure 2: The Nurse's Role Working with Individuals With Severe Mental Handicaps Living in the Community

The Collaborative Role

Collaboration included activities where the nurses worked in conjunction with others in a cooperative effort. All of the nurses spoke of collaborative activities many times throughout the interviews. These activities included: consultation, liaison, and team participation. The nurses collaborated with a large number of people including clients, caregivers in the schools and group homes, families, hospital staff, supervisors, other health professionals, and community resources.

Consultation

Consultation was a major part of the collaborative role and included activities where the nurses were providing information intended to influence others in decision-making. Nurses reported consulting with caregivers in the schools and group homes about approaches to client care. The nurses, for example, reported that people working directly with the clients were often asking for assistance around seizure management and medication requirements for clients. The nurses also consulted with caregivers about other topics like personal hygiene and how to prevent infections. Safety was also an issue discussed by many nurses.

Many of the HSCL nurses stated they responded to requests of caregivers rather than just going into group homes. Many of these nurses found this frustrating because the group home operators or service providers often did not recognize the value of their service. The nurses were also aware

of many group homes which did not request their services. The nurses were concerned about client health in these group homes. One nurse believed it was important to get out into the community and find clients rather than let them come to him, and although case finding was not identified as an activity by the other nurses, many of them had only a few clients and felt a need for more.

Consultation was also done with program staff before clients were placed into community programs on issues such as whether the client would be capable of working full-time or fully managing his financial affairs. Nurses spoke of needing skill to consult with others in a way that was non-threatening to them and did not discredit what they were doing. Consultation with community resource people was for the purpose of gathering and sharing information related to services for clients with severe mental handicaps. The nurses consulted with physicians, School Boards, various teams, hospitals, advisory committees, society and community agency staff about resources available for clients to help meet their nutritional, dental, and communication needs. Many of the nurses referred to this part of the job as "coordinating people and resources".

Other consultation activities included making referrals to other professionals, directing others through problem-solving activities, and organizing time and resources. Many examples of these activities were expressed. All of the nurses reported that they made referrals for clients to other health care services. This was identified by most as a component of "case management"

or taking responsibility for clients and their care. Referrals most frequently done were to occupational therapists, behaviourists, nutritionists, speech pathologists, and hearing or seating (wheelchair) clinics. Some nurses identified a "coordinator of services" function which was similar to case management. These nurses consulted with others to manage the health care of their clients.

Liaison

Liaison was also identified as a function performed by all of the nurses interviewed and included activities for communicating information between stakeholders. Each nurse identified specific people with whom they liaised: clients, caregivers, families, and physicians as well as different community groups, agencies, and resources.

The nurses, for instance, liaised with families and between the Ministries of Social Services and Health to ensure all information pertinent to clients was provided so required resources could be obtained. All of the nurses said that this aspect of the job took a great deal of time. Most discussed spending hours on the phone ensuring information was passed along, so that appropriate services and care could be provided for clients. Other groups liaised with regularly were other nurses at the health units, various teams, societies, and professionals. The groups reflected the specific needs of the individual clients and, as client needs were often complex, these groups were often numerous.

Team Participation

Another subcategory of collaboration, which was discussed by all the nurses, was team participation which included all activities where the nurses attended meetings, gave input, and worked together with other health care professionals as a member of a team. All of the nurses reported attending a lot of meetings. The meetings occurred with various teams of professionals, caregivers, and others.

The nurses did not discuss specific agendas for meetings but did describe some activities which took place during some meetings. For example, some nurses discussed a collaborative process of meeting with co-workers as a team to put problems on the table. The problems were discussed individually and team members were expected to suggest ways of dealing with the problem from their own perspective. The nurses felt it was important to put forward their own view during these meetings and also to be "moderate" when decisions were made. For example, the nurses would often accept the middle ground or what provided a reasonably safe environment in order to address the rights of the client to take certain risks, rather than having a totally safe environment that was risk-free. Some of the nurses found this difficult. The nurses also found it difficult to adhere to medical issues because they felt this contributed to fragmentation of client care. They were used to having a holistic view of clients, but now they felt they were only listened to when discussing

the medical aspects of care. The client was divided into compartments and each team member was only to be concerned with their one compartment.

The nurses attended other meetings as well. For example, one nurse talked about "organizing the Lower Mainland group" of HSCL nurses and rehabilitation therapists, and described a number of committees she had participated in including a transfer of function committee, the Lower Mainland Advisory Committee on Persons with Handicaps, and meetings with group home managers. These same committee meetings (in different regions) were attended by the other HSCL nurses as well. Other committees identified in which there was active participation by many of the nurses included HSCL team meetings, staff meetings, hospital liaison meetings, health unit meetings, Mental Health Team meetings, and Personal Service Plans (PSPs). One nurse, for example, stated "if we have a client in hospital and his needs have changed he's not going back to the same facility, we would be part of that plan (PSP) as to where's the best place" for him to go.

Meetings with hospital staff were not consistently described by the nurses. Some nurses stated they attended many hospital meetings and others did not. Many of the nurses discussed committee membership and participation as a significant part of team building and collaboration. Two of the nurses, however, were restricted even from visiting clients in hospital by their supervisors. Some of the nurses were also involved in discharge (from the institutions) planning and community meetings. One nurse stated she had

"involvement in the community on absolutely every level possible" and was asked to bring her clientele into the community picture. She found this fascinating "to be involved in processes that actually bring about change".

In summary, the collaborative role involved working in conjunction with others in a cooperative effort which included activities of consultation, liaison, and team participation. The nurses all stated that collaboration was very important and many found this the most challenging and difficult part of their job. Some nurses also stated collaboration was very rewarding and exciting.

The Support Role

Support included activities related to maintaining the health of clients or meeting the needs of clients and maintaining caregivers in their roles. This included subcategories of advocating, assessing, documenting, planning, providing direct care, and relationship building. Each of the twelve nurses interviewed identified these components of their role and many of the activities were the same for all of the nurses.

Advocating

Advocating referred to activities which focus on pleading the cause of others, more specifically to represent clients and caregivers in receiving appropriate services. The nurses advocated for clients, for the most part, around health issues.

Main themes discussed by the nurses included obtaining social services for clients, ensuring appropriate or adequate health care services, and looking out for clients' safety and well-being. Some of the nurses found the advocating role challenging when it involved physicians because the physicians often treated clients with severe mental handicaps differently than clients from the general population. One nurse related a couple of incidents where treatment had been withheld because "after all what did it matter they are not normal". Another discussed an instance when a client had a lump that group home staff were very concerned about and "the doctor just decided he didn't think it was worth pursuing". She found it difficult to go against what the doctor was saying but felt it very important to pursue this "in the client's best interest". Most of the nurses told similar stories.

A major problem related to advocacy that was identified in this study occurred when the nurse clearly recognized a health issue but this was not accepted by the caregivers. Most of the nurses discussed situations where this occurred and they believed the client was living at risk. One nurse, for example, was very concerned about a dysphagic client who had been assessed at the regional swallowing clinic. The recommendation from the clinic was that because of a fixed joint and high risk of aspiration, the client not be fed orally. However, this woman was being fed orally by other clients as part of a day program. The nurse felt the client was in a very dangerous position yet was unable to do anything about it. Similar stories were told by other nurses who

identified health concerns which were not believed or taken seriously by the caregivers.

Sometimes the nurses' advocating extended to representing caregivers or families as well as clients. One nurse also discussed helping caregivers to gain access to specialist and specific health services. Another assisted her clients' family by contributing information on their behalf to ensure respite care. All of the nurses saw advocating as a very important part of their job, yet difficult at times. They all expressed a great deal of satisfaction when their advocating efforts were successful, and believed their advocating function to be very different from that of Social Services. Social Services is responsible for funding so must consider costs incurred as well as availability of resources when providing services for clients. The nurses did not need to focus on costs and availability. As one nurse said "I can advocate directly for the needs of my clients, I can focus directly on what the needs of a particular client are".

Assessing

All nurses identified assessment as an activity they did as part of the job. Assessment referred to assessing health care needs of clients and "getting information" through a formal process. This process varied a little among the nurses but all of the nurses did assessments with clients regularly in order to get the necessary information to draw up a care plan. In conducting these assessments, nurses noted the importance of good observational skills, particularly for nonverbal clients.

Gathering information about client medications and whether they were suffering from the side effects of the medications was specified in one nurse's discussion of assessment. She stated that she was getting very comprehensive, specific data about the medical needs of the child. Some nurses included assessments of clients' psychosocial needs, behaviours, and environment as well, as part of their holistic perspective of their clients.

Another aspect of assessing was related to caregivers' competencies. Many of the nurses saw the caregivers as part of their clients' environment. The incompetencies of the caregivers directly influenced the health of clients and this created an ethical problem for the nurses. One nurse, for instance, spoke about "the uneducated caregivers". Another stated "the people in the group homes really don't even have any idea how to take a temperature or give a pill". One nurse assessed physicians as well when she noted that "some of them are really frightened of the clients".

Working cooperatively with others was also identified by all of the nurses as part of assessing clients' needs. The nurses worked with others in order to collect the data necessary for assessment. The data were directly related to clients' needs and the nurses worked collaboratively with caregivers, families, and physicians as well as clients to collect information. All of the nurses stated that it was important to spend time with clients. As one nurse said "you can't make assessments unless you spend time with clients". Specific activities with clients differed. One nurse discussed family planning with a client who had

recently delivered a baby. Another had many sessions with clients dealing with inappropriate behaviours, pointing out inconsistencies and helping them to "express their actual symptoms", and do things like keep simple health records.

Documenting

The word "document" was also used by all of the nurses and grouped activities which related to the written components of the job. Many of these activities were the same for all of the nurses. For example, all of the nurses spoke about writing up assessments, writing findings and progress notes in client records (or charts), and care plans. Other commonly cited written activities were filling out forms, making records, and keeping diaries. The In-School Support nurses spoke about getting consents necessary to certify special education assistants (SEAs) to the care plan. This involved a process where skills were learned, and both the nurse and SEA signed a document to reflect this. The HSCL nurses stated they were required to do a lot of additional paperwork for this new program. One such nurse stated "we have forms and tracking, that we have to do for HSCL" which included time and travel.

Many of the nurses expressed a dislike for this written version of the job but all recognized documenting as an important activity. Only one nurse singled this out as her "last priority" but clarified that this was because she hated doing it, not because she didn't think it was important. Another nurse stated that a highlight of the job was to "get through everybody's paperwork". Most of the

nurses agreed that the paperwork was extensive and time-consuming. One mentioned that this was "more than in any other job I've ever had".

Planning

Planning was done by all of the nurses interviewed in terms of sorting data, identifying client health care needs and issues, identifying services needed, identifying and solving problems and developing, and updating care plans with interventions. All of the nurses were involved in developing care plans and working from these. Working with others was an important part of planning too. The nurses developed their care plans with a lot of input from clients, families and caregivers, and activities to facilitate this were planned around the schedules of these other stakeholders. The nurses worked cooperatively to assist group home staff to address the needs of their clients. All the nurses interviewed spent time going back to group homes after the care plans were implemented to discuss areas of concern and explore how staff could deal with problems that arose. Most of the nurses identified needs of clients with the clients and caregivers, and developed strategies for care with clients and caregivers as well.

Another theme expressed by each of the nurses with regards to planning was health promotion and illness prevention. This was a very general statement made by the nurses, none of which gave any indication of what specifically they did in way of health promotion or illness prevention. The nurses planned interventions, juggled priorities, made judgements, and used

time efficiently in terms of client care and needs. The two nurses involved in the In-School Support Program were responsible, for example, for categorizing their clients into levels which reflected required health care needs.

Providing direct care

This component of the support role included all activities where the nurses interacted directly with clients. Providing direct care varied among the nurses. Some of them performed specific nursing procedures on clients, others counselled clients, or did behavioural or cognitive therapies with them. Most of the nurses did not do a lot of "hands on" care and did not feel it was an important part of the job. Three nurses, however, did a lot of direct care procedures with clients and some of the other nurses suggested that in future this aspect of their role would probably increase.

The most frequent psychomotor skills or procedures done with clients involved giving injections, changing dressings, catheterizations, and other basic nursing skills used for assessments like taking blood pressures, temperatures or weights. Some of the nurses stated that they did use these skills, but only in a teaching capacity to demonstrate to the caregivers how a specific procedure was done. Psychological aspects of direct care were also performed by some of the nurses. These included visualization relaxation techniques, self-hypnosis, behaviour modification programs, and rational-emotive therapy as well as counselling.

The direct care data provided by the nurses were very inconsistent in terms of the number of direct care activities, the types of direct care activities, and whether or not the nurses felt direct care was part of their role. Some nurses working in the same program, even in the same area, were very polarized on this function. For example, one HSCL nurse working in the Lower Mainland was doing a lot of hands on and stated "I think as time goes on I'll be doing more direct care as well". Another HSCL nurse, in the same area, stated emphatically that she did not see this as part of her job, except in certain extenuating circumstances. She described one such circumstance when a client required dressing changes and was in a temporary community placement with alternating caregivers. The nurse felt it was easier for her to do these procedures herself than try to teach an ever-changing group of temporary staff.

The nurses also had different understandings about what direct care meant. Some nurses stated that they did not do much direct care but went on to describe situations where "hands on" activities were considerable. For example, one nurse stated "I am doing no direct care" and then went on to describe giving injections and using cognitive therapies with clients. The nurses also expressed varying degrees of comfort with direct care. Some nurses were clearly uncomfortable with the psychomotor skills and interacting with clients. They stated they were novices in the field and needed to upgrade. Others were very comfortable doing nursing procedures and were frustrated that they had to spend so much time in meetings and couldn't do more. One

nurse, for example, stated "I like to be hands on". She identified the hardest part of her job was not doing direct care because, in her words, "I'd do a lot better job with the clients".

Relationship Building

The final subcategory for support was relationship building.

Relationship building activities were those done by the nurses in an effort to establish and maintain a positive working rapport with caregivers, physicians, families, clients, and others. The most frequently mentioned relationships were those with clients and caregivers. The nurses spent time just being there, empathizing, listening to, and hearing clients and caregivers. They were also helping or facilitating people in their positions working with clients all the time, supporting decisions and listening to complaints. The nurses described this as a supportive role to keep staff and clients "in place and happy".

Relationship building also included those activities which promoted or marketed the nurses and/or the programs they were working in, or public relations. The term "public relations" was mentioned specifically by only two of the nurses interviewed, but most of the others did talk about letting people know what they had to offer. Most of the public relations work was done with service providers, social workers, and clients. The main theme of public relations discussed by the nurses was difficulty marketing something that was not wanted. As one nurse stated "one of the toughest and hardest things to

deal with is trying to sell service that people could benefit from in which they did not see any value".

Some of the nurses suggested a possible reason for people not wanting them in their homes. They said there were many misconceptions in the community that the nurses were part of the government Licensing Board. The service providers were afraid to let the nurses into their homes because they thought the nurses were looking for licensing infractions which would result in closure. The nurses believed the misconceptions would "go on for some time" so public relations work was an important aspect of their job.

The nurses wanted to let caregivers know that they were around to help and explained what they had to offer in terms of service. Some of the nurses found this difficult and attributed this difficulty to personal shyness. These nurses sent letters to caregivers describing their program and role. Other nurses stated that they found it very frustrating when people only came to them for help with medical problems. They felt they had a lot more to offer in terms of providing a holistic approach to client care. This included addressing the clients' psychological and social needs as well as the physiological needs.

Specific therapeutic communication skills most frequently used in relationship building were active listening, empathy, caring, and warmth. It was also important for the nurses to gain trust and be non-judgemental. One nurse stated the most difficult part of her job was "keeping my mind broad enough to be able to hear the people who don't think the same way as I do". Other

nurses also felt that establishing relationships was the most difficult part of the job. As one nurse put it "the biggest thing is getting on track with the caregivers and just getting to know the community base". Another stated that the most challenging part of her job was "getting in the front door". This challenge was expressed by many of the nurses.

Once the initial contact was made, the nurses spent time just chatting with people to get to know them. Some of the nurses kept records of staff names so they could personalize conversations. Maintaining the relationships often required good listening skills as many of the caregivers wanted to discuss their concerns and issues about different aspects of care. As one nurse explained "I spend a lot of time just gaining trust". She gave "them (caregivers) a lot of positive reinforcement in what they're doing and let them know that I'm around if they need help". All of the nurses made similar statements. One, for example, mentioned that "we do (a lot of) allaying peoples' fears". The nurses felt it was important to let the caregivers know that they were capable of performing the job and that they were not alone. As one nurse put it "there's somebody out there if they run into trouble we're there".

Relationships with clients also presented challenges for the nurses. Some clients were frightened of strangers so it was important for the nurses to keep their distance and be aware of personal space requirements for these clients. One nurse stated that "sometimes on the first visit, I would just meet the person to try to gain some trust". Another, while discussing transfer of

function (the takeover of nursing services from another program), mentioned that she was spending a lot of time getting to know the eight clients that were involved, meeting with them informally as well as formally.

Many of the other nurses also talked about gaining trust and four of the nurses discussed "being there" for clients in terms of accompanying them to health care services. The nurses went with clients and caregivers to doctor's visits, prenatal classes, etc. This helped them to support the clients and caregivers to ask the right questions and get the information they needed to sustain them in the community. One nurse stated that sometimes clients would just want to come and talk with somebody because they were lonely in the community. This nurse sometimes took clients to community based facilities he would like the client to attend "as a way of introducing them so that they are with somebody that they're familiar with and hopefully trust". This would make their transition to the facility much easier. Relationship building was seen to be essential to the success of their program by many of the nurses interviewed.

In summary, the support component of the nurses' role included activities which are easily identified as components of the nursing process or traditional nursing skills.

The Teaching/Learning Role

The teaching/learning role was identified by many of the participants as one of the most important functions of the job. Teaching/learning included all activities related to teaching individuals and groups, such as identifying learning needs, planning and coordinating training, and the delivery of both formal and informal educational sessions. This category also included self-learning activities such as researching, updating, reading, studying, and attending workshops or conferences. The teaching/learning component of the role is divided into two subcategories of teaching (others) and (self) learning. All of the nurses suggested "a major teaching role" and one HSCL nurse stated "Our whole job or at least 98% of our job I would say is teaching". Teaching was identified as the most challenging part of the job for this nurse.

Teaching

The nurses taught many people many things in many ways. Teaching activities also included delegating nursing functions to caregivers. The nurses were delegating traditional skills like gastrostomy feedings and dressing changes. The In-School Support nurses taught SEAs specific nursing procedures like seizure management and catheterization. One nurse described a process where skills were taught, demonstrated back to her by caregivers, evaluated, and then "handed over". This process also required monitoring and follow up. The other nurses also taught specific procedures to clients and caregivers. A lot of time was spent teaching about seizures and medications.

These nurses also identified a monitoring function and evaluated how well things were going for clients and caregivers. Some stated they were "looking at standards of charting and recording" or going back and watching caregivers go through procedures.

A number of nurses were involved in setting up their new HSCL program. This included activities like developing protocols and resources as well as filing systems. These activities were required before the teaching could be done. Time was spent by all nurses "building up" their resource files and developing specific policies or procedures (such as seizure management procedures), and forms (such as forms for admitting a client to a community hospital).

Teaching included identifying learning needs for prospective learners as well as the preparation of teaching materials to assist the exchange of information. The nurses spent most of their teaching time with clients and caregivers, but many stated they were also providing inservices for others. For example, the nurses in the In-School Support Program provided inservices for all special education staff on topics such as health care needs of people with severe mental handicaps, cerebral palsy, incontinence, and infection control.

Most of the HSCL nurses were involved in similar teaching activities. The most frequently mentioned teaching topics included seizure management, medications, bowel management, universal precautions, catheters and dressings, and preventive signs and symptoms for specific conditions. They were teaching families, other professionals, community groups, and Societies.

Often the teaching would require gathering information or sharing information which was simply passed on to the caregivers.

The nurses did both formal and informal teaching. One nurse discussed informal teaching with clients and staff after (their) reading the completed health care plan. She spent time "making sure the staff understands that". She also provided the client or staff with appropriate literature and videos, and mentioned that she helped them use health care services by explaining what diagnostic tests were about and what they could expect. Another nurse stated that he spent time showing caregivers how to approach clients and how to frame their day. These activities were discussed by other nurses as well.

Formal teaching included presentations to community societies, associations, and the general public. A few of the nurses added a function of organizing and bringing people together for conferences, and one nurse was doing a major presentation at an upcoming health conference.

Learning

Self-learning was discussed by the nurses and approached in a variety of ways according to specific learning needs. Nurses identified their own learning needs which, in most cases, included updating on seizure management, and medications used for people with severe mental handicaps and multiple disabilities. The learning needs, however, were contingent on the nurses' own knowledge base as well as client needs. For example, some of the nurses felt they were novices in this field. These nurses spent a great deal of time seeking

out learning material and resources to increase their knowledge of people with mental handicaps in general. They went to many conferences and workshops on any related topic.

Other nurses, with a lot of experience working with people with severe mental handicaps, required updating on current nursing procedures and community practices. Some of the nurses were also involved in setting up speakers to come and talk to them. Most of the nurses stated that they spent time educating themselves; getting to know the resources and services that were in the community, building up their knowledge base by meeting with people, researching material, learning where they "fit", who all the players were, where everything was, sorting out the personnel and what they did, learning a new role, where all the lines were drawn, and learning the rules.

Another theme which emerged as part of learning referred to getting information on how to set up programs for specific areas or learning to teach. The nurses found learning and researching knowledge areas to be very challenging and enjoyed this part of the job, even though some also identified this as the most difficult component as well.

Other Findings

Although travelling is not categorized as a specific activity or function, it was clearly recognized as a means to accomplish all components of the nurse's role. The nurses spent time getting from one place to another, usually driving.

Travelling into the office then to the clients' homes and back again, and travelling to other community resources and agencies were discussed by each nurse. Many of the nurses also travelled to and from meetings and some explained additional travel requirements. The HSCL nurse in Maple Ridge, for example, spent two days a week in Mission and spent a lot of time on the road. Another nurse travelled from Vernon to Armstrong as part of his community territory, and a third travelled from Kelowna to Penticton on occasion, and had made three trips to Vancouver from Kelowna.

One nurse specified that he transported clients from home to community facilities, and another aspect of travel that emerged from the data was an issue around the use of government vehicles. As one nurse explained, caregivers were unhappy with government cars because the clients were trying to fit into the community and then, as she put it, "when anything happens, the government nurse shows up in a Ministry of Health car". Some of the nurses felt they had travel restrictions. One nurse, for example, stated she was not allowed to go to any meetings or "even the library" if this was outside the jurisdiction of her health unit. Other nurses, in the same program, frequently attended meetings outside their regions.

Time management was a skill which all nurses discussed as being a requirement for each component of the job. The nurses had varying degrees of comfort with managing time. One nurse identified this as the most challenging and difficult part of her job. Another stated it was the most exciting

component. All the nurses, however, agreed that their jobs required a lot of autonomy. As one nurse stated "you're very much on your own and you're accountable to yourself". Communication and interpersonal skills were also identified as important to the job.

Summary

Chapter four presented the demographics of the twelve nurses participating in the study and the research findings. Three distinct categories of data were described. These categories encompass the nurses' perceptions of the role of the nurse working with people with severe mental handicaps in the community and included collaboration, support, and teaching/learning.

Collaboration included activities where the nurses worked with others in a cooperative effort. This category included the subcategories of consultation (giving advice, opinions, or input intended to influence others in decision-making and making referrals), liaison (activities for communicating information between stakeholders) and team participation (attending meetings and working as part of a team). Support included those activities which may be seen as traditional nursing skills. These were organized into subcategories of advocating (representing clients and caregivers in receiving appropriate services), assessing (activities related to client health assessment and assessment of the clients' environment including caregivers, and data collection), documenting (the "written version of the job"), planning (health care interventions, sorting data

and problem identification) providing direct care (nursing skills used directly with clients) and relationship building (activities for establishing and maintaining relationships with others). Teaching/learning included activities related to teaching others (individuals and groups) as well as self-learning activities.

CHAPTER FIVE: DISCUSSION OF FINDINGS

The findings from twelve nurses working in the community with individuals with severe mental handicaps were presented in the preceding chapter. Three distinct categories of functions or roles emerged from the data; collaboration, support, and teaching/learning. These three roles were identified by each of the twelve nurses who participated in the study. The categories are now discussed in relation to the current state of knowledge.

Review of the literature reflected a limited state of knowledge about individuals with severe mental handicaps living in the community and most of the literature found was narrative in nature, rather than research based. Lord and Pedlar (1991) state that they are unaware of any reports of longitudinal studies in the context of deinstitutionalization in Canada (other than their own).

Knowledge of nursing services and perspectives of roles for nurses in this field was even more limited. This is likely because, until recently, very few people with severe mental handicaps have been living in the community. British Columbians are among the first to be deinstitutionalized and community nursing services for people with mental handicaps were not available in the past. Therefore, literature about the focus of practice for public health nurses and nurses working in similar fields was examined.

The Role of Collaboration

This category or role refers to activities where the nurses worked with other people in a cooperative effort for the purposes of consultation, liaison, and team participation. The nurses all agreed that collaboration was a major role for them. They spent a great deal of time doing collaborative activities. The role of collaboration for nurses working with people with severe mental handicaps living in the community was consistent with activities discussed in the literature from similar fields such as community health nursing, community mental health nursing, and working with children with developmental disabilities living with their families.

Collaboration and/or components of collaboration were discussed in the literature as roles identified for public health nurses and nurses working with groups similar to people with severe mental handicaps. For example, Kenyon, Smith, Hefty, Bell, McNeil, and Martaus (1990) identify collaboration as a competency for community nursing practice. They define collaboration as the ability to work effectively with others and to establish and maintain functional network systems that allow for the greatest client services. Collaboration in this sense requires political astuteness and maturity (Kenyon et al).

All of the nurses in this study discussed consultation, liaison, and team participation as components of the collaboration role. The Canadian Public Health Association (CPHA) identifies activities which may be interpreted as specific roles for public health nurses. These include activities of consultation

where the nurse uses knowledge to provide information to others and acts as a resource person and links those needing services to appropriate community resources (CPHA, 1990). The CPHA (1990) also discusses an activity of team member/collaborator where the nurse uses techniques to foster team building. These activities are very similar to many mentioned by the nurses in this study.

Team participation and consultation are also consistent with the new directions for health care suggested by the Canadian and British Columbia governments. These new directions include respecting the care provider and bringing health closer to home (Duncan, 1994). Some of the nurses in the study stated that as part of their collaborative role, they were involved with the community at all levels and provided a strong voice for their clients in decision-making on health care issues. This parallels a suggestion by RNABC that restructuring health care in keeping with health reform principles of greater community control and delivery closer to home includes ensuring that nurses have a voice in decision-making on health services issues (Duncan).

In a study focussing on future roles for public health nurses, consultant is identified as an executive or administrative function (Clarke, Beddome, & Whyte, 1993). The authors do not, however, go on to discuss the role specifically. Darbyshire (1988), editor of Mental Handicap Nursing, also suggests a consultative role for nurses in this field. The Ministry of Social Services and Housing and the Ministry of Health (1991) state that nurses would become the primary link to all facets of the health care system for people with

mental handicaps. This activity fits in with the subcategory liaison which emerged from the data in the study.

Kenyon et al. (1990) discuss leadership as the ability to work with multidisciplinary and multiagency groups, providing the nursing perspective of the program or task and to advocate for the clients in the context of these interactions. Many nurses in this study discussed this as part of team participation. Many of the nurses in this study were concerned about political networking and identified this as the most difficult part of the job because they were not knowledgeable in this area. This speaks to a need for political education for these nurses. Matuk and Horsburgh (1992) identify this need and cite a discussion paper prepared by a Working Group of the Federal/Provincial/Territorial Nursing Consultants (1991) where community and public health nurses were frustrated by their lack of skills in interdisciplinary collaboration.

Collaboration was also identified in the literature as part of developing partnerships. Partnerships include activities where a person shares or associates with others. The CPHA (1990) discusses partnerships in terms of health promotion where community health nurses initiate or participate in activities in partnership with colleagues, others in the community, and other sectors. The nurses in this study were working towards developing partnerships with clients, caregivers, and community resources as part of their collaborative function.

Most of the nurses also found the collaboration role frustrating at times. Caregivers and service providers had a distorted vision of the community nurse's role and saw the nurse strictly as a provider of medical care or a monitor looking for group home licensing infractions. Some caregivers were unable to see that the community nurse had more to offer such as assisting with clients' behavioural problems, obtaining community resources, and teaching. The nurses expressed concerns that clients' care was fragmented because of the failure to draw on their nursing expertise.

The nurses were also concerned about safety issues for their clients and were having difficulty balancing this with an increasing emphasis on clients' rights. This brings up a significant ethical issue. How many risks are clients allowed to take and what is the nature of the risks? Is the client's medical care adequate? The adequacy of medical care in the community for people with severe mental handicaps is identified in the literature as a major concern voiced by families (MSSH, 1991). Medication errors in particular are identified in the literature as a significant health concern (Spangler, Gilman, & Laborde, 1990).

Other collaborative activities included case management, case finding, organizing and coordinating activities, and facilitating meetings. The role of manager is identified in the literature as a role for public health nurses by both the CPHA (1990) and the American Nursing Association (ANA) as reported by Anderson and McFarlane (1988). This role is also suggested as a future role by

Clarke et al. (1993). Specific activities included in this study's collaboration role were also identified in the literature.

Some of the nurses in this study described themselves as coordinators and facilitators of health care services. Coordination or case management is considered a nursing function frequently in the literature (Anderson & McFarlane, 1988; Bean, 1981; Clarke et al., 1993). The RNABC suggests better utilization of nurses to deliver community-based care and case management services are suggested as a strategy for restructuring health care (Duncan, 1994).

Wilson and Kneisl (1992) discuss case management as a function for community health nursing and suggest that the role is grounded in Social Work. They state that the nurse as case manager is expected to coordinate services and ensure their delivery to meet the needs of clients. The case manager assesses total needs, establishes goals, and then obtains the set of services required to meet them (Wilson & Kneisl). The case manager is also expected to be the primary care agent, human contact between the clients and the bureaucracy, advocate for clients and at the same time, the representative of the formal organization (Wilson & Kneisl). Many of the nurses in this study described this aspect as the most difficult part of the job. This difficulty was also noted by Aviram (1990) who states that critics feel if case managers are to fulfil their potential, they would need resources, administrative authority and salaries that would attract professionals to this role.

Kenyon et al. (1990) define case management as the ability to establish an appropriate plan of care based on client assessment and coordinate the necessary resources and services to the client's benefit. This requires good understanding and knowledge of community resources, communication skills, negotiating and conflict-resolution skills, as well as analytical skills necessary to identify problems and set priorities to identify the best resources for referral (Kenyon et al). Many of the nurses in this study identified these same skills as being very important. Kenyon et al. also describe a role of health care system management which is consistent with the collaboration role described in this study. This role requires the ability to manage client care across multiagency and interdisciplinary lines using many sets of rules, regulations, and guidelines (Kenyon et al).

The CPHA (1990) identifies resource manager, coordinator, and facilitator as specific functions, and Clarke et al. (1993) discuss enabler as a future role similar to facilitator. This role requires a shift in power base to a partnership relationship between nurses and caregivers. Case finding was discussed by one of the nurses in this study. Kenyon et al. (1990) also discuss case finding and define this as the ability to identify others in the home or community who may be in need of services.

The degree of comfort with the collaboration role differed among the research subjects. Three of the HSCL nurses were very uncomfortable with this role and mentioned that they preferred the direct care aspects (or found them

more important). It is interesting to note that these three nurses had come from staff nurse positions in the institution and had little or no experience with such an autonomous job. The nurses from the institution who came from higher levels of nursing function (head nurses or supervisors) found this part of the job comfortable and had problems with the direct care activities. This highlights the importance of nurses being prepared for the roles they are taking on, which will be discussed in more detail in Chapter Six.

The Role of Support

This category encompasses those activities which are often considered nursing process, traditional nursing roles, functions related to maintaining the health of clients, or meeting the needs of clients and maintaining caregivers in their roles. The support role includes the components of advocating, assessing, documenting, planning, providing direct care, and relationship building.

The components of the support function for nurses are so closely related that it is difficult to discuss them separately. For example, assessing is often a prerequisite for advocating and planning. Once the client has been assessed, and problems or potential problems have been identified, advocating for appropriate services and providing direct care provide ways of dealing with those problems. This close relationship of these components was also evidenced in the literature. Wilson and Kneisl (1992), for example, state that

the nurse needs to build relationships, assess clients, and connect them to pertinent services, then reassess and replan as necessary.

Advocating includes activities which focussed on representing clients and caregivers in receiving appropriate services. Advocacy is clearly an important concept to consider when providing health care services for people with severe mental handicaps. This specific client group cannot often speak for themselves and caregivers are often uneducated in health care issues. It is therefore critical that the nurse represent the client to ensure appropriate services are obtained.

Darbyshire (1989) clearly identifies advocacy as a role for nurses working with people with mental handicaps. The ANA identifies advocacy as a nursing activity for public health nurses (Anderson & McFarlane, 1988) and Clarke et al. (1993) suggest it as a future role. The CPHA (1990) discusses a facilitator role which includes advocating activities. Wilson and Kneisl (1992) identify advocating as a role for community health nurses and Bean (1981) discusses advocating as a basic function for nurses working with developmentally disabled children living with their families.

Health concerns were discussed in terms of advocacy by the nurses in this study. The nurses assessed clients and found problems or situations where the clients were "at risk" or in danger health-wise. The nurses however, did not feel that the caregivers were listening to them. As part of their advocacy function, the nurses would try to obtain appropriate care for the clients but sometimes came up against the caregivers or service providers who disagreed

with the initial problem. The consultative, collaboration role emphasized that the nurses influence others but clearly they are not the decision-makers for clients. The two functions of advocacy and consultation were incompatible in these situations and often left the nurses feeling powerless. The nurses identified client health problems and planned accordingly, but the caregivers disagreed and would not follow through with the plan. The North American Nursing Diagnosis Association's (cited in Drew, 1990) definition of powerlessness, the perception that one's actions will not significantly affect an outcome or perceived lack of control over current situations, describes these nurses' situation.

According to Wilson and Kneisl (1992) the nurse needs power to implement change through caring and expertise. Power is described as the ability to control others, or authority, and the literature on powerlessness focuses on the concept of locus of control (Drew, 1990). Rotter (1966) distinguishes an internal locus of control or tendency of the individual to view life events as occurring as the result of his/her behaviours, and an external locus of control when one perceives outside forces as determinants of events, resulting in the expectation of personal powerlessness. The lack of control over client care was an external locus of control for the nurses in this study. The nurses felt that their concerns were not listened to, and that they had no influence over the health of their clients in these situations.

Many of the nurses in this study were used to having power over client care and health in the institutional setting but were now experiencing difficulty adjusting to the community shift. Matuk and Horsburgh (1992) suggest that to empower nurses to respond effectively to the new directions shift, it is imperative that the profession be reclarified as a specialty with a distinct philosophy and mission. Education is the key to facilitate this process and empower nurses to meet the challenges effectively (Matuk & Horsburgh).

Assessing, in this study, refers to assessing health care needs of clients and assessing caregivers and others as part of the clients' environment. Assessment is identified as a nursing role for nurses working with people with mental handicaps by Blackwell (1979), for public health nurses by the ANA (Anderson & McFarlane, 1988), and for nurses working with families with children with developmental disabilities by Bean (1981). Kenyon et al. (1990) also discuss assessment as a competency for community nurses and define assessment as the ability to assess the physiologic, environmental, and psychosocial characteristics of the client and family. This is consistent with the findings of this study. Many of the nurses reported assessing these characteristics of their clients.

During the assessment, the nurses in this study identified a number of health issues for clients. These included seizure management, hygiene, medication side effects, and mental health issues. Other health issues identified in the literature include the prevalence of overweight and obesity (Bell & Bhate,

1992) which is associated with coronary heart disease, hypertension, gallstones, diabetes, gout, decreased lung function, and osteoarthritis (Royal College of Physicians, 1993). The nurses in this study were also concerned about the nutrition of their clients and saw this as something that needed to be addressed. General feeding problems, dysphagia, and lack of appropriate community resources often hampered nutritional intake, and sometimes the caregivers did not recognize the importance of adequate nutrition.

Planning included sorting data, identifying and solving problems (including potential problems), and developing and updating care plans with interventions. Many of the articles reviewed discuss planning as a role for nurses. The APHA for instance, focusses on planning (Anderson & McFarlane, 1988), as does Bean (1981), and Clarke et al. (1993) suggest planner as a future executive role for public health nurses.

Kenyon et al. (1990) define planning in terms of "decision-making priority setting" which is the ability to identify problems accurately, prioritize them appropriately and plan and initiate interventions with positive outcomes for clients. "Caregiver value orientation" is also discussed by Kenyon et al. as a competency for community health nurses. Caregiver value orientation is the ability to focus on long-term as well as short-term health care needs and to address those needs which are expressed as well as assessed in the care plan (Kenyon et al). These ideas are similar to those expressed by the nurses in this

study. Often care plans were developed from information expressed by caregivers, particularly when clients were non-verbal.

Wilson and Kneisl (1992) state that the community mental health nurse develops a nursing care plan with specific goals and interventions delineating actions unique to the client's needs, and that this is used to guide therapeutic interventions and achieve desired goals. Many of the nurses in this study described such a care plan. Health promotion, maintenance, and continuity of care are used by community health nurses in a holistic approach to health care (Stanhope & Lancaster, 1992). These functions could be incorporated into the study "planning" component as identification and solving of potential problems. Clarke et al. (1993) also acknowledge a future health promotion role.

Providing direct care refers to specific nursing procedures performed on or with clients, including counselling and therapy. The findings in the literature reflect the inconsistent findings in the research study in reference to direct care. The CPHA (1990) identifies care-service provider as a specific role for public health nurses. Specific activities and therapies are also noted in the literature. Wilson and Kneisl (1992) state that one of the roles of the community mental health nurse is to provide psychotherapy and the ANA identifies counselling as a nursing activity (Anderson & McFarlane, 1988) for community health nurses. Bean (1981) discusses counselling as a basic function for nurses working with developmentally disabled children living with their families. She also identifies implementing nursing interventions as a basic component of the nurse's role, as

does the APHA (Anderson & McFarlane, 1988). Clarke et al. (1993), however, do not see a role for direct care in the future. This corresponds with the opinion of many nurses in this study.

Relationship building referred to activities to initiate and maintain relationships with client and caregivers. Such activities included public relations activities, "just being there", empathizing, listening to and hearing clients and caregivers, as well as helping or facilitating people in their positions working with people with severe mental handicaps in the community.

Public relations was specifically mentioned by only two nurses in the study, but most of the HSCL nurses stated they spent time "selling services" and "clearing up misinformation". Although it is beyond the scope of this study to clarify the source of this misinformation, it is reasonable to consider that because the HSCL Program is new and many of the service providers have been managing quite well without nursing services for a number of years, some resistance exists. It is widely known that change is a difficult concept for many people. Promotion of the program was considered necessary because of these misconceptions and the newness of the service which provided no experiential base of knowledge. This may not be the case with public health nurses working in well established positions. Matuk and Horsburgh (1992), however, identify a similar problem and state that in the past many traditional activities were replaced by competitive multidisciplinary workers and that nurses' skills

have not been overtly recognized as essential to carry out programs and services.

Public relations was not found consistently in the literature as a nursing role. The CPHA (1990), however, identifies "social marketer" as an activity for community health nurses and states that the nurse uses marketing techniques and skills to promote community health programs and healthy living, as well as raise and foster awareness of the role of the nurse. Using social marketing strategies to describe services is important for public health nurses because the public will not always come to public health nurses with problems and seek out their services (Working Group, 1991). Matuk and Horsburgh (1992) also suggest that the nurses will confidently articulate their expanded roles to the community. These activities or functions are similar to those discussed by the nurses in the study to sell their services and programs.

Communication skills were recognized by the nurses in this study to be an integral part of relationship building. It was important for the nurses to gain trust and be non-judgemental when collaborating with others. This was of particular importance when they had trouble getting through the door of a group home because the caregivers were afraid the nurses would be looking for things they did wrong. Relationship building referred to activities which were often encompassed by the broader role of communicator or supporter in the literature. Communication is discussed by the CPHA (1990) as a specific role to establish helping relationships.

The role of support in maintaining the health of clients with mental handicaps and in staff retention in group homes has been documented. Lack of support systems for caregivers is identified as a major contributing factor for staff turnover rates in the literature (George & Baumeister, 1981). Although staff related issues are identified as critical to the success of a group home (Baker, Seltzer, & Seltzer, 1977), these issues have not been sufficiently addressed. The Ministry of Social Services and Housing and the Ministry of Health (1991) state that nurses would support the physical and medical well-being of all adults with mental handicaps in government funded resources. Blackwell (1979) states that a qualified nurse is the most effective professional for general support for people with mental handicaps and Bean (1981) also identifies supporting as a basic function for nurses in terms of client health maintenance.

Merker and Wernsing (1984) suggest that acute medical problems should be treated in the physician's office as the commotion of an emergency department would exacerbate behaviour problems. This is consistent with the relationship building aspect of the nurse's support role in this study. All of the nurses discussed working with community physicians and five nurses went to the doctor's office with clients. Only one nurse mentioned that a client "went to emerg." and this was following a visit to the office where the physician referred him on because of a lack of specific procedural facilities and equipment. She went with her client to the hospital emergency department to

provide support as well. Relationship building in particular was seen by many of the nurses to be essential to the success of their program.

Documenting includes everything which made up "the written version" of the job. Documenting was not found in the literature discussing roles for nurses, but a great deal of time was spent by all of the nurses in this study doing paperwork and they believed it to be an important aspect of their job. Perhaps documenting is included as part of the broader function of implementing nursing interventions in the information reviewed, but no evidence for this was found.

The Teaching/Learning Role

This role was identified by many of the nurses in the study as the biggest or most important function of the job. One nurse stated "98% of the job is teaching". Teaching/learning included all activities related to teaching individuals and groups, such as identifying learning needs, planning and coordinating training, and the delivery of both formal and informal educational sessions. This role also included self-learning activities such as updating, reading, studying, and attending workshops or conferences.

The nurses identified teaching as a major function and agreed that caregivers had many learning needs. Again problems arose when caregivers did not recognize their knowledge deficits and did not allow the nurses to intervene. This is another issue which clearly needs to be reviewed. For the most part,

the nurses spent a lot of time in teaching activities with caregivers. This fits with a suggestion made by Savage (1984) that regular inservice training should be built into the group home system. Lack of staff training is identified as a major contributor to staff turnover rates (George & Baumeister, 1981). Lack of knowledge of caregivers was discussed by each of the twelve nurses in this study as well. The nurses spoke about "untrained caregivers" who had little awareness of procedures related to monitoring clients health such as taking temperatures or in maintaining health by giving medications correctly. This issue may be addressed through nurses teaching caregivers. Concerns for the health of residents may also be addressed through this role, and the importance of the nurse to support clients and advocate for them is highlighted by caregivers' lack of health knowledge. Some of the nurses were teaching community groups as well as clients and caregivers, and most saw this as an expanding role in the future.

Education or training was identified as a specific role for nurses by most of the sources referenced. Darbyshire (1988) suggests an educative role, so do Blackwell (1979), Bean (1981), and Kenyon et al. (1990), who define teaching as the ability to identify learning needs, plan and implement teaching appropriate to those needs, apply theories relevant to the learner, and adapt the teaching in the context of the client's own environment and value system. This definition is consistent with the activities described in this study as part of the teaching function. Both the CPHA (1990) and the ANA (Anderson &

McFarlane, 1988) recognize educator as a specific role, and Clarke et al. (1993) identify this as a future function for public health nurses. Providing psychoeducational approaches for caregivers and teaching self-care activities are roles listed by Wilson and Kneisl (1992) for community mental health nurses.

Other teaching activities identified in this study include delegating nursing functions, developing standards and guidelines, setting up programs, and evaluating health care and services, or monitoring. The Ministry of Social Services and Housing and the Ministry of Health (1991) state that nurses would monitor the physical and medical well-being of all adults with mental handicaps in government funded resources. Bremer (1987) also discusses professional monitoring of health status as a part of the role for public health nurses working with the elderly. Bean (1981) identifies evaluation as a nursing activity, as does the American Public Health Association (APHA) as cited in Anderson and McFarlane (1988). Wilson and Kneisl (1990) also identify coordinating and monitoring follow-up care in residential facilities as a role or function for community mental health nurses. Early detection of health issues and problems is essential when striving for optimal health for clients with severe mental handicaps.

Some of the nurses in this study stated that they were responsible for setting up the HSCL program on their own. Protocols, policies, and guidelines were required before they were able to plan teaching. The literature does not

discuss program development as a function for field staff. Program development, in most situations, was done by consultants and program managers. Some of the activities discussed by the nurses as part of program development, however, were identified in the literature at varying levels. For example, standard and policy development, program evaluation, and intersectoral work were discussed by the nurses in this study. These were identified in the literature as activities nurses participated in, but were not entirely responsible for.

The CPHA (1990) discusses policy formulator (developing policies) as an activity for community health nurses. CPHA suggests that nurses identify the need for policy and program development, participate in and monitor its implementation and evaluation, as well as assist in establishing clear nursing philosophies, policies, standards of practice, and program objectives with measurable outcomes. Many of the nurses in this study stated they were developing policies, procedures, and protocols on a regular basis.

Policy formulator was also suggested as a future role for public health nurses by Clarke et al. (1993) who suggest that in the future, community health nurses will participate in health care policy formulation, program development and evaluation, as well as intersectoral work as stated by Shamansky (1989).

The learning component of the role was not found in the literature pertaining to nursing functions, but learning is discussed for nurses in general. I believe this is because the roles for the nurses in my study are new and a

certain amount of updating, reading, and learning is required. Learning would be required for anyone starting a new position even if the role was not new. Self-learning is an important part of professional development for nurses and considering that one of the nursing standards (Registered Nurses Association of British Columbia, 1992) includes self-learning as part of accountability, perhaps it should be addressed more.

The changing roles of the nurses in this study presented a number of issues to consider. Many of the nurses were uncomfortable with the new skills required. The most discomfort was expressed in relation to consultation, liaison, relationship building, and teaching components of the job. Communication and observation skills were very important for carrying out these functions. Kenyon et al. (1990) discuss nurses moving from acute care to community settings. These nurses frequently express feelings of isolation and are unable to adequately cope with the many demands of their practice (Kenyon et al). Kramer (1974) describes this as specific shocklike reactions of new workers when they find themselves in a work situation they suddenly find they are not prepared for. This is consistent with the situation of the nurses interviewed. The need for training and support of nurses in new roles was identified in each aspect of the nursing role described in this study.

In a discussion of health care initiatives for people with mental handicaps living in the community, a primary care provider role is identified by Criscione, Kastner, O'Brien, and Nathanson (1994). This care provider is

capable of overseeing the medical care of individuals with mental handicaps and possesses specific knowledge and expertise of the unique medical and social needs of this population. This role is currently being provided by nurse practitioners with advanced educational qualifications in New Jersey (Criscione et al). It is reasonable to suggest the same educational requirements for British Columbia. The CPHA (1990) states that community health nurses are required to have a BSN. Kenyon et al. (1990) recommend education beyond the level of a BSN for community health nurses and state that professional experience as well as educational preparation is essential to building maturity. The Working Group (1991) suggest educational requirements for future public health nursing students to include collaborating on multidisciplinary teams to promote healthy populations and Wilson and Kneisl (1992) suggest that the minimum educational requirement for a psychiatric nurse consultant is at graduate level.

Dieman, Jones, and Davis (1988) recognize that a four year baccalaureate program cannot reasonably produce proficient nurses beyond entry level and Matuk and Horsburgh (1992) recommend that after entering practice, inservice, continuing-education, and graduate education programs are avenues to foster professional and self-development. Kenyon et al. (1990) suggest that the diverse competencies required by the community health nurse give direction to expanding the decision-making, priority-setting, teaching, and case management skills of newly hired nurses, and that the gaps left between basic education and proficiency needs must be filled. Education must address

the reality that community health nursing is an advanced area of practice (Kenyon et al).

Duncan (1994) states that nurses need opportunities to develop new skills in areas of policy development, political action, and forming partnerships and these can be obtained through continuing education, workshops, and other informal means. Joint appointments and other collaborative mechanisms to develop programs to assist students and practicing nurses to acquire new knowledge and skills and effectively implement new roles and functions have also been suggested (Black, Edwards, McKnight, Valaitis, & VanDover, 1989; Kernen, 1985; Zink, 1989). Collaborative team work between education and practice will provide a cornerstone for continued professional development (Selby, Riportella-Muller, Quade, Legault, & Salmon, 1990). Matuk and Horsburgh (1992) suggest that this team work will strengthen both, sensitize public health nursing students and practitioners to the needs of the profession, and foster collegial relationships between education and service.

Other Activities

All nurses spent time getting from one place to another and planning their days. Many of the nurses in this study spent a lot of time travelling and some very little. Travelling was not found in the literature. Time management was mentioned frequently as a part of the coordinator role for public health nurses and community mental health nurses (Anderson & McFarlane, 1988;

CPHA, 1990; Kenyon et al., 1990; Stanhope & Lancaster, 1992; Wilson & Kneisl, 1992).

Summary

This chapter discussed the research findings in relation to the current state of knowledge. Review of the literature reflected a limited state of knowledge about nursing services for people with severe mental handicaps; nevertheless, the three categories of functions identified in the study were compared with the functions of nurses practicing in the community with other client groups. Information on the focus of practice for public health nurses and nurses working in similar fields provided evidence to support the findings in the study. Most of the role categories and activities of subcategories derived from the study were consistently described in the literature. Public relations and learning were exceptions. It was suggested that this was because the roles for the nurses in this study were new and a certain amount of "selling services" and self-learning could be expected. Documenting and travelling were also missing in the sources referenced but the study participants spent a lot of time documenting and travelling and felt these were important aspects of the job.

Only one role was discussed in the literature but not mentioned by any of the nurses in this study. This was the function of researcher. Although some of the nurses discussed research in terms of a self-learning activity, participation in research activities was not indicated, nor did the nurses discuss

the utilization of research in their practice. This too may be explained by the fact that these nurses were in new roles and perhaps needed a little time to settle in before considering nursing research activities. It may also be a reflection of their education level which is another issue, given the emphasis in the literature.

The three roles identified in this study are very closely related and sometimes the discussion of themes and findings overlapped. This points to a more holistic view of the nurse's role in working with people with severe mental handicaps living in the community. This also emphasizes the problems and themes that run through the role components. Evidence was found in the current state of knowledge to support the findings of this study, however, and a clear direction for recommendations and nursing implications is provided.

CHAPTER SIX: SUMMARY, CONCLUSIONS AND NURSING IMPLICATIONS

This chapter presents a summary of the research study and findings. Conclusions generated by the study findings are presented, and implications of these findings for nursing practice, education, and research are discussed.

Research Summary

This study explored and described nurses' perceptions of their role in working with individuals with severe mental handicaps in the community. A qualitative, descriptive method was used to collect and analyze data. Twelve community nurses working with people with severe mental handicaps in the community participated in semi-structured interviews which were tape recorded then transcribed verbatim. The data were analyzed using a process of inductive content analysis.

Three distinct categories of nursing functions were identified and described from the data. These categories were collaboration, support, and teaching/learning. Collaboration included all activities where the nurses worked in conjunction with others in a cooperative effort and was divided into components of consultation, liaison and team participation. Support included activities related to maintaining the health of clients or meeting the needs of clients and maintaining caregivers in their roles. Support was broken down into

advocating, assessing, documenting, planning, providing direct care, and relationship building. Teaching/learning encompassed activities related to teaching individuals and groups as well as self-learning, and was divided into these two subcategories.

The categories of nursing roles were discussed in relation to the current state of knowledge. Information on the focus of practice for public health nurses and nurses working in similar fields provided evidence to support the findings in the study.

Conclusions

The following conclusions may be drawn based on the findings of this study.

1. Nurses working with individuals with severe mental handicaps living in the community performed a number of functions as part of their job. These functions can be divided into three roles: collaboration, support, and teaching/learning.
2. Collaboration and teaching/learning were stated to be major roles by all of the nurses.
3. Most nurses working with people with severe mental handicaps in the community were doing case management activities and saw this as the future focus for their jobs.

4. **Assessment, advocacy, planning, and relationship building were also activities deemed to be important by nurses working with individuals with severe mental handicaps living in the community.**
5. **Some of the nurses stated direct care was very important, others stated they did not do direct care.**
6. **Nurses expressed a feeling of powerlessness as a result of the bureaucracies in this field.**
7. **Nurses with experience working with people with severe mental handicaps and nurses with higher levels of education appeared to be more comfortable with collaborative and teaching activities while nurses with little or no experience and nurses with lower levels of education or training seemed to be less comfortable with collaborative and teaching activities.**
8. **Observation, communication, and interpersonal skills were identified by the nurses as being important in their work.**
9. **A great deal of time was spent, by nurses working in the community with people with severe mental handicaps, in documentation and travel.**

Nursing Implications

This study has both practical and scientific significance. Implications for nursing practice, education, and research may be delineated. As health care

moves increasingly towards community based services, it is important to describe a unique role for nurses.

Implications for Nursing Practice

Insight into the new roles for nurses working with people with severe mental handicaps living in the community gives direction for skills and functions required by these nurses. The findings of this study provide information to add to a very small body of knowledge for nurses and may be used to further develop these roles. I intend to submit the findings to the Program Manager of the HSCL Program to facilitate role development. This program is currently undergoing a service evaluation and such information will be valuable for the Planning Committee. One of the characteristics of a profession is defining and delimiting its own roles, therefore, a nursing perspective for the ongoing development and assessment of nursing roles is important.

Nurses working in the community with people with severe mental handicaps will need to collaborate with clients, caregivers, and others to ensure the health needs of their clients are met. These nurses will need to support the clients and caregivers in their efforts to provide successful community living, teaching and learning as necessary. Community nurses in this field will need to advocate for people with severe mental handicaps and educate others, including their colleagues in community health, with regards to the needs of this particular client group.

Health promotion and illness and accident prevention are important aspects of the nurse's role. For example, the nurses will be involved in preventing the spread of communicable diseases, ensuring adequate nutrition for clients and preventing complications from conditions (such as quadriplegia) which already exist for their clients.

Case management is a future role for nurses working with people with severe mental handicaps in the community. Some nurses are already doing a lot of case management activities and most of the nurses interviewed in this study suggested coordination or case management activities would be increasing in the future. Identifying problems in the adequacy of care was also discussed as a future role for nurses in this field. As a preventive measure, the nurses will need to evaluate the care provided for their clients and come up with innovative measures to ensure problems are recognized by the caregivers or service providers and dealt with accordingly. Teaching will be the key to facilitating the development of caregiver awareness.

Teaching functions provided many implications for the future. Learning needs assessments for clients and caregivers were suggested as well as potential teaching opportunities. Potential issues and problems could be anticipated in many situations and training could be planned for the future. For example, long term medication usage produces a number of side effects and problems which may be dealt with in advance.

There were also suggestions made to provide support for nurses through a nurse specialist in this field, and an advisory or management role for one of the HSCL nurses. This management role would include acting as a resource for the other nurses in this program. It is important for the government to model supportive behaviour for the nurses. If the nurses are expected to get out and support clients and staff in their community positions, the nurses need to be supported in their positions as well. Networking activities are required to link all of the nurses working with individuals with severe mental handicaps living in the community. Regular teleconferences or meetings should be provided as well as informal networking opportunities at conferences and community forums.

Networking would also enhance consistency in program delivery. For example, at the present time, all of the HSCL nurses are developing their own teaching packages and protocols for seizure management. This creates the potential for 33 different models being used throughout the province and suggests a lack of coordination. A nurse advisor could coordinate efforts. Under this nurse's direction, one or more nurses could develop a specific training module and pass it on to the others. Many modules have already been developed for the In-School Support Program. These could be accessed and used as well.

Direction is also provided in this study for administrators or supervisors of nurses working with individuals with severe mental handicaps living in the

community. When selecting individuals for these nursing positions, knowledge and competencies related to these roles and components of roles may be evaluated to ensure the nurses have appropriate beginning skills and abilities to perform the job. These competencies include observation, time management, communication, and interpersonal skills. Nurses with experience in consultation, liaison, team participation, assessment, advocacy, planning, relationship building, and teaching could be recruited to these positions. Nurses with these skills and competencies currently working in the institutions could be approached by these administrators and enlisted for future jobs.

A secondary implication for hospital nurses is that people with severe mental handicaps are now becoming part of the general public and using generic health care services. Nurses in health agencies, hospitals etc. will be required to provide care for these clients when their services are used. It is important that these nurses have good observation, communication, and interpersonal skills to facilitate this. It is also imperative that these nurses know that there are community nurses available to act as resources for these clients.

Time spent phoning, documenting, and travelling needs to be addressed. For example, if the nurses are spending weeks waiting for phone calls to collaborate with others, client needs are not being addressed in the meantime. Perhaps a system could be set up where an alternate person could coordinate messages or specific times set up for calling. Documentation should be re-evaluated and duplication of reports should be discouraged. Only those

documents which are necessary should be required. Perhaps a tracking system to weed out that information could be developed. Travel time should be assessed and perhaps schedules could be readjusted to keep travel to a minimum. Some client visits could be made at the day programs where a number of clients could be seen at one time and some clients could come into the health unit. This would be more consistent with generic services and normalization. This would also limit the occurrences when the government nurse would arrive at the group home in a Ministry of Health car.

This study also has practical implications for areas of nursing beyond the deinstitutionalization of people with mental handicaps. The government move to place more health care services into the community is already having a major impact on nurses in all fields. This nursing perspective of what nursing roles are in relation to individuals with severe mental handicaps can assist with the development and assessment of nursing roles in other areas such as community psychiatry, early surgical discharge, paediatrics, long term, and continuing care.

Implications for Nursing Education

This study has a number of implications for nursing education. As the large institutions for people with mental handicaps close, all services for these people, including nursing services, will be in the community. These people will be using community clinics and acute care hospitals as well as all the other health care services in the community which are available to the general public.

Nurses in all these areas need to be oriented to working with people with severe mental and multiple handicaps and how to meet their needs.

The information provided by this study gives direction to schools of nursing for curricula changes as this focus of nursing care and education expands. For community nurses working in this field, a BSN is suggested as a minimum requirement. Nurses currently working in the institutions with people with severe mental handicaps should be encouraged to work towards this requirement and be supported by government.

Currently, the only nursing program in British Columbia which provides educational theory and practise working with people with mental handicaps is the Douglas College Psychiatric Nursing Program. Theoretical concepts necessary for nurses to work with individuals with severe mental handicaps need to be incorporated into all the nursing programs in the province, including those programs available for Licensed Practical Nurses (LPNs). All nurses, including LPNs, will be required to provide services for people with severe mental handicaps as these people are fully integrated into the general population.

The roles identified in this study also give direction for skills and functions to be learned as part of the basic and orientation programs in this field. Nurses working with individuals with severe mental handicaps need specific knowledge and expertise with regard to the medical and social needs of this population in order to coordinate services for their clients. These nurses

need the ability to manage client care across multiagency and transdisciplinary lines. This requires advanced knowledge in communication, observation, assessment, consultation, teaching, policy development, partnership, advocacy, networking, interpersonal relationships, public relations, marketing, and politics. Theory and skills in each of these areas should be incorporated into each nursing program.

Political education should include decision-making at the provincial level, as well as delineation of roles and responsibilities for each component of the public service. Ministry of Health and Ministry of Social Services roles need to be defined as well as roles of specific local societies and community resources. The government move to regional and municipal health boards must also be incorporated into this training (as it occurs). Knowledge and practise in social marketing techniques, case management, health promotion, and illness prevention are also required to prepare these nurses for future roles as case managers.

Nursing administrators are implicated in that the new roles are incorporated into existing programs like Home Care. This reflects expanded or new roles for nursing administrators in these areas who will require appropriate education and a body of knowledge. For example, Public Health and Home Care supervisors and Continuing Care Managers are responsible for the supervision of nurses working with individuals with severe mental handicaps living in the community. These administrators need to know the roles and

functions fulfilled by these nurses. They also need to know about the client group in general, the concept of community living for people with mental handicaps, and issues arising from community living which have implications for community nurses.

Many of the components of the nurse's role identified in this study are new and the nurses appear uncomfortable with them. Ongoing inservice education, therefore, is very important for these nurses. The programs they work in need to provide regular updates on all issues related to their roles and they also should be encouraged to attend community forums and conferences.

Due to the complexities of the functions and independent skills required for the roles of the community nurses working with people with severe mental handicaps in the community identified in this study, it is reasonable to consider a baccalaureate degree as the minimum requirement for these nurses.

Academic positions should be established at the universities and colleges for experts in the field to provide the necessary educational support for changes in curricula to occur. This could be done in partnership with the government to provide joint appointments for specialists who could be brought in to the universities and colleges.

Implications for Nursing Research

The findings of this study also have implications for nursing research and program evaluation. These findings provide a small baseline of knowledge for

nurses working with individuals with severe mental handicaps in the community and point to additional research required in this field as well as across disciplines.

Exploration of a number of areas of investigation is suggested.

1. The size of the study was limited to twelve participants. Further qualitative descriptions, or replications using the same methods, from all nurses working in this field would improve the validity and reliability of the study by providing a clearer, more definitive picture of the nursing roles. Validity and reliability could also be improved by quantifying the results of this study. A quantitative survey listing the roles and components of roles identified in this study could be forwarded to all nurses working in this field. The nurses could be asked to validate the findings. For example, the nurses could be asked to check off the components or roles they agreed were part of their job. Percentages could be established according to the number of nurses indicating each component.
2. What are the client health issues requiring nursing attention? Although a number of issues were identified in this study, it is important to validate this information. This could be done with another qualitative study and the results could be quantified with a survey.
3. Caregivers' support has been identified as a significant factor for caregiver turnover. Research is indicated to explore whether the rate of

staff turnover in the group homes change now that these nurses are in place to provide support and education for the caregivers. A multisectoral study is indicated to compare turnover rates in the group homes where the community nurses in this study are interacting with caregivers with those in group homes where this service is not available.

4. The preventative and health promotion aspects of the roles identified in this study need to be validated. This could be done by looking at acute care hospital days used by clients with access to nurses working with individuals with severe mental handicaps living in the community, and comparing those days with the days used by clients without access to these services.
5. The nurses in the study were caucasian, and mostly of Canadian origin, therefore assumptions pertaining to cultural influences cannot be made. Further exploration, including nurses from other cultures would provide this information and improve validity and reliability.
6. The nurses' roles may change over the next five or ten years as a result of the final closure of the institutions, community acceptance, or the nurses becoming more comfortable in their jobs. A longitudinal study to qualitatively explore these roles using similar methods would identify changes in these roles and point to causes for these changes. Validity and reliability would be improved by quantifying results.

7. How do the nurses rank the importance of these roles and components of the roles? A quantitative survey, using a questionnaire with a Likert-type scale could be used to answer this research question. The same type of survey could be done to answer how much time is spent on each role or component of the role.
8. Further research is indicated to explore the nurses' perspectives of what support they need to carry out their roles.
9. Further research is also indicated to describe and explore aspects of the job which may be considered unnecessary. This could be done using a qualitative study similar to this study. Themes emerging from the data in this study could be listed and a quantitative survey could be used to validate the information with all nurses working in this field.
10. It is important to identify which nursing strategies are most effective in improving client health by looking at outcome measures such as number of days of illness over a specific period of time. The nurses' perspectives of how client health was improved will provide valuable information for planning services for the future. Perspectives of clients, families, and caregivers should be explored and described as well.
11. It is noted that inservice education is required on a regular basis for nurses working with individuals with severe mental handicaps living in the community to fill in the gaps between nursing education and practice. Once this education is provided, it is important to explore

whether the nurses feel they are more effective in their roles as a result.

This is inservice program evaluation and could be done through a qualitative approach, similar to the one used in this study, followed up with a survey to quantify results.

12. It is also recommended that a baccalaureate degree be the minimum educational requirement for nurses working with individuals with severe mental handicaps living in the community, and that theory and practice related to people with mental handicaps be integrated into the curricula of the colleges and universities. These programs will need to be evaluated as well.
13. The various nursing service programs need to be evaluated, and alternate forms of care delivery explored and compared. For example, health team approaches and special services are used in some parts of the United States for people with mental handicaps living in the community. These programs could be compared with the programs identified in this study.

These are examples of possible future research studies and program evaluation needs generated by the findings of this study.

Summary

This study has explored and described community nurses' perceptions of their role in working with individuals with severe mental handicaps using a qualitative, descriptive method. Three distinct roles were identified and

described from the data using inductive content analysis: collaboration, support, and teaching/learning. These roles were further broken down into components and evidence was found in the literature to support the findings.

Collaboration and teaching/learning were stated to be major roles by all of the nurses, and most of the nurses were doing case management activities and saw this as their future focus. Assessment, advocacy, planning, and relationship building were also activities done by nurses working with people with severe mental handicaps living in the community, and the large amount of time spent travelling and documenting should be reviewed.

Nurses were frustrated with some of the components of their job and expressed a feeling of powerlessness as a result of the bureaucracies. This was a major problem for the nurses when caregivers did not recognize their own (caregivers') knowledge deficits and did not allow the nurses to intervene with clients. The nurses with experience working with people with severe mental handicaps and nurses with advanced education appeared to be more comfortable in their roles than nurses without experience or advanced education. Observation, communication, time management, and interpersonal skills were important in the nurses' work.

It was suggested that ongoing inservice education and support are required for nurses working with individuals with severe mental handicaps living in the community to fill the gaps between education and practice. It is realistic

to consider a BSN as a minimum requirement and nurses currently working with this client population should be encouraged to work towards this degree.

Finally, as a result of this study, thirteen areas for potential research activity were outlined briefly.

REFERENCES

- Adolph, V. (1978). Woodlands: 100 years of progress. New Westminster: Ministry of Human Resources.
- American Association on Mental Deficiency. (1983). Classification in mental retardation. Washington: Author.
- Anderson, E., & McFarlane, J. (1988). Community as client: Application of the nursing process. Philadelphia: J.B. Lippincott Company.
- Aviram, U. (1990). Community care of the seriously mentally ill: Continuing problems and current issues. Community Mental Health Journal, 226, (1), 69-88.
- Baker, P., Seltzer, G., & Seltzer, M. (1977). As close as possible: Community residences for retarded adults. Boston: Little, Brown and Co.
- Bank-Mikkelsen, N. (1976). Psychiatry and architecture: The right to normal living conditions. World Hospitals, 12 (1), 52-54.
- Bard, J., Jiminez, F., & Tornack, R. (1993). Integration in the school setting: An outcome based health support program. Vancouver: British Columbia Rehabilitation Society.
- Bean, M. (1985). Nursing role in developmental disabilities. In Jarvis, L. Community health nursing: Keeping the public healthy. (2nd Ed.). Philadelphia: F.A. Davis Company.
- Bell, J. & Bhate, M. (1992). Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community. Journal of Intellectual Disability Research, 36, 359-364.
- Bersani, H., & Heifetz, L. (1985). Perceived stress and satisfaction of direct-care staff members in community residences for mentally retarded adults. American Journal of Mental Deficiency, 90 (3), 289-295.
- Black, M., Edwards, N., McKnight, J., Valaitis, R., & VanDover, L. (1989). Experiences of nursing joint appointments in a teaching health unit. Public Health Nursing, 6, 135-140.

- Blackwell, M. (1979). Care of the mentally retarded. Boston: Little, Brown and Co.
- Bremer, A. (1987). Revitalizing the district model for the delivery of prevention-focussed community health nursing services. Family and Community Health Journal, 10 (2), 1-10.
- Campbell, M. (1987). The U.B.C. model for nursing: Directions for practice. Vancouver: University of British Columbia.
- Canadian Public Health Association. (1990). Community health - public health nursing in Canada: Preparation and practice. Ottawa: Author.
- Clarke, H., Beddome, G., & Whyte, N. (1993). Public health nurses' vision of their future reflects changing paradigms. Image: Journal of Nursing Scholarship, 25 (4), 305-310.
- Criscione, T., Kastner, T., O'Brien, D., & Nathanson, R. (1994). Replication of a managed health care initiative for people with mental retardation living in the community. Mental Retardation, 32 (1), 43-52.
- Darbyshire, P. (1988). The ombudsman's home truths. Nursing Times, 84, (28), 60.
- Darbyshire, P. (1989). Advocacy: Who knows best? Nursing Times, 85, (2), 64.
- Dieman, P., Jones, D., & Davis, J. (1988). BSN education and PHN practice: Good fit or mismatch? Nursing Education, 36, 231-233.
- Drew, B. (1990). Differentiation of hopelessness, helplessness and powerlessness using Erik Erikson's "Roots of Virtue". Archives of Psychiatric Nursing, 4, (5), 332-337.
- Duncan, S. (1994). Nurses' participation in health care reform: Will it make the difference? Nursing BC, 3, 14-17.
- Field, A. & Morse, J. (1985). Nursing research: The application of qualitative approaches. Rockville Md: Aspen Systems Corp.
- Fowler, J. (1986). Survey research methods. Applied social research series, 1, (4). Beverly Hills: Sage Publications.

- Friedman, M. (1981). Family nursing: Theory and assessment. New York: Appleton-Century-Crofts.
- Gambert, S., Liebeskind, S., & Cameron, D. (1987). Lifelong preventative health care for elderly persons with disabilities. The Journal of the Association for Persons with Severe Handicaps, 12 (4), 292-296.
- Garvin, B., Kennedy, C., & Cissna, K. (1988). In Waltz, C., Strickland, O., & Lenz, E. (1991). Measurement in nursing research (2nd Ed.). Philadelphia: F.A. Davis Company.
- George, M., & Baumeister, A. (1981). Employee withdrawal and job satisfaction in community residential facilities for mentally retarded persons. American Journal on Mental Deficiency, 85 (6), 639-647.
- Heal, L., Sigelman, C., & Switzky, H. (1978). Research on community residential alternatives for the mentally retarded. In N. Ellis (Ed.), International Review of Research in Mental Retardation, 9, 210-249.
- Jarvis, L. (1985). Community health nursing: Keeping the public healthy. (2nd Ed.). Philadelphia: F.A. Davis Company.
- Keill, R. (1991, January 23). When help hurts. The Royal City Record, pp.4,10.
- Kernen, H. (1985). The merging of education and practice. In M. Stewart, J. Innes, S. Searl, & C. Smillie (Eds.), Community health nursing in Canada, 592-602. Toronto: Gage.
- Kenyon, V., Smith, E., Hefty, L., Bell, M., McNeil, J., & Martaus, T. (1990). Clinical competencies for community health nursing. Public Health Nursing, 7, (1), 33-39.
- Kirk, M. (1983). More than just money. Nursing Mirror, 157 (17), 5-7.
- Kramer, M. (1974). Reality shock. St. Louis: C.V. Mosby.
- Krippendorff, K. (1980). In Waltz, C., Strickland, O., & Lenz, E. (1991). Measurement in nursing research (2nd Ed.). Philadelphia: F.A. Davis Company.

- Lakin, K., Anderson, D., Hill, B., Bruininks, R., & Wright, E. (1991). Programs and services received by older persons with mental retardation. Mental Retardation, 29, (2), 65-74.
- Lord, J., & Pedlar, A. (1991). Life in the community: Four years after the closure of an institution. Mental Retardation, 29, (4), 213-221.
- Lynn, M. (1985). Reliability estimates: Use and disuse in recently published nursing research. Nursing Research, 34 (4) 254-256.
- Markoff, J., Shapiro, G., & Weitman, S. (1977). Toward integration of content analysis and general methodology. In Heise, D. (ed). Social methodology (pp. 1-58). San Francisco: Jossey-Bass.
- Massey, P. (1988). Sticking to the status quo. Nursing Times, 84, (28), 65.
- Matuk, L., & Horsburgh, M. (1992). Toward redefining public health nursing in Canada: Challenges for education. Public Health Nursing, 9, (3), 149-154.
- McCord, W. (1981). Community residences: The staff. In J. Wortis (Ed.), Mental retardation and developmental disabilities: An annual review, 12.
- Merker, E., & Wernsing, D. (1984). Medical care of the deinstitutionalized mentally retarded. American Family Physician, 29, (4), 228-233.
- Ministry of Social Services and Housing. (1991). From institution to community: Family participation in community placement planning. Victoria: Author.
- Ministry of Social Services and Housing & Ministry of Health. (1991). Planning for the future: A proposal for services for people with mental handicaps. Victoria: Author.
- National Institute on Mental Retardation. (1981). Orientation manual on mental retardation. Toronto: NIMR.
- Nye, F. (ed.). (1976). Role structure and analysis of the family (Vol. 24). Beverly Hills: Sage.

- O'Connor, G. & Sitkei, G. (1975). Study of a new frontier in community services: Residential facilities for the developmentally disabled. Mental Retardation, 13, (4), 35-38.
- Oiler, C. (1986). Phenomenology: The method. In L. Munhall & C. Oiler (Eds.), Nursing research: A qualitative perspective. Norwalk: Appleton-Century-Crofts.
- Orem, D. (1991). Nursing: Concepts of practice, (4th Ed.). Toronto: Mosby Year Book.
- Price, M. (1984). Quality or quantity. Nursing Mirror, 159, (6), 6.
- Registered Nurses Association of British Columbia. (1992). Standards for nursing practice in British Columbia. Vancouver: Author.
- Riemen, D. (1986). The essential structure of a caring interaction: Doing phenomenology. In L. Munhall & C. Oiler (Eds.), Nursing research: A qualitative perspective. Norwalk: Appleton-Century-Crofts.
- Rotter, J. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological monographs, 80, (1).
- Royal College of Physicians. (1983). Obesity: A report of the Royal College of Physicians. Journal of the Royal College of Physicians of London, 17.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8, 27-37.
- Savage, P. (1984). Towards community living. Nursing Mirror, 159 (6), 4-5.
- Schinke, S., & Wong, S. (1977). Evaluation of staff training in group homes for retarded persons. American Journal of Mental Deficiency, 82 (2), 130-136.
- Selby, M., Riportella-Muller, R., Quade, D., Legault, C., & Salmon, M. (1990). Core curriculum master's-level community health nursing education: A comparison of the views of leaders in service and education. Public Health Nursing, 7, 150-160.
- Shamansky, S. (1989). Who governs? Public Health Nursing, 6, (1), 1-2.

- Spangler, P., Gilman, B., & LaBorde, R. (1990). Frequency and type of incidents occurring in urban-based group homes. Journal of Mental Deficiency Research, 34 (4), 371-378.
- Spradley, B. (1990). Community health nursing: Concepts and practice (3rd Ed.). Glenview, Illinois: Scott, Foresman/Little Brown Higher Education.
- Stanhope, M., & Lancaster, J. (1992). Community health nursing: Process and practice for promoting health (3rd Ed.). Toronto: C.V. Mosby Company.
- Stern, P. (1980). Grounded theory methodology: Its uses and processes. Image, 7 (1), 20-23.
- Waltz, C., Strickland, O., & Lenz, E. (1991). Measurement in nursing research (2nd Ed.). Philadelphia: F.A. Davis Company.
- Wilson, H., & Kneisl, C. (1992). Psychiatric nursing, (4th Ed.). Redwood City, California: Addison-Wesley.
- Wolfensberger, W. (1979). Normalization. Toronto: National Institute on Mental Retardation.
- Woods, N., & Catanzaro, M. (1988). Nursing research: Theory and practice. St. Louis: C.V. Mosby Co.
- Working Group of the Federal/Provincial/Territorial Nursing Consultants. (1991). Discussion paper: Educational requirements for community health nurses. Toronto: Author.
- Zink, M. (1989). Curriculum analysis of home health content in associate degree and baccalaureate degree nursing education. Public Health Nursing, 6, 8-15.

Appendix 1: Information Letter to Prospective Participants

Dear

I am a registered nurse presently enrolled as a student in the Master of Science in Nursing (MSN) program at the University of British Columbia. I have worked as a nurse and educator in the field of mental handicaps for 20 years. Most recently I have been assisting with program development of nursing services for people with severe mental handicaps who live in community residential facilities.

For my Master's Thesis I am studying the experiences of nurses who work with people with severe mental handicaps in the community. The purpose of this study is to increase understanding of nurses' roles with individuals living in the community with severe mental handicaps from the perspectives of the nurse.

As a nurse currently working with people who have severe mental handicaps in the community, your participation in this study would be of great assistance. Participation in the study is comprised of an in-depth interview (approximately one hour), in a location of your choice, and a follow up interview to validate information collected. All information collected will be confidential. The interviews will be audiotaped and responses will not be shared with anyone other than myself and thesis committee, without prior consent from you. You may withdraw from the study at any time, and any responses will be deleted from the study at your request.

Participation in this study is voluntary. Please do not feel obligated in any way to participate. I have asked supervisors to distribute the letters so you are anonymous to me. If you are interested, please contact me directly.

Your responses will provide valuable information for the ongoing development and assessment of the roles for nurses working with people with severe mental handicaps in the community. A report of the findings of this study will be forwarded to the Ministry Planning Committee.

If you have any questions please do not hesitate to call me or my thesis advisor Connie Canam. Thank you for your consideration.

**Connie Canam
Assistant Professor
UBC School of Nursing**

**Jean Church
Graduate Student
UBC School of Nursing**

Appendix 2: Participant Consent Form

Title of Study: Nurses' perceptions of their experience working with people with severe mental handicaps in the community.

Investigator: Jean Church, B.S.N., R.N.

Faculty Advisor: Connie Canam, B.N., M.S.N., R.N.
Assistant Professor

You have been invited to participate in a research endeavour which examines the nurse's role in working with people with severe mental handicaps in the community. The purpose of this study is to increase understanding of the roles for these nurses, as perceived by them.

Participation in the study is comprised of an in-depth interview in a location of your choice, and one follow up interview to validate information collected. The length of time required for the interview will be determined by you. When you feel you have finished or exhausted your description, the interview will end.

All information gathered will be confidential. The interviews will be taped, but no identifying information will be used. Responses will not be shared with anyone other than myself and my thesis committee, without prior consent from you, and the tapes will be erased when the study is completed. No names or identifying information will appear in any written reports or the final thesis document without prior consent from you. Anonymity and confidentiality of information will be maintained.

Participation in this study is voluntary. You are under no obligation to participate and may refuse, or withdraw from the study at any time without jeopardizing your employment. Should you consent to participate, you have the right to refuse to answer any questions or to stop an interview at any time. Any response or tape will be erased at your request at any time during the study.

Your responses will provide valuable information for the ongoing development and assessment of the roles for nurses working with people with severe mental handicaps in the community. A report of findings of this study will be forwarded to the Ministry Planning Committee.

Thank you for your participation and please feel free to call me or my faculty advisor if you have any questions or concerns regarding the procedures of the study.

.....

I understand the nature of this study and give my consent to participate in it. I acknowledge receipt of a copy of the participant information letter and consent form.

Date Signature

Appendix 3: Trigger Questions

The following are questions which may be used to elicit information from the research subjects during the unstructured interviews.

1. Describe for me what your job involves.
2. What is a typical day for you at work?
3. Based on your experience, what things do you do, as a nurse in the community, working with people with severe mental handicaps?
4. Are there any other things that you are doing as part of your job?
5. What types of activities are you involved with in the community related to people with severe mental handicaps?
6. Can you say a little more about the skills you are using in your work?
7. Describe the most challenging part of your job.
8. What activities, in your job, would you say are the most difficult?

Appendix 4: Category Scheme

Coding Instructions

Themes The themes are taken directly from the text and for the most part are direct quotes. Included in themes should be any wording which relates to roles or activities performed by the nurse as part of the job.

Categories The categories are mutually exclusive and some categories are divided into subcategories. Criteria for assigning content is presented along with key words and/or examples for each category.

1. **Collaboration** This category includes all activities where the nurse works jointly with others in a cooperative effort. This includes consultation, liaison, public relations, relationship building, team participation and working with others to meet specific goals cooperatively. Key words or phrases used are discuss, talk about, chatter with them, work together to, meet or get together.
 - a) **Consultation** This subcategory includes giving advice, opinions, or input intended to influence others in decision-making. Consultation also includes specific case management activities, facilitating, and keeping people on track. Key words or phrases used include consult, influence, advice sought/given, opinions given, guidance, suggest we need, help them, be a resource to them, make referrals, keep people on track, coordinate.
 - b) **Liaison** This subcategory includes phoning activities and meetings used for the purpose of communicating information between stakeholders. Key words and phrases used are liaise with, give information to, let them know, communicate it to.
 - c) **Team Participation** This subcategory includes all activities where the nurses attended meetings, gave input and worked together with other health care professionals as a member of a team. Key words and phrases used are meet, attend meetings, team work, get-togethers.

2. **Support** This category includes activities which are used to assist or sustain clients, caregivers, or others in their positions or decisions including listening skills and just being there for this purpose. Key words or phrases used are listen to, try to really hear what they are saying, just being there, support, empathize, allay fears.
- a) **Advocating** This subcategory includes activities which focus on pleading the cause of others, more specifically to represent clients and caregivers in receiving appropriate services. This includes ensuring clients are seen by professionals, ensuring clients and caregivers are benefitting from services etc. Key words and phrases used are make sure that he is seen, make sure that this is done, see that he is benefitting.
 - b) **Assessing** This subcategory includes activities related to client health assessment and assessment of the client's environment including caregivers and data collection. Key words or phrases used are assess, investigate, find out, do home visits.
 - c) **Documenting** This subcategory includes all regular activities done as paper work. This includes writing in diaries, filling out care plans, completing forms, making records of training and writing in client charts. Key words and phrases used are record, document, write, put down, fill out.
 - d) **Planning** This subcategory includes activities related to planning health care interventions including sorting data, problem identification and problem solving. Key words or phrases used include sort, figure out, work on care plan, prioritize, thinking, looking at the whole situation.
 - e) **Providing Direct Care** This subcategory includes all activities where the nurse interacts directly with the client to provide health care procedures, counselling, etc. Key words or phrases used are do nursing care, do procedures, talk to client about, give care.
 - f) **Relationship Building** This subcategory includes activities for establishing and maintaining a positive working rapport with caregivers, clients, families, physicians and others. Relationship building also includes activities to promote the nurse or the program. Key words and phrases used are just try to meet them, gain some trust, get my foot in the door, promote, tell them what we are doing, let them know we are their resource, doing PR.

- 3. Teaching/Learning** This category includes activities related to teaching and learning including identifying learning needs.
- a) **Teaching** This subcategory includes activities for teaching others both formally and informally. This includes planning and coordinating training, as well as the delivery of inservice programs. Teaching also includes delegating nursing functions, developing policies, standards and guidelines necessary to initiate the training, and evaluating or monitoring health, care and services. Key words or phrases used are inservice, teach, train, plan training, monitor, develop standards, follow-up.
 - b) **Self-learning** This subcategory includes learning activities required to teach others. Key words or phrases used are update, study, upgrade, training for self, research, attend workshops or conferences.