

**“RUNNING TO STAND STILL”
NURSES’ ROLES WITH CHILDREN AND FAMILIES
IN THE COMMUNITY IN SCOTLAND:
RELATIONSHIPS BETWEEN POLICY AND PRACTICE**

by

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Abstract

The community care reforms, enacted in the National Health Service and Community Care Act 1990, have been a catalyst for change in the roles of community nurses and families in Scotland. The ability of health visitors, for example, to plan and deliver comprehensive care to families is changing as their work becomes more closely linked to the priorities of general practice. Health visitors are experiencing less control over their own priorities, including their preventive work with families.

In addition, deinstitutionalization is creating pressures for nurses to deliver more acute care in the community. Children with chronic illnesses and disabilities, until recently cared for by nurses in hospitals, are now being cared for primarily by their families, even when specialized nursing procedures are required. Health visitors and other nurses are taking on new components of work, focused increasingly on hands-on care, in order to assist families with their care. The concept of patient/family participation, where families and nurses negotiate the extent of family involvement for hospitalized children, has taken on new meaning in the community. Neither nurses nor families have sought these role changes, nor have they negotiated them.

The impact of policies on nurse and family roles thus challenges a taken-for-granted view of roles, where role behaviours and expectations are controlled and negotiated by individuals within their role relationships. Nurses' traditional interest in and research on roles has focused primarily on this micro level of care, the relationship between client and nurse. While important, this focus has impeded nurses' understanding of policy and power, and the context for changes to nurse and family roles in the community. Such understanding is needed.

This qualitative study, conducted in Scotland, describes and explores the impacts of UK community care policies on nurse and family roles. Feminist and critical social theories provide analytical perspectives that contribute to an understanding of the socio-cultural, political, and economic context in which role changes are occurring. The researcher conducted interviews with 26 health, social services, and voluntary sector participants. Their descriptions of role changes emerge in six themes, two of which demonstrate organisational constraints on nurses' roles in the context of the general practice, and in nurses' work with social services in the provision of community care. Two themes demonstrate changes to traditional community roles, and the erosion of care as the holistic nature of nursing work is fragmented among nurses, families, and other carers in Scotland. Family roles and respite care are reconceptualized in two final themes that illustrate how families take on tasks and work previously that of nurses.

Issues of power, gender, and economics emerge as underlying and inter-related forces in policies that are leading to a reconceptualization, not only of roles, but also of nursing itself. The researcher argues for a new paradigm for nursing that will assist nurses to understand and challenge the power relations that are changing the nature and meaning of both roles and nursing in the community.

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Dedication

I dedicate this thesis to the memory of two people who have been an inspiration to me in this work, and in my life, of which this work is now so much a part:

Dr. David Fish, my first research supervisor, shared my excitement for this Scotland-based project, and encouraged me to take the opportunity for what we both saw as a life-changing experience;

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Chapter One

Introduction

Nursing throughout the western world is changing with developments in nursing research, knowledge, and technology, and with an increased recognition of the social and environmental factors affecting health. Yet while nursing is changing, and is expected to change, there is a lack of understanding about nurses' roles and the nature of role change. The context of role change, the effects on clients, and the impact of role change on even nursing itself, are often taken for granted or misunderstood. This research seeks to illuminate the nature and impacts of role change arising in the context of government policies in Scotland.

Role theory, from which common perceptions of roles have derived, suggests that the behaviours that constitute roles are controlled by what role partners expect or demand, and by what the person intends (Brooks & Kleine-Kracht, 1983). In this view role change, to the extent it occurs, happens through the processes of interpersonal negotiations (Fein, 1990). Feminists have criticized role theory, however, because of its failure to adequately explain role change (Armstrong & Armstrong, 1990). In my research, I have found that both feminist and critical social theories offer perspectives that have assisted my analyses.

My interest in nurses' roles and role concepts shifted from a British Columbia (B.C.) perspective when I learned that I was the recipient of a grant that would enable me to study in Scotland. From September to December 1997, I studied and conducted

research as a graduate¹ student in the Department of Public Health at the University of Aberdeen through an arrangement sponsored by the North Consortium's Student Mobility Project.

The focus of my research in Scotland is on nurses' roles with families and children who have special health care needs in the community, and through this lens, I explore relationships between nurses' roles and social policy. Children with special health care needs are defined for the purpose of this research as:

a heterogeneous population of children having in common the need for specialized health care services. The definition includes children...who have a broad range of disabilities or chronic illnesses diagnosed at any time during childhood, including the prenatal period. Such chronic conditions may necessitate adaptations for daily functioning, prolonged or periodic hospitalization or special services in educational settings. (Todaro, Failla, & Caldwell, 1993, p. 262)

Families affected include those who have children born with neurological disorders, children who have experienced disabilities as a result of accidents or injuries, and children suffering from chronic illnesses. The policies of primary interest in my research are social policies - government policies intended for the public good (Hill, 1980). The nurses' roles are those of community-based, registered nurses, primarily health visitors and other nurses, including those in a variety of specialist positions. I also make references to the roles of district nurses and school nurses, although I was unable to directly interview them. Additional participants contributed to my understanding of nurse or family roles, and to the provision of services to families and their children.

The focus on roles, and the emergence of role-related themes in my thesis, evolved during the research process. I originally intended to use the term role mainly as a way of

¹ Termed 'post-graduate' in Scotland.

categorizing or describing the activities and behaviours that comprised nurses' roles, and the ways in which they organised their provision of services. The focus that emerged, however, in the research discussions with nurses and other participants, was a profound interest in the roles of nurses and families, the concept of role, and the impact of government policies in changing roles. The title of my thesis thus captures this central and underlying theme of role change, which is expressed in the voice of the health visitor who said, "The nurse's role is changing all the time. It's running to stand still."

The concept of role arises in every context related to nursing. In nursing practice, role reflects diversity, for example, in the differing roles of health visitor, district nurse, or school nurse. Role also describes the nature of nurses' work and nursing care. Thus, a health visitor may refer to her role in health promotion, or her educative role, thereby describing components of the work. As Baldwin and Birchenall (1993) suggest, components of nurses' roles can be elicited from the work nurses do. In addition, educators use the concept of role to socialize student nurses to the nurse role. In research, one of the ways in which nursing practice is studied, is from the perspective of tasks and activities that comprise the role (McFarlane, as cited in MacLeod, 1996).

Role is also used to describe a relationship. The roles of nurses are enacted through the nurse-client relationship in the nurses' provision of services. Ideally these services are based upon and responsive to the needs of the clients. When the client is a child in the home or a community setting, the nurse strives to be responsive not only to the child and his/her needs, but also to those of family members and their role in the provision of care. Nurses and families can be understood to be primary role partners within the role relationship. Whether nurses are engaged in practice, education, administration, or

research the focus of their interest and concern is the client. In my view, the nurse-client relationship underscores what it means to be a nurse or to nurse, and is thus fundamental to nursing itself. This view of the centrality of the relationship between the client and nursing is consistent with that of Bishop and Scudder (1991), who define nursing as both the care of patients, the practice, and the study of that care, the discipline. In this way, the terms nursing, nursing practice, and nurse role emphasize a defining interest in the client - client as individual, family, or community.

Despite the centrality of the nurse-client relationship, factors external to it are vital in shaping the relationship between nurses and families. Williams, Cooke, and May (1998) state:

Professional-patient relationships, at whatever level of analysis, are not natural events that happen. They are socially constructed. They are fabricated or manufactured through human agency, and within a context or structure that is defined by powerful social institutions. They reflect the existing dimensions of power relationships between individuals and groups....(p. 120)

Roles must therefore be understood within a socio-cultural, political and economic context. It is within this context, which I term the 'context of care'², that both policy and roles are formed, and the relationships between them are situated.

Government policies of the 1990s have dramatically altered the organisation and financing of both health and social services in Scotland and throughout the countries of the United Kingdom (UK). These changes and others that will be described later, are defining new roles and relationships between nurses and doctors, and nurses and families, and are

² In order to assist the reader in understanding whose voice is speaking, I provide the following guide. Single quotation marks, or inverted commas, are used to introduce a technical or invented term. Short quotations cited directly from literature, and short quotes from participants (beginning in Chapter Three) are presented in double quotation marks. Longer quotations from either literature or participants are provided in the form of a block quotation.

reshaping role boundaries for those who work at the interface between health and social services. The government policies of primary interest in my research are the community care reforms, enacted in the National Health Service and Community Care Act (DOH, 1990) which accelerated the shift from acute care and long term care settings to care in the community. Although not intended for children, the legislation is affecting the care of, not only adults, but also children in Scotland.

Although these policies are relatively recent, care in the community is not new. Many families have provided and do provide care relatively unassisted to their sick and disabled family members. Similarly, nurses as midwives, health visitors and district nurses also have a long tradition of providing care to families and children in the community. What is new, however, is the nature of care in the community subsequent to the reforms. With changes in the level and complexity of care for children in the community, nurses' and families' roles are undergoing significant changes. They and other carers, called caregivers in Canada, are now providing care that was provided until recently in hospitals and institutions by nurses. Families, as the primary carers, are assuming responsibility for increasingly complex nursing tasks. New nurse roles are emerging to assist families to provide this care. Within this context of change, families, health visitors and other nurses are experiencing pressures to reconstruct their roles.

Government policies do not account for all the changes affecting roles. Additional policies that are contributing to change in nurses' roles concern nursing as a profession and a workforce. These nursing policies include those related to the regulation of nursing, nursing education, workforce issues, and the domain of nursing practice. They fall within the control of nursing as a profession to the degree that the authority for professional

control is delegated to the United Kingdom Central Council (UKCC), the licensing body for nurses, health visitors, and midwives. Policies that have an impact on nurses' roles are not, however, isolated from one another. Nursing policies, for example, may be developed in order to contribute or respond to changes in government policies affecting health needs and services. It is not within the scope of this research to examine policies³ relating to nursing education, nursing as a workforce, or specific nursing practices.

The remainder of this chapter is intended to convey additional introductory elements. These include my interests in the research, the purposes this study seeks to address, a review of concepts arising from literature that are central to the study, and an overview of the organisation of the thesis.

Interests in the Research

Prior to commencing my research in the autumn of 1997 in Scotland, I had been working for six years as a nurse consultant with a branch of the provincial government in British Columbia. In this role I worked with families, nurses, doctors, social workers, and other service providers to plan for the hospital discharge of adults and children with special health care needs to homes and families in various B.C. communities. Many of the children, due either to the complexity of their care requirements, and/or the inability of their families to manage their care at home, had been living in long term care institutions for varying periods of time. My research interest evolved from my need to make sense

³ The discussion of policies in this research omits detailed reference to some of the specific UK policies cited in the literature as giving shape to nursing practice. Recent examples include Project 2000 (UKCC, 1986), which looked at the training and education of nurses, midwives and health visitors to help them meet health care needs in the 1990s and beyond. The Scope of Professional Practice (UKCC, 1992) document was intended to help nurses, midwives, and health visitors to become more responsive to patients' needs (Jowett, 1997). This research draws on policies that the participants felt had important impact on their roles. They referred primarily to government policies.

out of two major issues, the first, the way that resources were allocated to these and other families, and the second, the increasing fragmentation in nurses' roles and work.

The concern with resource allocation heightened when I participated on a provincial screening committee to determine which children and families would be eligible for a generous degree of financial help and agency support from the provincial government. These resources were intended to meet families' perceived needs for care including therapies, rehabilitative equipment, home renovations, respite in 'associate' families, and on-call nursing consultation. The final decision regarding eligibility was centralized with a small leadership group in the provincial capital.

The decisions regarding resource allocations demonstrated inequities among families in B.C.. Although not clearly stated, it gradually became apparent that a key criterion of eligibility for resources was based on the extent to which the child had been living in an institution, or the degree to which the child's family had used hospitals or other institutions for respite. Families already living in the community, often struggling with minimal support from government, were ineligible for all but a small portion of the financial support and services available to the others. On rare occasions, if a family exerted pressure and demonstrated that they would likely be placing the child in a hospital, they also became the recipients of these resources and services. However, this information was not readily available to the public or to other families in the community who continued to struggle on their own.

I was also concerned with the way in which nurses' work was becoming increasingly fragmented among different nurses and care providers in the community, with

the result that some families were being inundated with too many providers, while others had too few. To help address this problem, I was asked to participate on a provincial committee of nurses to assist in developing nursing standards for a program of nursing support to children with special needs living in the community. The goal of the program was to integrate up to five different provincial programs providing some aspect of nursing support potentially, at times, to the same families.

During the course of my involvement, the committee developed nursing standards that integrated key principles drawn from both research and practice. Through consultation with nurses working in both urban and rural areas, we were able to develop standards and guidelines that recognized the need for nurses with expertise in child and family care, and the need for one consistent nurse available in regions to plan and coordinate services for families.

Despite the excellence of the product, a set of nursing practice standards (B.C. Ministry for Children and Families, 1997)⁴ and a program entitled, The B.C. Nursing Support Services For Children with Special Health Care Needs in the Community, the program did not fully address our original concerns regarding service equity and fragmentation. Families whose children were previously institutionalized continue to receive preferential treatment to families who have always cared for their children at home, and regional differences and problems continue to reflect a patchwork approach to service provision.

These experiences, and others, led me to ask questions about the way in which

⁴ The standards are currently undergoing revision.

nurses' roles and work evolve and are realized in practice, what role nurses have in policy decision making, what leads nurses and other professionals to comply with decisions that promote inequities in care, and what is the nature of relationships between policy and nursing practice. These issues emerge in my research.

Purposes and Goals of the Research

The purposes of this research flow from the problem it seeks to address. The traditional focus of interest in nursing has been and is the client, and the role relationship between client and nurse. While central to nursing, this micro view has, nevertheless, limited nurses' vision and understanding of the policy context within which the roles of client and nurse are situated, one that is contributing to profound change in nurses' and families' roles. My research is based on the assumption that the nature of changes occurring in the policy context can and do have negative impacts on the health and well-being of children and families. Chooporian, cited in Stevens (1989), supports this concern:

Nursing ideas lack an archeology of the social, political, and economic worlds that influence both client states and nursing roles. The unequal class hierarchies, power relationships, political interests, and economic policies that produce ideologies such as sexism, racism, ageism, and classism interfere with health and cause illness. (p. 56)

Issues of power, politics, economics, and other socio-cultural forces that create inequities in and barriers to health, are thus vital to nurses' roles in promoting the health of families. My purposes, therefore, in conducting this research are to describe nurses' roles with families and children with special health needs in Scotland. Through these descriptions, I explore relationships between policy and roles and illuminate ways of understanding roles and role change within this macro context. A goal of my research is to contribute to a

reconceptualization of nursing that locates and understands nurses' and family roles in a broader context than has traditionally been realized by nurses. A new paradigm for nursing has the potential for promoting health through emancipatory change for both nurses and families.

Review of Selected Literature

Role Concepts and Nursing Knowledge

Role concepts derived from role theory⁵ and expressed in the nursing literature tend to obscure a relationship between roles and the policy domain. Within this section, I discuss definitions and characteristics of role found in role theory and nursing literature that illustrate this point. For example, the definition of role as a set of behaviours associated with a given position (Johnson, 1993; Strader & Decker, 1995) conveys a neutral⁶ view that locates role with the individual in her/his status. Status itself is neutral, consisting of a collection of rights and duties (Biddle & Thomas, 1966). In another definition, role is described as having at least two components: actual behaviours, and normative expectations concerning the behaviours (Biddle & Thomas). These views locate role in the cultural context in which status and social expectations are central in shaping roles.

In later interpretations of role theory, Lopata (1991) described the social role as one which goes on, not just through the behaviour of one person, but also through interrelationships among several in the "role set" (p.1), thus emphasizing the relational aspect of roles. Professional roles are understood to have their origins in the expectations

⁵ In Chapter 2, I discuss background to and perspectives in role theory.

⁶ Neutral, as in "not aligned with or supporting any side" (Random House Dictionary, 1987, p. 1292).

of three sources: peers, clients and the public (Lipsky, 1980, p. 46). Kibrick (1963), drawing from role theory to analyse nurses' perceptions of their role, identified at least four role components: knowledge, activities, attributes, and relationships. Together, these definitions of role confine role primarily to the individual and her/his relationships, situated either within a neutral organisational or relatively stable cultural context. In more recent nursing literature, role itself is often a given⁷, whereas it is the component of work, such as the nurse's role in, for example, health promotion that is of interest.

The concepts of 'role strain' and 'role conflict' tend also to confine role to the individual or her/his relationships. For example, role strain is defined as the felt difficulty in fulfilling role obligations, that is, if pressure is strong and enduring it results in strain (Goode, 1966, p. 282). In this view, Goode notes that institutions are made up of roles, and thereby points to the link between social behaviour and social structure (p. 9). Role conflict addresses the potential for conflict that may arise from the fact that an individual has a plurality of roles, or from perceived or incompatible expectations (Biddle & Thomas, 1966, pp. 275, 287). In my research I have found, however, that these definitions are inadequate.

Among nursing's concern is the way nurses conceive and are socialized to their roles. Corwin and Taves (1962) suggest that role conceptions are the images of the rights and obligations a person perceives to be associated with her position. In their view, these conceptions are important because they provide expectations that guide the nurse's conduct, and generate attitudes such as personal goals and motives.

⁷ When I first became aware of an apparent lack of analysis of roles in the more recent nursing literature, I asked a Sociology instructor for the current thinking on role theory. He said, "It just is" (B. Rae, personal communication, October 4, 1999).

Role socialization represents a stage in role development in which professional values and norms are internalized in behaviour and self-concept (Hickey, Ouimette, & Venegoni, 1996). Nursing's interest in socialization appears to arise from nursing history, and an interest in the moral character of nurses. Rafferty (1996) alludes to the importance of the early socialization of nurses in her statement: "Nurses became the objects as well as the subjects of reform" (p. 4). The socialization of nurses continues to be a focus in nursing education today. Feminists are critical of socialization, and some argue that, because of its impact on children through the inculcation of gendered values, it is one of the four⁸ main social structures that need to be transformed before women can be liberated (Humm, 1995, p. 270).

Gender refers to the social and cultural dimensions of being male or female, in contrast to sex differences between the two. Gender differences are mainly due to social factors such as socialization practices, social rewards, status differences, and expectations (Basow, 1992, p. 2), and tend to reflect a social devaluing of women and women's contributions. One area in which this devaluing occurs is in the context of work, discussed later under the topic, the issue of care.

Role negotiation appears as a relatively recent concept in nursing literature, one that evolves, as Callery and Smith (1991) suggest, from the concept of patient participation. This concept usually refers, in the case of children and families, to parental involvement in the care of the hospitalized child. In the nursing literature, negotiation tends to refer to discussion that results in a mutual agreement (Knight, 1995). The research by Callery and Smith (1991), however, concerning role negotiations between

⁸ The others are production, reproduction, and sexuality (Humm, 1995).

nurses and parents, suggests that nurses hold a position of power relative to the patient, and they state: "It is only the nurse who has the power to relinquish control and to choose to negotiate with the parent about roles or about care" (p. 776). Whether the negotiations take place in the hospital or community, these views suggest that nurses themselves own, control, and negotiate their roles.

A contrasting view suggests that, although efforts to achieve negotiation may occur between individual nurses and clients, and between nurses and other role partners, the parties involved are not necessarily equal (Callery & Smith, 1991), nor does either party necessarily control the process or the outcome. Negotiation takes place in a context of power in which more powerful groups control the allocations, as well as the definitions of the situation (Twigg & Atkin, 1994; Hugman, 1991).

Power

There are many definitions and analyses of power in the social sciences and nursing literature. I will discuss two contrasting views, one that sees power as an element of relationships, and another that sees it in the context of social structures. In the first view, power is essentially behavioural in focus (Hugman, 1991). The individuals or groups whose preferences prevail in conflicts, are those who exercise power (Gough, 1994a). This focus on the individual is consistent with notions of autonomy that link personal freedom and responsibility with the individual (Scott, 1998) rather than with social structures. Similarly, in this perspective, role is linked to the individual, and the qualities an individual brings to his/her role (Scott, 1998).

In a contrasting view, power is located not so much in individuals or groups but in systems of domination where it involves the shaping of people's preferences so that

neither overt nor covert conflict exists (Gough, 1994a). In this way, the relations of power can become both accepted and routinised. Miles (1991) points to the relations of power in health care, stating:

The practice of healing operates within the framework of a complex division of labour... that is hierarchical in character, some occupations and groups of workers being accorded higher prestige and financial rewards, and wielding more power, than others. (pp. 124-125)

Power, expressed through systems, institutionalizes inequalities, entrenching ideologies such as sexism, racism, and ageism, and it is therefore, the system that is biased, not simply individual behaviour (Gough, 1994a, p. 76).

Power is further discussed in the following sections concerning policy, and is also defined and discussed more fully in Chapter Three, where it emerges in the theme of role conflict to illustrate a relationship between roles and the policy domain.

Policy

There are differing views of policy, some of which also obscure a relationship between roles and the policy domain. Among the views of public policy, that is, policy formed by government bodies, I draw upon two reflected in the literature. One view defines policy simply as the principles that govern action directed towards given ends (Mason & Leavitt, 1993). This definition considers policy as a neutral conveyor of procedures and goals to be implemented for the common good (Cheek & Gibson, 1997), unrelated to a political or ideological grouping. A notion underlying public policy in the United Kingdom is that central government should properly concern itself with the prevention of distress and strain among all sectors of society (Oakley, 1994), a view that

has led to descriptions of Britain on the whole as a welfare state.⁹ As a category of public policy, social policy concerns the welfare of the public. In essence, if governments are performing their role on behalf of their citizens, all social policy could be described as public or government policy.

In a contrasting view to that of policy as neutral, a number of writers (Cheek & Gibson, 1997; Edelman, 1988; Hill, 1980) consider policy to be an expression of values by a politically dominant group. Social policy, of which health policy is a component, shapes and influences decisions that control and ration health resources (Masterson, 1994), and includes both decisions about the allocation of values and the actions that allocate values (Ham, 1992, p. 94). Social policy must be seen, therefore, as a political process, where politics itself is concerned with access to power.

According to Howlett and Ramesh (1995), these differing views on neutrality and political interests have evolved into distinctions in the literature between policy study and policy analysis. Thus, these two approaches to policy contribute to conflicting conclusions about the public policy-making process, and differing interpretations of policies themselves (Howlett & Ramesh, 1995, p. 9). The neutral view of policy is one commonly presented by government, nursing organisations, and public institutions, thereby reinforcing an approach to policy study that lacks analysis of the relations of power operative in the policy process.

The Policy Process

The policy process itself may be viewed as a neutral activity. For example, a

⁹ The term originated in Britain in the 1940s to contrast with the notion of a "power state", which lacked a moral and spiritual commitment to the welfare of the people (Oakley, 1994, p. 2).

common assumption concerning the policy process is that government decision-making and spending is based upon a body of knowledge and research that formulates social policies (Edelman, 1988). Studies of the consequences of social research have confirmed, however, that direct links between social research and policy are rare (Callahan & Jennings, 1983). Another assumption is that government ministers decide policy and civil servants carry it out. In reality, civil servants have considerable influence over policy making (Masterson, 1994).

Current policy analysts separate the policy process into stages of formulation and implementation. Howlett and Ramesh (1995) suggest that policy formulation is conceptualized in terms of the key actors in policy development, what brings them together, how they relate to one another, and how their interaction affects the process (p. 125). They also suggest that policy decision-making involves choosing from a number of alternative policy options, including doing nothing, that are identified in the process of policy formulation (p. 138).

Policy implementation, the process of carrying out a policy decision, was at one time assumed simply to happen. It is now viewed, however, as a more complex process and the particular approach depends on one's analyses. One view assumes a top down approach in which public officials in organisational roles ensure that policies are carried out, while an opposing view assumes the bottom up approach, where those affected by and involved in the policy help to implement it (Howlett & Ramesh, 1995, p. 153.) Consistent with the latter view, Lipsky (1980) suggests that street level bureaucrats, such as front line workers in public services, make policy in two related aspects: through the

discretion they exercise in decisions about clients, and through their combined activities, in which individual actions add up to agency behaviour (p. 13).

In a similar view, Twigg and Atkin (1994) describe the behavioural/pluralist concept of policy, which accepts that policy may be vague and contradictory, and created at all levels of the organisation (p. 24). They note that, for informal carers in particular, for whom there is largely a policy vacuum in the UK, most of the relevant policy is implicit, that is, embedded in the everyday patterns of practice in organisations. This contrasts with explicit policy, which is formally defined and determined at the top of the organisation (Twigg & Atkin, p. 24).

Shifting to a more critical perspective on policy and policy processes, Cheek and Gibson (1997) state that it is necessary to examine not only the text of the policy, or its implementation, but also the relationship between processes of production and implementation and how they are constituted through dominant ideologies (p. 671). In other words, policy is developed by and implemented through dominant groups and their prevailing ideologies, and must therefore, be understood in this way. Critical perspectives do not regard social reality as authentic or natural, but rather consider the relationship between power, knowledge and the social world, including that of policy (Cheek & Rudge as cited in Cheek & Gibson, 1997). Fairclough (as cited in Cheek & Gibson) asserts that common sense assumptions are embedded in language, and that these assumptions are in fact ideologies that serve as mechanisms of power (p. 670) expressed through policies and the policy process. These critical perspectives are useful to my own analyses.

Policies and Nurses

In a search of the nursing and allied health and social sciences literature, I found only a limited number of references describing nurses' relationship with the social policy domain. The majority of the references I found reflected American nurses' growing interest and participation in the area of health reform. Although not necessarily specific to nursing, I found additional contributors to the topic of policy in the fields of social policy, sociology, political science, and feminist and critical social theory.

In the following I highlight elements drawn from within two perspectives described by Spurgeon (1997) as 'reactive' and 'proactive'. The former seeks to understand the consequences of policy for nurses, and the latter illustrates how nurses may influence and shape policy.

Reactive relationships.

There is a marked lack of discussion in nursing literature on how the practice of nursing is shaped by social policy (Salvage, 1992). Policies determine, however, the context in which nurses provide and clients receive care, for example, whether it will be in an institutional or community setting, whether care will be privately or publicly funded, what individuals and groups are entitled to receive care, and what resources are allocated to fund services. The implementation of policy decisions includes the specific program and services that are delivered in homes, institutions, and communities and by whom the services are provided. Thus the relationship between nursing practice and policy is critical when we consider that both nurses' daily working lives, and the daily lives of clients are defined and controlled by social policy (Gough, Maslin-Prothero, & Masterson, 1994).

Policies influence nurses' roles at a number of levels: the state, the profession, the organisation, the unit within the organisation, and the individual (Cheek & Gibson, 1997). At the level of state policies, such as the National Health Service (NHS) and Community Care Act 1990, Walsh and Gough (1997) suggest that the actual impacts on nurses' roles are unintentional. In Spurgeon's (1997) view most of the UK's health reforms since the 1990s have not contained direct statements about what nurses should and should not do, however, they have had a continued impact on the nursing profession. Among the consequences he identified are: (a) an inability to deliver the level and standard of care nurses would wish because of a combination of workload and resource constraints, (b) constraints on nurses' capabilities by the medical hierarchy, and (c) new roles and new demands on roles (p. 34-35). These impacts are demonstrated in my research. Further consequences of the reforms would seem to be, suggests Cole (1997), an increasing fragmentation of where and how care takes place as the Trusts, responsible for providing health care, follow their own agendas (p. 27).

Similarly, Fatchett (1990) suggests that while UK government policies beginning in the late 1980s did not explicitly address the role of nurses they did, nevertheless, marginalise community nursing in general and the health visitors' role in particular. For example, the Griffiths Report (Griffiths, 1988) was described as being "locked into the idea that medical [and health] needs are met by doctors, and arranged by the general practitioner (GP), that nursing occurs in hospitals, and that other needs in the community can be met by social services" (Fatchett, 1990, p. 216). In addition, the organisation of nurses' roles in the community subsequent to the reforms places them under even closer control of general practitioners than previously (Neave, 1994). Thus the notion of

expertise and expert practice in relation to the caring and care interventions (the work of nurses) has been rapidly deconstructed in government policies - a move from which community nursing has struggled to recover ever since (Walsh & Gough, 1997).

These examples of the reactive relationship suggest differing perspectives on the impacts of policy, which warrant further analyses. In one view, the impact of policies on nurses is unintended. A second view raises, however, a question about intention: does the lack of explicit policy statements concerning nurses reflect unintentionality, or does it simply obscure intention?

In her study of the relationship between nurses and policy, Robinson (1992) observed that many nurses misunderstand policy and its relationship to their work. Traditionally, nurses have seen their roles operating primarily at the micro level of health care, the level of individuals and their health care needs. Policies about which nurses are most knowledgeable are those surrounding the nurse patient relationship and include policies to guide specific practices such as resuscitation, the use of restraint, incident reporting, and drug administration (Cheek & Gibson, 1997). The majority of nursing literature relating to policy focuses on those policies that guide specific practices (Cheek & Gibson, 1997). These clinical or micro level policies are vital to safe and effective client care. However, micro approaches alone are likely to obscure broad societal problems, which ultimately influence the lives of people in a health and social care context (Iatridis, 1994).

Proactive relationships.

Factors that underlie the influence of nurses on policy are complex and multi-faceted. These factors include: (a) the historical organisation of nursing as an occupation,

(b) the ways in which nurses arrive at an understanding of their roles, and (c) the way in which nurses understand and resolve value conflicts in their everyday and professional life (Gough, Maslin-Prothero, & Masterson, 1994). In her study of nurses' influence on policy, Robinson (1992) found that education is also a crucial factor in producing nurses who are not afraid to participate in policy making and to make creative contributions to planning, delivery and evaluation of health care (p. 5). I would add that nurses' position within a hierarchical structure, discussed along with power in Chapter Three, also contributes to nurses' relative powerlessness within both the policy arena and their daily working environment.

In contrast to the medical profession, which forms a powerful interest group in shaping health policy, the nursing profession traditionally has had relatively little power (Masterson, 1994b). Historically, nurses only followed policies for which they had little, if any, responsibility for developing (Sprayberry, 1993). In his analysis of the healthcare hierarchy, Hugman (1991) suggests that the hierarchical relationships between medicine, nursing, and also other caring professions mirror the gendered power relations of the broader social structure.

During the past decade, nurses in Britain have seen an even greater degradation of their power and influence (Gough, 1997) than previously. Under the 1990 reforms, the power of doctors was strengthened. Consultants (specialists) were given the opportunity for management roles with responsibility for devolved budgets, and GPs were given control of purchasing services through fundholding arrangements (Masterson, 1994b). Nurses, who have less lobbying power than doctors, have been given relatively few executive positions. Witz (1994) says that historically, any changes derived from an

agenda set by nurses have been successful only when they have synchronized with wider organisational and governmental concerns. She also asserts that nursing interests have always been, and for the most part, continue to be subordinated to those of more powerful groups such as the medical profession (p. 39).

Concepts related to power also extend to nurses' power as an occupation and their roles with clients. A common view (Sprayberry, 1993) is that if nurses organise in ways that promote and consolidate their power, they can influence policy, as well as become more empowering to clients. Eichler (1980) says protesting one's powerlessness is the first step towards gaining power, however, only as a group finds a collective voice and collectively questions the legitimacy of a existing power structure, can they begin to challenge the validity of the viewpoint of the powerful group (p. 18). In a contrasting view, Cahill (1996) suggests that nurses must surrender a degree of power and control in order to empower their patients. In the healthcare hierarchy nurses lack power, but in terms of relative power, patients have the least. The issue of power is central in the relationships between policy and nurses, but also leads to questions concerning the position of families in the relationship.

Policy, Nurses and Families

The nursing literature offers little by way of conceptualizing the relationships between policy, nurses and families. Meister (1993) does, however, describe a relationship in which policies and nurses are agents for the families. Within this view, social policies and nurses provide access to economic, social, health, and education resources, although they operate at different levels: social policies determine access for groups of families, while nurses affect access primarily for individual families. This

conceptualization produces three sets of relationships: social policy and families, social policy and nurses, and nurses and families. This description of relationships suggests that nurses and policy have equivalent power to act on behalf of families, a view that I dispute in my research.

The literature offers some alternate views that suggest policy and nurses do not necessarily affirm or serve the interests of families. For example, in their study of the needs of families and other informal carers in Britain, Nolan and Grant (1989) observed that, while the philosophy of community care supports the notion of autonomy, and individual wishes, there is an element of financial expediency involved (p. 950) that may contradict this notion. Although the study was not confined to parent carers, there were indications that nurses and other professionals may be placing responsibilities on carers without recognizing their limits to provide care. In their literature review concerning what carers would like to receive or are not currently receiving, Nolan and Grant (1989) identified five key areas: (a) information, (b) being recognized and valued for their work, (c) skills training, (d) emotional support, and (e) some form of regular respite (p. 951). While they described the need for nurses to take a more active role with carers, they also identified factors that are crucial determinants of role definitions, among them: the knowledge and value of nurses, the orientation of doctors and administrators, the structural components of the service, and consumer education (Nolan & Grant, 1989, p. 958).

In another study, Kirk and Glendinning (1998) conducted a review of research literature concerned with trends over the past fifteen years toward the provision of care in the community, with a focus on hospital level care in the home, that is, the relocation of

hospital services to parents and other carers (p. 381). They observed a lack of research focusing on the impact of high technology care at home on informal carers in the UK and North America, or on the experiences for those both giving and receiving this care. Of particular interest, was their suggestion that the “centrality of the nurse-patient relationship in the nurse’s construction of nursing” (Kirk & Glendinning, p. 375) may actually contribute to a lack of attention to the needs of informal carers. They also observed that the participation of informal carers in traditional nursing challenges nurses’ professional power, and can “lead to concerns about deprofessionalization and role erosion”¹⁰ (Kirk & Glendinning, 1998, p. 377). The issue of role erosion focuses predominantly in the literature on external threats to nurses in their professional role, rather than to the erosion of patient care.

The Issue of Care

Caring is postulated as the central and unifying domain for nursing knowledge and practices (Chinn & Kramer, 1995) in both Britain and North America. Care has played a central role in divisions between doctors and nurses, where doctors and curing, are socially more valued than nurses and caring (Witz, 1994). Care has a multiplicity of meanings both within and between cultures. For example, in Canada, care as both verb and noun, and caring as adjective and verb are strongly, though not exclusively, associated with nursing. Care/caring, terms which are used interchangeably, also refer to a specific kind of relationship between two people.

¹⁰ The topic of role erosion also emerges in the literature, particularly with regard to health visitors (Walsh & Gough, 1997; Meerabeau, 1998), and the Registered Nurse (Mental Handicap) (Baldwin & Birchenall, 1993).

In Britain, caring refers to a relationship, usually between two people, one of whom is dependent and is looked after at home for no pay by the carer (Ungerson, 1990). The relationship often refers to adults because children are already assumed to be the recipients of care. However, the term carer - one who does the looking after - is also applied to parents, relatives and friends looking after children who require special care due to chronic illness or disabilities. In other words, carers provide care exceeding that which is implicit in normally dependent relationships between family members, a kind of caring that is distinguished as informal care (Qureshi, 1990). The implication is that informal care is based on feeling and a relationship between those involved. Taking place within the private domestic domain, informal care is regarded as spontaneous, unplanned, unregulated and unobservable, in contrast to formal care, which takes place in the public domain, and is provided by statutory services and charitable agencies within both home and institutional settings (Qureshi, 1990). Yet the majority of caring does take place, and always has taken place within the home, with only a relatively small portion occurring in hospitals and other institutions (Maslin-Prothero, 1994).

The issue of care must also be understood in terms of the marketplace. In market-driven economies, such as the UK and Canada, the value of the work and the worker is generally measured in terms of monetary remuneration, wage labour and employment, the traditional domain of men (Neysmith, 1993). Within this context, women's work, typically domestic and caring work, is underpaid and undervalued. Brown and Smith (1994) suggest that the dilemma for women in their caring roles is heightened in the context of community care. They state:

There is a vicious circle: the fact that women do the work makes it appear unskilled and undemanding, and the fact that they are skilled enough to care without straining the appearance of an 'ordinary' relationship further undercuts their need for proper recompense. (p. 47)

These observations are relevant to the roles of both nurses and family carers, of whom the majority are either women, or men involved in work that is considered to be the natural domain of women.

Organisation of the Thesis

This chapter has provided an introduction to the nature, scope and purposes of the research, and to central concepts that emerge in the research and related literature. These concepts, which relate to roles, policy, the policy process, power, and issues in care, are further developed through the research findings.

In Chapter Two, I provide a discussion and explanation of terms specific to the context of care in Scotland, and I review the research process through which I obtained and analyzed my data, or research findings. The findings are presented as themes and sub-themes, within three consecutive chapters. Chapters Three and Four contain themes that concern primarily nurses' roles, with those of families in the background, while Chapter Five brings family roles and issues in respite care to the foreground. Chapter Six concludes with a discussion and summary of the themes, and presents the implications and significance of the research.

Chapter Two

Research Context and Design

Introduction

My effort as a novice researcher to conduct research in another country and different health care system is a story in itself, of which I will describe a small part before discussing the research context. When I began my research in Scotland, I believed that I faced three major challenges. The first challenge was to gain an understanding of the context of care: the health care system, the policy field, organisational structures, roles and services. The second challenge was to find within this context both content and meaning relevant to my research goals. The third challenge was to obtain nurses and others to participate in my research. As I sought to meet these challenges, I found that in fact they were one - the single challenge of attempting to conduct research in a different culture with its own traditions, history, systems, institutions, ways of doing, describing and being. My task became one primarily of letting go of pre-conceptions, expectations, and of the known and familiar through my use of language, definitions, and descriptions. When I was able to begin to accomplish that, and I remember the moment of discovering at an intuitive level that this was my task, my research began to progress!

Because my research is concerned with roles, nurses' experiences *in their roles* and also with others - doctors, social workers, families, carers - *in their roles*, the content is both subjective and contextual. Thus I have found it useful to combine the research context and design together in this chapter. In the first section, the context of care in Scotland, I discuss specific terms, policies, and meanings that will assist the reader to understand that context. Among these, I briefly discuss information related to levels of

government, specific policies, organisations, community nursing, and children with special needs. I will further discuss these and other items in my findings as the need arises. In the second section of this chapter, the research design, I discuss the theoretical perspectives and methods that have guided my research.

The Context of Care in Scotland

Central and Regional Governments

Central government, situated in London, England holds administrative powers, some of which are devolved to local governments or offices in the other countries that also comprise the UK, that is, Scotland, Wales, and Northern Ireland. The policies, organisations and processes that shape health and social services differ. The relationships and the distribution of power between the state, regional, and local governments are still evolving to the extent that, in 1999, Scotland established its own parliament.

Public policy-making involves production of Acts of Parliament (Hill, 1980), which includes principles and guidelines for all the countries of the UK. Policy documents themselves, some of which are produced as White Papers, may provide either country-specific sections, or guidance to aid in the development of the country's own policies. For example, Caring for People (1989b) provides direction for the delivery of community care in the UK, however, there are sections that are specific to Scotland and Wales. As another example, the White Paper, Designed to Care (Scottish Office, 1997), is the Scottish equivalent to England's The New NHS (Department of Health, 1997), although there are differences between the two.

Local (government) Authorities

National legislation defines the powers of local authorities, and may set limits to those powers (Hill, 1980), although as I indicated, the relations between different levels of government are changing. There is no single UK local government system, but rather different systems in England, Wales, Scotland and Northern Ireland (Masterson, 1994b). Elected officials are responsible for policy-making at local levels, however, central government policies set the guidance for the delivery of public services. For example, the NHS and Community Care Act 1990, while having profound impacts on the organisation of the NHS, also established new roles and responsibilities for local authorities in the planning and provision of community care, discussed more fully in Chapter Three.

The National Health Service

The National Health Service in the UK was established in 1948 as the first health system in any developed nation to offer free and universal entitlement to state-provided health services (Klein, 1995). In Scotland, the jurisdiction of the NHS has been administratively devolved to the Scottish Executive Department of Health, which receives funding from the Scottish Government (A. Kiger, personal communication, September 1, 2000). Health services in Scotland and the UK are based in two main sectors: secondary or hospital-based care, and primary health care, the first point of contact between patients and health services.

The NHS and Community Care Act 1990 marked a fundamental shift in the organisation and financing of health care in the UK. The nature of these changes had been outlined in the community care reforms, contained primarily in two government

documents, Working for Patients (DOH, 1989a) and Caring for People (DOH, 1989b), which preceded the Act. Laing and Cotton (1996) state that, in keeping with the political ideology of the Thatcher era, the government attempted to change the NHS from an internalized professional bureaucracy to a decentralized network of separate organisations operating within the framework of a market structure. This framework is called an internal market, developed to encourage competition, choice, and flexibility in the NHS.

At the time my research was conducted in 1997, the organisational units responsible for the delivery of health services included both providers and purchasers. The former included self-governing providers, called NHS Trusts and other units responsible for buying health care on behalf of populations they represent. The purchasers consisted of health authorities (Regional Health Boards in Scotland) and fundholders, that is, general practitioners responsible for their own practice budgets (Laing & Cotton, 1996). The NHS and Community Care Act 1990, and the role of the NHS, Trusts, and GP fundholders are discussed more fully in Chapter Three. Organisational changes in Scotland, subsequent to 1997, have eliminated GP fundholding, and led to other developments outlined as follows.

Recent Policy and Organisational Changes

Designed to Care (Scottish Office, 1997).

This White Paper was released just prior to my departure following my initial research in Scotland; implementation began officially in the following year, and was still underway during my second trip in June 1999. Designed to Care introduced another restructuring of the NHS. Existing acute Trusts have been merged to form one acute

Trust in each health board area, and community care Trusts are now called Primary Care Trusts (A. Laing, personal communication, July 10, 2000). The role of GPs as purchaser fundholders has been replaced by collaborative organisational structures called Local Health Care Co-operatives (LHCC) which, as the operational arms of Primary Care Trusts, are responsible for developing service provision within a geographic area (A. Laing, personal communication, April 21, 2000). These structures will allow GPs to develop extended primary care teams encompassing community nurses and professions allied to medicine, thereby offering a wide range of services in a multi-practice framework (Scottish Office, 1997). Designed to Care (1997) outlines some of the new directions and relationships for primary and secondary care, within this framework: (a) concentration on population needs, (b) increased decision making for local areas rather than local GP practices, (c) multidisciplinary membership in LHCC, and (d) abolition of the NHS internal market with its emphasis on competition. These changes are still in progress.

Modernising Community Care: an action plan (Scottish Office, 1998a).

The Scottish Office produced this action plan for improving the management and delivery of community care services by outlining strategies for better collaboration between the statutory, public, and private sectors. During my 1999 research trip, participants stated that a plan was underway for improvements in joint working between Health and Social Services, however, the changes arising from this plan were in the early stages and are still in progress.

Nurses' Roles

As discussed in Chapter One, there are various ways of describing nurses' roles. Baldwin and Birchenall (1993) offer a description of nurses' roles in the UK by identifying the role components belonging to all the professional groups in nursing. The components are: clinician, helper/counselor, advocate/advisor, manager, teacher/educator, therapist (p. 851). They suggest that with the exception of the clinician role, all other role components are equally important to each of the different nurses' roles in the UK. The clinician role, which is de-emphasized in some community nurse roles, such as those of health visitors, is often misunderstood as simply the direct or hands-on care involved with nursing procedures. The clinician role does, however, incorporate all other role components, resulting "in a focus of care that covers all aspects of an individual's life" (Baldwin & Birchenall, p. 851).

In Scotland and Canada, the term community nurse is used loosely to refer to community-based nurses. Recent changes in the UK in nursing education have recognized the specialization of community health care nursing which includes current areas of practice, as well as new titles for registration (Ross & Mackenzie, 1996). This development brings together a range of different specialisms including health visiting, district nursing, school nursing, learning disabilities nursing, general practice nursing, community children's nursing, public health nursing, and community mental health nursing, in a core educational course (Northway & Walker, 1999; Ross & Mackenzie, 1996). Differences still persist, however, in relation to entry requirements, length of courses, the status of the qualification, access to educational opportunities, and the terms, conditions, and settings for work (Northway & Walker, 1999). The National Board for

Nursing, Midwifery, and Health Visiting for Scotland (NBS) is the statutory body responsible for ensuring standards of education and training for nurses, midwives, and health visitors in Scotland.

In my research, I often refer to the roles of health visitors, district nurses, school nurses and learning disabilities nurses, as well of the roles of a variety of nurses in specialist posts under the general term nurses, or health visitors and other nurses. Where I use the broad categories, it is either for ease of description, or for maintaining confidentiality, and I intend no disrespect by not acknowledging distinct qualifications. District nursing and health visiting are the two most traditional community nursing qualifications. In order to work in either, nurses and health visitors now qualifying are required to have a degree. There are a variety of arrangements by which nurses who were previously qualified without a degree can seek further education. Individuals working towards a health visitor qualification are referred to as student health visitors (A. Kiger, personal communication, September 1, 2000), and they work under the direction of health visitors. Among the discussions that are ongoing among the different divisions of community nursing is whether or not there will be a shift toward further specialization, or toward a single generic community nurse role (Northway & Walker, 1999). There are many changes taking place in nursing education in Scotland and the UK, but the details are outside the scope of my research.

Children with Special Health Care Needs in Scotland

The term, 'children with special needs', is used in Scotland more commonly than 'children with special health care needs'. This latter term represents a significantly

smaller subgroup, generally consisting of children with more complex health problems and care requirements. For ease of description, however, I use the terms interchangeably to describe children with a range of conditions including chronic illnesses, physical disabilities, congenital and developmental problems, and learning disabilities. A number of children with special needs, for example, those with cerebral palsy, may have a combination of the preceding conditions.

It is difficult to estimate the number of children with these special needs in Scotland and the UK, because estimates depend on the choice of concepts and the methods used (Lindsay, Kohls, and Collins, 1993). From the Office of Population and Census Survey (OPCS) 1989 estimates, however, there were 360,000 children under 16 with special needs in the UK, and in Scotland there were approximately 30,000 such children (Lindsay et al., 1993). In Aberdeen alone, an estimated 1200 children with disabilities live in private households, among whom are those requiring care and support due to visual or hearing disabilities, long term health or development difficulties (Aberdeen City Council and Grampian Health Board, 1997). Local and regional planning is still underway in Grampian to further identify needs and develop services.

The Setting

I conducted my research in two regions of Scotland, the Grampian region, and to the south, the kingdom of Fife. Because I lived in Grampian, and conducted most of my research there, I will provide some details specific to it. Grampian covers the north-east portion of Scotland bordering the North Sea, and a broad area of towns and villages inland. The city of Aberdeen, with an approximate population 215,000, is the largest city and a seaport and centre for the massive North Sea oil and gas industry. The Grampian

Health Board is the health authority responsible for the region. In 1997, within the city of Aberdeen, Grampian Health Care Trust provided health services delivered in the community and Aberdeen Royal Hospital Trust was the provider of acute care services. The Trusts have now been re-organised as I indicated earlier.

Local authorities, through their Social Services departments and in partnership with Regional Health Boards, are responsible for the delivery of community care services, as defined by legislation and discussed fully in Chapter Three. Within Grampian, Aberdeen City Council is the local authority for the city of Aberdeen, while Aberdeenshire Council is responsible for the area of Grampian outside Aberdeen.

This section has provided information and terms that will, I hope, assist the reader who is unfamiliar with them. In the section that follows on research design, I lead the reader on my own research path in Scotland.

Research Design

This research employs a qualitative approach in order to generate knowledge concerning nurses' roles. The focus of the research is an exploration of the relationship between government policy and nurses' roles from the perspective of nurses and others involved in the provision of services to families. The research design shapes the structure of the exploration, and describes a flexible set of guidelines that connects theory to strategies of inquiry and methods for collecting data (Denzin & Lincoln, 1994, p. 14). Dreher (1994) says that the most important element in design is the consistency between the method (methods) and the research questions, the phenomena being studied. Research also requires a consistency between the method and the belief systems or perspectives that guide the researcher in her/his particular worldview (Denzin & Lincoln,

1994). In this section I discuss the research design in relation to the research approach, theoretical perspectives, and the methods through which my exploration occurs.

Research Approach

In preparation for my research, I initially developed a proposal to conduct a comparative study of nurses' roles with families/children with special health needs in Scotland and British Columbia. As my research in Scotland progressed, I realized there was richness in the emerging data that was complete in itself, and would serve a Master's thesis requirements. My original proposal also included an intention to explore not only policy, but also programs, and nursing education and their influences on nurses' roles in Scotland. As I began to meet and talk with participants, their stories and descriptions centred on policy, and thus, I later declared policy as the focus of interest.

A qualitative approach invites this openness to discovery, and to what emerges in the data. It emphasizes the value and validity of the subjective experiences of participants and locates their experiences in context (Driscoll & McFarland, 1989). The data that emerge in a qualitative study are thus fundamentally suited for locating the meanings people place on the events, processes, and structures of their lives, and for connecting these meanings to the social world around them (Miles & Huberman, 1994, p.10). In seeking ways to understand roles in a policy context, a qualitative research approach is, therefore, consistent with my purposes, and enables me to describe, explore, and interpret the phenomena.

Although a qualitative approach provides the broad direction and methods of research, the methods of data collection and analysis are not neutral, but are shaped by a theoretical perspective (perspectives) that focuses the inquiry (Driscoll & McFarland,

1994). Within these perspectives are philosophical principles that guide the research in three major areas: (a) ontology, which poses the question, “What is the nature of reality?”, (b) epistemology, which asks, “What is the relationship between the inquirer and what is known?”, and (c) methodology, or “How do we know the world, or gain knowledge of it?” (Denzin & Lincoln, 1994, p. 13). Research perspectives thus guide the questions that are asked, how they are asked, who is asked, and even how the responses are heard, or attended to and interpreted.

Theoretical Perspectives

I explored three main theoretical perspectives during the research process - feminist, critical social theory, and role theory.¹ This exploration is consistent with the views of Denzin and Lincoln (1994), who suggest that the researcher as theorist works “between and within competing and overlapping perspectives and paradigms”, and hence, the value of combining multiple methods and perspectives is a strategy that adds rigor, breadth, and depth to any investigation (p. 3). I will briefly describe the perspectives.

Feminist and critical social theories.

Both feminist and critical social theories contribute to the philosophical assumptions guiding my research, as well as to my critique of role theory, from which traditional analyses of role and role concepts are derived. Feminist and critical social theories share some common assumptions: (a) that all research, theory, and practice are political because the social, economic, political, and historical processes of society affect them, (b) that oppressive power relations are common in society, and (c) that research provides the potential for emancipatory change (Reinharz, 1992; Campbell & Bunting, 1991; Stevens & Hall, 1992). Theorists within each perspective agree that knowledge is

¹ There is no single feminist, critical social or role theory, although each is often expressed in the singular.

socially constructed and that, in order to understand patterns of human behaviour, it is necessary to understand “personal meanings of social structures and the communally agreed upon meanings of those structures” (Campbell & Bunting, 1991, p. 10). Those meanings are implicated in relations of power and knowledge that regulate what is considered to be reasonable and true (Kincheloe & McLaren, 1994), meanings which some feminists term, taken for granted (Olesen, 1994). Taken-for-granted meanings are those which are accepted “without question or objection”; they “are assumed” to be (Random House Dictionary, 1987, p. 831). Kincheloe and McLaren (1994) assert that the oppression characterizing contemporary societies is most successfully maintained when subordinates accept that position as natural, or necessary (p. 140). In other words, the relations of power, and even their effects on individuals or groups, are taken for granted.

Critical social theory is primarily concerned with understanding patterns of human behaviour by understanding social structures (Calhoun, 1995) and the power within them. Stevens (1989) says that the ultimate goal of critical social theory is to facilitate liberation from constraining social, political, and economic circumstances. Critical social theory, while not opposed to helping the individual, is primarily concerned with knowledge for the emancipation of all humanity or of particular oppressed groups (Campbell & Bunting, 1991). In the critical theory paradigm, knowledge and its creation and interpretation are grounded in language (Campbell & Bunting, 1991, p. 5). This orientation to language is of interest to the study of policy because it points to the symbolic and value-laden nature of words and text (Alasuutari, 1995; Campbell & Bunting, 1991). In this view policy analysis can be a means to exposing hidden power

imbalances and unstated but implied intentions. These analyses direct us, as Smith (cited in Kirby & McKenna, 1989) suggests, to “examine who produces what for whom [and] where the social forms of consciousness come from” (p. 33), a process which can have potential for liberation.

As part of their interest in liberation, feminist theorists have tended to focus on division and domination according to gender as their primary interest (Campbell & Bunting, 1991). Post-modern feminist approaches have, however, been expanding their areas of interest and analyses to those who, as Kirby and McKenna (1989) suggest, “find themselves on the margins” (p. 33). The margin is the context in which those who suffer injustice, inequality and exploitation live their lives, not only in terms of unequal distribution of resources, but also in terms of knowledge production (Kirby & McKenna, 1989). It is also, therefore, where dominant groups establish their social values and norms. Research from the margins is of interest to professions such as nursing, in which the roles of nurses, and of the women and families with whom they work, are often devalued, as my research demonstrates. Feminists are interested in the personal, the individual experiences of nurses and families, while also emphasizing the relationship between the personal and political (Reinharz, 1992). The relationship between the two emerges in my research in the relationships between roles, and between policy and nursing practice.

Feminist and critical social theories also share some commonalities with regard to research methods. Theorists in both areas may cross disciplines, and may also involve multiple perspectives and multiple methods, which can be both quantitative and qualitative (Reinharz, 1987; Campbell & Bunting, 1991). Both feminist and critical

social theorists question the power base that researchers have traditionally employed as creators of knowledge (Campbell & Bunting, 1991). A difference, however, is the feminist condition that researchers and participants should be equal partners, a view that critical theorists critique as an example of how hidden power imbalances can be overlooked (Campbell & Bunting, 1991).

A feminist perspective confirms the importance of the researcher's voice. On the use of *I* by the researcher, Riger and Gordon (cited in Reinharz, 1992) suggest that the active instead of passive voice is a revolutionary change for social science research, "since it acknowledges that the research was done by a human being, with human limitations" (p. 212). Thus I have introduced my voice, and some of my experiences into the research, while at the same time attempting to avoid cross cultural assumptions or comparisons.

Feminists also confirm the importance of minimizing the distance and power relationship that can arise between the researcher and participants (Acker, Barry, & Esseveld, 1991). Harding (1987) says, for example, that we need to avoid the detached stance "that attempts to make the researcher's cultural beliefs and practices invisible" (p. 9). Thus, I have avoided the use of language that belongs to traditional experimental science, for example, the word subject. Using the term participant instead of subject is, according to Reinharz (1992) a signal that the researcher is operating in a feminist framework. I have also attempted to avoid the use of academic jargon that is often confusing, but more importantly, may create distance between the researcher and others. Where I do use academic terms, I strive for clear definitions.

Feminists value the voices of participants, whereas in critical social theory investigations, dialogues generally tend to be scarce (Campbell & Bunting, 1991). Both feminists and critical social theorists recognize, however, that language itself is often incongruent with the realities of individual experiences, and implicated in relations of power (Devault, 1990; Kincheloe & McLaren, 1994). Language can, therefore, be used to mask or obscure meanings. Feminist theories advocate a deconstructive² strategy (Hooyman & Gonyea, 1995) that searches for and reveals implicit meanings and hidden assumptions. I have employed a deconstructive strategy in my policy analyses, and in my critique of roles and role theory, both in the following section on role theory, and throughout the thesis.

Role theory: an overview and critique.

In Chapter One, I introduced role constructs derived from role theory, including those upon which nursing tends to rely. In this section, I provide a theoretical overview of various interpretations of role theory, which have been useful in assisting my early understanding and critique of the concept of role. Feminist and critical social theories have helped to guide this effort.

Calhoun (1995) acknowledges the early contribution of role theorists, in suggesting that the sociological analysis of role was a step beyond the essentializing of biological or psychological human identity, and it facilitated recognition of the construction of self in social life (p. 198). Among early role theorists, Biddle and Thomas (1966) described role theory as a new field of inquiry concerned with the behaviour of a given individual, an aggregate of individuals and groupings of individuals

² The constructivist or interpretivist believes that to promote understanding one must "elucidate the processes of meaning construction" and thus uses strategies to clarify how meanings are "embodied in language" (Schwandt, 1994, p.118).

who display given behaviours. Among early theorists, the so-called 'functionalists' provided theoretical constructs derived primarily from the domain of psychology and earlier psychoanalytic studies, which emphasized the expectations and behaviours or functions associated with roles (Biddle & Thomas, 1996).

Later role theorists included the stream called symbolic interactionists, who focused on face-to-face micro level interaction (Johnson, 1993, p. 115). Lopata (1991) suggests that these interactions are located and examined in the family, religious, political or work organisations, thereby pointing to the complexity of interaction involved in each role (p. 3). Some role partners, for example, those within the role set of the family, are familiar, may seldom change or have little difference in status, whereas more complex role sets, those involving role partners who are differentially located in the social structure in terms of status, may include unpredictable and changing expectations or responses (Coser, 1991). In this view, roles do not result solely from a shared meaning, but also from negotiations (Armstrong & Armstrong, 1996, p. 40). Yet as Armstrong and Armstrong point out, the theories do not explain why women so consistently lose in their negotiations, and why their work is culturally devalued (p. 40).

Much of Parson's early work in the functionalist stream of thought concerned men and women, and the division of labour in the family (Johnson, 1993). He tended to see the power divisions between generations, such as parents and children, but viewed distinctions in the family between men and women in terms, not of power, but functions: the male as instrumental and the female as expressive (Johnson, 1993). Feminists have criticized his work, in which roles appear neutral, with men and women - husbands and wives - filling different but equal roles (Johnson, 1993; Lupton, Short & Whip, 1992).

To a large extent, nursing research literature reflects this taken-for-granted perception of roles as being neutral. Roles are commonly viewed in terms of tasks, activities, and behaviours, or they are studied in terms of ways in which nurses conceive their roles, or are socialized to them. Feminist theorists disagree with these implications, which imply an uncritical acceptance of appropriate behaviour (Armstrong & Armstrong, 1996, p. 42) linked to a cultural norm.

That roles are located in culture contributes to their formation. For example, cultural norms create the expectations that support role behaviours, where a norm is an idea in the minds of members of a group about what the members or others should do, or be expected to do, under given circumstances (Biddle & Thomas, 1966). Cultural values are the attitudes and beliefs that justify the norms (Strader & Decker, 1995). Armstrong and Armstrong (1996), in a critique of role theory, suggest that by focusing on the norm, a well accepted alternative pattern (to a behaviour) becomes identified, not as an alternate pattern, but a deviant one (p. 128). Calhoun (1995), a critical social theorist, offers a further critique in suggesting that culture is not a static collection of norms, values and beliefs, but it is a dynamic dimension of social practice. This view underlines the unpredictable and changing nature of roles themselves.

Feminist and critical social theories thus bring new perspectives to the study of nurses' and other roles. In challenging taken-for-granted assumptions concerning roles, these theories point to their unpredictable and changing nature, to the power differentials that exist within the contexts in which nurses' roles are situated, and to the relations of power and their contribution to role change.

In summary, theoretical perspectives provide, not only a way of seeing the world and the phenomena being studied, but also a way of doing the research. This process of *doing* is what research is ultimately about. Said, cited in Kirby and McKenna (1989) states that research is, in essence, an activity that occurs in a time and place by a specifically located person for certain ends (p. 32). The methods of data collection, which I now describe, are central to that activity.

Methods of Data Collection

A qualitative approach enables the researcher to use multiple methods to access information or data. I employed several methods that contributed to gathering information including participant interviews, the interview setting, site observations, and document analyses. Before discussing each of these, I will describe the participants in my study and how they came to be participants.

Research participants.

Research participants are not required to be experts. Their contribution is knowledge, experience or both depending on the nature of the research. Participants must be willing and able to critically examine their experience, or the phenomenon, and their response to it (Morse, 1991). My research participants fulfilled two important criteria: they had knowledge and experience of roles and work, either with the nursing care of children in the community, or with the needs of families or provision of services to them, and they demonstrated a willingness to offer their experiences, insights, and concerns. Participants were nurses who worked in a variety of community nurse roles, and other women and men from social services, health administration, education, research, and the voluntary sector. I have not identified the specific roles or programs to

which individuals were attached because of confidentiality issues, which I discuss later in this chapter under special considerations.

During the course of my research, I also obtained information from those involved in a Respite Special Interest Group meeting in 1997 in the Grampian region, where I received permission to take notes from the discussions. I did not identify or quantify the meeting participants, among whom were families, carers, and others from statutory and voluntary sectors, however, I have included some of their views and experiences concerning respite care in Chapter Five. In Appendix A, I provide a summary of the number of research participants I interviewed, their broad role categories, and the time periods for the two stages of my research in Scotland.

I perceived initially that the role diversity among my participants, posed a limitation in the research design. However, as the research progressed, I found that the diversity contributed to the depth, as well as the confirmability (Miles & Huberman, 1984) or validation of the data. Participants from the voluntary sector brought perspectives on the needs of families that confirmed the views of nurses, and at times, also offered alternate views. The contributions of both nurse and non-nurse participants added to the richness and scope of the data, and helped to address questions pertaining to policies, services and perceived needs of children and their families.

My contact with participants occurred in two stages, the first in the fall of 1997. In the first stage of data collection, I conducted individual interviews, and one focus group interview, each approximately sixty minutes in length. Eighteen months later in the summer of 1999, I conducted individual interviews with a sample of my original participants, and a focus group interview with most of my original group. The focus

groups consisted of health visitors and health visitor assistants, the latter, registered graduate nurses who are qualifying as health visitors.

In beginning my research, one of the challenges was to find participants in a country where I knew almost no one, and had chronic problems with the phones in public boxes. In my initial efforts to obtain participants, I turned to methods of nomination and network sampling, that is, finding key individuals to recommend other knowledgeable, interested participants (Morse, 1991). Dr. Stuart Watson, Coordinator of the MSc program at the time in Aberdeen University's Department of Public Health, provided some names and telephone numbers, and an office from which I could make telephone calls! As the research progressed, my contacts and participants recommended others, and the network process expanded.

I had hoped to locate participants in both rural and urban areas of Scotland. When my participants spoke of the rural areas, I thought of rural in terms of, for example, the north of Scotland and the Orkneys. I later learned that rural, in Scottish terms, could mean fifteen miles or so outside Aberdeen! I was able to interview some participants who worked in rural areas, but was unable to achieve the balance of urban and rural participants I had intended. Most of my participants worked in Aberdeen, or provided services from Aberdeen throughout the northeast of Scotland, while a small number worked in the neighbouring region of Fife.

Interviews.

My primary method of data gathering was through the use of semi-structured interviews both with individuals and in focus group discussions. Key questions and probes, included in Appendix B, provided opportunities to guide the research and seek

clarification on certain points, while open-ended questions enabled participants to describe perceptions and experiences in their own words. Reinharz (1992) suggests that open-ended interview techniques produce non-standardized information that allows researchers to learn from the differences among people. Because of the diversity of roles among the various participants, individual interviews provided the most useful way of gaining both depth and scope in the information-gathering process. Thus, I was able to access information about roles, services, and trends and the context in which these were situated, and my research participants were able to discuss their experiences, as well as explore areas they wished to develop or have me understand.

The focus group interview process was also extremely valuable. A key benefit of focus groups is that attitudes and perceptions, for example, those regarding nurses' roles, are not developed in isolation, but through interactions with others (Morse & Field, 1995). These group interactions contributed to the richness of the data as participants in the group clarified, responded or reacted to one another's points of view.

Recording.

During the individual interviews, I took extensive notes to which I added, usually within twelve hours, additional notes and observations. I felt I could manage these interviews with note-taking and thereby avoid the presence of a tape recorder, which is intimidating for some people. For the focus group discussion, however, which involved eight nurses, I used a tape recorder and later transcribed the conversations into text. Throughout the research, I have also kept a research journal in which I have written my impressions, reactions and comments regarding the research process itself. Before I left for Scotland, the late Dr. David Fish, my first research advisor, suggested I would return

with two possible theses, one that I gathered from participants, and one gained from the research process itself. He was correct!

Interview setting.

A key criterion in selecting the interview setting is that it is conducive to a sense of equality between the person gathering information and the person whose knowledge is sought (Kirby & McKenna, 1989). This is important because of the potential for an imbalance of power in the relationship between the researcher and participants, to which setting may contribute. Thus I conducted the interviews primarily in the offices or meeting rooms at participants' work sites, which met my criterion for neutrality, as well as that of convenience, for people working under time constraints.

Site observations.

During the course of my research, I had the opportunity to visit two community care settings in Fife and Grampian to observe the care of children with special needs. The visits provided a context in which I could visualize the nature of care for children in small community facilities. These observations were separate from the interviews of my research participants. The interactions with staff were informal and I did not take extensive field notes. In other words, when I observed the setting and the care required by the children, I was not simultaneously interviewing or observing participants. This is an important distinction because one of the problems with validity in participant observation is the change in behaviours of participants when the observer is present (Morse & Field, 1996).

During the time period when one of the site visits occurred, I did have the opportunity to speak informally with a group of licensing officers responsible for

enforcing standards in licensed community facilities, some of which were homes for children. Unfortunately, the extent and nature of their concerns was beyond the scope of my research, and therefore, I have not included these individuals as participants.

Documents.

The review of documents provided an unobtrusive way of gathering information (Marshall & Rossman, 1995) regarding policies, particularly from documents that were not readily available in British Columbia. These included UK government and Scottish Office policy documents pertaining to health and community care, UK nursing documents, and policies pertinent to the care of families and children with disabilities or other special health care needs. Relevant documents were purchased, photocopied, or annotated to provide information for later analyses.

Data Analysis

A main task for the researcher is to explain ways that people in particular settings come to understand, account for, take action, and otherwise manage their day to day situations (Miles & Huberman, 1994, p. 7). The researcher strives to achieve this through analyses of the interview data, although data collection and analysis may occur concurrently.

The processes of analysis in qualitative research are intended to reveal multiple layers of meaning. Morse (1994a) describes the processes that are key to the qualitative approach, among which are comprehending, synthesizing, and theorizing. Comprehending involves learning everything possible about a setting or the experiences of participants (Morse, 1994a, p. 26), and it evolves through the research. Comprehending is assisted through a thorough review of literature, suspending

assumptions derived from the literature or other sources, conducting an active inquiry which includes attending to words and seeking meanings, and making extensive notes and records.

The process of seeking comprehension has been both exciting and overwhelming. I read extensively prior to and during my term in Scotland in order to gain an understanding of the context in which nurses' roles and work are situated. I attempted to suspend my assumptions in order to view experiences from the participants' perspectives. I also read extensively following the stages of data collection, in order to compare my findings with the literature.

Active inquiry is also critical in aiding the process of comprehension. So much was new and unfamiliar, including words, such as Trusts and fundholding, and for some words, I immediately sought clarification in documents or discussions. However, while some words and phrases I heard appeared familiar, they actually conveyed different meanings, although at times I was unaware of the differences. For example, when a participant referred to the voluntary sector I erroneously assumed this meant volunteers (unpaid), and learned only later, that it referred to the non-profit sector. On another occasion, when a nurse said she was "chuffed" about an aspect of her work, I initially equated the meaning with the Canadian colloquialism huffed, which is virtually opposite to the meaning pleased, that she intended! I gradually learned to clarify meanings of words and not make assumptions about them.

Coding, a central process in data analysis, helps with comprehending as the researcher sorts the data and uncovers underlying meanings in the text (Morse, 1994a). The idea of coding, or indexing, is that the researcher applies a uniform set of headings

and sub-headings at relevant points (Mason, 1996) in the production or review of the text. Meanings and patterns emerge through sorting the descriptions and stories into smaller and smaller categories. I made a brief attempt at coding by using a computer program designed for qualitative research analysis, but I found I wanted a more tactile connection with my data through pen and paper. Even with that, however, my initial efforts at coding were inadequate, as I tried to fit the descriptions of participants into categories such as health promotion activities. After periods of reflection and writing, I began to recognize that what nurses and others were saying about nurses' roles and services to families could not be readily categorized, because they were in a profound state of change.

The process of comprehending thus gradually shifted to the next stage, synthesizing, the sifting part of analysis (Morse & Field, 1996), which further aided my understanding. Through a process of further reflection and writing during which I considered the questions, "What are the participants actually saying about role change?" and "In what ways can I understand and realize meanings?", certain words and phrases caught my attention. This stage was one of immersion in the data. I heard in my dreams and waking hours the voices and experiences of my Scottish participants. My experiences of immersion in the data are consistent with van Manen's description (cited in Bergum, 1991) of thematic analysis as "a deeply reflective activity that involves the totality of our physical and mental being" (p. 65). Eventually, through further sifting, reflecting, and writing, patterns began to emerge as dominant themes. As an example, health visitors had provided various descriptions that indicated changes in and constraints

to their roles, arising in the context of the GP practice. My theme, GPs are directing health visitors work in the context of the GP practice, reflected their descriptions.

Patton (1990) says that interpretation means the researcher goes beyond the descriptions, and through an inductive process, begins to attach meanings and significance, offer explanations, make inferences, make the obvious obvious, and the hidden obvious (p. 423). For a time, I stepped back from my themes and descriptions and began to notice relationships between them, all linked to roles, role change, and the organisational and policy context in which changes were occurring. I turned to theories to seek further understanding of policies, organisations, change, and the nature of roles themselves, thus gradually shifting to theorizing. In some cases, I then re-named my themes. Thus, in the example of the theme I gave earlier, GPs are directing health visitors work, I re-named the theme, Role conflict, to reflect succinctly what I understood my participants to be saying. Within this theme, I identified smaller categories or sub-themes, such as Hierarchy, which gave a focus for further interpretation and understanding. I chose, as Patton (1990) suggests, quotations from participants themselves to retain the link between their experiences and the emerging theory. These quotations are included in the theme headings in the findings chapters.

The process of theorizing requires asking questions of the data that either will create links to established theory (Morse & Field, 1996), or from which theory will emerge. I had begun to see ways in which nursing theory is linked to taken-for-granted notions derived from role theory, and my research forced me to challenge these notions. My research is thus grounded in the experiences of nurses and in the experiences of others who work with families and children in Scotland. The nature of these experiences,

and the ways in which they are perceived, contribute to the discipline of nursing, and to ways of conceptualizing nursing. This relationship is consistent with the view that the practice of nursing informs and also challenges nursing theory development through conceptual meanings (Chinn & Kramer, 1995, p. 160). According to Chinn and Kramer (1999) the approach is also consistent with grounded theory methodologies which, while initially inductive, also use deductive approaches to examine propositions of theory (p. 123-4).

Issues of Rigour

Among the criteria that have been identified for maintaining rigour in qualitative research are: truth value/credibility, applicability/fittingness, auditability/consistency, and confirmability (Morse & Field, 1996; Sandelowski, 1986). Sandelowski (1986) describes a study as credible when other people can recognize the experience when confronted with it after having only read about it. Credibility is strengthened by confirmability, which is achieved when the participants are given the opportunity to review and validate the research findings.

One of the ways in which I have demonstrated credibility and confirmability is by validating my preliminary findings by means of a second set of interviews in June 1999. On this occasion, I selected a sample of my original participants according to the needs of my study (Morse, 1991) at that time, in other words, those who had a breadth and depth of knowledge that would enable them to critically appraise my findings. With my participants, I reviewed a four page summary of my findings, including the themes and their descriptions. In seven individual interviews and a focus group discussion, participants confirmed the five major themes that I had identified, and the written

explanations that I provided. Some of the participants in the focus group, while confirming that GPs are directing health visitors' work, did not agree with my interpretation as one of potential or actual conflict. One health visitor expressed the view that the current arrangement was better for practice. Another nurse participant said, however, "It's not potential, it's real," a view also confirmed by others. These differing views are described in the findings. Most of the participants added to the information I reviewed with them, that is, they identified further changes and their effects, both positive and negative, on practice and service provision. Only the final theme, 'issues in respite care', has been re-named to include the two themes discussed in Chapter Five, however, the issues are similar.

While validation strengthens credibility, Morse (1991) suggests that bias can threaten it. In Morse's (1991) view, bias may arise from one's role as an insider who has closeness to the subject. Because I have had in depth clinical and consultative experiences working with families and children with special health needs, and was studying a peer group, I initially perceived a risk of bias. Kirby and McKenna (1989) assert, however, that the more familiar the researcher is with the experience being studied, the better is the potential for understanding. Olesen (1994) reinforces this view in stating that bias is a misplaced term. She says that if the researcher is reflexive, that is, thoughtful about the research process and the researcher's place in it, she or he can evoke these experiences as resources that contribute to new perceptions (Olesen, 1994, p. 165). The use of a journal during the research process, as I indicated using, assisted me to clarify the nature of my knowledge and influence. One limitation in my research is likely

in my failure to contribute from my experiences to the extent that some participants would have liked.

Applicability of the research can be demonstrated through its fittingness, which means that the findings fit or can be transferable to contexts outside the study situation, and are well grounded in the typical and atypical elements of the experiences studied (Morse & Field, 1996; Sandelowski, 1986). Patton (1990) says that it is important to understand that, in qualitative analysis, the emphasis is on understanding and extrapolation, not on prediction and generalization (p. 424). Extrapolations are speculations about the likely applicability of findings to other similar, but not identical conditions (Patton, 1994).

The nature of my research would indicate that the findings are applicable to nurses and families in Scotland, where changes of a similar nature have been taking place subsequent to the reforms, although specific situations and the organisational responses across regions vary. For example, some regions have developed children's community nursing teams to provide support to families at home. Similarly, there are insights and issues that arise in my findings that may be applicable elsewhere to nurses, families, and other carers caught in rapid shifts from institutional to community-based care. For example, my site observations confirmed that the care requirements for children with special health care needs in a small community home in Scotland, and the approaches to care provision, are similar to those I have seen in British Columbia.

Auditability, a third criterion for demonstrating rigour, refers to a conceptual trail of evidence by which interested parties could reconstruct the research process (Morse, 1994b). This includes ordering and dating field notes to keep interviews and any changes

in context (Morse & Field, 1996). I have done this in both field notes and journals, within the requirements for confidentiality.

Confirmability is achieved when auditability, credibility and applicability are established (Morse & Field, 1995, p. 33). Sandelowski (1986) describes confirmability as neutrality. I would, however, challenge the need for neutrality which would contradict the contribution of the researcher's own ethical and emotional relationship with the inquiry and the participants (Clandinin & Connelly, 1994; Reinharz, 1992).

Special Considerations

The unique nature of my research, conducted as it was in another culture, introduced special considerations regarding cultural sensitivity. Other special issues are of an ethical nature, important to any research. I discuss each.

Cultural sensitivity.

As a guest at the university and visitor in Scotland, I wanted to demonstrate cultural sensitivity through my interest in and respect for traditions and views that might differ from my own. Arising from these differences, however, there are also risks in conducting research in another culture. As Calhoun (1995) states:

We face difficulties in interpreting social life that is differently constituted from our own; our resources for making sense of it, for giving meaning to what we can observe of it, derive from our own culture and from previous experience... we run the risk of failing to grasp meanings operative in other contexts while constituting for ourselves meaning that were not at work there. (p. 49)

As a Canadian graduate student and nurse, with knowledge of and experience in Canadian nursing and policies, I had no first hand experience with the history and culture of Scotland, or their implications for Scottish nurses and families. I felt it vital that I

maintain an awareness of the historical and cultural experiences which might differ from or be similar to my own, while making no assumptions about either.

For example, nursing in Canada is a gendered profession, composed primarily of women whose work is lower in status, autonomy, and pay than that of physicians. Yet there are variations among and between nurses' roles. As a nurse working in the community in British Columbia, my work has involved a relatively high degree of autonomy. I do not take orders from physicians, and they are not responsible for directing the work that I do. However, some of my experiences have been unique to my nursing roles and not necessarily to nursing in Canada. In recognizing the diversity within Canada alone, I felt it was important to suspend assumptions about the nature and organisation of nursing in Scotland. These considerations guided my research approach.

Ethical considerations.

Issues of vulnerability, consent and confidentiality are critical considerations in any research, and I addressed them in the following ways:

(a) vulnerability

This refers to the risk of harm that may be posed by the researcher during the research process. Before I initiated my research in Scotland, I sought ethical approval from the University of Northern British Columbia's graduate research ethics committee, which I later received, see Appendix C. Faculty in the Department of Public Health at the University of Aberdeen also reviewed my proposal before I initiated the project. Although my research did not warrant the high degree of concern required with vulnerable groups or individuals, it held some ethical considerations. Nurses in Scotland

are predominantly women, and the focus of discussion was about primarily women in families caring for their disabled children.

In doing research with and about women, Finch (1990a) suggests that, if one takes the view that the powerful are fair game for the researcher, then women in patriarchal societies are always relatively powerless. Gender relations cannot be divorced from the context that makes them essentially political questions (Finch, 1990a). Although uncertain of the implications of gender for nurses and women in Scotland, the potential vulnerability of some participants heightened my awareness.

(b) Consent and confidentiality

Consent and confidentiality procedures are important considerations in any research. Measures were taken to obtain participants' consent and to protect their confidentiality. Participants volunteered, either by contacting me or by responding to my invitation for their involvement. When I had sufficient time before we met, I forwarded a letter, see Appendix D, outlining my research project and discussing relevant issues of consent and confidentiality. There was only one incident during the research process, when after revealing a sensitive issue, a participant expressed concern about confidentiality. Despite the absence of expressed concern by others, I have taken suggested measures (Morse & Field, 1995; Morse, 1991) to protect the confidentiality both of participants, and the information they provided. These efforts included: (a) ensuring audiotapes were stored privately, (b) maintaining anonymity by using a numeric system in place of names, (c) changing or eliminating non-essential information, such as a location, sex or age of an individual or their health circumstances, which has no relevance to the discussion but could potentially be revealing, and (d) assuring

participants that they were not required to provide any personal information in their efforts to contact me through the departmental secretary.

Morse (1994b) underlines the importance of these efforts to ensure anonymity for the participants, and states that the text should not identify which informants provided quotes, nor should quotes be tagged with participant numbers that may place them at risk of being identified (p. 232).

I also provided my participants with the name and contact number for Dr. Alice Kiger, Director, Centre for Advanced Studies in Nursing, in case they had any questions regarding my research. Dr. Stuart Watson, co-ordinator of the MSc program at the University's Department of Public Health, in which I was studying, was also available to assist me and to be a research contact.

Summary

In this chapter, I have provided information, which I hope is useful to the reader who is unfamiliar with Scotland. In the findings chapters, information is further expanded and interwoven with the stories and experiences of the twenty-six participants in the study. This chapter has also captured central elements of the research process, through which I have asked certain questions, explored theories, heard, and analyzed the stories and experiences of my participants, and examined their stories in light of theories. Themes and meanings have emerged from my analyses and interpretations. In this way, both the researcher and participants are knowers who are centrally implicated in the production and confirmation of knowledge (Reinharz, 1992). The responses of my participants to the themes indicate that most would agree with the overall findings, although this does not ensure their agreement with all the interpretations. The

contribution of, or error in interpretation is clearly mine. In the following pages of Chapters Three, Four and Five, readers can hear the voices and stories of my participants and, as knowers themselves, determine where they find meaning.

Chapter Three

The Organisation of Care

Introduction

The findings in my study, contained in the following three chapters, consist of the experiences and voices of my participants presented in categories, themes, and sub-themes that have emerged from my analyses and interpretations of data in light of critical, feminist, and role theories. Among the participants' rich descriptions, I also provide a context drawn from theories, history, policies, and the roles of organisations, to assist the reader in understanding the organisation of health and social care in Scotland.

In this first of three findings chapters, I introduce the context for the planning and provision of primary health and community care services in Scotland. The National Health Service and local authorities, the organisations in which the roles of many of the nurses and other participants in my research are situated, also provide a context for policy implementation, thereby linking policy and roles. The first theme, role conflict, explores the impact of organisational change on the roles of nurses in their professional relationships with general practitioners. The second theme, role confusion, explores its impact on the roles of nurses in their work primarily with social workers. The introduction of the community care reforms was the catalyst for many of the changes and impacts described.

The community care reforms that culminated in the NHS and Community Care Act 1990 introduced sweeping changes in the organisation and financing of the NHS and local authorities in Scotland and throughout the United Kingdom. A key feature of the

government's plan was to "establish an increasingly important distinction between the purchase and provision of health and social care" (Department of Health, 1989b, p. 49).

As mentioned in Chapter Two, changes affecting the NHS included the development of Trusts for the provision of health services, a new role for Regional Health Boards and general practitioners as purchasers, and the introduction of an internal market to health care. The reforms emphasized a greater role for primary care and strengthened the position of GPs in setting priorities for primary health care services.

In Scotland, primary care is medical care based in the GP practice, distinct from secondary care that is hospital-based care under the direction of consultants. Primary care falls under the over-arching term of primary health care, the first point of contact between patients and health professionals (Department of Health, 1989b). Primary health care professionals include GPs and primary care nurses working outside the hospital who have been prepared through education to deliver primary health care in the community (Ross & Mackenzie, 1996). The World Health Organisation provides a broader definition of primary health care that will be discussed later. According to central policy in the UK, the drive for change in the NHS should be led by primary health care and GPs working in general practice (Ross & Mackenzie, 1996).

In addition to changes in the NHS, the reforms introduced a new role for local authorities in the provision of community care. Social Services located with local authorities are expected to assume an enabling role rather than one directly linked to the provision of services. They are responsible for arranging 'packages of care', promoting competition between providers, and strengthening the role of families, the voluntary, and the private sectors in community care.

Caring for People states that community care is about the health as well as the social needs of the population (Department of Health, 1989b, p. 33). Primary health care services are part of community care, that is, the health component of community care services. Thus, community care involves both the NHS and Social Services, however, the lead responsibility for community care falls to local authorities.

In placing the responsibility for community care with local authorities and their Social Services departments, the reforms also placed upon them responsibility for leading collaborative planning of services with health partners. The government proposed a “fresh start to collaboration and joint planning” (Department of Health, 1989b, p. 49), which has had a mixed history of success and drawbacks.

The reforms also introduced new ways of thinking about health and social care. They emphasized principles of consumer choice and flexibility of services, independence, and better value for money (DOH, 1989b), and they introduced concepts drawn from the market place such as purchasing, contracts, efficiency and consumer satisfaction. This market perspective also introduced new relationships among providers and purchasers, and challenged traditional roles and relationships between doctors and nurses, Health and Social Services, and ultimately between service providers and clients. Although my research was conducted four years after the reforms were implemented in 1993, people in Health, Social Services and voluntary agencies spoke about the continuing effects of these radical organisational changes.

Organisational change is not confined to organisations. It also involves the cultures, structures, and practices within both organisations and the wider social context in which they are situated (Itzin, 1995a). Change of a radical nature is likely to engender

both resistance and conflict because it often involves scarce resources, divergent interests, and unclear expectations (Kettner, Daley, Weaver & Nichols, 1985). Change within organisations requires alterations in behaviour, interactions (Kettner et al.) and roles.

Individuals within organisations typically have a number of role relationships; for example, nurses have role relationships with doctors, managers, social workers, clients and families. Hugman (1991) provides a perspective on roles and organisations which sets them in the wider social structure:

The structures of organisations must be examined in the context of the wider society of which they are part, ... the actions of both workers and management are also affected by the roles and statuses they occupy inside as well as outside the organisation, and these are influenced by other forces such as education, ... race, gender, and the family. (p. 64)

These perspectives provide a way of thinking about organisations, roles and some of the role-related themes that emerged in this research with respect to nurses and their role partners: doctors, social workers, and families in this study.

Context to the Theme of Role Conflict

Before discussing the theme of role conflict, I will turn to the context in which role conflict is situated. This context includes the historical relationship between nurses and doctors, the history of the health visitor role, and the current concept of primary health care in the United Kingdom.

The Historical Relationship between Doctors and Nurses

In the literature, it is clear that there has always been a tension between nursing and medicine. In the early days of organised nursing in Britain, Florence Nightingale addressed this tension:

Nursing and medicine must never be mixed up. It spoils both, keep medicine and nursing perfectly distinct. Do not let a nurse fancy herself a doctor. If you have medical women let them be as entirely distinct from nurses as medical men are... a smattering of nursing does a doctor good. A smattering of medicine does a nurse harm. (Rafferty, 1996, p. 44)

Nursing and medicine are not, however, distinct. For the most part, nursing interests have been, and continue to be subordinated to more powerful groups such as the medical profession (Witz, 1994). In the past forty years, nursing has fought to relinquish the tradition of handmaiden to the doctor (Pietroni, 1994), one which saw nurses trained by doctors, subject to doctors' orders, and assistants to doctors. In an effort to achieve professional status, nursing has been shaped by a proximity to medicine. In the struggle for greater power, nursing has shifted between aligning itself with medicine, and seeking autonomy through a distinct theory and practice.

Nurses' struggles have involved and do involve not only the disciplines of medicine and nursing but also those within the nursing hierarchy itself. Conflicts within the nursing profession over the relevance of nurse education and leadership gradually led to the introduction of the concept of the manager-nurse, and ensured that nurses had an effective voice on management committees (Pietroni, 1994). Nursing in Britain made further gains following the Project 2000 report concerning nursing education, which shifted the education of nurses to academic settings (Pietroni, 1994).

In the mid 1980s, however, the government introduced the Griffiths Report with its concept of 'general management', a strategy that was intended to reduce the power of doctors in the NHS through the introduction of general managers and the methods of business management (Neave, 1994). Although doctors managed to retain much of their power in the new structure, nurses lost the representation they had achieved on the

decision-making bodies (Neave, 1994). With no clear roles in management and no power in decision-making, nurses who had previously provided a voice throughout various levels of the NHS, became effectively silenced (Neave, 1994).

While general management diminished the power of the nursing profession generally, the community care reforms of the 1990s had significant impacts on the role of nurses in the community. New fiscal arrangements between the National Health Service and GPs provided GPs with greater financial incentives for preventive care. It also introduced the option for GPs to become fundholders, an arrangement that offered the opportunity to purchase or commission services, including the services of nurses in primary health care. Although GP fundholding ended in 1998, and was replaced by local health care co-operatives (LHCC), the GP practice remains central to the working relationship of health visitors and GPs. Before discussing the implications of this relationship, it will be useful to discuss the history of the health visitor role.

History of the Health Visitor Role

Although health visitors have a long history of working with doctors, their role at its inception was independent of both medicine and traditional nursing. The health visitor role developed in the mid-nineteenth century in response to the conditions of poverty, disease, malnutrition, poor sanitation and infant mortality accompanying rapid industrial growth in Britain (McClymont, Thomas, & Denham, 1991). In contrast to sick nursing, it was described as “the work of home health-bringing” in providing surveillance, education and supportive care to the apparently well (McClymont et al., 1991, p. 15). Initially, health visitors worked with all age groups, but during the latter half of the century, caught between the dominant medical profession and the emerging professions of midwifery,

nursing and social work, their work became concentrated on child health and sanitation (McClymont et al., 1991). As the twentieth century progressed, health visiting fell under the domination of medical officers of health (Cowley, 1995) where it became more clearly identified with health education and promotion. Successive documents in the UK have since confirmed the focus of the health visitor role on health education, health promotion, and disease prevention (Cowley, 1995).

Policies of the past two decades have introduced new pressures on health visitors to maintain their role in health promotion and primary prevention. For example, the introduction of general management discussed earlier, affected the roles of nurses generally but those of health visitors in particular (Gough, 1997). The nature of managerial control, with its focus on efficiency, made it increasingly difficult for nurses in the community to defend their work. Health visiting, in particular, was not easily translated into discrete quantifiable episodes (Gough, 1997). The new system marginalized the non-medical, social and community-based approach taken by health visitors and has left health visitors with concern for the long term viability of their role (Cowley, 1995).

Organisational changes introduced by the community care reforms have raised further concerns about the viability of the health visitor role. Prior to the reforms, the NHS employed health visitors. They defined their own priorities and visiting patterns, drawing their caseload from either a defined geographical area or a population served by a primary health care team (Cowley, 1995). In the 1990s, most health visitors became employed by NHS Trusts, and their work became more closely linked with the GP

practice. This arrangement has placed the health visitor's role in a new relationship with that of general practitioners in primary health care.

Primary Health Care

The concept of primary health care as a strategy in achieving 'health for all' (World Health Organisation, 1978) has gained priority in the UK as well as in other parts of both the developed and developing world. The World Health Organisation (WHO) defines primary health care as:

Essential care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation at a cost the community and country can afford. It forms an integral part both of the country's health systems of which it is the nucleus and the overall social and economic development of the country. (1978, p. 2)

In 1978, a WHO conference in Alma Ata (in the former USSR) affirmed that health care is a fundamental right for all, and that there is a need for an equitable distribution of health resources. Participants at the conference argued for the expansion of primary health care to include multidisciplinary teams who could use non-technological based approaches to help improve the health of communities (Abel-Smith, 1994). This argument emphasized the importance of public health and health promotion in fostering health and preventive health strategies for individuals and communities and also the role of community health nurses as an integral force in the delivery of primary health care.

A common working definition for primary health care in UK government documents is the first point of contact for people seeking advice, support, and treatment (Ross & Mackenzie, 1996; Department of Health, 1989b). The WHO definition and this latter one, point to differing and sometimes conflicting views of health and health care that emerge in the research.

Community nurses, GPs, and the practice nurses that GPs employ, have a central role in primary health care. GPs and their practice nurses provide health services in GP surgeries and health centres. Many community nurses also work from this general practice base. Community nurses include primary health care nurses who work in GP practices, homes, schools, clinics and health centres. Among them are health visitors, discussed in the theme of role conflict.

Role Conflict: Health Visitors and GPs in Primary Health Care

“So many doctors want to see nurses in a subordinate role.”

The community care reforms emphasized the important role of both GPs and community nurses in the primary health care team. A team is a group of people who relate to each other to contribute to a common goal (Ovretveit, 1993). Caring for People (1989), for example, recognizes the gate-keeping role of GPs, while also acknowledging the “skills and expert knowledge” with which nurses are able to assist people (p. 35). In promoting fundamental changes in the organisation and financing of the National Health Service, however, the reforms also altered the nature of the working relationship between nurses in the community and general practitioners.

The discussion in this section focuses on nurses in the community in their professional relationship with general practitioners. The organisation of GP practices is central to this discussion. The issues I discuss emerged from the interviews and focus group discussions with health visitors, the only group of nurses among the participants in my research who were attached to GP practices.

The current organisation of nurses’ roles within the GP practice places health visitors in a situation of potential and actual role conflict. Role conflict may be described

as role expectations which are either conflicting or which are perceived to be incompatible between self and others (Biddle & Thomas, 1966). Role conflict may also be understood as systemic, that which arises from conflicting expectations, values, or practices within a social context. The theme explores the nature of role conflict experienced by health visitors in Scotland who face pressures to take on the GP practice priorities. Role conflict is explored in three inter-related sub-themes: hierarchy, power, and the struggle for autonomy.

The Hierarchy

The National Health Service is understood to be a bureaucracy. A characteristic of a bureaucratic organisation is generally considered to be one that has a clear hierarchy (Williams, Cooke, & May, 1998). However, as A. Laing (personal communication, April 21, 2000) pointed out, it may be more accurate to regard the NHS as a distinct hierarchy of professions. As a demonstration of power, hierarchies may be seen as the organisational means whereby the actions of members of certain occupations are controlled (Hugman, 1991, p. 66). Through exploring the ways in which their work is organised, health visitors' place in the hierarchy can be understood. In Scotland, most health visitors are employed by a community or combined acute care/community Trust within their respective health board regions. In addition to their status as Trust employees, most health visitors along with district nurses, are attached to or aligned with a GP practice. At the time the research was conducted, these arrangements varied, depending on whether the practice was a fundholding or non-fundholding one. A health visitor explained that in the fundholding practice, the GP buys community nurse services from the employer Trust. In the non-fundholding practice, the Health Board buys the

services of the nurses on behalf of the practice. These arrangements, whereby nurses are employees of the Trust but also are attached to GP practices raises questions about who is in charge. The nurses' reporting relationship is to nurse managers employed by the Trust. The link with the GP practice is that of a member of the primary health care team for the provision of community nursing services. As members of a team, both doctors and nurses can make distinct and complementary contributions, but the relationship is not that clear. "Doctors have the budgets," said a health visitor, "and they want to tell nurses what to do."

Nurses operate within a line management system in which, as noted, they are employees of the NHS Trust. Doctors work as relatively independent agents (Twigg & Atkin, 1994). This fact alone places nurses and doctors in different positions with regard to status and power. With the power and responsibility to manage their budgets, some GP fundholders may have perceived that they were also responsible for managing the work of nurses attached to their practice. According to a nurse in a manager role, "depending on the GP practice, nurses may not be able to provide the services they want."

The GP fundholding arrangement is no longer present in Scotland or the UK. As I noted in Chapter Two, GP fundholding has been replaced with local health care co-operatives. Nevertheless, the demise of fundholding has not fundamentally altered the nature of the relationship between doctors and nurses, as the findings will demonstrate.

In GP practices that were fundholders, GPs controlled their own budgets to cover the cost of running the practice and buying drugs and some non-emergency hospital services (Baggott, 1994). During its existence, the fundholding scheme was calculated

according to a number of criteria, including the number of patients on the practice list.¹

One of the principles underlying fundholding was that GPs would compete for patients in order to generate revenue. Those practices that used their budgets most effectively would attract patients and expand their services (Baggott, 1994), thereby generating funds that could be reinjected into the practice for expansion. Fundholders were able to specify within their budgets the volume of community services they required and purchase the nursing services that met the needs of their practice (Walsh & Gough, 1997).

In purchasing nursing services, some GP fundholders appeared to regard the nurses themselves as a practice resource over which they had control. A health visitor conveyed this perception in stating, “fundholding practices don’t want their nurses, *their* [italics added] nurses doing things that are related to patients not on their list.” According to A. Laing (personal communication, March 1999), some GPs apparently thought they were “buying nurses, not just nursing services, and saw the Trust as merely a labour agency”, thus the effect for nurses was not merely one of attachment to the practice, but one of management by it.

The notion of management also extended to nurses in non-fundholding practices.

A health visitor who had recently moved from a non-fundholding practice said:

I found you would get things not related to our work, because they couldn’t give it to a fundholding practice...their money is allocated for health visitor time, so we got extra, public health duties given to us.

The fundholders were paid only for so many hours of nursing time, and thus, according to another health visitor, “they’re quite - you’re not going off to do that because that’s not

¹Patients register with a GP practice, which constitutes the practice list.

our [italics added] patients.” Fundholders were seen to be exerting an even tighter degree of control on health visitors’ work than non-fundholders.

Some nurses expressed concerns that the focus on money in health care affected not only nurses but also clients. A perception expressed was that by one nurse was that “the patient is looked at different in terms of what they might cost.” For example, one nurse said that some fundholding practices were reluctant to pay for expensive drugs or procedures that would diminish the practice budget. There was also an expressed view by nurses and others that some patients received specialized services before the patients from the non-fundholding practices.

The concerns expressed about clients and the provision of services raises questions about the position of clients themselves in the hierarchy of health care. These questions are not the primary subject of this study. However, the issue of hierarchies leads to the issue of power in relation to role conflict.

Power

Power has many dimensions including hierarchy, status, and autonomy. Power, as a dynamic in administration and leadership settings is about the ability to exert control and influence (Hugman, 1991). Pieranunzi (1997) suggests that power is a concept that remains ambiguous and controversial, but is nevertheless present in all relationships and influences their course and outcome.

Doctors have demonstrated power in the NHS since its inception. One of the foundations of the National Health Service in Britain was the dominant medical view that the causes of ill health could be found from the scientific study of disease, and at least partially as a result, the acute services received priority funding (Neave, 1994). Both this

medical-centred approach and structure in the NHS have helped to maintain the power of the medical profession.²

The power of the medical profession may be demonstrated in both overt and covert ways. A notion of power is embedded in one health visitor's description of her role and work:

When you are actually going through the training we are taught to look at everybody's health and concentrate on cradle to grave but when you actually come out in practice, maybe because of the way policies are delivered or whatever and GPs or fundholding, our work with children really domineers.

The construction of health and social policies is a demonstration of power and expresses the interests of dominant groups, such as doctors, working through government. Within the policy arena, the operation of power is the process by which the interests of one group are recognized and acted upon over the interests of another (Gough, 1994a, p. 68). Thus, even when policies are not intended for nurses, they can impact on nurses' roles and nurses' work.

For example, work with children has always been an important feature of the health visitor's role. Contact with families begins in the antenatal period or with one statutory visit to every family with a new baby (Cody, 1999). Health visitors assess infants and children for the early detection and prevention of problems in growth and development. They provide advice and support to parents, make referrals when specialized assessments or services are required, and work closely with social services to plan interventions for children at risk for abuse or neglect. Currently, all children under

² This medical-centred approach to health services is also reflected in policies related to community care, which will be discussed later.

the age of five and their families receive at least one visit for the purposes of health promotion and preventive care (Cowley, 1995).

But increasingly, health visitors are taking on work with children that is shaped by the priorities of the GP practice to which they are attached. A health visitor explained how work with children taken on by GPs becomes part of nursing work. "GPs get a fee for every immunization they carry out," she stated. "Now most health visitors are carrying out immunizations."³

This passing on of work relates to the practice of delegation, defined as the referral of a set of tasks from one professional group to another (Ross & Mackenzie, 1996). A nurse manager stated that the delegation is primarily in areas of financial incentives for GPs. This statement requires some explanation of the contract the GPs hold with the NHS.

Since April 1993, the contract for physicians has included a community element from which GPs, or health boards in the case of non-fundholders, must purchase a range of community health services (Laing & Cotton, 1995). Depending on their practice population and the nature of their practice priorities, GPs may elect to receive special fees for discretionary services such as screening which emphasize work with children or the elderly. The contract also includes financial incentives for some aspects of community care for children such as immunizations (Ross & Mackenzie, 1996). In this way, the delegation of tasks from doctors to nurses is itself a demonstration of professional power.⁴

³In contrast to community nurses in Canada, nurses and health visitors in the community in Scotland have only recently begun to administer immunizations.

⁴ The same may be said of nurses who may delegate nursing tasks, for example, to nurse assistants.

Although work with children is an activity consistent with the health visitor role, increasingly the nature and frequency of this work is linked with GP practice priorities.

Similarly, health visitors described an increasing emphasis on their role in health promotion as one that is linked to priorities of the GP practice. As one health visitor observed:

There are a lot of changes in the last couple of years in government policies, as well there is a bigger slant toward health promotion and the GPs are getting encouragement, yes encouragement shall we say, financial and otherwise, to take on these health promotion activities which they then pass on the health visitors and assistants.

Changes that health visitors have observed in their work include more group-oriented activities such as coronary health clinics, a decline in home visits, and as one nurse said, "more one-off things" like health promotion clinics and fairs with children.

Activities the nurses described as health promotion may actually encompass one or more of three role functions: health education, health promotion and public health (Ross & Mackenzie, 1996). Health education is planned individual intervention aimed mainly at affecting the voluntary actions of individuals (Ross & Mackenzie, 1996). The health visitor's educative work with children and families is among the health education initiatives. Health promotion encompasses health education and is aimed at social and political action and change that provides opportunities for improving health status among individuals or groups (Ross & Mackenzie, 1996). Public health tends to be focused on disease prevention, primarily at a population level. It is likely that the health visitors' increased focus on health promotion will actually be directed to secondary prevention such as screening for the early detection of disease. This initiative is more in keeping with the priorities of general practice (McClymont et al., 1991).

The shift described by health visitors to more group and population-based health is consistent with WHO directives discussed earlier. It is also consistent with the policy paper, Working together for a healthier Scotland (1998b), which describes an opportunity for nurses, particularly health visitors, to develop the public health and health promotion role through assessment, planning, and teaching with groups of people (Hoskins, 1998). Despite some consistencies with policies, health visitors perceive that it is the priorities of the GP practice that are taking precedence in determining the nature of their work. A health visitor gave an impression of the health visitor role within the GP practice stating, "We are becoming more prioritized."

While nurses are expected to follow the practice priorities, they are also facing restrictions to meeting their own, although not all health visitors in the study identified this as a concern. One health visitor expressed the view that taking on the work from GPs is actually better practice. "GPs have more time for clinical work," she said. This apparent accommodation to the role of doctors may reflect a preferential valuing of doctors' work, sometimes subscribed to by nurses. Witz (1994) suggests nurses often describe their own value either in terms of their proximity to or distance from doctors. In other words, the extent to which nurses can assist doctors may either enhance or diminish the perceived value of nurses' work.

The community care reforms and other policies surrounding the organisation and financing of health care have continued to perpetuate the structures and practices that favor and reward the interests of doctors. As Ham (1992) states:

Medical dominance does not imply a conspiracy against subordinate groups, but rather it reflects the power of doctors, their control of key resources such as

expertise and knowledge, and their ability to achieve acceptance of their own concept of health. (p. 229)

The struggle for autonomy emerged as a concern for some nurse participants, and these concerns arise in the next sub-theme.

The Struggle for Autonomy: Handmaiden versus Professional

Autonomy is often linked with power and the ability to control one's work.

Autonomous work is the discretion about the type of work people do and the balance of time spent on different activities (Ovretveit, 1993). The struggle for professional status in nursing is often characterized as a struggle for autonomy and power. Health visitors and other nurses expressed concern, however, not only for their work, but also for families and children. They also expressed contrasting views on the extent to which their relationship within the GP practice was impacting negatively on their ability to determine the nature and content of their work.

In the view of one health visitor, the organisational arrangements surrounding community care are strengthening traditional power relations between doctors and nurses, and diminishing the ability of nurses to direct the nature of their work:

With respect to doctors, I have seen more of a back to the handmaiden attitude than ever since community care came in... Doctors don't realize how much work health visitors and nurses do. So many doctors want to see nurses in a subordinate role.

Within an historical and cultural context, female nurses have taken a subordinate, non-professional role in the male-dominated medical division of labour (Witz, 1994), a difference that persists to the present day. Sex divisions and gender divisions of labour continue to fall along similar lines. Miles' (1991) analysis of the division of labour for males and females in the NHS in Britain reveals that seventy-five per cent of the workers

are women, but their distribution in the hierarchy is very uneven. Approximately twenty per cent of doctors are women as against more than ninety per cent of the nurses. Three quarters of the semi-skilled and unskilled manual workers in the health labour force are women, most of them employed part-time (Miles, 1991).

Gender divisions also reflect the distribution and exercise of power, and the differential valuing or devaluing of work. Nurses' work is caring work, typically seen as women's work. Some perceive it as a low status activity that is based on innate skills, and does not require professional education (Gough, 1997).

The role of the nurse as handmaiden, described by the health visitor, is consistent with evidence cited by Itzin (1995a). Itzin states that in both the public and the private spheres there is a hierarchy of value and power in all relations between women and men that is gendered; the work men do is accorded greater value than the work women do (p. 261). Gender provides a way of conceptualizing roles and work, and both doctors and nurses have been socialized to these views.

The role of handmaiden is, however, one to which nurses themselves may be inadvertently contributing. Nursing has always struggled with its identity, its status as a profession. Topics such as nursing's discrete body of knowledge and theory and nursing's scope of autonomous practice, elements which mark professional status, are frequently debated in nursing literature. Chaska (1990) states that by not agreeing on phenomena such as the knowledge and theory that are of unique concern to nursing, the discipline is vulnerable to adopting knowledge from other disciplines. Many nurses believe that the answer to advancing nursing is learning more about, and practicing, components of medicine.

Two of the participants who held specialist roles expressed a preference for taking on components of medicine that may be delegated by doctors to nurses. They described developments in Scotland that may allow nurses to perform minor surgeries and to prescribe certain medications, which to some degree, may increase nurse autonomy. One specialist nurse spoke of the interest some nurses have in learning an endoscopic procedure for the insertion of a type of gastrostomy tube. This training provides nurses with an opportunity to extend their role particularly through the acquisition of medical skills.

In the current debate in Britain about the future of nursing, some nurses are advocating an extension of the nurse's role, one which enlarges the role by incorporating medically derived tasks, devolved to nurses by doctors (Witz, 1994, p. 31). Many nurses welcome the opportunity to take on work that previously was confined to medical practice. As one nurse participant said, "It makes the work more interesting." Some nurses may see this work as a way of enhancing their role and status as a profession. For some nurses, socialized to expect medical dominance, role extension may not be perceived as conflictual. For example, one health visitor, observing that the reforms had led to changes in the degree of nurse autonomy, stated, "We didn't have the same contact with the GP practice [in the past] that we have now. I suppose we were more autonomous at that time. But I much prefer the way it is now." In a later interview she said that it's up to the individual if they are autonomous. "I didn't start a smoking clinic even though the doctors wanted it," she said. In this view, autonomous practice is a matter of personal choice or preference, or it may also point to the role of resistance in response to medical power.

In contrast to the health visitor's stated preference, autonomous practice was an important consideration for three of the four nurses in my research who expressed satisfaction with their roles. These nurses were not attached to GP practices and had relatively independent specialist roles in the community. They also saw themselves as able to contribute meaningfully to a team that included doctors and other professionals. The notion of autonomous practice is consistent with the concept of an expanded role, one that provides an opportunity for nurses to develop nursing knowledge and theory by building on the strengths and value of nurses' traditional concerns for clients. This building on nursing knowledge and theory assists nurses to understand and re-define their roles in relation to clients rather than in relation or reaction to medical colleagues. Consistent with the UKCC Scope of Professional Practice (1992) document, the expanded role also enables nurses to consolidate their autonomous scope of practice (Redfern, 1997).

In contrast to the perception among most of the health visitors that the organisation of care was constraining their ability to direct their own practice, the role of school nurses is moving toward an expanded role and greater autonomy. According to one participant, the school nurse "is now a professional doing her own work. She refers to the doctor only as necessary." I did not have an opportunity to interview school nurses directly, however, the participant I spoke with described significant role change among school nurses in response to government policy, and said that recent government policy concerning health care in schools has changed the emphasis in school health and promoted an expansion of the nurse's role. In the past, the participant stated, every child in school received a medical exam, but following the guidelines of the new program, the nurse now

makes an assessment and decides whether or not to refer the child for medical review or other services.

This opportunity to have greater control over decisions surrounding the care of the children has helped to empower the nurses. One nurse who had previously worked as school nurse, said that the schools nurses still have a long way to go in becoming autonomous. However, the participant who described significant role change, also provided a striking observation of the impacts of the change:

It has made a tremendous difference in their attitude. Others see the change in the nurses. They have something they can say they are doing which is their professional responsibility. It brings out their skills, gives them an ability and desire to seek more skills. They want to learn more now. Before there was no place for them to go...I see the change going from handmaiden to professional in their own right.

This observation underlines the relationship between autonomy and job satisfaction, one that is confirmed by a UK study (Spurgeon, 1997) assessing professionals' views of their own roles. The study found that where empowerment offered real autonomy and control over the content of their work, there were much higher perceived levels of satisfaction and effectiveness. These findings are consistent with those of Pieranunzi (1997), whose research with nurses revealed power and empowerment to be transformative, contributing to the "richness of lived experience" (p. 162). UK studies of doctors and nurses have reported that conflicts arose from the unequal balance of power between doctors and nurses, as nurses struggled to reconcile their subordinate image with the development of professional autonomy (Cowley, 1995).

The discussion of autonomy has focused largely on the scope of practice, and the implications for nurses and health visitors' roles. But what are implications for clients, in

this study, children and families? In follow-up interviews I conducted with participants in June 1999, health visitors confirmed that practice priorities are controlling the nature and content of health visitors' work. One specialist nurse stated that things were "getting worse" than they were when I was in Scotland eighteen months prior. The nurse said:

Health visitors are not able to do the nitty gritty of health visitor work such as breast feeding follow up. The GPs won't allow it. They are paid according to the number of people who go to the clinic, so they want health visitors to do the well man and well women clinics...Mums are coming in with babies that have problems. Health visitors used to visit weekly for at least six weeks. Now they might visit twice.

In the words of one manager, the "real work" of health visitors is not being done, and the direct contact work with families has been pushed aside. Other work, such as the preschool health checks by health visitors is also gone, the manager said. The concerns expressed by some of the nurses throughout this discussion reflect distress, not only with their changing roles, but also with the impact that the changes are having on the health of children and families.

The role conflicts stimulated by the reforms are perhaps only now emerging as health visitors and other nurses in the community begin to identify changes. These changes concern the conflict between nurses' own expectations for the provision of comprehensive preventive care to children and families, and those expressed through the organisation of the NHS and GP practice.

At the time of the follow-up interviews, the purchasing role of GP fundholders and health boards in Scotland was being replaced by that of local health care co-operatives under the guiding Scottish policy document Designed to Care (1997). The intention is that the groups, consisting of GPs, nurses and other professionals, will work with health

boards, NHS Trusts, local authorities and community groups to develop health improvement programs (Payne, 1997). Some nurses expressed the view that the establishment of LHCC to replace GP fundholding could make a positive contribution to redefining health care priorities and greater opportunity for nurses to influence care.

For example, several health visitors said that the local health care co-operatives had selected priorities that influenced their role, but they had input into those priorities. The priorities included coronary rehabilitation, teen health, and computer technology. A health visitor stated, "The other things will carry on that have been part of the role." Some nurses and other participants said, however, that it was too early to determine what, if any impact, the LHCC would have on the nature of work for nurses in the GP practice, or what voice they would actually have in the arrangement.

In essence, the structure of health care organisations provides a framework for the influence and power of medicine. The nature of financing GP contracts gives GPs the opportunity to make key decisions about nursing services and in what ways they will utilize nurses' roles, a view confirmed by Witz (1994). Through special incentives for physicians in primary health care, government policies have impacted, intentionally or unintentionally, on the ways in which nurses organise, prioritize, and deliver nursing care.

Role conflict suggests another, underlying theme, that of value. It raises questions concerning the value of nurses' roles and nurses' work. If nurses' roles in their work with children and families are valued, why are they constantly subject to external forces promoting their change? And what about families? In what ways does change affect them, and reflect how they are valued? I explore these questions in the next chapter.

In this chapter's next and final theme, the discussion shifts from conflict to confusion, as I explore relationships between policy and roles at the interface of two organisations, the National Health Service and Social Services departments under local authorities.

Role Confusion

"Health for this, Social Services for that, but it isn't very clear."

Introduction

The roles of nurses in the community are situated primarily within the organisational structure of the National Health Service. In delivering nursing services, nurses work not only with GPs in the context of the GP practice, but also with social workers within Social Services departments, where they are involved in the provision of community care. As demonstrated in the preceding theme, the way in which roles are organised and policies are implemented helps to shape the nature of work and the interactions between the groups involved.

Role confusion emerged as a major theme in my discussion with nurses and other research participants from Health, Social Services, and the voluntary sector in Scotland. The participants characterized the confusion as arising in the context of what many termed a "Health and Social Services divide", which they said is creating barriers to the effective delivery of community care services in Scotland. I have used the term role confusion to describe a lack of clarity in the role boundaries between nurses and social workers, as well as between the roles of their employer organisations, the NHS and local authorities. Each organisation respectively, is responsible primarily for the health or social care components of community care.

Community care, described primarily as social care, was not actually intended for children (DOH, 1989b), the client group, who along with their families, are the focus of this research. However my research demonstrates that, although the community care legislation was not intended for children, it is having an impact on the care of children and their families. This finding is consistent with the policy statement outlined in Caring for People (DOH, 1989b):

There is no intention of creating a division between childcare and community care services; the full range of social services authority functions should continue to form a coherent whole. (p. 3)

Although the community care reforms have given Health and Social Services new directions, the divide itself has a lengthy history. Before turning to the discussion of role confusion, it would be useful, therefore, to discuss the historical and legislative context for community care.

Context to the Theme of Role Confusion

Community care in Scotland and the rest of the UK derives from policies that have spanned several decades, and concern the roles and responsibilities of the NHS and Social Services departments under local authorities. Historically, there has been a division between Health and Social Services that is rooted in the differences between the organisations and the professionals working within them (Pietroni, 1994). Social Services departments are situated outside the management structure of the NHS, thus not only have the professionals in each organisation been separated, but each has different lines of management and accountability (Pietroni, 1994). These structural arrangements have posed obstacles to achieving the goals set by the government for collaborative or joint working between the two organisations.

In the past decade the government of the UK introduced the community care reforms, which provided new directions for community care. Subsequently, all areas of activity in both the NHS and Social Services have been completely re-organised (Pietroni, 1994). The Act also delegated to Social Services departments the lead responsibility for planning and delivering community care.

Organisational changes in both the NHS and Social Services have also promoted changes in the roles of nurses and social workers. Social workers have taken on new roles as purchasers and care managers as distinct from their previous role as care providers. Nurses in the community, as discussed in the previous theme, are taking on priorities associated with the GP practice to which they are attached, as well as carrying responsibilities in line with their employer Trust. They are also taking on the health care services needed to help maintain in their homes children and adults with health needs who would have otherwise resided in hospitals or institutions.

Within this environment of change, those working in Health and Social Services have a mandate to collaborate. Government directives have attempted to overcome the historical Health and Social Services divide by defining more clearly the respective responsibilities of the NHS and Social Services departments.

As I indicated, the theme of role confusion emerged from interviews that described the lack of clarity in role expectations or in role boundaries experienced by community nurses and other participants. Although participants spoke to some extent about the negative impacts of role confusion on families, their primary focus was the nature of confusion and its effects on professional roles and organisational relationships. My analysis of research interviews and policy statements also revealed factors that contribute

to role confusion and serve as real or potential barriers to joint working. I will now discuss the theme of role confusion through three sub-themes: policy, the professionals, and the organisations.

Policy: Conceptualizing Health and Social Care

The community care reforms outlined central government's policy and direction for the provision of community care. Caring for People explicitly stated that the distinction between health and social care governs the funding of health and social service authorities, and that there may be areas where the distinction between health and social care is blurred (DOH, 1989b, p. 50). One of the stated purposes of the document was, therefore, "to clarify roles and responsibilities" (p. 4).

One participant from an agency in the voluntary sector reflected, however, on the failure of policy to give explicit direction to Health and Social Services organisations for the provision of community care:

It's been a problem since the NHS and Community Care Act 1990. Things have been divided up. Health is responsible for this, Social Services for that, but it isn't very clear. Before the Act, I think people just took on more generic tasks. The Act has forced people to think about what they are providing and what it costs.

The relationship between policy definitions of health and social care, and the costs of care are central to organisational and role confusion. Health care in Britain can be freely accessed, whereas social care is means-tested to determine cost to the service user. Government policy documents associated with the Act attempted to clarify respective roles and responsibilities for community care by drawing a distinction between health and social care. In other words, the Act forced people to think about whether they are

providing health or social care because each must be viewed differently in terms of cost. Yet the distinctions between the two are conceptually flawed, as I will explain.

Caring for People defines health care as services provided under medical and/or nursing supervision that remain the responsibility of the NHS (McKay & Patrick, 1995). Social care is assistance with daily living, home adaptations, budgeting, housing, respite, employment and education (DOH, 1989b, p. 10). Social Services departments under local authorities are responsible for planning these services. But community care is also defined as social care - the care provided for people to remain living independently in their own homes or with assistance in residential settings (Ross & Mackenzie, 1996). Caring for People states that community care is about health as well as the social needs of the population, and says that Health and local authorities would need to work closely, especially in areas in which "it may well be difficult to draw a clear distinction between the needs of an individual for health and social care" (DOH, 1989b, p. 33).

Herein lies a key source of confusion. Community care, the services people require to help them maintain well-being and independence in their own homes and communities, involves both health and social care. Furthermore, the definitions of social care and community care fail to acknowledge all the health care that goes on in people's homes and all the caring work by families. Thus the definitions provided in policy perpetuate a division in the delivery of community care services by failing to provide a conceptual framework that addresses the relationship between health and social care.

Health visitors explored an aspect of this relationship in a discussion about their role with children and families:

HV 1: It's crisis intervention. You really can't deal with the health issues because there are so many social problems, financial problems, just deprivation. You can't really focus on health issues.

HV 2: That depends if you want to separate health from social issues.

HV 3: I don't think you can separate them. I find it much easier in a placement area like this [not deprived] to set up a plan and say these are the health promotion issues for this family that I want to set up at this age and that, and you can do that much more readily [here]. You might go in to a family and they don't have any money and electricity is cut off, so discussing home safety and healthy diet becomes a fairly low priority. Your wondering how you are going to get the children warm is a much bigger priority so it is quite different [in a deprived area].

This discussion demonstrates one of the relationships between health and social care: the negative effects of unemployment and deprivation on nutrition, safety, warmth and well being. The health visitor's assessment and plan of care are guided by recognition of this relationship. In this example, the health visitor recognized that the social care needs related to deprivation, such as food and shelter, took precedence over her immediate goals to promote good nutrition and safety. In essence, she described the critical role of social determinants in health, and thus she revised her plans and priorities for the family. This perspective on planning underlines the need for a conceptualization of community care at the policy level that is consistent with good practice and reflects the inter-relatedness of health and social care.

The community care policies generally do not reflect this inter-relatedness. By defining health care as services provided under medical and nursing supervision (DOH, 1989b), they reflect a bio-medical approach, one that tends to view health as the absence of disease and health care predominantly in terms of treatment and cure. This view medicalizes health, and fails to address the social determinants of health such as poverty, unemployment and education. Yet successive studies in the UK have demonstrated

relationships between ill health and the cycle of deprivation, for example, the way in which chronic illness and accidents in children increase in relation to the family's poverty (Allsop, 1984). The failure to provide a conceptual bridge in policy between health and social care ultimately leaves professionals struggling to gain clarity about their respective roles and responsibilities.

Hugman (1991) affirms this view of the lack of clarity between health and social care, and the ambiguity it creates for nurses and social workers. He states that the boundaries between the caring professions are constructed around concepts of health and social problems, but that when clarity between these is lacking, as it often is, there is an impact on professional relationships (p. 101).

The Professionals

In this sub-theme, I discuss the work and professional culture of nurses and social workers, and the ways these contribute to role confusion. In Scotland, social workers who are called care managers, take the lead responsibility for assessing clients' needs for such things as respite care, aids and equipment. Nurses in the community, along with GPs and other primary health care workers, are responsible for the health component of community care.

One nurse who works with children described her concern about the role of Social Work in planning community care services:

If care can be done by carers, it's social work. If we need a nurse, it's health budget. With the Care in the Community Act, the Social Work department will get a cut of health money. Social Work has more money, but they don't always understand the needs.

In taking the lead for assessment and planning, social workers must determine whether the client need is for health or social care. But they are only responsible for assessing people “whose needs extend beyond health care to include social care...” (DOH, 1989b, p. 18). If they perceive that there are health needs, there is an expectation that they will involve doctors and/or nurses in the assessment process (DOH, 1989b). Yet the requirement for health or social care cannot be determined by who performs the task. Tasks change and are often more complex than originally anticipated. Different professional groups also share tasks or components of tasks. These situations create role confusion often associated with role overlap, or a blurring of role boundaries. There is a lack of clarity about who does what, and who takes responsibility. This lack of clarity is heightened by situations in which one profession questions whether others have the skills and knowledge to do the work (Ovretveit, 1993).

The work.

Nurses and social workers are educated for different kinds of work, differences that have historical roots. Early social work in Britain provided care to the respectable working classes, whereas nurses were found with the poor and working classes (Hugman, 1991). Although these distinctions have altered in modern day, nurses and social workers often misunderstand and even mistrust the nature and content of one another’s work.

One participant in the voluntary sector who works with both Health and Social Services expressed her concern about the provision of services by workers from both sectors:

It isn’t clear what is considered social or health, and if both are doing holistic assessments it’s very unclear. There are huge gaps and a need for more joint training.

The delivery of nursing and social care services flows from the assessment. But social workers and nurses may differ in their approach to the assessment process itself. The Royal College of Nursing in the UK defines assessment as the process of collecting information about the individual and from that information making decisions about their health status and the best way of working towards improving or maintaining health (Hope, 1995). Assessment is a process, not a one-off activity, and it should be comprehensive, dealing holistically with the individual (Hope, 1995).

The concept of a holistic assessment is one familiar to nurses and health visitors. Health visitors and other nurses, whose traditional area of practice is in the community, conduct assessments based on an integrated approach, one which assumes that people are biological, psychological, social and spiritual beings who live in equally complex environments (McClymont et al., 1991). Nursing assessments may also be defined by the dominant demands of the role: district nurses, for example, may concentrate more on physical needs, while health visitors may tend to focus on the developmental needs of the child and family (Ross & Mackenzie, 1996).

In contrast to health visitors and other nurses, the role of social workers as care managers is no longer one of direct involvement in service provision in Scotland. Their assessment is supposed to be led by the assessment of needs of individuals rather than by the services available (Henwood, Wistow, & Robinson, 1996), however, they also may be constrained by the expectation that they provide services within the available resources (DOH, 1989b).

A health visitor challenged the notion that community care is led by the assessment of needs. She stated, "It's not needs led, it's money led." Ross and Mackenzie (1996) support this view in affirming that the introduction of care management into community care is based on value for money considerations (Ross & Mackenzie, 1996). The concept of value for money reflects a utilitarian approach that often underlies the need for rationing of resources (Elliot, 1995). In contrast, nurses' work is often guided by a rights-based ethic (Elliot, 1995), one that emphasizes the individual's right to services. Thus a key issue in service delivery is how money is allocated following assessment. Regardless of whether or not both social workers and nurses conduct holistic assessments, there may be different considerations in the way that decisions for services are managed.

Social workers are expected to assess people whose needs extend beyond health care to include social care (DOH, 1989b), and thereby determine a service response. But what do these distinctions mean for families? For example, incontinence is a common problem related to age and/or disability. But "social workers used to think incontinence wasn't a health issue," said a nurse who works with disabled children, "and some social workers have been telling district nurses what a patient does or doesn't need in terms of care." From a social care perspective, incontinence is viewed as an activity of daily living, one that may require non-nursing help to assist the family in maintaining an individual's care at home.

In contrast, many nurses view incontinence as a source of mental, physical and social distress. It can also be a sign of a more severe and underlying medical condition that must be investigated. Furthermore, whether or not it is preventable in a particular client, there are nursing strategies required and available to minimize its impacts on the

individual's skin integrity, activity, self esteem, and opportunities for socialization. There may also be significant cost factors in managing incontinence that need to be addressed. While nurses themselves may not be required for daily care, their role in assessing and planning care may be vital to ensuring that these issues are addressed.

The issue of what constitutes a health or social need must thus be considered within the broader question of what constitutes need. The concept of need is usually linked with service provision (Ovretveit, 1993). Different perspectives, however, between nurses and social workers on client needs, work, and service provision may be heightened by mistrust and differences between the professions themselves.

Roles and professional cultures.

Each profession has an occupational culture characterized by different philosophies, values and assumptions. Each profession differs in a number of other factors: (a) its sense of mission, aim and tasks, (b) its focus and orientation, (c) its ideological base and its technology, (d) its status and prestige, and (e) its orientation to clients, patients and other professionals (Pietroni, 1994). Research among health and social care students supports the view that, not only are students not trained for interprofessional collaboration, but they also may be receiving training that educates against it (Pietroni, 1994). Some of these differences between nurses and social workers appear to be further intensified by the changes that have occurred following the reforms, as I will demonstrate later in this discussion.

One of the ways of reducing the barriers between professions is for each professional group to understand their differences. A participant from a charitable agency described a need for joint training and stated, "There need to be joint assessments. Maybe

people need to go out together.” An effective but often unrecognized method of learning about one another’s work consists of professionals working together. Joint assessments, in particular, reveal the extent to which health and social needs and services overlap. Clients rarely have health care only or social care needs only, and it is unlikely that any one profession can meet them all (Cutler, 1998).

Working together facilitates clarity surrounding respective roles. In the example provided earlier where social workers stated that incontinence was not a health issue, joint assessments could expand the views of both nurses and social workers. Nurses contribute their understanding of the role of preventive health care and education in dealing with incontinence, which are much broader issues than the task of cleaning and bathing someone who is incontinent. Social workers contribute to an understanding of their budget constraints in choosing care providers, and of the policies and practices that guide decision-making. Both may contribute their understanding of family systems and of the impact of disability and illness on families. Joint assessments and planning also enable the nurse or social worker to determine who is best suited to take responsibility for care management with a specific client. Joint assessments thus facilitate joint planning and help to identify the contributions each profession can make.

One health visitor in a specialist role who regularly conducts joint assessments with a social worker reflected on their value, and stated, “We learn from each other...Part of the nurse’s role is to be an advocate. Social workers are equally interested in helping clients.” The role of advocate, one shared by both nurses and social workers, recognizes the primacy of the client’s needs. This shared recognition helps to reduce rivalry and the

struggle for power (Ross & Mackenzie, 1996) that often occurs between professional groups.

However, Hugman (1991) points out that it may not be professional differences but role similarities which are leading to confusion and struggle between nursing, social work, and other remedial therapies. The growth of the community as the location of professional intervention has emphasized the extent to which the caring professions lay claim to similar skills and practices (Hugman, 1991, p.102) for similar groups of clients, and are thus engaged in a struggle for professional power. This struggle may be exacerbated by struggles between the respective organisations.

The Organisations

An organisation is commonly thought of as a collection of workers with varying roles designed to achieve explicit goals in the output of goods or services (Tyson & Jackson, 1992). Others see it as a form of negotiated order in which groups and individuals contest for positions of power while also influenced by wider social, economic and political forces (Williams, Cooke, & May, 1998, p. 93). Thus, although this discussion involves two specific organisations, the NHS and Social Services, it also concerns the nature of organisations themselves.

Inter-professional collaboration is shaped or impeded not only by professional groups but also by the employer organisations. The nature of organisations is explored in relationship to three factors: organisational culture, responsibility, and change.

Organisational culture.

Organisations, like professions, have their own culture and power structure.

Organisational culture is part of the taken-for-granted, everyday reality that is difficult to

see, and refers to the shared symbols, language, practices, and deeply embedded beliefs and values (Newman, 1995).

The NHS and Social Services, as discussed earlier, constitute two distinct and different organisational cultures. A participant who conducts research in the voluntary sector described one aspect of their cultural differences:

If community care is going to come in, we need to work together...Local authorities don't want to meet with health board appointees; Social Work tends to work with the Trust.

This statement refers to the fact that local authorities are elected officials while health board members are appointed. This seemingly minor difference illustrates an important consideration between organisations: the way in which agencies are organised affects their relationships with one another, their perceptions of power and status, and their preferred ways of doing business. These ways of doing things are an aspect of organisational culture, where those in positions of leadership and power have much influence on what is and is not done and how things are done (French, 1995). Organisational arrangements may themselves serve as barriers to joint working.

One health visitor provided her view of the new way of doing business since the introduction of the community care reforms:

It's been too focused on management, bringing in management consultants. They tried to make it [community care] a business, run things with accountants. Money rules their brains. They wanted competition, now they want cooperation. The reason people's responsibilities have changed is money.

Traditionally, both the NHS and Social Services operated as bureaucracies or as bureau-professional regimes involving different but relatively stable balances of power (Newman & Clarke, 1994). However, the 1990 Act and community care reforms changed

the model of organisation within and between health and social services to one associated with business and the market (Ovretveit, 1993) and introduced new relationships.

Consistent with the notion of an internal market, the legislation shifted the provider function formerly held by social workers to new players - providers largely in the

voluntary and private sector who would compete to deliver the best value for money.

This value for money theme was consistent with the management culture, introduced in the 1980s in Britain, which posited that the manager, compared to the professional or bureaucrat, is driven by the search for efficiency rather than professional standards or bureaucratic rules (Newman & Clarke, 1994). Transfers to the private sector became justified not only in terms of increasing competition and efficiency but also in terms of greater consumer choice and control (Neave, 1994). These changes have increased the complexity of relationships and inter-organisational work.

However, policy rhetoric has now shifted from the need for competition to the need for cooperation between the different sectors. The plan is for agencies to coordinate the different types of services in order that a population or person gets the services they need without gaps or duplication (Scottish Office, 1997).

In the second set of interviews I conducted in June 1999, there were indications that organisational differences are continuing to impede cooperation between nurses and social workers. The impact of organisations on workers' efforts to collaborate is confirmed by Ovretveit (1993), who says that the type of cooperation between organisations influences how practitioners work together in the community. A nurse said that there is a will between workers at the ground level to collaborate, but another participant added, "funding is a big issue."

Responsibility: who pays?

The focus on resources seemed to many participants to serve as an underpinning for poor cooperation, role and organisational confusion, and negative impacts on services. A participant from an agency in the volunteer sector explained, "People cared for and carers are caught in a resource fight about who pays."

Participants from all sectors expressed their concerns about the negative impacts of the Health and Social Services divide on families. For example, nurse participants reported difficulty in obtaining pieces of equipment for children with special needs because of a lack of clarity about whether the equipment was classified as health or social care. Based on the guidance (DOH, 1989b), home adaptations, equipment or aids that promote independence constitute social care, and their funding is considered to be the responsibility of Social Services. According to one nurse participant, either Health-employed nurses and occupational therapists (OTs) or Social Services employed OTs may be involved in assessing for aids or equipment. Thus, while the assessment may come from one department, the responsibility for funding may be shifted to another, depending on whether the need is seen as a social, health, or even an education type of requirement. The ensuing debates leave those who have assessed the need struggling in their efforts to meet it, and families caught in the middle.

An administrator, who described a concern related to the provision of respite care for children and their families, provided another example that illustrates a lack of role/organisational clarity. Respite care, like aids and equipment, is considered social care because it assists the family to maintain the child or cared-for person at home. The concern requires a brief history: Respite services refer to temporary relief for a carer from

their caregiving role. The community care legislation does not address the provision of community care services such as respite to children under 16, but local authorities nevertheless have obligations to children with or affected by disability. These provisions are expressed in The Children (Scotland) Act 1995, and require local authorities to provide services that minimize the effect of the disability on the child or his/her family (Watson, 1996). This definition includes the provision of respite, defined by Caring for People (1989b) as social care.

The administrator participant explained the concern. Social Services will sometimes fund carers to provide respite for children and their families. On occasion, nurses employed through the NHS may also be involved in the provision of respite for children and their families. But according to the definition in Caring for People (1989b), services provided by a nurse are health services. Yet neither Health nor Social Services have funding dedicated for children's respite, which has to be found from whatever pot of money the agency involved in the provision of respite has. A participant from the voluntary sector described the need for respite as one of the most pressing concerns for families who have children with special needs. This example illustrates that the divide is really a gap filled with needs and services for which neither organisation may necessarily assume fiscal responsibility.

One participant from the voluntary sector described the struggle for resources in terms of the devolution of power. She stated, "In terms of people fighting about who pays for what; budgets have been devolved and people are caught in a resource fight; there are less resources for services."

In implementing the community care reforms, the central government in Britain devolved budgets to regional health boards and local authorities, ostensibly to give communities greater control over their own needs and resources (Gough, 1994a). Critics view this shift from centralized to regionalized control primarily as one of shifting responsibility - "passing the buck" to a lower level of authority (G. Weller, personal communication, October 21, 1998). There is no clear evidence, however, that regionalization has been accompanied by a greater share of the resources (Davis, 1993).

Funding constraints are affecting the provision of community care services for both regional Health boards and local authorities. A health visitor said, "Community care has decreased the amount of resources. It's a fish net, full of holes." This image is consistent with the gaps in service provision and staff shortages also described by participants.

Community care was intended to provide a cheaper alternative to institutional care, particularly for the growing number of elderly in Scotland (DOH, 1989b). With the closure or downsizing of institutions people are moving into the community, "but we are finding it's not cheaper," stated a nurse who works with children. "To move a child into the community and have a night nurse with them can cost 54,000 pounds per year," she said. Nurses are, however, infrequently involved in respite care for children in the home.

Some critics of community care state that the main motivation is actually cost cutting, not because community care is cheaper, but because it shifts the burden of care to families and individuals (Bagilhole, 1996; Davis, 1993; Finch, 1990b). The issue of respite care and the shift in responsibility for care to families will be the focus of discussion in Chapter Five.

Change: the impact on individuals and their work.

Change emerged as a dominant thread throughout the theme of role confusion, and indeed, through all the major themes. In this section, I explore organisational change within and between Health and Social Services, and the impact of change on nurses and social workers in their efforts to collaborate.

Organisational change can be positive for individuals and their work. It can improve working conditions, help workers to feel more valued, reduce inefficiencies, and promote more comprehensive and responsive services. Change can also create disequilibria, distress and confusion.

The organisational changes that followed the implementation of the community care reforms were profound. One nurse described the impact as “change upon change” and another nurse said, “The whole system is still in a muddle from all the changes.” Other research also confirms that the reforms posed a major cultural challenge for those working within health and social services, who had to come to terms with radically new philosophies and approaches (Hiscock & Pearson, 1999).

Organisational restructuring constitutes a loss of stability which impacts on individuals in their roles, relationships and the work environment. Stability is a vital ingredient if collaboration between individuals and agencies is to be fostered and maintained. Nurse participants identified proximity of setting as an important factor in maintaining good relations. A health visitor who described good working relationships with social work colleagues stated:

We had a care manager based at the clinic for about a year and they moved earlier in the year. And that was very good when they were here because you were able

to stop in and have a chat and discuss anyone you were concerned about that might need extra services at all.

The informality of communication, stopping for a chat, was seen as conducive to building relationships, and the frequency of contact as helpful in overcoming differences in perspectives. Another nurse expressed the view that pressures on social workers have affected the nature of working relationships. "They've had budget cuts, and change of staff as well," she said. Organisational change may interfere with opportunity to establish and maintain relationships. One health visitor described the impact:

I found there is a deterioration in communication with the Social Work department. There seems to be high mobility. They don't stay there any length of time for you to develop a relationship with them.

Ovretveit (1993) states that the quality of communication within a team is a good index of its level of organisation and of the health of relationships between members. However, problems that at first sight appear to be communication problems are often problems with the design and structure of the team (Ovretveit, 1993). Staff mobility and attrition of staff may be symptomatic of role strain and overload, often associated with organisational restructuring. Similarly, role overload may be attributed to too much work, too many different roles and expectations, or to taking on a level of responsibility that is too great (Ovretveit, 1993), and relationships at work may suffer as a result.

The collaborative planning in which nurses did participate involved an informal grouping of practitioners. In informal arrangements, there is no agreed and binding common policy (Ovretveit, 1993), and opportunities for contact are often unplanned and infrequent. These arrangements can be difficult to maintain even in stable environments.

One health visitor described changes not only in relationships, but also in priorities that she has observed since the introduction of the community care reforms:

The other things is childcare. I have phoned up and asked them [social services] to take on things they would have taken on previously. They just wouldn't entertain it. They don't have the funds, they don't have the staff... where they used to be able to do preventative work.

As noted earlier in the chapter, each profession and agency has different ways of defining need, setting priorities and planning a service response. Health visitors, in their role with children and families, strive to intervene in situations to prevent crises. Their work is aimed at prevention, although their priorities are changing within the GP practice. Preventive care is often the lowest priority, however, for the allocation of scarce resources. With the introduction of market priorities in community care, the role of social workers is now more one of rationing resources and securing contracts than of providing services (Ross & Mackenzie, 1996).

One nurse found that the change in relationships required her to use pressure to ensure action. She said, "You have to put everything in writing. I used to just phone them up. Now I put everything in writing and they have to take some action." Lacking power or effective leadership to achieve their aims, nurses may resort to more formal measures to achieve desired ends.

Collaborative work may also suffer due to fear and uncertainty. A health visitor suggested that the degree of collaboration might relate to individual reactions to change:

I think it depends on personality. Whether or not you are professionally jealous. There is lots of that going on... concerns about the different roles comes from professional jealousy, fear of job loss, and suspicion between professionals.

Ovretveit (1993) challenges the popular notion that problems of cooperation arise from personality conflicts. He states that many problems of cooperation arise from poor organisation and structural contradictions and conflicts. Organisations that undergo massive change create uncertainty arising from loss of roles, relationships, and resources.

Many nurses in the community are already experiencing a loss of autonomy and control in their work within the context of the GP practice. The competing demands on nurses' roles in the community may further threaten their autonomy. While practicing within the policy remit of one organisation, local authority, they remain accountable to health authorities (Ross & Mackenzie, 1996) and increasingly, to the GP practice. In addition, the funding barriers between health and social care may prevent them from realizing their full role in care (Ross & Mackenzie, 1996). These structural faults are likely to heighten individual concerns about job stability, uncertainty about role changes, and fears of being devalued.

The organisational expectations and structures surrounding nurses and social workers thus appear to pose barriers to joint working. Both are struggling to retain their professional roles and identity in what one writer calls "the murky world of inter-professional work", including the barriers of different organisational structures, priorities, and funding mechanisms (Ross & Mackenzie, 1996, p. 83).

A study by Hiscock and Pearson (1999) also confirmed the impact of change on workers. They noted that practitioners in both health and social services were highly preoccupied with the pace of change within their own organisation and professional environment, prompted by the introduction of market mechanisms and the drive for cost

containment. Thus the development of external links with others, and joint working was hardly seen as a consideration.

There are two additional factors, power and gender, which some writers regard as barriers to collaboration between professional groups and organisations (Hugman, 1991; French, 1995; Witz, 1994). These issues did not emerge explicitly in my discussions with participants concerning the relationships between Health and Social Services, and the nature of role confusion. I discuss them later, however, in my concluding analyses.

The discussions in this theme project a somewhat pessimistic view of the ability of professional groups and organisations to work collaboratively. Participants I spoke with in June 1999, however, indicated that there are some signs of improvement in funding arrangements to facilitate the provision of equipment and services, and in other local efforts underway. Successes in joint working may ultimately reflect the effort and commitment of individuals to improve the delivery of health and social services.

Summary

The themes of role conflict and role confusion demonstrate ways in which government policies, implemented through organisations responsible for health and social care, are impacting on nurses' roles and their provision of services. Role conflict underlines the relations of power among the state, public organisations, and the medical and nursing professions, and the gendered social context in which nurses' and women's work are systemically devalued. Role confusion draws attention to the lack of clarity in policies that widen differences already existing between organisations and professional groups, thereby further impeding collaboration and affecting the provision of services to families. While issues of power do not emerge explicitly in the theme of role confusion, as

I have noted, the struggle for resources is a struggle for power. Government policies may, at times, be deliberately obscure in their intentions, in order to minimize the state's visible role in that struggle.

In the next chapter, nurses and other participants further describe relationships between policy and nurses' roles and work in the community. In the first theme, role strain, I explore ways in which, not only the organisation of care, but also location is exerting pressures and constraints on nurses' roles.

Chapter Four

The Location of Care: Care in the Community

Introduction

In this chapter, through the themes of role strain and role fragmentation, I explore the nature of nurses' roles with families and children with special health care needs in the community. Although the focus is on nurses and carers other than families, it is important to remember that families are the primary carers, and that the roles of nurses and others involved in the provision of care are mainly supportive roles. Within both themes, government policies continue to emerge as a major force in shaping both roles, and the support that families are receiving in the context of care in the community.

The community is and always has been the primary location of care for most children. Even children with chronic diseases or disabilities have been cared for predominantly in their communities and homes by their families. However, through much of the twentieth century in Scotland, families have also had the option of hospitals and long term care institutions, for children who required episodic or long term care by doctors and nurses. While care in the hospitals continues to be available for children with acute care needs who require hospitalization, the nature and availability of chronic and even episodic or acute care are changing.

Chronic and episodic care include, in nursing terms, both direct and indirect care. Direct care is the hands-on care provided by nurses, and/or the management of tasks that promote or maintain physical health, medical stability or comfort. Indirect care involves the planning, coordinating, educating, supporting and training that must go on to ensure that the family and child's needs for management of illness, health maintenance and

health promotion are met. Care also signifies the relationship that develops and exists between nurses and children and families.

Care is changing with its relocation from hospitals to the community. Changes in policy, technologies, organisations and attitudes are contributing to a new type of care in the community. Policies of the 1990s in Scotland and the UK have promoted the concept of care in the community, primarily for the elderly and other dependent groups in the adult population, as well as changes in the nature and location of care for children whose care requirements were previously met by nurses in hospitals and institutions. The roles of nurses in the provision of care are changing to respond to a shift in the provision of increasingly complex care to families and other carers in the community. At the same time, nurses' roles are becoming fragmented into more task-focused and technical care as boundaries shift between nurses, families and other carers.

The expectations surrounding the nature and provision of care for children with special health care needs are outlined in public policies that address the respective roles of governments, statutory, voluntary, and private agencies, and families. For example, some of the expectations of nurses and families in the provision of care are made explicit in policy. The roles of nurses in community care are referred to, for example, in Caring for People (1989b) in terms of the part they play in the primary health care team. Expectations of nurses and families are also contained in implicit policy - that which is operative (Twigg & Atkin, 1994). Policy may also have unintended consequences affecting those for whom the policy was not specifically intended. The themes that follow reveal implications of policies for nurses, and ultimately for families.

In the theme of role strain, I explore pressures for nurses to take on new components of work, and I discuss some of the changes emerging among nurses as a profession. In the theme of role fragmentation, I extend the discussion of emerging changes to explore ways in which nurses' roles and work are being divided, as well as changes to nursing itself. The discussion of these changes prepares the context for Chapter Five, in which I explore the changing roles of families.

Role Strain

“Health visitors may not be trained to do the tubes.”

Nurses are experiencing pressures on their roles associated with the shift from care in institutions to care in the community. These pressures may be described as role strain. Goode (1966) first described role strain as the difficulty people have in meeting their role obligations, and attributed strain to limitations in the allocation of energies to fulfil role obligations. However, this way of conceptualizing role strain does not reflect the experiences of nurses as described in the interviews.

In my research, role strain emerges as pressures on nurses to meet new role obligations and expectations, which arise in the context of policy developments, organisational changes, and other trends that are reshaping nurses' work with families. Role strain also arises in the context of emerging change in families' roles, as families and other carers take on responsibility for nursing tasks including technical care for children with special health care needs. I explore role strain through a discussion of three sub-themes: the nature and complexity of care in the community, role change, and generalist versus specialist roles.

The Nature and Complexity of Care in the Community

The nature of care for children in the community in Scotland is becoming increasingly complex. Care which once occurred only in hospitals is now taking place primarily in homes. Participants described the changes occurring in the care of children in terms of three main factors: policies, technology, and attitudes.

Policies.

The community care reforms of the 1990s, as mentioned, were mainly intended to reduce the institutional costs for the growing population of elderly in Britain, as well as for people with learning disabilities and mental illness. One of the goals stated in the reforms is to enable these groups to lead independent lives in their homes or in homelike environments to the extent possible (DHSS, 1989b). Although the legislative context of community care was intended primarily for adults and children over sixteen years, one participant in an administrative role described the influence on care for children:

The Community Care Act has likely influenced thinking about the care of children in the way that it did adults, perhaps especially with respect to children with learning disability, that is, if adults with learning disability were going to be in the community then children shouldn't be admitted to hospital in the first place.... It is always difficult to assess the extent of the impact of the piece of legislation because of other changes in thinking that were going on - people feeling that admission to hospital should be increasingly the exception for children both drove the legislation and was driven by it.

The Community Care Act 1990 and its associated reforms thus appear to have had an indirect but profound impact on the care of children in Scotland, an effect associated at least in part with the nature of policies themselves. Policies emerge in a cultural context and are influenced by societal values and trends. There had long been a societal view that children institutionalized for any reason, usually children that are learning disabled or who have been taken into care by the state, could be better cared for with families or in

family-like settings. In line with this thinking, policy initiatives have been underway for many years in Scotland to reduce the length of stay for children in hospitals and to move children living in institutions to their homes or smaller home-like places (Scottish Office, 1999). The costs of institutional care also advanced the need to restrain costs in acute and long term care and to promote options for community care. Thus, although the community care reforms were intended for adults, they propelled changes already underway in the care of children. "It was," stated the administrator, "an idea whose time had come."

Some participants described a direct correlation between The NHS and Community Care Act 1990, implemented in 1993, and the care of children. One nurse who works with children said, "Before the Act, children with special needs would have just stayed in hospital, but now we are moving them to the community." Another nurse stated, "The emphasis now is on care in the homes unless it's unavoidable to come to hospital." The reforms appear, therefore, to have propelled two trends, moving children out of institutions and keeping them out.

Most of the children who have resided in long term institutional care in Scotland, primarily children with learning disabilities and other health problems, have now been discharged to their families or to homes in the community. In Fife, I visited one of the community homes where four children who had been in institutions for the learning disabled are now cared for by carers hired by the voluntary sector, and in this setting, I was able to observe the nature of their needs and care. Although there are still some children living in institutions in Scotland, the numbers are reduced, and there are few new admissions. One participant indicated that there are still one or two schools in the

voluntary sector in Grampian that take children with various disabilities, usually with some element of learning disability or challenging behaviour. For the majority of children who now have or will develop chronic illnesses or disabilities, however, care will be primarily at home with their families.

The trend toward the provision of care for children at home is consistent with guidance in The Children (Scotland) Act 1995 (Scottish Office, 1995) the lead legislation relating to the provision of services for children. One participant said that the Act enshrines children's rights, derived from the UN charter, and places a large responsibility on local authorities for children's planning. The Act also emphasizes the responsibility of parents for the upbringing of their children and for promoting their health and well-being. Guidance to the legislation states:

Most of the work to help children in need whose health or development may be impaired is carried out with children living at home and being cared for by their parents with support from social workers and services such as day care, family centres and primary care services. (Social Work Services Group, 1997, p. 2)

Because the Children's Act is relatively new, it is unclear how it will influence the role of the state versus that of the family in the provision of care over the long term. A social work participant stated that it is too early to anticipate its full application in the provision of services to children with special health care needs and the effects on families.

However, my research confirms the central role of policies of the 1990s in shaping the provision of care by families for children with special needs.

Technology.

In addition to the influences of policies, technology has also played a role in facilitating and promoting changes in the care of children. The influence of technology was described by a nurse in the study as a force for change that is both helpful and

problematic. She said, "The complexity of services is increasing as children live longer. We are problems of our own success."

Only a relatively small percentage of children with special needs require technology in their daily lives, but the use of technology in health care generally is creating a growing number of children for whom complex technological care is required. For example, developments in neonatal care have provided the capacity to sustain life for pre-term low birth weight infants who might otherwise die. Some of these children suffer from respiratory and other chronic conditions requiring the use of supplemental oxygen and even mechanical ventilation.

Similarly, technology has helped to increase the longevity of children with chronic illnesses and disabilities. According to one nurse participant, children with cystic fibrosis, who until recent years would have died in their teens or early adulthood, are now living into their late twenties and thirties. Many have intravenous therapy at home during the course of a month, and some will go on to have lung or liver transplants that may even further extend their lives. Tatman and Lessing (1998) cite UK data derived from an Office of Population Censuses and Surveys (OPCS) General Household Survey which showed that the prevalence of chronic illness in childhood more than doubled between 1972 and 1991. The prevalence of children who are dependent on or require some form of technological intervention in their daily lives at home is also increasing. One nurse who works with children and families described trends she has observed in the past five years:

Currently in the area between Grampian and Inverness, we have three children ventilated, and five with tracheostomies. More kids requiring oxygen are being sent home... We have a number of children with cerebral palsy. There are concerns about aspiration, they need suction at home, some have a gastrostomy.

We have lots of gastrostomies. Also lots of kids with N/G's¹ [nasogastric tubes] who will later have surgery.

Another nurse involved with the care of children, said that nurses were seeing more children with tube feeds, and new ones every month. In Grampian and the Northern Isles during the autumn of 1997, there were fifty-nine children with feeding tubes living in their homes. By the summer of 1999, however, this pace had not been sustained. Such fluctuations in numbers demonstrate one of the difficulties in planning and providing for this group of children.

Until recent years, the administration of enteral feedings to children through tubes positioned in their nose or stomach (gastrostomy) was rare, and would have been unheard of outside a hospital environment. Similarly, other requirements for care are now being met in homes and to some extent, in schools. This care may include suctioning of secretions from the airway, seizure management regimes, the administration of medications or nutrients by oral, systemic and enteral routes,² and the provision of treatments to reduce the severity and pain of musculo-skeletal deformities.

Technology facilitates this transition to community care by providing compact, mobile equipment that can be used in homes, schools, and other community settings by children, families, nurses, and other carers. A nurse described her efforts to access money for a portable gastrostomy pump so that a "Mum and her child can get out more." With this type of practical assistance and care, many children with special health care needs are able to lead relatively active lives in their homes and communities.

¹ Nasogastric tubes are inserted through the nose, down the esophagus and into the stomach sometimes as a temporary feeding tube until a gastrostomy tube is surgically inserted in the stomach.

² The systemic route refers to a route into the body, for example, by injection or an intravenous; enteral route refers to entry into the stomach or intestinal tract, for example, a suppository or gastrostomy tube.

Attitudes

In addition to the changes associated with technology, attitudes toward people with disabilities and chronic illnesses are also changing. One nurse in a specialist role explained, "There is an increased willingness to give nutritional support to children who in the past might not have got it." Instead of asking 'why are we doing this?' now doctors and nurses are saying 'why aren't we doing this?'" she said.

Attitudes toward health, illness and disability are socially constructed and culturally driven. Attitudes toward disability, for example, generally reflect a social rather than individual phenomenon (Middleton, 1992) and tend to be based on a perceived norm. Decisions made, however, by health care professionals and families concerning the care of a child may gradually influence the norm. As more children with special health care needs live in the community, there is an increase in the visibility and viability of children with disabilities functioning with or without technological supports and adaptations. Over time, the attention shifts among health professionals and others from the disability and its limitations to the child and his or her potential, from "why" to "why not?"³

Attitudes toward illness and disability also appear to be changing in response to resource rationing. Participants from various sectors put forward the view that hospital beds should be used only for those who are acutely ill. Hospital admissions at one

³ For example, I observed these attitude changes toward children with disabilities among professionals in my own work of planning for the discharge of children from hospitals and institutions. At initial planning meetings, doctors and nurses often were reluctant to consider the government mandated discharge of children in their care. Several doctors stated: "These children [with complex disabilities] don't usually live very long." Many of the doctors and nurses had only seen these children living and dying in hospitals. But when I accompanied some children and their families for follow-up care after discharge, I saw a gradual shift in attitude from pessimism concerning a group of children to a recognition of the individual child with his/her own unique ways of being and communicating, a greater willingness to offer treatment, and an expressed satisfaction with positive outcomes subsequent to discharge.

hospital had been recently audited to determine whether admissions for children reflected the appropriate utilization for acute care or whether they were providing respite to families. The audit suggested that they were not providing respite, although as Lindsay et al. (1993) indicate, the cause for admission may not be stated as respite. Decisions about the utilization of resources are driven at least in part by their scarcity, thereby shaping attitudes about what constitutes appropriate hospital or community care.

In the descriptions of nurse participants, government policies have been an impetus to profound changes in the care of children with special health needs. Policies arise, however, in a socio-cultural and economic context in which technology and cultural attitudes have helped to create an environment that has enabled the changes to occur. The next sub-theme describes the nature of role changes and their effects on nurses' work.

Role Change: Reconstructing Community Nurse Roles

There is an assumption that the role of the nurse can be recognized and that it has discrete boundaries, content, and expectations. However, the shift to care in the community for children is exerting pressures on nurses' roles that are contributing not only to role change, but also to a reconstruction of roles themselves. This sub-theme expands the theme of role strain by exploring pressures toward change as nurses support families who themselves are providing increasingly complex and technical care for children. Caring for People (1989b) addresses the role of nurses and other statutory service providers in stating that they should "do all they can to assist and support carers" (p.9). Role change is explored through three dimensions: the pressures on traditional

community nurse roles, changes to role content and conception, and resistance and adaptation to change.

Pressures on traditional community nurse roles.

The roles of nurses are often described by the work they provide to a population within a given location. Health visitors and district nurses, for example, have a lengthy history of work in the community. They are among a diverse group of nurses who comprise the specialization of community health nursing in the UK (Ross & Mackenzie, 1996). Within their specific disciplines of district nursing and health visiting, both provide generic services to a broad population. They also have a common core training that they undertake prior to pursuing their practice preference. The roles of nurses are also described by the components of work they provide to a population. A manager referred, for example to the direct care component of the district nurse's work in describing the district nurse as "equivalent to the ward nurse, but in the community". A major feature of district nursing work has been with elderly people in their homes. Similarly, health promotion is a major component of health visitors' work. Although health visitors work with people across the age spectrum, their focus has been health promotion with children and families. As discussed, however, in Chapter Three, health visitors are gradually taking on more clinical and group work associated with the GP practice.

The traditional roles of health visitors and district nurses are changing.

Increasingly, they are becoming involved in the care of a growing number of families and children with special health care needs, although their work with children with complex and technical care requirements has only emerged since the shift from hospital care to the

community. Currently in Grampian, the numbers of children on district nurses' caseloads are proportionately small. According to one manager, district nurses with caseloads of sixty to eighty patients may have "a few children." Health visitors, whose caseloads average two hundred children from birth to five years, will have a number of children with special health care needs that varies depending on the population and the GP practice involved. One nurse specialist described some of the role-related changes involved:

Health visitors don't like hands on but will order supplies. District nurses will be more hands on, but district nurses may not be children trained. Health visitors may not be trained to do the tubes. Sometimes neither wants involvement.

The care requirements for children with special health needs are presenting pressures for nurses to take on new components of work, which are centred primarily in the management or provision of direct and often technical care for children. The provision of direct care lies outside the role of health visitors, and district nurses do not usually work with children who have special health care needs. The pressures of change challenge the way nurses conceive their roles.

Changes to role content and conception.

The pressure to take on work that lies outside one's role poses new expectations about what constitutes the role content. I have defined role content as the theory, knowledge, and skills that comprise the role. The pressure to take on work that lies outside one's role also challenges the way one identifies with and defines the role. This process involves role conception, the way one conceives of self as a nurse. Corwin and Taves (1962) define role conception as the images of the rights, obligations, and expectations that a person perceives to be associated with the role. Experienced nurses

who have already developed a conception of themselves as nurses, and of the work they do in that role, may be reluctant to integrate new expectations that call for changes in the way they work and conceive of their roles. In the next sub-theme, I will discuss this issue of resistance and adaptation to change.

The uncertainty arising from role changes was a central concern for one nurse in her efforts to access help for families in the community:

I don't know who to ask for to provide the family [nursing] service. It's different for every child. Each time, you have to determine who will help. What is their level of understanding of the child? What is their expertise? What is their role?

Those now seeking to access services on behalf of families, or families themselves, can no longer anticipate the role required or the level of expertise that will be offered by the individual in that role. "The role is changing all the time", said one health visitor, "it's running to keep still." The services sought may not fall within the role of either the district nurse or health visitor because neither has been previously required to give this care to children in the community. The nature and composition of the role has become, therefore, unique to the individual nurse, based at least in part on the extent to which the nurse is able to gain the knowledge, skills and experience required to fulfill new obligations. Uncertainty is heightened because the needs of each child and family are also unique, and the knowledge and skills that may serve in one situation can prove to be inadequate to meet the demands of another.

In essence, the roles of nurses in the community are in a process of reconstruction as both the expectations surrounding the role content and conception are changing. Yet the rapid and continuing process of change has thus far precluded a process of resocialization to new roles. Resocialization involves a process of redefining a role to a

changed theory base and new role expectations, and forever alters the sense of “what nursing is...” (Hickey et al., 1996, p. 34). This process is confirmed when individuals within the group that comprises the nurse’s frame of reference, for example, other health visitors or district nurses, also ascribe to the changes. The reference group thus provides a set of norms, values and a standard for performance in a given role (Hickey et al., 1996), from which normative role expectations evolve.

It is unclear how far role reconstruction will proceed, or whether nurses will be resocialized to new roles. Education is a vital component in facilitating new role expectations, however, a nurse in a specialist role described the education for nurses that is taking place as mainly “on-the-job training for health visitors and district nurses before a child is discharged from hospital” so that the nurses can provide the appropriate care and support to the child at home. The training nurses receive prior to a hospital discharge differs from the educative process required to enable nurses to integrate new theory and expectations. The former involves the requirements and expectations for child-specific care, for example, assisting families to provide enteral nutrition. The latter involves coordinated planning between the nursing profession, educators, nurses and their employer organisations, for example, to assist nurses in acquiring and adapting to new role content. In the context of rapid change, this educative process does not appear to be taking place. This view is supported by Perkins and Billingham (1997) who state that the needs of children and families in the community today do not seem to match current nursing roles and services. The third factor under the sub-theme of role change describes nurses’ responses to change.

Resistance and adaptation to change.

In Chapter Three, I discussed the impacts of organisational changes on nurses in their working relationships with social workers. In this section, I consider ways in which nurses are responding to the pressures promoting role change in their working relationships with children and families.

Tyson and Jackson (1992) suggest that adaptation to change is largely consistent with an individual's main personality attributes. However, they also note it is the situation and the environment that determine the response and behaviour that take place. Resistance, on the other hand, is one of the ways individuals may react to and cope with the stress associated with change (Wade, 1993) including threats to role concept.

Some nurses are responding with resistance to the expectations and requests of families. A health visitor described resistance to the request made by a family for technical help:

A child with a central venous line came home from hospital to be cared for by her parents. Mum didn't want to change it [the central venous line]. She wanted a nurse to do it. But the district nurse wouldn't help change it. She felt she didn't have the skills. The health visitor wouldn't help. Mum finally went to the hospital to get the help.

The care needed for a central venous line, an indwelling line implanted near the base of the neck into the large vessel that enters the heart, involves nursing knowledge and skills which have implications for comfort and safety. Children are being discharged from hospital with this and other care requirements for which nurses in the community either are not trained or may not have current skills. Nor may this type of care provision be consistent with their role expectations.

Role strain is associated with change or the pressure to change. These may be marked by anxiety, uncertainty, and stress (Carnall, 1990). Any change process involves not only learning something new, but also unlearning something that may be already well integrated (Itzin, 1995b) into roles and relationships.

A nurse who provides training to other nurses described fear as a factor affecting the willingness of nurses to take on specialized care. She spoke of the differences she observed between rural and urban⁴ nurses in particular, and stated, "City nurses are very frightened doing things for children, such as kids on ventilators." Ventilator care has been, until recently, perceived to be intensive hospital-based care, thus, having to cope with new technology and change can constitute a source of role strain.

Nurses have not initiated role change out of a desire to alter their roles. The pressures to take on new role obligations have arisen in the context of changes associated with the shift from institutional to community-based care, and nurses have not been involved in the planning and implementation. Thus the process of change must be understood within and managed by the organisations in which the changes arise. As I demonstrated in Chapter Three, however, organisations themselves appear to be struggling with change.

During the research process, I found that some nurses show a greater readiness than others to adapt to new role expectations, whether or not they have organisational support. One nurse described, for example, the responsiveness of some nurses to families in their need for direct nursing care:

If there weren't enough district nurses in the practice to take on direct care, GPs would direct health visitors to do the work. Or it could also be part of a good will

⁴ Differences in the roles of urban and rural nurses emerged in my research, however, the findings must be further explored and discussed in another study.

by the health visitor to aim toward continuity, that is, the health visitor might provide direct care if they are already involved with the family anyway.

Health visitors are already experiencing a number of other demands for role adjustments associated with changes to their work within the context of the GP practice, as discussed in Chapter Three. This example further illustrates the impact of the GP practice on the nature and content of nurses' work. It also illustrates adaptation at the level of the individual suggestive of role flexibility.

Role flexibility may reflect an individual's coping style, but it may also be understood as an organisational strategy that is gendered. Newman and Williams (1995) suggest, for example, that in attempting to make sense of the consequences of organisational changes, we must "consider a more multifaceted and fluid understanding of the category 'woman'" (p. 108). In this view, the organisation searches for flexibility in professions such as nursing, with employees being increasingly expected to deploy a range of skills and a flexible approach (Newman & Williams). Role flexibility is more complex, therefore, than an apparent adaptation to strain. In the third sub-theme under role strain, I expand on this notion of role flexibility in a discussion of an emerging division of work between generalist and specialist roles.

Generalist versus Specialist Roles

The increased complexity of care in the community is exerting pressures on traditional nurse roles, while at the same time, creating an increased need for nurses in specialist roles. Although participants did not frame their discussions in terms of a generalist versus specialist debate, their views reflected this dichotomy.

The distinction between generalist and specialist nurse roles is confusing. Haste and Macdonald (1992) describe a number of key elements used to define a specialist

nurse. These elements include specialty training, role independence, personal accountability, and being an expert. In contrast, nurses are considered generalists to the extent that they can respond with a certain level of expertise to a range of needs, conditions, and population groups (Perkins & Billingham, 1997). The term generalist tends to say more about the provision of generic or broad-based services than about the characteristics of the nurse. Yet, as noted in the preceding discussion, generalist nurses may also receive training to take on specialized care. I will discuss trends in Scotland regarding specialist and generalist nurses under three sections: community children's nurses, learning disability nurses, and emerging specialist roles.

Community children's nurses.

Currently in Aberdeen, health visitors and other nurses in generalist practice are unable to meet all the specialized care requirements for children in the community. According to one nurse, "Some children are in home with mechanical ventilation under acute management [by nurses] from Sick Children's."⁵ This means that where nurses in the community are unable to provide the skills required to care for or assist families in their care at home, pediatric hospital nurses who, in this example, have the technical skills to manage ventilator care, provide their expertise. The nurse said that there is an aim in some jurisdictions "to have specialist nurses in pediatrics⁶ trained to care for the child in the context of the family." The availability of specialist children's nurses working in the community could potentially relieve the strain on the roles of generalist health visitors and district nurses and fill gaps between newly emerging specialty roles in Scotland.

⁵ The main acute care hospital serving children in Aberdeen and the North East of Scotland.

⁶ A nurse with advanced education in pediatric care as distinct from a nurse in a specialist role who may or may not have advanced pediatric education.

Increasingly, there is a perceived need for children's community nursing to provide care and support to children and families in their homes (Whiting, 1997). One nurse in a role working with children described the need "to strengthen links between the hospital and the community". Having a trained pediatric nurse is very reassuring to parents, she said. Education and experience in pediatric care prepare the nurse to understand, assess, and promote the child's optimal physical, cognitive, and emotional health through the developmental stages. Education and experience in community nursing prepare the nurse to understand the role of the family and community systems integral to the health of both the child and the family. Thus a combined pediatric and community education emphasize pediatric clinical knowledge and skills relevant to community and home settings (Whiting, 1997).

Yet not all nurses support the requirement for specialist children's nurses in the community. One nurse participant, for example, stated, "Grampian doesn't have enough acutely ill children [in the community] such that there is a requirement for pediatric trained nurses to work in the community." The nurse did, however, see a role for specialist children's nurses to "start providing consultation in the community to other nurses" and added, "A general model is common throughout Scotland." In this model, a limited number of specialist pediatric nurses would provide consultation to generalist nurses in the community, rather than creating a team of specialist nurses. The model was under consideration in June 1999 when I conducted follow-up interviews. This model is consistent with the view of Perkins and Billingham (1997), who suggest that it is necessary to address the training needs of nurses already in the community without expecting them to receive specialist training.

This approach to service provision reflects a management strategy common in times of fiscal restraint. It is a way of dividing labour, aimed to deploy generalist or flattened roles that can provide a broad base of service and absorb staff cuts and service reductions, while reducing the number of higher cost jobs. Higher cost specialized services, if they exist, are often the first to go. This strategy is consistent with the organisational search for functional flexibility discussed in the preceding sub-theme.

Thus, under the rhetoric of flexibility, nurses' labour and skills are being used in new ways as jobs change, with increased pressure on staff to become multi-skilled and to take on multi-functional roles. This approach often intensifies employment inequalities (Newman & Williams, 1995) as a predominantly female nursing workforce takes on an increasingly greater workload.

One nurse, herself in a specialist role, stated that there is also a pressure from GPs to flatten roles because of costs. Although most community nurses working in primary care are not employed by GPs, it is generally acknowledged that the thrust of primary care is GP led, as demonstrated in Chapter Three. Yet the issue for GPs surrounding the specialist nurse role may not solely be one of costs. One nurse participant said that GPs want to see the inclusion of more nurse roles in the GP practice, and added, "GPs are not happy that school nurses did not go into the GP practice...where they will be used as handmaidens for GP clinics." Similarly, nurses in specialist roles tend to work outside and are autonomous from the GP practice. Thus the issue, I believe, may be one, not only of costs, but also of control.

Nevertheless, there is actually an increase in some specialist positions evolving in Scotland, which I will discuss later in this sub-theme, regarding new emerging roles.

Trusts in Glasgow and Edinburgh employ pediatric community nurses. In Aberdeen, there are a number of nurses with a range of educational qualifications who are filling the role of specialists working with children who have special health care needs.

Learning disability nurses.

In contrast to the differing views concerning children's community nursing, a generalist trend seems likely for those children and adults specifically designated as learning disabled. Generic services, in this regard, are those that meet the needs of the general population. A nurse in the learning disability field described the trend:

With the closure of specialist hospitals such as Woodlands [in Aberdeen], more people have treatment at the generic services...Health is going to push for more generic service. The service will fall down...The social worker learning disability team has been scrapped.

Although children with learning disabilities are often among those with special health care needs, their care is commonly viewed in the context of care to the learning disabled. This care is shaped by a philosophical debate, one that has its strongest voice among some advocates for children and adults with learning disabilities. The underlying view is based on the principle of normalization, which calls for a demedicalization of disability, and a recognition that disability is socially constructed (Ross & Mackenzie, 1996, p.130).

One nurse in the learning disabilities field described changes in the nature of care for people with disabilities:

The future of nurses in the area of learning disabilities is bleak. Shortly nurses will not be trained in this field. The thrust of community care is to social care, social services provision. Nurses are not normally involved in this [social care].

Proponents of normalisation perceive that people with disabilities need social care, that is, assistance with daily living. One of the main emphases is on inclusion in society. Specialist services are understood to set people with learning disabilities apart and

reinforce their separation from the rest of society. People with learning disabilities should, therefore, be provided services within the framework of generic services available to all (Alaszewski & Wun, 1994). Community care, which separates health from social care and emphasizes the latter, appears to reinforce this view.

Jones (1989) suggests, however, that one of the unintended effects of the philosophy of normalization is that it is used to justify limiting resources to those that are generic. In other words, if children or adults with disabilities are to be treated like others in society they should receive the same services. Yet it is reasonable to question whether this assumption, coupled with cutbacks in social and health services, leaves families and their children vulnerable (Abbott & Sapsford, 1987; Jones, 1989). In my experience, many children and adults with learning disabilities have health problems that often are simply not addressed or go unrecognized.⁷ Research studies also demonstrate that the health needs of people with learning disabilities are less well met than those of the rest of the population (Cook, 1998). These health problems often include the need for both health and social care. People with disabilities should, in my view, be fully included in society, but they should also have access to health care and where needed, specialized services.

Whether the focus is children or other groups in the community, the availability of resources in the community is the fulcrum on which the issue of specialist versus generalist care swings. Participants from all sectors described community care as understaffed and under-resourced. Furthermore, resource constraints in the public sector frequently have their greatest impact on women who predominate in part time, lower

⁷ For example, in British Columbia, health professionals have begun only in the past few years to recognize the potentially serious health effects that often occur in persons with Down's Syndrome, particularly as they age.

salaried and service oriented roles (Armstrong & Armstrong, 1996). Nurses, as the largest group of employees in the health sector, the majority of whom are women, are experiencing the pressures of resource constraints on their work with children and families. It is apparent that a long term trend toward generalist nurses in the community is likely, given that the rest of Europe is moving in this direction (Cole, 1997).

Emerging specialist roles.

Despite the expected trend toward generalist care, there is actually a burgeoning in Scotland of new nurse roles, many of which are specialist roles. Some of these are emerging to bridge the need for specialized care that cannot be met by traditional nurse roles in the community. Among nurses in specialty posts who participated in the research, most had obtained their positions within the past five years. This fact indicates that new nurse roles have been developing in community care subsequent to the Act. Some of the nurses directly stated that their roles developed subsequent to the Act and the changes it initiated in community care. Specialist positions serving families and children with special health care needs in Scotland include hospital-community liaison nurses, nutrition nurses, palliative care nurses, and nurses working in disease-specific outreach posts in either hospital or community settings.

Surveys (Laurenson, 1997; MacPherson, Donald, Caldow, & Kiger, 1996) conducted in Scotland also confirmed the development of new and specialist nurse roles. MacPherson et al. (1994) conducted a survey on the role of the specialist nurse and identified sixty separate job titles among one hundred and eighty-four respondents who used the title of specialist nurse. They found a broad range of qualifications and employment patterns among those using the title. Although MacPherson et al. did not

identify the length of employment in these positions, the specialist nurses were described as one of the more recent developments arising in the past five years in Scotland. Approximately fifty percent of the nurses identified work with either adolescents or children as part of their responsibility (MacPherson et al., 1996).

It is unclear to what extent the demand for more complex care in the community for children has contributed to the overall development of new nurse roles. However, it is apparent that the community care reforms, although not intended for children, are contributing to profound changes in care in the community for children, and to new ways of organising nurses' roles and nurses' work.

In the theme of role strain, I have explored pressures that nurses are experiencing, including those that are leading to a reconstruction of roles themselves. Many of these pressures arise from policy and organisational changes that are thrusting more technical and complex care for children on nurses not accustomed or educated to provide this care. There is little research to demonstrate whether the pressure to take on this new work may be damaging to the important work nurses now do with families and other groups in the community. In the next theme, role fragmentation, I explore further changes in nurses' roles and in nursing itself, as nurses' roles with families become increasingly fragmented.

Role Fragmentation

“There is a lack of clear criteria about who does what.”

In this theme I explore changes to nurses' roles and work with families that are occurring as both become more narrowly defined into role components or functions. The components of nurses' work, activities which constitute nurses' roles, are being divided, not only among nurses and families, but also other non-nurse carers.

The notion of fragmentation is confirmed in one analysis which states that there is a trend whereby the skills of those in helping services, such as nurses, are being broken up in line with the fragmented market and its provision of services from a multiplicity of sources, including public, private, voluntary and informal (Gough, 1994b, p. 258). The discussions in this section will provide content and meaning to this statement.

The fragmentation of a role into components or functions is not unique in nursing history. At one time, hospital nurses, for example, sometimes structured their work on a ward in a way that one nurse assumed the primary role function of administering medications to all the patients. Thus, for a given day or week, the nurse's role was that of medication nurse while another nurse might be the dressing nurse who spent the day changing dressings. This approach may be understood as a way of dividing labour.

The shift to care in the community is, however, promoting unprecedented change in the division of nurses' work. The concept of holistic care is being altered as nursing itself is redefined and more nursing work is divided among nurses and non-nurse care providers. This discussion considers dimensions of role fragmentation for nurses working with children, and their real and potential impacts on families. The dimensions are explored in two sub-themes: deconstructing nurses' work and reconceptualizing nursing.

Deconstructing Nurses' Work

Deconstruction is a term used commonly in feminist research to describe a breaking down or pulling apart (Humm, 1995).⁸ The term applied in this research

⁸ There are various philosophical streams that offer ideas related to deconstruction. The term is used in my research to suggest the dislocation of a stable or essential meaning (Humm, 1995).

underlines, not only fragmentation, which concerns a separation into parts, but also the way in which roles are both socially constructed or deconstructed.

Those managing various parts of the health care system are using strategies aimed at reducing the costs of health care in the community. In the theme of role strain, I discussed strategies to reduce costs by dividing work among nurses in generalist roles and between nurses and a relatively small core of specialists. Another strategy is, however, to divide nurses' work, not only among nurses, but also among families and other carers. These strategies are deconstructing the holistic nature of nurses' work. I discuss deconstruction with reference to two primary issues: holistic versus fragmented care, and the responsibility for care.

Holistic versus fragmented care.

Principles of holistic care are foundational to nursing practice. As mentioned in Chapter Three, holistic care mandates a focus on the whole person, and the recognition that the parts of an individual are interconnected and interdependent (Kramer, 1990). The commitment to holistic care is expressed in the document, the Scope of Professional Practice (1992), which guides the practice of nursing, midwifery, and health visiting in the UK. The document states that the nurse, midwife, or health visitor must ensure that any adjustment to the scope of professional practice must be achieved without compromising or fragmenting existing aspects of professional practice and that a concentration on activities can detract from the importance of holistic nursing care (UKCC, 1992).

One nurse in a specialist role described the division of work that is occurring for some children in school and home settings:

Some schools hire bank nurses to come in and do a feed. A lot of district nurses aren't pediatric trained. But health visitors deal with children. They may both end up seeing the child, the district nurse for the pump, feed and so on, and the health visitor for growth and development.

This description of care reflects a division of work structured primarily around technical or task-oriented care. In the example given, the roles of the 'bank' nurse, a nurse hired by a private agency, and the district nurse are concerned primarily with the provision of direct care related to the gastrostomy equipment and/or feed or potentially to some other technological device. This division of work reflects a departure from the holistic perspective that underpins nursing practice.

Underlying the principle of holistic care, there is recognition of the need for the nurse to have knowledge about the child's environment, other health issues the child may have, and the learning and support needs of family members and others caring for the child. One obligation in the performance of a task, such as doing a feed, or changing a tube, is to ensure that the nurse has knowledge about and a relationship with the child to the extent that s/he can promote comfort and safety. The hour or so provided by the bank nurse who goes to the school to administer the feed is, therefore, only a component of the care required. The performance of the task must also be integrated with theory and knowledge integral to safe, effective care. In other words, there is more to a technical task than just doing it.

The safe management of enteral feeding requires knowledgeable carers who can manage, for example, problems associated with reflux and discomfort arising from abdominal cramps that may occur in some children at any time. In holistic care, the nurse does not separate a child's needs into components or parts, some of which can be disregarded. Thus, a child receiving enteral feedings also requires mobility, skin care,

and a balance between intake and elimination. In the absence of an holistic approach, who is responsible for assessing and assisting with these other needs, providing the training to carers, and ensuring that knowledge and skills remain relevant and adapted to the child and his/her changing requirements?

The responsibility for care: Where is the 'named' nurse?

Holistic care is not only about safe and comprehensive care, but it also concerns the issue of responsibility for care. Participants raised this issue as a concern. One nurse in a specialist role said, "There is no single nurse role responsible" for children with special health care needs. Despite the fact that health visitors, bank nurses, district nurses, and even specialist nurses may be involved with a child, "People need one person they can go to," she said. These concerns were echoed by one participant from the voluntary sector who said, "There's a named nurse in the hospital, but not necessarily in the GP practice or community."⁹

The concept of the named nurse is consistent with principles of holistic care in which a designated nurse is responsible for working with the client or family to develop an integrated plan of care based on a comprehensive assessment. Similarly, in family centred care, a concept that also guides nursing work with families, a primary nurse takes responsibility for the overall planning and coordination of care. This concept does not exclude the involvement of other nurses, but it avoids placing the burden for coordinating, planning and even training on families.

⁹ In the **NHS Patient's Charter Services for Children** (HMSO, 1996), children should expect to have a named nurse in the hospital who is responsible for the nursing care (p. 16). According to the Charter, where there are children's community nursing teams set up, the sick child who is cared for at home, should also be told the name of the children's community nurse who is responsible (p. 13).

Although the notion of a primary nurse developed in hospital settings, the principles of family centred care are consistent with good community practice. During the summer of 1999, a plan was underway in Grampian to review the provision of care for children in the community and to hire a specialist children's nurse to coordinate services to children with special health care needs.¹⁰ Grampian, unlike some areas of the UK, does not have a community children's nursing team.

What are the consequences for families when there is no clearly defined role responsible for assessment, training, education, coordination, and support? One nurse portrayed the burden of work on families in her description of what support looked like for one family and child with special health care needs for whom she provided care. The young boy involved had complex health problems including epilepsy, metabolic and skin disorders, and the need for a tracheostomy for breathing. Over a period of time, the child and family saw a number of different nurses in their home for dressing changes, for the provision of respite care, and for assessment and guidance related to disease specific issues. The nurse stated:

I worked two days a week to provide respite for the mother. Some nurses worked other days and there were also some nurses who worked different nights. Some came at various times throughout the day. The mother showed me how to do trach [tracheostomy] care. By the time I left, there were about fifteen nurses involved, plus carers.... This was not a good model of care.

This example was likely an unusual one in terms of the numbers of nurses and carers involved and it demonstrates, as the nurse pointed out, an ineffective use of resources. But it also underscores a reality for families and children - that the processes of support can actually deplete rather than assist families. Families may be faced with a variety of

¹⁰ Within the past year, money has become available through the Diana Memorial Fund for services to children in the UK.

different people in their home providing different aspects of care. In this situation, the mother trained the nurse to look after the tracheostomy so that she could receive respite care. Some of the value of nursing respite must certainly be diminished when the parent needs to train a nurse in order to receive respite.¹¹

Research studies have identified the family's role in coordinating and managing care with a variety of professionals as a source of physical and emotional exhaustion (Anderson, 1990; Jones, 1989; Storey, 1993; Tatman & Lessing, 1998). The issue of coordination is a concern not only for nurses but also for others involved in the care of families. An article by Watson (1996) on services in Scotland for families who have children with disabilities, referred to a report regarding families who have been in contact with ten different professionals in the previous year, but noted that only 55% of the parents could identify a person who helped them to access and co-ordinate the input from different services. The role of families in the provision of care is explored more fully in the next chapter. The deconstruction of nurses' roles, and the changing roles of families are contributing to a reconceptualization of nursing itself.

Reconceptualizing Nursing

Despite the numbers of nurses and other professionals that may be involved with families, nurses play a decreasing role overall in the provision of care in the community. As I discussed in this chapter's introduction, and will demonstrate further in Chapter Five, families provide the bulk of care. The nursing care that is provided, however, is becoming fragmented, not only among nurses and families, but also among other carers

¹¹ In my own work with families in Canada I learned that, although parents are eager and willing to provide child - specific information, for example, about comfort measures during suctioning, they do not want to spend their time teaching nurses how to perform technical skills. Parents also want nurses who can help to support their own knowledge and skills.

who are not nurses. The latter may be formal (paid) carers from the voluntary or private sectors, and also informal or unpaid. Carers may be anyone who assist families in the provision of care. This sub-theme concerns the role of formal, non-nurses carers in the provision of care.

With the growing numbers of families and carers involved in the provision of work once considered to be nursing, the question that emerges in my research is: What is nursing? Reconceptualizing nursing involves a new way of thinking, not only about nurses' roles, but also the nature of nursing itself. The process of reconceptualizing nursing is explored in the following sections: Who does what work?, what value is nursing?, and the relationship between cost and nursing care.

Who does what work?

In the theme of role strain, I discussed the uncertainty about which nurse would fill what role in the provision of care to children and families. The uncertainty is heightened as care also shifts to other carers. One nurse specialist described the provision of care by either nurses or carers as "very dependent on who is willing to take on care. In education, for example, some teachers themselves will learn gastrostomies. "Others say it is a nurse's job," she said. Another nurse stated that there is a lack of clear criteria about "who does what, which filters into schools as well." The tasks and procedures that have been viewed as nurses' work are now being taken on by others outside nursing, on either an unpaid or paid basis. Increasingly, non-nurse carers, who are generally lower cost care providers, are involved in the provision of care in schools, small community homes and respite centres, and in the home as a help to families. One nurse said that there are more carers than ever now, and "they are being asked to do tasks

which are medical,”¹² she said. Clearly, the deconstruction of nurses’ roles is now well underway.

It is unclear how far the fragmentation and deconstruction of nurses’ roles will extend. One participant from a voluntary agency that provides carers, called care attendants, to people ranging in age from infancy to centenarians, described the training and current work of carers. The care attendants receive basic training in order to provide personal care, medications, first aid, stoma care, and assist with activities of daily living. “We haven’t been asked to give insulin, but could do it with training from a district nurse,” she said. She added that even when a nurse does the training, nurses don’t have an official role for monitoring. Some of the care attendants are themselves nurses, but the attendant is not there as a nurse, is not employed or paid as a nurse, and doesn’t have to be currently registered.

Similarly, in another agency I visited that provides respite care for children and adults with learning disabilities, many staff members are nurses. The care requirements of the children receiving respite are frequently similar to those of other children with special health care needs, for example, the need for gastrostomy care and feedings, seizure management, and the administration of medications. But according to one participant, the nurses’ qualifications are not recognized because it is a social-based organisation.¹³ The practice of hiring low cost care providers or of not recognizing the qualifications of registered nurses in social care settings may overlook the reality of the often complex nature of social care.

¹² My understanding from our discussion is that the term medical was inclusive of nursing.

¹³ This is potentially a concern, as according to the Scope of Professional Practice (UKCC, 1992) document, registered nurses remain accountable to their code of professional conduct, even if their posts do not require nursing qualifications.

I explored with some participants the process by which care formerly provided by nurses would be taken on by non-nurse carers. One participant made the following distinction between nurses and carers:

We have carers doing ventilation now, tracheostomies in mainstream schools...In terms of how you determine what is nursing - giving IMs [intra-muscular injections] by non-nurses is not OK. There are more risks in IMs. But protocols for trachs can be straightforward. There are no situations [in this region] where nurses [from primary care teams] provide nursing care in schools. It's not seen as nurses' role.

This issue of safety in the performance of a nursing procedure appears to draw the boundary between care by nurses or non-nurses. Yet the issue involves important considerations discussed earlier with regard to the holistic nature of nursing care.

Nursing is more than the visible demonstration of a psycho-motor skill. For those outside nursing, however, the procedural component of nursing work may be all that is understood about the nursing role. If nursing care is perceived only as tasks that can be safely guided through the use of protocols, then there is no need for a nurse.

In addition, while some procedures are relatively straight-forward, the care required may not be. An individual's needs may be complex and unpredictable, requiring nursing judgment that cannot necessarily be described in protocols. Some procedures, like changing a tracheostomy tube weekly, are required only on an episodic basis. Unless the child has consistent carers, there may be little opportunity for a number of different carers to develop their skill and safety over time. If the issue of safety is to be fully addressed, these factors are also considered in determining who provides care.

The question arises: Who decides on the care provider? One nurse described the process for determining the safe provision of respite care for a child following hospital discharge:

Usually a consultant [medical specialist] makes the decision.... There may be a difference of opinion. We all go around the table and decide. The idea is that a carer is capable of doing any task they are trained to do which parents do. I have carers who are asked to change a trach tube or a g-tube [gastrostomy], and we have all of them come in and train them. If we feel they can do it safely, and they feel they can, then we go ahead.

Nursing tasks are being handed over to carers in the community, but if there is a difference of opinion it is doctors who ultimately decide, even though it is nursing care, not medical care that is involved. The process resembles one of delegation, in which a doctor delegates medical care to a nurse, or a nurse delegates to a nurse assistant. Yet the process is not one of nursing delegation, since nurses do not necessarily retain the responsibility for monitoring and evaluating the care given by carers.

If a care assistant or other non-nurse carer is performing a task, formerly considered nursing work, the principles governing nursing practice have no jurisdiction, unless the assistant is calling himself a nurse or is providing care under a nurse's supervision.¹⁴ The issues of judgment, unpredictability of individual response, and continuity, which nurses would normally consider in deciding whether or not it is safe to delegate to non-nurses, may not be understood or recognized by those involved in the decision. According to some nurse participants, this issue of responsibility for assisting carers has not been fully addressed.

There are indications, however, that nurses are beginning to take a formal role with carers in the community. During the interviews I conducted in July 1999, one nurse stated that some provisions were being made for training care workers who provide respite to children, and for reviewing their skills.

¹⁴ The Scope of Professional Practice (UKCC, 1992) document states that, in institutional and community settings where health care assistants are part of a team involving nurses, midwives and health visitors, they must work under the direction and support of those registered practitioners.

What value is nursing?

The practice of shifting care to non-nurse care providers points to a fundamental issue: the value of nurses' work and nurses' contribution. The emphasis on the procedural aspect of nursing work diminishes the many other components of nurses' work in the community which, as I noted earlier, are not as readily apparent. This work includes the assessment that provides for early identification and prevention of other problems, the educative aspects of child and family care, the planning and coordinating of care with other professionals and agencies, and the emotional support that develops within a consistent caring relationship between a nurse and the child and family.

Within the organisational constraints discussed in Chapter Three, and the pressures toward the provision of complex care in the community, these vital components of the nurses' role are being diminished or lost. In addition, the therapeutic function associated with nursing tasks may also be lost as tasks become separated from nurses' knowledge, skills, and therapeutic relationship. One of the means of access to the therapeutic function of nursing, the heart of the caring role, has always been through its more routine tasks (Ross & Mackenzie, 1996).

The focus on the procedural aspects of nursing is contributing to a reconceptualization of nursing itself. Participants offered differing views as to whether the tasks are even part of nursing. For example, one nurse participant said, "Gastrostomies are not a nursing procedure. Parents and carers do it at home. So there is no reason it can't be done by others [aides] in the school." The fact that families and other carers can and do provide care appears as the rationale for stating it is not nursing work. Simply stated by another participant, "If a parent can do it, there's no need for a

nurse"! Nursing itself is being reconceptualized, as nursing care is defined out of nursing altogether. One participant from the voluntary sector expressed an underlying reality which nurses themselves did not address, in stating, "There is no definition of what's nursing." Without a definition or an understanding of what constitutes nursing, how can the value of nursing be recognized or understood? This reconceptualization of nursing appears, therefore, to be a way of further fragmenting and deconstructing nurses' work.

The relationship between cost and nursing care.

A nurse specialist offered a view about what does define nursing. She said, "Gastrostomies *are* [italics added] a nursing procedure, but they can be taught by a qualified person to lay people. If they didn't take it on, the child would be cared for in hospital." A critical element in defining the nature of care is, therefore, the cost of care. The cost of institutional care was one of the underlying motivations for shifting care from hospitals to communities in the first place (Walker, 1993).

If nurses' roles and work can be fragmented, and the components shifted to lower paid workers and families, the costs can be reduced. In shifting nursing work outside the scope of professional practice to non-nurses, health care is often managed through the lowest cost care provider (Armstrong & Armstrong, 1990; Gough, 1994b). The organisational search for role flexibility, discussed in the theme of role strain, may also be called a search for multi-skilled workers. Multi-skilling is a strategy to ensure that many workers have a broad range of skills, but the strategy is often one of de-skilling, where a minimum level of training is given to non-nurse carers for the completion of a technical task (Armstrong & Armstrong, 1990).

This relationship between money and nursing also recalls another discussion in Chapter Three. In the theme of role confusion, the policy definition of health care is care provided by doctors, nurses, and other health professionals. But in the community, what once constituted nurses' work is seen as social care, the tasks or procedures carried out by assistants, aides and other carers and of course, families. If the care can be defined as social care, families and local authorities pay the bills.¹⁵ In essence, the cost of care appears to be defining what does and does not constitute nursing work in the community and who provides it.

Summary

Policies in Scotland have promoted a shift in the location of care from institutions to the community for children with special health care needs. The themes of role strain and fragmentation describe pressures on nurses in the community to provide more technical, task-oriented care, and highlight changes in nurses' roles that are already taking place. The nature of fragmentation that is occurring threatens the holistic nature of nursing care. Nurses' work is being deconstructed as the content of roles themselves change, and as work is divided among nurses, families and other carers to meet organisational requirements.

The challenge facing those who are planning and delivering community services is to avoid a fragmented, task-oriented approach and to involve nurses and families in collaborative approaches to role change. The critical issue underlying the reconceptualization of nursing that is occurring is that it concerns, not only the fragmentation of nurses' roles, but also, ultimately, the erosion of care itself.

¹⁵ There is also a view that the work of families in the care of their sick or disabled children is neither health nor social care but simply family care - part of the parenting role. This view is discussed in Chapter Five.

The exploration of themes in Chapters Three and Four have been concerned primarily with the roles of nurses, and to a lesser degree, with those of non-nurse carers and families. The emphasis on the roles of nurses and formal carers in the provision of services may create a perception that families and children with special health care needs enjoy a vast network of formal support. Yet despite the range of services offered, formal care constitutes a relatively small proportion of the care that goes on in the home. The location of care in the community is changing the meaning of care for nurses and families.

Chapter Five

Meanings of Care: How Does Community Mean?

Introduction

The term care has conveyed different meanings in policy and in the experiences of participants throughout this study. Policy, for example, Caring for People (DOH, 1989b), states: “The great bulk of community care is provided by friends, families and neighbours” (p. 4). This statement conveys meanings of care that are reminiscent of neighbourliness, friendliness and concern for others (Pereira, 1993), as well as a location, the community, a place where people help one another. Care also describes the nature of nurses’ roles with families, and the work of nurses, families, and other carers.

Meanings of care emerge in my research from the experiences of participants conveyed in the preceding role-related themes of conflict, confusion, strain, and fragmentation. This chapter draws on those meanings of care, as well as on those centred in the home with families. These meanings emerge from group discussions and interviews with participants from various sectors of the community, including carers themselves.

The question, “How does ‘community’ mean?”¹ arises in these contexts. It asks, in what ways does the notion of community itself convey meanings of care? For example, during the course of my research, I noticed that community as a location, the place where care for children with special needs is primarily located, gives new meaning to words simply because of their relationship with community. Words such as nursing and family

¹ The question is adapted from the title of a book by Yanow, D. (1996). *How does a policy mean?* Washington: Georgetown University Press.

care are taking on new meanings in the community. The question posed by "How?" asks that these new meanings are noticed, and that there is an attempt to understand the way in which new meanings emerge (Yanow, 1993). "How" invites an interpretative paradigm to promote an understanding of the changes affecting the roles of nurses and families, and their care in the community.

Most families, however constituted, engage in some degree of health care, including health care for their children. Graham (1984) said that for most of us it is families that met our health needs in childhood for warmth, shelter and comfort. But as mentioned before, the role of families in Scotland and their relationship with health care is changing. This change is taking place within the home, in the context of care in the community, and in a shifting boundary between the roles of nurses and families.

The roles of nurses and families meet at the interface between formal and informal care. Formal care involves the provision of services by nurses and others from public, private, and voluntary agencies. Despite the range of services that may be available to families, formal care constitutes only a small proportion of the care that occurs in homes.

Increasingly, care in its community location is understood to be informal care, the care provided by the community (Kirk & Glendinning, 1998), usually in the context of the family or marital relationships. It encompasses three key assumptions: that it occurs within the context of the family where, mainly female relatives² take on the most arduous tasks of caring, that it is provided on an unpaid basis, and that it is based upon feelings such as obligation and love (Kirk & Glendinning, 1998).

²Data from a General Household Survey in the UK suggests that apart from spouse caregiving relationships, it is mainly female relatives who take on the majority of care (Kirk and Glendinning, 1998).

As families take on more of the work of caregiving, there are relatively few options for relief. Respite care is the term used to describe ways in which carers and the cared for person obtain relief from one another or from the tasks of care that are integral to caring for children with special health needs. The discussion in this chapter explores ways in which the location of care in the community gives new meaning to the roles of families, and to concepts of what constitutes family or nursing care.

The first theme, reconceptualizing family roles, explores the changing concept of family roles and family work. The second theme explores the nature of respite care, which is now understood to be the critical issue in support for families. These two themes together provide a picture of meanings of care, and how community means.

Reconceptualizing Family Roles

“Some parents change trach tubes, although they prefer a nurse.”

The care required by children is described as parenting in western cultures. Families, with reference to those that have children, usually involve the care that is given by someone in a parenting role.³ But families caring for children with special needs are unique families, often called carers. Their care extends what is normally considered to be parenting (Kirk & Glendinning, 1998) however, it may still be understood to be part of the parenting role.

The roles of families are being reconceptualized as they take on work at home that was formerly provided by nurses in hospital settings. The ways in which this process is occurring is explored through four dimensions or sub-themes: the parent-child

³ This statement is not intended to overlook the diversity of families associated with culture, class, ethnicity, religion, and other variables. A discussion of diversity has not emerged to any degree in my research, and must therefore remain a topic for another study.

relationship, an image of care, public policy, and relationships between policy and culture.

These dimensions give meanings to family care.

The Parent-Child Relationship

One nurse in a specialist role with children and families reflected on the nature of family roles in the changing context of community care. She stated:

Families are the primary carers. This is true in the hospital and community. We ask a lot of parents but they take it on. The children thrive.

Parental care, in western culture, is traditionally provided as part of a parent-child relationship. Many parents are rewarded by the way in which their children respond to care and this interactive process fosters and strengthens the parent-child bond. This is often the case regardless of the nature of care requirements. But families of children with special health care needs in Scotland are providing the tasks and procedures and other dimensions of care that, until this decade, belonged in the domain of nursing practice. This change is occurring in the context of a growing emphasis on patient/parent participation (Kirk & Glendinning, 1998) throughout the western world.

Patient participation was originally promoted as a means of reducing the adverse effects of hospitalization on children (Kirk & Glendinning, 1998), particularly the separation of the child from the family. A premise underlying patient participation is that the family, like the child, is also a patient or client whose role and involvement in care contributes to positive outcomes. Thus, the concept fosters the idea of a partnership between health professionals and families that engages families in decision-making and in the performance of clinical procedures in the hospital environment. It also implies a negotiation in the respective roles of families and nurses for the provision of clinical care,

defined as “arranging some matter by mutual agreement or compromise” (Callery & Smith, 1991, p. 774).

Parent participation in the care of hospitalized children has evolved, however, to the performance of nursing procedures (Kirk & Glendinning, 1998) and other specialized care in the home.⁴ One nurse described the nature of care that some parents provide in the home for their sick and disabled children:

Flushing a Hickman line⁵ is no longer a nursing procedure in the community.... Some parents change trach [tracheostomy] tubes, although they prefer a nurse. Mothers will do n/g [nasogastric] tubes if trained. They prefer a nurse... many parents don't like to do it because the child gets distressed.

The relocation of nursing care to the home and community is changing the meaning of family care and the way that care is provided and understood. Primarily a parent, usually Mum, provides the care that involves the performance of nursing procedures. The parent's preference for a nurse to provide care does not alter the fact that it is parental responsibility, nor does the invasive and sometimes distressing nature of this care. The care itself may require, therefore, that children experience their parents not only as nurturers, but also in ways that may be hurtful. The negotiation that was implied by the concept of patient participation in the hospital setting, does not appear to have a place, at least not in the community. As Strauss (cited in Callery & Smith, 1991) suggests, the usual definitions of negotiation make no distinction “between negotiation and other modes of attaining desired ends - such as persuasion, education, appeal to authority, or the use of coercion or threat” (p. 774).

⁴Some jurisdictions in Scotland have discrete programs called, Hospital care at home.

⁵A Hickman line provides an access port near the base of the neck to enable administration of fluid and/or medications into a major vein that leads back into the heart.

The meanings of care in the community are leading to a reconceptualization of both families' roles and nursing itself. The latter theme is further captured here in the statement that "flushing a Hickman line is no longer a nursing procedure in the community." If nursing care is no longer understood to be nursing in the community, this makes it easier for government and indeed for nurses and families to expect that the work is part of the role of families. The dynamic interaction between the roles of nurses and families thus changes the nature of caring work for both. Yet what are the social conditions in which this interaction is situated? And if nurses are failing in their negotiations with families, who is negotiating with them? I return to these points in the final chapter.

An Image of Care

The stories told by families would provide the most complete understanding of their caring work, but I did not have the opportunity to interview families for this research. One nurse who works with families and children provided an image of family care in response to my question about the care of a child with a gastrostomy:

If the tube fell out, the parent might replace it or the district nurse. We have one family where the grandpa does the tube when dad is away, the [dad's] girlfriend does the feedings. Each family has a different person to depend on.

This image of care may be seen and understood in several ways. One view speaks to the process of care, the day-to-day experiences of the family in caring (Williams, 1993) for a child with special needs. These experiences include the ways in which the family must organise, plan, and coordinate care among both formal and informal supports to ensure that the needs of the child are met. The image describes diversity in family composition, roles, and responsibilities. It underlines the complexities involving work and other

demands, the needs of other family members who are aging, and loss as family roles and members change.

The image also describes the uncertainty in care. Uncertainty surrounds the unexpected and unpredictable events that occur in the care of a child with special health needs. Uncertainty is also the question: "Whom can we depend on this time?" Who is available? Whose role is it? Finally, although there also are many other images, there is one suggestive of family rights and expectations. What right does the family have to receive support from a nurse, or care by a nurse? What can the family expect in terms of the frequency, nature and cost of care? What right does the child have to receive care from one consistent knowledgeable person, whoever that person may be? These are some images of care which, while provided by one nurse, reflect the responsibilities, complexities, and uncertainties of care by families, also described by others.

Public Policy

A function of public policy is to address the issue of rights - to give meaning and structure to the roles and responsibilities of the family versus the roles and obligations of the state with respect to children. Some of the expectations of families are outlined in explicit policy statements. For example, Caring for People (1989b) while acknowledging as I noted earlier, that the great bulk of community care is provided by friends, family and neighbours, also states that "it is right that they should be able to play their part in looking after those close to them" (DOH, 1989b, p. 4). Similarly, The Children (Scotland) Act 1995, the lead legislation on the care of children in Scotland, states: "Parents should normally be responsible for the upbringing of their children and should share that responsibility" (Social Work Services Group, 1997, p. vii).

Within this and other policy statements, however, there are implicit and taken-for-granted assumptions that families will meet the requirements for care, whatever is involved. Brown and Smith (1994) affirm this view in stating that the policy rhetoric of community care hides the labour and sometimes intensive care for family members by defining the specialized medical or nursing tasks as part of the informal responsibilities of families. The labour is hidden in the language of care (Ungerson, 1990) and is assumed simply to be a normal part of a loving parent-child relationship.

The language in policy also conveys other meanings. Policy does not specifically address the role of either men or women. In The Children Act (Scotland) 1995, the term “family, in relation to a child, includes any person who has parental responsibility for a child and any other person with whom the child has been living” (Social Work Services Group, 1997, Volume I, p. 1). By describing the role of family and person in gender-neutral terms (Brown & Smith, 1994), there is a sense that men and women are interchangeable in their roles, an implied equality. There is, however, also an implicit assumption that women will be available for unpaid care in the home. The structure of society is itself gendered, and care is normally understood to be women’s work. Thus there is a consistency between the expectations of society and those outlined in policy, the expectation being that a loving parent, usually the mother, will do whatever is required to care for her child.

The language of policy also promotes the concept of choice for families, or women, in their caring role. For example, the Children (Scotland) Act 1995 states that some of the principles such as “choice and flexibility” used in the care management of vulnerable adults may be helpful in thinking about assessing and coordinating packages of

services for children who are disabled (Social Work Services Group, 1997, Vol. I. p.31). The Act also requires that the family's views and preferences regarding their child's care must be taken into account.

But what choices does policy offer for parents or families who are unable for whatever reasons to provide the care for their sick or disabled child? A health visitor described a situation in which a child with a ventilator was coming home from the hospital. The parents didn't want the child home from the hospital because they felt they couldn't manage, so the child was sent to foster care, she said. This example illustrates the sometimes ambiguous nature of policy - the difference between what is stated or implied in policy and the actual outcome. When families are faced with the care of a child with complex needs and care requirements, the real choices appear to be mandated at least in part by fiscal considerations. In other words, institutional care is not an option.

One nurse who works with adults and children with disabilities stated, "The issue of moving people with complex needs from institutions is a political issue that needs to be addressed. There are issues of funding, care in the community, who takes responsibility." Although these statements were made with specific reference to adults and children who have moved or are moving from institutions, the issue of funding emerges as a consistent theme throughout this research. In terms of the roles and responsibilities of families, the ever present and increasing concern about levels of public expenditure and responsibility underlie all family policy decisions (Weir, 1994). In this way, cost gives meaning to the notion of family care in the community, and to the way in which the concept of family itself is understood.

Relationships between Policy and Culture

The assumptions contained in policy regarding family roles are linked, not only with cost, but also with socio-cultural expectations. A participant from the voluntary sector described these expectations stating, "Unless you are involved with families, you think services are just provided. But it's not automatic. The societal expectation is that you are a Mum first."

The nuclear family⁶ with the woman at home is still presented as the norm to which all women should aspire (Newman, 1995) even though this does not reflect the socio-economic reality for many families. In Britain most women work, have at least one child, and carry out the majority of caring and household tasks (Newman, 1995). Yet government policies that address the responsibilities of parents for care conform to this cultural ideal - that mothers will care for their children whatever the circumstances (Kirk & Glendinning, 1998). The reality of the family is that it is still gendered and hierarchically structured to the disadvantage of women (Newman, 1995).

Cultural attitudes and societal values also constrain the choices available to women. A participant from a charitable agency stated:

Most people care for someone because they want to. But there is a problem with society accepting that some people don't want to and can say, "No, I don't want to give care."

⁶ Wuest (1993) states that the ideology of familism is the dominating principle of social organisation in Western societies. She adds that the ideology of the nuclear family fosters relationships of domination and subordination, patterns of domestic labour, altruistic caregiving of children and the elderly, and patterns of dependency, all of which serve women poorly (p. 409). These views are confirmed by other writers in the UK, who also describe the implicit assumptions in social policy that women will be available for unpaid care of sick and disabled children and relatives (Brown and Smith, 1994; Finch & Groves, 1983; Mohan, 1995; Ungerson, 1990). A review of research in Canada, Britain, and the United States found that at least seventy per cent or more of caregiving is done by women (Armstrong and Armstrong, 1990).

Women, in particular, have a socialized reluctance to say, "No" which can be readily exploited. From a socialization perspective, the ways in which women internalize their identity may mean that they often set their priorities in terms of others (Finch & Groves, 1983), thereby intensifying their own expectations of themselves as carers. The expectations women place upon themselves were demonstrated in one research study where, for mothers of children with congenital disabilities, even the act of asking for help was considered to be an admission of failure (Twigg & Atkin, 1994). Typically mothers see themselves as competent and able to provide care for their children whatever the requirements. The need to ask for help may challenge self-perception and expectations for one's own competence.

But Anderson and Elfert (1989) suggest it is this very notion of competence that is part of the lived experience of women, experience that is used by the state and by health professionals to maintain women in home as unpaid caregivers. Thus, while the notion of family care is being reconceptualized in the community, the role of women as unpaid caregivers remains the same. Families, particularly women, as informal and unpaid carers, now have a central role in the provision of increasingly complex care in the community. The nature of family roles and family care also give new meaning to the concept of respite.

Meanings of Respite

"Mums are coming into hospital and they are dead on their feet."

The concept of respite is understood in different ways among both those who need it and those who are in some way involved in its provision. I had the opportunity to attend a respite special interest group meeting in Scotland, and hear views from both. The issue of

respite also emerged in interviews with nurses and other participants. The contributions through group interviews, along with my individual interviews, provided meanings to and concerns about respite in the context of care in the community. These meanings and concerns emerge in the following sub-themes: what is respite?, respite in policy, and respite in practice.

What is Respite?

A participant stated that the words used to describe respite affect the meaning and perception of services. He said that, for example, the terms holidays or breaks, often used to describe respite, “devalue its importance.” But another participant stated that respite should be “whatever the person needs - a holiday, break, or regular care.” This latter argument focused on the view that people seeking respite should not have to demonstrate their need as a crisis; that respite for carers is a right, and they should feel no apology if what they require is a holiday.

These and other definitions and comments reflected the view that, not only is respite a right, but also a critical need. One person, for example, described respite as “an essential break for the carer and person cared for from a routine, and responsibility that would otherwise become intolerable.” Another person described respite as “the difference between coping and not coping, surviving and not surviving; a lifeline.” These views reflect the need for respite, identified primarily by or on behalf of carers. The issue of need raises the question, What counts as a service for carers?

Carers are not really clients; they may be helped as a by-product of services that operate to increase the independence of the cared-for person (Twigg & Atkin, 1994). In

other words, the nature of care that comes to carers is intended to help maintain the cared for person in the community through sustaining unpaid care.

Respite, formally provided, is arranged by Social Services as part of a package of care (Twigg & Atkin, 1994) intended to support the relative independence of the cared for person. Each package differs, and is arranged case by case. In some situations, the carer receives respite through provisions made for the child to go temporarily to another family's home, or to a respite facility. Respite may also mean that someone is paid to come into the home.

Formal respite care may be given by anyone who is paid to provide it. One participant stated, "The main requirement is to be a caring person." A nurse participant explained that the Social Work department, which advertises for carers, selects formal carers, often someone with nurse auxiliary training. Nurses are also sometimes available to families as formal respite providers. As one administrator said, "Where there is a need for a nurse to provide respite, the decision is made on a case by case basis." A nurse participant said, "Sometimes the carer is a nurse and sometimes not, every case is decided individually. There is a need for guidelines." But, she added, "Sometimes there is a need for a nurse to give parents a good sleep."

So what do respite carers actually do for families? Carers may provide personal care, cleaning, help with nursing tasks, an opportunity for an occasional good sleep. It is unclear, however, on which occasions a good sleep is required, and why sometimes nurses are chosen to provide it. Twigg and Atkin (1994) suggest that there is a negotiated element that lies between carers and service provision. But this negotiation occurs in a context of power, in which service providers not only have control over the nature and

source of the allocations, but also to some degree over the definitions of the situation (Twigg & Atkin, 1994, p. 29). Thus, in one situation a worker may perceive a need for a nurse, while a similar situation may be perceived or treated differently.

Despite the varied nature of formal respite care, it is generally recognized in Scotland that the vast majority of respite is provided through informal carers. A nurse stated that many carers are members of the child's family. "It's hard introducing people into a child's home; it's not easy for the family," she said. The stress of incorporating a stranger into one's home to care for the child may be a reason why formal respite services, even when available, are sometimes not utilized. In some situations nurses who know the child from the hospital setting will offer their services to the family for respite on a volunteer basis. One of the documented benefits of informal carers is the provision of emotional support which may not be available through formal respite services (Storey, 1993). The "natural carer" is thus supported by the "natural community" (Brown & Smith, 1994, p. 44).

The provision of respite care is still evolving in Scotland. More research with families is required to determine the type of service provision that is most helpful to them. As the authors of a study of respite care services in Scotland indicated:

One suspects that in the case of ... carers, there is very little recognition of their needs and interests, and they spend much of their time as shadowy figures in the background. (Lindsay et al., 1993, p. 18)

The current approach to packages of care largely consigns the work of caring to families and their informal care, meanwhile bolstering it, where necessary, by packages

paid for and rationed by public agencies (Brown & Smith, 1994). Thus both government policy and agencies are central to the provision of respite care.

Respite in Policy

It is now widely recognized in Scotland and throughout the UK that carers save the government about thirty four billion pounds per year in unpaid informal care. In recognizing the value of this unpaid care, the government gives policy recognition to the importance of relief for carers, provided as formal respite care.

The Children (Scotland) Act 1995, for example, states: "...respite should be provided as part of a planned package of care to support the family," and that a flexible community based respite service is "likely to be cost effective when compared with the cost of family stress and breakdown" (Social Work Services Group, 1997, vol. I, p. 43). Similarly, Caring for People states that many carers need help to manage what can become a heavy burden and that the provision of care is one source of help (DOH, 1989b, p. 9).

The government has also recognized the needs and rights of carers through the Carers (Recognition and Services) Act 1995 (HMSO, 1995) which gives carers the right to request that local authority make an assessment of their needs, separate from those of the cared for person. There is, however, a gap between the recognition of need and the provision of funds and services. As one agency participant stated, "The Act gives carers legal recognition, but there are no resources to match." This apparent contradiction is consistent with Yanow's (1996) view, that policy has layers of meaning, including the cognitively known, rational, and literal elements, and the symbolic elements that carry value and feelings. The analysis offered by the agency participant reflects on the symbolic nature of the Carers Act, which reflects the valuing of carers in the absence of any

meaningful implementation. Day-to-day rationing practices contradict policy statements that appear to value carers.

Respite in Practice

Designated as social care, the provision of respite falls under the responsibility of local authorities. Social workers have an obligation to assess the needs of carers who request an assessment, but have no obligation to meet the need. Someone has to pay for respite, and someone has to provide it, and the funds for both are lacking. In terms of respite care for children in Grampian, there are no designated resources. The availability of respite care across Scotland varies depending on the local authority and funding arrangements involved. One administrator said, "There is very little respite care for children in Grampian. We are talking with local authorities about this."

The lack of resources for respite is demonstrated in the concerns expressed by participants. One participant who seeks alternate family carers⁷ to provide respite for children with special needs said she had thirty-three children on a waiting list, among them, a child with complex needs who has been on the waiting list for five years. A participant in the voluntary sector, in referring to carers for both adults and children, stated, "Families are afraid to talk about what they have in case they lose it." And carers at a special interest group meeting said that "unless you prove you are in crisis you won't get respite".

These statements raise questions about the ways in which resources are allocated.

⁷ Share the care is an example of a respite program in Scotland whereby alternate families provide temporary care for children in their homes.

Lipsky (1980) states that street level bureaucrats, such as social workers and nurses, actively interpret agency rules and regulations which are understood as constituting policy. Thus, policy is implemented through the workers' day to day practice. In this way, the state maintains the benevolent stance expressed in policy, while others do the mediating work of rationing and setting priorities for the allocation of limited resources (Hugman, 1991). Services may be rationed by varying the total amount available, or by varying the distributions of a fixed amount (Lipsky, 1980, p. 87). My research suggests that services may be rationed to those who are in crisis, to those who have the information, and to certain designated groups of clients, a finding supported by Hugman (1991). Within this sub-theme, respite in practice, I discuss each of these factors.

Being in crisis.

A nurse in Scotland described the process by which families may obtain respite:

They [families] obtain respite through the social worker, but we instill guilt if they ask too often. The norm is about two days per month. They d'nay like asking.... We would like to see families offered regular respite care. They [the children] used to be small people. Now they are growing into adults and they are killing their parents. We hope they are coping, we turn a blind eye. Mums are coming in to hospital and they are dead on their feet.

The nurse's experience with families conveys a desperate image of families in crisis. So why do families wait, and what is the role of professionals in the process? Hugman (1991) asserts that one aspect of the caring professions is the exercise of power to create meaning - meanings about the good or bad client, and about the opportunity to practise professional skills in a way that is valued professionally. Guilt has meaning for families, and particularly for women who are seeking help to care for their children. The process of

instilling guilt demonstrates that guilt itself can be a useful tool for rationing in a resource-constrained environment.

The meaning that guilt holds for families needing help, as described here, is consistent with research findings on respite utilization patterns. Research cited by Storey (1993) states that parents' hesitancy to use respite is attributed to guilt, worry, fear of being perceived as unloving or unable to cope, denial of their circumstances and concern about the possible inadequacy of respite situations and providers.

Some families are reluctant to seek respite at all, even when in crisis. A nurse who works with children described a family that tried to manage on their own in caring for a young child:

Several months later [after discharge]... [the parent] disconnected the ventilator, and said, "Enough is enough." The child could have died but didn't. We should never have let that happen. Families can't do it on their own...its proved in Scotland, unless parents have respite, they can't do it.

This story provides a sad but thoughtful contradiction, parents can't do it on their own, but they are doing it. Despite this nurse's recognition of the need for respite, there were differing opinions among nurses about whether some families actually want or need respite. One nurse stated that rural families tend to rely on their extended family more, but another nurse said there was an urgent need for respite in rural areas. One manager stated that many parents don't want respite, however, families may not know what is available, or as I noted earlier, whether they deserve respite.

The need for information.

The perception that parents don't want respite may relate, at least in part, to the information that is available to them, or the way in which it is provided. Participants from

the voluntary sector said that many families lack information about the availability of services, and are even afraid to talk with one another. As one participant from the voluntary agency said, "Families are afraid to talk about what they have in case they lose it." The rationing processes, which may be deliberately obscure, can leave clients fearful and uncertain of whether they deserve help, or how long they can hang on to it.

Another barrier, according to one research participant, is that many social workers and health professionals are not aware of respite services. Another participant said that Health doesn't see respite as their responsibility unless there are specific health procedures, and then people should "go to a health place" for it. Some people do turn to the hospital for the provision of respite. A nurse said that "although we aren't supposed to, there's an open door for children with special needs."

It is clear that giving or withholding of information about funds and services is another way that agencies ration resources (Lipsky, 1980), and also that some families have better access to information sources. In addition, some agency workers are more willing than others to seek and to provide information, thereby disregarding their role as rationing agents.

Belonging to the right group.

Resources may be rationed not only to people in crisis, or those who have sufficient information to expect it, but also they may be held back and rationed to special priority groups. One person from a voluntary agency said that each person's need is a priority, but she also added that the client group most in need of respite care are "parent carers, parents of children with disabilities." The parents of children with disabilities are quite isolated, and if the children go to school, they are picked up, so the parents don't get

a chance to meet others, she said. She added that there are better services for people when there are specific diseases and support groups for them.

Children with learning disabilities are among the groups who receive greater support and service provision than other children's groups. In Aberdeen, for example, families whose children have learning disabilities, a sub-group of children with special needs, can access an average one weekend per month of respite through Archway, a charitable organisation. The services are not available to children with physical disabilities despite the fact that a learning disability may be the only variable in care requirements between the two groups. A limited number of other residential respite facilities in and around Grampian are also available primarily to children with learning disabilities.

When I asked why there was a distinction between people with and without learning disabilities, one participant said, "There's a cheque in hand for people coming out of institutions." This statement reflects the priority funding given to those with learning disabilities, and others designated mentally disabled, most of whom were until recently, placed in institutions. The participant expressed a concern for all the others with special needs living in the community for whom little is available. This disparity is confirmed in a study (Lindsay et al., 1993) in Scotland that says developments have tended to be for children who have learning disabilities. For those children whose disabilities are physical only, or who have other problems, there are few respite services available, although the pattern of provision does vary around the country (Lindsay et al., p. 1993).

Inequities between families appear to hinge, in part, on the way needs are perceived. Children with learning disabilities whose families require respite fall under the definition of social care, whereas children whose needs are perceived as physical, would

likely fall under the responsibility of health. As discussed in Chapter Three, the way in which health and social care are understood creates a division that produces inequities for children and their families.

Lipsky (1980) addressed the issue of inequities in services stating that the enactment of policy through government agencies is based on the “myth of altruism” (p.71), in other words, the belief that the services benefit clients. Lipsky stated that the assertion that agencies provide fair benefits and treatment is usually unexamined, and provides a means for structuring a range of further assumptions about public policy.

Summary

With the recent shift in the location of care to the community, the roles of nurses and families are undergoing rapid change in the care of children with special health needs. This last findings chapter demonstrates the power of the state in shaping nurse and family roles, and illuminates relationships between gender, costs, and care. The themes, reconceptualizing family roles, and meanings of respite, demonstrate ways in which policies and practices concerning care in the community are changing meanings of care for and by families. At the same time as families are faced with the responsibility for care, they are also struggling to obtain the care and support they need in order to manage.

Due to the explicit nature of public policies pertaining to families, these gaps between policy intention and implementation are relatively easy to discern. Policies such as the Carers Act and The Children (Scotland) Act 1995, articulate the needs of children and families, acknowledge the burden placed upon parents, and outline plans for the provision of services and resources. They fail, however, in the delivery of vital elements of nursing support to families, and in the funding and provision of respite services to assist

mainly women who are being reconceptualized as nurses. Power, gender and the cost of care underlie the nature of care in the context of the community, and thereby provide insights to how community means. In the next and concluding chapter I discuss and summarize the research findings, which reveal, in essence, the erosion of care to families.

Chapter Six

Relationships between Policy and Practice: The Erosion of Care

Introduction

My study began with an opportunity to gain knowledge in Scotland about the roles of nurses with families and children with special health care needs in the community. My intent was to gain an understanding of their roles and provision of services within the social policy domain in Scotland, an interest that arose from my own experiences and concerns. This interest and concern initiated my studies in the field of policy. The research has been, therefore, both a personal and professional journey toward deeper understanding, which has led to new questions and has also provided unexpected insights. In exploring relationships between policy and nurses' roles, I have also gained knowledge that has illuminated relationships between policy, nurses and families, and has provided new ways of understanding policy and role itself.

Policy and roles are socially constructed and context bound. Both spring from the values embedded in culture and the way in which power is organised and realized through policy-making processes. Social and cultural values, expressed through the power of the state and interest groups, also shape policy and roles in public institutions.

Nursing's traditional focus on the micro level of care and on the professional struggle for autonomy and recognition, has impeded nurses' understanding of power and policy, and of the nature of changes occurring in nurse and family roles in the community. In my research, feminist and critical social theories provide explanatory and interpretive approaches that illuminate these changes through drawing attention to the relations of power that shape both policy and roles.

In the nursing literature, the language used to describe the terms policy and roles conceals any notion of a relationship between them, and the neutrality of the terms masks other meanings. As Alasuutari (1995) points out, in the study of human experience, reality and social life are always essentially mediated through meanings. Meanings concerning policy, nurses' and families' roles, and the relationships between them emerged in my research in the role-related themes of conflict, confusion, strain, fragmentation and reconceptualization. These meanings, discussed in this chapter, reflect the erosion of nursing care to children and families in Scotland. In this chapter I discuss, summarize and conclude the findings, as well as present their significance and their implications for education, policy, research, and nursing practice. I begin with a descriptive summary of nurses' roles with families and children in the community.

Discussion and Summary

Nurses' Roles with Families and Children who have Special Health Care Needs

It is evident from my research in Scotland that, apart from a few exceptions that I will discuss, there is no single nurse role in the community involved in service provision to families and children with special health care needs in the community. Children with chronic illnesses and disabilities who, until recently were cared for by nurses in the hospital or institutional environment, are now cared for primarily at home by their families. Overall, the picture of service provision is marked by change in both nurse and family roles.

There are, however, a variety and growing number of differing nurse roles in the community involved in the care of families and children with special health needs. The nature and extent of involvement depends on the role. In the Grampian region of

Scotland, there are a relatively small number of specialist health visitors and other specialist nurse roles concerned almost exclusively with children who have special health care needs. Nurses in these roles provide educative, liaison, planning, and supportive functions to both nurses and families, through services that may bridge hospital and community. Some of the nurses also provide direct care, education, and support related to specific diseases such as cystic fibrosis, or specific care related to such areas as enteral nutrition.

There is also a small but growing involvement among generic nurses, mainly health visitors, district nurses, and other nurses in the community with families and children who have special health care needs. While meeting their primary role functions with the general population of children, families, or elderly, the nurses are also taking on specific care or procedures, such as changing a gastrostomy tube, with children who have special needs. Nurses from the hospital settings may also have varying degrees of involvement with a child's care-specific requirement in situations where families, carers or nurses in the community cannot provide the care. Increasingly, care for families and children in the community has become family care with families supported, to the extent support is available, by nurses and other carers.

This summary provides an overview of nurses' roles with families and children with special health care needs. At the descriptive level, however, it does not fully reflect the experiences of nurses and families engaged in the care of children with special health care needs in Scotland. It is my intent and hope that the themes and issues that I now summarize, more accurately reflect those experiences.

The Organisation of Care

My exploration of policy and roles introduced new relationships: the relationships of power between the state, organisations, professional groups, nurses, and families. This view of the centrality of power is consistent with Hugman (1991) who suggests that the power of the state is embedded in policy and is exercised through the mediating power of professions, and I would add organisations. The themes of role conflict and confusion describe and illuminate the role of power in these relationships.

Role conflict.

Despite increases in nursing theory, knowledge, and skill coupled with growth in the complexity and diversity of nurses' roles, hierarchies have been and continue to be the predominant organisational structure in which nurses' roles and work are situated. This relationship between hierarchies and nursing is generally accepted and is, to a large extent, taken for granted. The hierarchy appears natural because it is a reproduction of social relationships throughout society (Hugman, 1991).

Hierarchies constrain nurses' roles and their ability to shape their work. The nature and impact of these constraints emerged in the research in the theme of role conflict. Nurse participants expressed concern about the degree of control that is now being exerted over their work within the GP practice. This control is constraining opportunities for health visitors to carry out their educative and health promotion work with children and families and individuals across the lifespan. Participants talked about how these constraints are also having negative effects on the health of mothers and infants who previously would have received regular and more frequent follow up in home

settings. Nurses are experiencing pressures to do more group and clinic work that also reflect priorities of the GP practice.

The reforms did not explicitly devalue nurses' contributions or subordinate nurses to the GP practice. However, the failure of policy makers to be explicit about the role of nurses, or to anticipate potential deleterious impacts on nurses and families, reflects a systematic devaluing of nurses and other carers, primarily women, and their contributions of caring and unpaid work.

It is unclear from my analyses whether policy makers, while not explicit about the role of nurses, intended nevertheless that nurses adapt their role functions to the priorities and demands of the GP practice. Policy decisions are made in the context of political, economic, and cultural realities (Gough, 1997), which involve the state, organisations, and professional groups, shaped by varying degrees by relations of power. Within this context, doctors in Britain have been able to fully participate in the determination of policy outcomes (Hill, 1980), in contrast to nurses who lack the power to shape health services and patient care. The value of nurses' roles and contributions on behalf of families has been overlooked or misunderstood both in policies and hierarchical organisations.

Role confusion.

Nurses described confusion as another factor impeding their role contribution. To a large degree, role confusion emerges in the experiences of participants as a product of organisational confusion, which is itself reflective of the policy process and the nature of organisations and professional groups.

The community care reforms created a conceptual barrier between health and social care, by emphasizing their differences rather than recognizing their similarities, and

they deepened barriers already existing between the organisations and professional groups responsible for the delivery of health and social care. Role and organisational confusion thus reflect the gaps between policy formulation and policy implementation. On the one hand, the reforms mandated a requirement for joint working between Health and Social Services and their respective employees. But on the other hand, they actually helped to strengthen the traditional Health and Social Services divide.

Nurses described the impacts of the divide, which is creating barriers in their efforts to access services and resources such as respite and medical equipment on behalf of children and families. Social workers, who have the lead role in conducting assessments for community services provision, appear at times to be mediating not only client services but also nurses' work. Whether or not this is intended, it appears to have enhanced a struggle between nurses and social workers for professional control of nurses' work. As Hugman (1991) asserts, relationships between caring professions including those between nursing and social work, also constitute a form of hierarchy. The lack of shared power and authority in making decisions about clients and resources contradicts the notion of collaboration explicitly stated in the community care reforms.

Confusion also appears to arise from differences in organisational aims and priorities. This finding is confirmed by Lipsky (1980), who says that there is a fundamental tension in service organisations between individual client treatment versus efficient agency performances that may impede collaboration. This tension creates ambiguity in the roles of workers and in organisational direction. A lack of clarity in roles and responsibilities may also be an attempt on the part of organisations to obscure responsibility. Thus, what appears to be confusion may be attributed, at least in part, to

the struggle for resources. This struggle, played out as a struggle for power, often leaves families without either resources or power.

The themes of role conflict and confusion thus reflect the impacts of policies on nurses and families, expressed through organisations. The impacts, whether intended or unintended, constrain and devalue nurses' work. The nature of these constraints on nurses' roles and work, which emerged in the experiences of participants, is confirmed by Baines (1991) who says that the large bureaucratic organisations in which nurses are traditionally employed act as a formidable barrier in nursing:

Women as direct service professionals in these organisations have had limited autonomy, control over their work, and influence in policy and resource allocation. Hierarchical divisions...all reflect differences in power, esteem, and autonomy. Dichotomies of this nature ensure rigid role definitions and organisational structures that fail to uncover the complexities and solutions involved in a collective responsibility for caring. (p.68)

The nature of organisations calls attention to the issue of gender. Gender did not emerge as an explicit issue with my research participants; in other words, they did not name it. The issue of gender was, nevertheless, implicit in discussions concerning the loss of autonomy, and the changing nature of nurses' roles, particularly as they described their work with doctors. As Witz (1994) points out, gender divisions are pivotal in understanding roles and relationships between doctors and nurses and the systemic devaluing of nurses' caring role.

The Location of Care

My discussion shifts from the organisation of care to its location in the community. Role strain and role fragmentation describe the effects of policies, which,

while they may not be explicitly intended for nurses or families, are having consequences for both.

Role strain.

Health visitors and other nurses are taking on tasks more traditional to the hospital setting in response to deinstitutionalization and the increased complexity of care in the community. Nurses' work is becoming more focused on tasks, and the holistic and preventive nature of work is giving way to the pressures for more visible and complex technical care. The demands for increased and changing role performance in the face of technological changes, in addition to those already occurring within the GP practice, constitute sources of role strain. Many nurses, along with other participants, expressed feeling overwhelmed by the changes and repeated changes that have been occurring. Carnall (1990) confirms this view of role strain in stating that it can be caused by not being involved in decisions, having inadequate managerial support, having to cope with technological or other changes, and having to maintain standards of performance even under difficult circumstances. Role strain thus reflects the responsibilities of employer organisations, and it is within those settings that nurses and others must receive support for change.

Role fragmentation.

To a large extent, nurses have always coped with the pressures of change and the need to adapt to new role requirements. Within the context of the current pressures for care in the community in Scotland, however, nurses' roles are not only being strained, but also deconstructed as their work becomes increasingly fragmented between families and the statutory, private, and voluntary sectors. Families are now the primary carers for

children with special health needs, even where nursing care is concerned. Respite care and technological and other supports are being divided among health visitors, district nurses, private nurses, specialists in the hospital and community, and lower cost formal carers. These divisions constitute an erosion of nursing care to families.

The fragmentation of nurses' roles and work can best be understood as an organisational strategy to promote a cost-saving division of labour. Part of the strategy is the flattening of roles with the expectation that most types of work can be done equally well by any member of a team, a process that Ovretveit (1993) calls skill dilution. Beyond a certain point, however, skill dilution becomes de-skilling, a situation in which the profession-specific work for which individuals were hired in the first place becomes so small that it is lost (Ovretveit, 1993).

De-skilling represents a failure on the part of policy makers, nursing leaders, other health professionals, and at times nurses themselves, either to understand or defend the nature of nurses' work. While Benner's (1984) work was among the first to highlight expert practice in the hospital setting, similar efforts are needed in community nursing practice to demonstrate the value of community nurses' knowledge, skills, and contributions to families. As Zerwekh (1991) asserts, expert practice in the community remains shrouded in vague generalizations because it is superficially documented, inadequately funded, and lacks descriptive models (p. 213). Leipert (1992) states that the value of community health nursing has implications for the roles of community nurses, and a decline in practice is due, at least in part, to a lack of clarity about its value.

Nursing both as a profession and practice, rather than guiding and participating in planned role change, is itself being reconceptualized within the context of the role-related

changes taking place in the community. Nurses and others outside the profession who work with families express differing views of what now constitutes nursing in the community. While many of the nurses in the research recognized the impacts of policies on their roles, most felt unable to control the changes or their impacts on families. Some nurses also felt that the changes benefited health care, in allowing more time for GPs to carry out their clinical work.

In speaking with nurses concerning the relationship between policy and their roles, my approach was to suspend an assumption that the relationship was unilateral. I invited nurses to describe how they perceived their own ability to influence policy. Apart from opportunities to influence nursing or organisational policies, nurses perceived their roles separate from the policy domain. A nurse summarized a predominant view of nurses' ability to influence policy in stating, "It goes on behind closed doors". This view conveys the notion of power embedded in the policy process, and the exclusion of nurses from that process.

Meanings of Care: Reconceptualizing Family Roles and Respite Care

The notion of care in the community gives new meanings to family care, to respite, and to nursing itself. Family roles are being reconceptualized through the relationships between care and community. Policies have an explicit role in defining the centrality of families in the care of their children and the services available to them. A review of policies and practices, however, demonstrates contradictions between what is stated in policy and how policy is implemented. For example, although families and other carers can request an assessment of their needs as carers, there are no resources to guarantee their needs can be met. Similarly, the principles of choice and flexibility expressed in

policies concerning the provision of respite and other services have little meaning when respite funding and resources are limited or inaccessible. Rationing practices thus contradict the principles and values expressed in policy.

There may be no explicit intention in policy to promote the overwhelming changes that have occurred and are continuing to occur in the shifting boundary between nurses and families. Nevertheless, the boundary between nurses' and family roles has shifted more dramatically than the boundary between nurses and any other carers (Kirk & Glendinning, 1998) in the community. Parents are taking on the daily and often complex and technical care formerly provided by nurses in hospital settings.

Although these changes reflect role interactions between nurses and families, my research indicates that these changes have not been sought by or negotiated between nurses or families. While some parents may welcome the opportunity to provide that care, the research demonstrates the need for available and consistent planned respite and other support services to assist them in that role. The research also suggests that, while the shift from nursing roles to family care has not been explicitly outlined in policy, the changes are nevertheless intended, non-negotiable, and underlined by gender.

There is a commonality in nurses' and families' work that is based on gender. The work of nurses and family carers, both of whom are predominantly women, is caring work, and in terms of the way this work is perceived, it is also gendered work. The construction of gender is not simply a general pattern of male bias that leads to the devaluation of women's work in society, but it is also the constitution of an economy that relies on a universalized category of labour (Calhoun, 1995, p. 167). This category is not really labour, however, because it is simply caring work. The very lowest cost care

provider is thus the woman (Armstrong & Armstrong, 1996) who does nursing work for no pay in the home.

Conclusion

In Chapter One, I introduced a concept of the relationship between policy, nurses, and families in which policy and nurses act as agents for families. This view was not confirmed in my research, which reveals policy as the main agent acting on, and at times in opposition to, nurses and families rather than supporting their roles and potential. Nurses themselves may fail to recognize ways in which policies, and the organisational practices through which they are expressed, are detrimental to their roles and work with families.

My research findings reveal relationships between policy and nurses' roles that demonstrate an erosion of roles and an erosion of care for children and families in Scotland. Nurses' roles in primary health care and within the context of the GP practice are changing in ways over which nurses appear to have little control. The holistic nature of nursing care is in danger of being lost, and with it the knowledge, and educative, planning, preventive, supportive, and coordinating functions that are vital to the health and well-being of children and families.

The experiences of nurses, families and other carers involved in the care of children with special health needs in the community are still relatively recent in Scotland. Before the NHS and Community Care Act 1990 (DOH, 1990), children with special health care needs were cared for mainly in secondary care. In the context of continuing, rapid and unpredictable change, therefore, it is unclear how extensive the expectations for care by families will be, or what the impacts may ultimately be on their health and well-being. Similarly, it is unclear how far the erosion of nurses' roles will extend, as long as the

organisational practices to reduce or control costs also constrain, redefine, and fragment nurses' work.

A deconstruction of the language and meanings in policies related to community care reveals three issues - power, economics, and gender - that collectively are contributing to a devaluing and deconstruction of nurses' and families' roles. As Wuest (1996) asserts, the caring role is thus socially constructed and reconstructed within a context of social and economic relations in both the home and workplace. Power, economics and gender emerge as major forces in shaping roles and the relationship between policy and nursing practice.

Nurses' roles and the relationship between nurses' and families are not, as role theory suggests, merely assigned by or negotiated within a cultural context. My research locates roles within a context in which some roles and groups have had, and continue to have higher status and influence in organisations, policies and decision-making. Roles are also situated within and shaped by a context that includes the dominant values, ideologies, and relations of power from which policies derive (see Diagram, Appendix E). The way in which the state and public institutions are organised, structured, and financed ultimately shape nursing work and the relationship between nurses and families. Similarly, the way in which family and its public function of caring for the young are defined, affects the availability of resources to families (Weir, 1994).

Nursing has failed to critically examine the gendered nature of roles, and the context that shapes and changes them. With a defining interest in the client and in the role relationship between nurses and clients, nursing has taken for granted the roles and role concepts, such as socialization, which incorporate gender biases that further constrain

nurses and other women. Nursing also promotes negotiation with families, and with others who collaborate with nurses in the planning and provision of care, but it is only beginning to critically examine the concepts of role negotiation and patient participation and their implications and meanings for families.

There is little evidence in my research of the negotiated aspects of roles suggested in the nursing literature and described in some interpretations of role theory. For example, negotiations between role partners, whether nurses and families, nurses and doctors, nurses and social workers, do not appear to figure prominently in shaping roles. Twigg and Atkin (1994) suggest that where negotiation does occur between nurses, other professionals and clients, it means teaching clients the appropriate responses (p. 29). Similarly, negotiations may occur between nurses and doctors, or other professional groups, however, Callery and Smith (1991) state that the negotiations can be cooperative, conflictual or coercive.

Role concepts derived from role theory have offered some useful insights into the nature of roles: the importance of the individual's role conception, the concept of role validation by the reference group, and the expectations of role partners in shaping roles. Although role theory locates the origin of professional role expectations with peers, clients, and the public, the expectations of nurses and families in this research do not appear to account for the role developments and changes that are occurring. As a matter of interest, Johnson (1993) suggests that there may be merit in retaining the concept of role for certain structural analyses but argues that there is a need to give careful attention to each role's implication for power (p. 128).

Nurses are often viewed by others, or view themselves, as responsible for the lack of power in their role. For example, the writers in an American nursing text suggest that the biggest hindrance to empowerment is the individual nurse, and her tendency to be passive and dependent (Strader & Decker, 1995). In a similar vein, a UK based article states that women who are suffering the effects of discrimination and oppression within the family and workplace, are encouraged to turn to therapy rather than to action or resistance (Brown & Smith, 1994). Yet even this latter view, while implicitly acknowledging the social context for powerlessness, nevertheless places responsibility for change on women themselves. As Edelman (1988) suggests, proposals to solve chronic social dilemmas by changing the attitudes and behaviour of individuals are expressions of the same power structure that created the problems itself (p. 27).

I would argue for macro perspectives on role, gender, and power. Dunn, Almquist, and Chafetz (1993) suggest that, while macro perspectives do not deny that individual characteristics and behaviours play a role in the creation and maintenance of gender inequality, macro level variables such as communities, labour markets, states, and nations are paramount (p. 69). This understanding has the potential to promote empowerment.

Nurses can become agents for and partners with families in practice and in the policy domain. There is a need, however, for nurses to reconceptualize both nursing and the nursing role to promote a new understanding of role and its relationship with policy. The construction of a new paradigm for nursing does not require that nurses discard the micro perspective, that is, their interest in the nurse-client relationship. Nurses can contribute to a new paradigm that alters oppressive social circumstances for nurses and

families by defending and expanding their knowledge in practice, policy, and research, and by challenging the power relations that seek to devalue both nurse and family roles.

Implications of the Research

Nursing Education

Nursing education has a vital role in facilitating change in the historical trends that continue to constrain nurses' roles. The emergence of a new paradigm for nursing is dependent upon the expansion of the knowledge on which nurses base their practice (Gough, Maslin-Prothero, and Masterson, 1994). There are significant efforts underway in some jurisdictions in the UK to facilitate an integration of socioeconomic and political consciousness in nursing curriculum (Isherwood, 1995). Sweeping changes introduced by the Project 2000 (1986) initiative that heralded a new approach to the initial preparation of nurses in the UK, provide a base for the development of a broader perspective (Gough et al., 1994).

The Project 2000 document also emphasizes the need to produce flexible practitioners who have the confidence to cope with uncertainty and change (UKCC, 1986). One of the approaches increasingly offered is education that offers a growing emphasis on reflective practice. Reflection assists individuals to awareness that can reveal sources of oppression (Gough et al., 1994). This awareness assists nurses in promoting change in their own environments, as well as those for families and communities.

Policy and Practice

The research raises serious concerns about the erosion of care and the impacts on the health of children and families. These concerns have implications for policy and practice. In the practice arena, there must be a concerted effort by regional and local

health authorities and medical and nursing leaders to understand and address the concerns of research participants, and others who may also share their concerns. Some initiatives have already been taken, for example, the effort in Grampian to assess the need for a coordinated model of service provision for children and families. There have also been efforts undertaken by a Respite Special Interest group in Grampian, as well as by national agencies in Scotland and the UK, to lobby for improvements and changes in the provision of respite care. These initiatives must be supported and further developed by health boards and local authorities.

At the level of public policy, the current trends in Scotland and the UK have led to a GP-centric model of primary health care that has limited the realization of the vision of primary health care (Witz, 1994), and are constraining the roles of nurses. There is a need, therefore, for a return to the original vision of primary health care advanced by the World Health Organisation and by Scottish Office documents, such as Working Together for a Healthier Scotland (1998). This vision of primary health care includes an essential role for community health nurses in promoting health and preventive health strategies for individuals and communities.

The establishment of Local Health Care Co-operatives in Scotland provides an opportunity for all the members of the primary health care team to define present and future goals to address the needs of children and families. Regional health authorities have a vital role to play in seeking the involvement of nurses and others on the team whose contribution in Scotland, unlike England, is voluntary. There are also signs in Scotland of the will to achieve a more egalitarian model for health care planning and health care. In 1998, for example, a conference of doctors and nurses in Scotland voted overwhelmingly

against doctors dominating the Local Health Care Co-operatives¹ (Agnew, 1998). In addition, there is increasing recognition in Scotland and throughout the UK, of growing inequalities in health arising from people's circumstances, a recognition which must convert to action.

Research

Meanwhile, there is a pressing need for research to determine the impact on children and families related to the complex care that is increasingly becoming part of families' roles in Scotland. While it has been demonstrated² that parents are able to perform clinical procedures (Kirk & Glendinning, 1998), their perceptions and experiences and those of their children have not been well explored.

There is also a need for evaluation research sponsored by health and local authorities that will guide the enforcement of safe practice standards among the agencies and variously qualified staff and other carers involved in the provision of care for children in community settings. Concerns regarding disparities in standards and/or their enforcement for the care of children in private care homes and licensed facilities were brought to my attention, but I was unable to fully explore the concerns in order to address them in this research.

Research also has a key role in engaging nurses and families in change. Feminist participatory research enlists the participation of groups and communities in social change, while feminist advocacy research relies on groups - nurses, families, and others - to identify research issues in order to promote policy change (Gottfried, 1996).

¹ LHCCs are termed primary care groups or PCGs in England.

² In my role training and supporting families, I have seen competent care by parents and informal carers demonstrated.

My perception from meeting and talking with nurses, social workers, carers, and others in the statutory and voluntary sectors in Scotland, is that each group has made and is making an enormous contribution to strengthening services for families. These contributions will continue to emerge through a collective will to identify new directions for policy, education, research, and practice that value the roles of nurses, and engage and support families.

Significance

In conclusion, the significance of my research is the contribution it makes to the recognition of the profound changes affecting nurses' and families' roles in Scotland, and to an understanding of the context in which these changes are occurring. These changes are in progress, and point to the need for further research and action to minimize the impacts. Ultimately, the significance of changes affecting nurses' roles is the impact on and erosion of care to children and families.

My research also challenges nurses to a critical analysis of role theory, which has provided an accepted view through which nurses understand and take for granted nurses' roles. In illuminating relationships between policy and nurses' roles, I add my voice to a small but growing number of nurse researchers who call for theories and education in nursing that locate and understand nurses' and families' roles in a socio-cultural, economic and political context. Without this understanding, which will assist nurses and others concerned with health and social care in the community to challenge existing power relations, there will continue to be erosion and devaluing of nurses' roles and ultimately of nursing itself in the community.

The responsibility for change does not, however, rest solely within nursing. Ultimately, the provision of services to children and families is a social responsibility. There is, therefore, a social benefit to reconceptualizing the roles of nurses and women as distinct from their historical and cultural roots that subordinate them to medicine and other male-dominated systems of power. Through this process, there is a potential to affirm the value and contribution of caring work by both nurses and families. This effort can begin with the development of a new paradigm that assists nurses to understand and challenge the processes that perpetuate oppression.

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Appendix A

Numbers of Research Participants and their Broad Role Categories

Interview period: October, November, December 1997

<u>Role category</u>	<u>Number of participants</u>
Health visitors and health visitor assistants (focus group)	eight
Health visitors/nurses and nurse specialist roles	seven
Nurses and others in education and research	two
Nurses and others in administrative roles	four
Social workers and others employed by local authorities	two
Participants from the voluntary sector	three
Other: special interest group meeting in which I participated	unspecified
Total number of participants in individual/focus interviews:	twenty-six

Interview period: June 1999

Health visitors and health visitor assistants	eight
Health visitors/nurses in various specialist roles	four
Nurses and others in administrative roles	one
Social workers and others employed by local authorities	one
Staff from voluntary agencies	one
Total individual/focus interviews in this period	fifteen

Total interviews for both periods

Total number of individual interviews	twenty-five
Total number of focus group interviews (two groups of eight)	sixteen

Appendix B

Key Interview Questions and Probes¹

1. Describe some of the medical conditions and nursing concerns that come to mind when discussing your role with families/children with special health care needs.
2. What education and experience are required for you to work with families and children with special health care needs in the community?
3. Describe the types of settings in which you work with families and children.
4. What is your role in working with children and families in the various settings?
Probes: What does your work involve, for example, direct (hands on) nursing care, training of others, consultation and support, or other?
5. What changes have you noticed in your role with families/children with special health care needs?
6. What trends have you observed in the care of families/children with special health care needs? Probes: What importance do you attribute to government policies in relation to your role and services for children and families?
7. Describe the programs currently providing services to families/children with special health care needs in the community.
8. What differences, if any, have you observed in services to families and children in urban and rural areas of Scotland?
9. Describe your level of satisfaction with your current role.
10. To what extent do you feel that you can or do influence policies in your work with families and children?

¹ Some questions are modified depending on the role of the participant, for example, nurse or non nurse.

Appendix C

Approval from the Ethics Committee

**UNBC Research Ethics Committee
Certificate of Ethics Approval**

Name of Researcher(s): Carolyn Schellenberg

Title of Research Project: The Role of Nurses With Families/Children With Special Health Care Needs In The Community - Influences of Policies, Programs, and Nursing Education

I certify that this project was given ethics approval by the UNBC Research Ethics Committee

Signed: _____



Date: Sept. 10/97

Associate Vice President Research and
Dean of Graduate Studies

Appendix D

**Letter of Introduction
and
Participation Consent Form**

INFORMATION LETTER

BACKGROUND INFORMATION My name is Carolyn Schellenberg and I am presently doing graduate work in the Public Health Department at the University of Aberdeen through an exchange program. I will return to Canada at Christmas to complete my Master's degree in the Community Health Science Program from the University of Northern British Columbia. For my research thesis, I am interested in comparing the roles of nurses in Scotland and British Columbia who work with families/children with special health care needs in the community. I would like to learn more about policies, programs, and nursing education as they affect nurses' roles.

My nursing career has included work in both hospital and community settings. For the past 6 years, I have been working with a branch of the Ministry of Health in British Columbia which plans community care for adults and children moving from long term care institutions. I have chosen to focus my research on nurses' roles because community nursing care is changing rapidly with the changes that are taking place in health policies and programs. Families frequently need support in the home to plan care for chronically ill or disabled children who formerly would have received care in hospitals.

My research is interested in drawing from the perspectives and experiences of nurses and other health professionals who are planning and/or providing services for families and their children. If you think you would be interested in participating in my research or in learning more about it, please read the Participation Consent Form and feel free to call me if you have any questions.

You can call me at the University of Aberdeen and leave a message for me if I am not in.

Telephone: 01224 663123 ext. 43309

Thank you for considering this request.

Carolyn Schellenberg

Carolyn Schellenberg, RN (MSc student)

Alice Kiger

Alice Kiger, PhD, University of Aberdeen
Telephone: 01224 53329

PARTICIPATION CONSENT FORM

You are invited to participate in a research study titled
"The role of nurses with children/families with special health care needs in the community

A comparative study in Scotland and British Columbia"
The purpose of this study is to gain a better understanding of the role of nurses working with this population in communities, and to better understand the influences of policies, programs, and nursing education on nurses' roles.

What is involved? Your involvement will take no more than 3 hours of your time. I will invite you to participate in either an individual 1 hour interview or a 1 - 2 hour focus group discussion with other nurses, or both. I will take notes during the individual interviews. The focus group discussion will be taped so that I can concentrate on the discussion with all the participants.

Potential benefits and concerns. Participation in the study involves no known personal risks or discomforts, or direct known benefits for yourself or others.

Participation is voluntary. If you choose not to participate or wish to withdraw from the study it will in no way jeopardise your work or alter your relationship with your agency or other health professionals.

Information is confidential. You can refuse to answer any questions or stop or leave the interview at any time. You can also request that any portion of the notes or tape be erased. All tapes will be transcribed (typed). No names or identifying information which would disclose your identity will appear in any of the written reports. All tapes and notes will be kept in a secured place and will be erased at the end of the study. The information obtained will be written into a thesis and may be presented at conferences or in publications to educate other health professionals.

Questions? If you have any questions now or at anytime during the study please contact:

Researcher: Carolyn Schellenberg, BSN, RN, MSc student
Tel. 01224 663123 ext. 43309

Advisor: Alice Riger, RN, PhD, University of Aberdeen
Tel. 01224 53329

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

Signature: _____ **Date:** _____

Witness: _____ **Date:** _____

Appendix E

Diagram (as follows)

The Context of Care

In Chapter One, I define the context of care as the socio-cultural, political, and economic context in which the relationships between policy and roles are formed and situated. The words surrounding the circle identify specific factors that contribute to this context.

Some factors, such as hierarchies, are discussed mainly in one specific chapter, in this case Chapter Three. Factors such as history, politics, power, economics, values, beliefs, organisations, and professions are discussed in one or more chapters, but also serve as background to discussions throughout the findings. Politics, for example, is addressed in discussions pertaining to the role of the state and the policy process, and economics emerges repeatedly in reference to the cost of care. Similarly, the term beliefs is used to include attitudes and ideologies discussed, particularly in Chapters Four and Five. Gender is implicit in the Chapter Three findings, and becomes visible in Chapters Four and Five in the analyses. The factor of class does not emerge in the findings, but warrants further examination in a future study in terms of its relation to power, economics, professions, and other factors. Finally, while state is not listed as a separate factor, its role and/or impact is linked with all the others, thus influencing policy, nurse and family roles.

The arrows demonstrate the *primary* direction of influence. The middle vertical arrow indicates policy influence on the roles of nurses and families, as well as on the relationship between them, expressed by the horizontal arrow.

The Context of Care

