# "UNDERSTANDING THE CONTEXT IN WHICH WE LIVE": AN INTERPRETIVE DESCRIPTION OF THE STRUCTURAL AND RELATIONAL FACTORS THAT INFLUENCE THE CARE-SEEKING EFFORTS OF PERSONS LIVING IN POVERTY

by

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# ABSTRACT

# UNDERSTANDING THE CONTEXT IN WHICH WE LIVE: AN INTERPRETIVE DESCRIPTION OF THE STRUCTURAL AND RELATIONAL FACTORS THAT INFLUENCE THE CARE-SEEKING EFFORTS OF PERSONS LIVING IN POVERTY

In Canada, poverty rates, the gap between the rich and poor, and the health inequalities that follow continue to rise in disturbing proportions. There is therefore a compelling imperative for nurses to broaden their understanding of poverty and health inequalities and to reconstruct the model of health to include sociopolitical factors that reflect society's values and conflicts. The traditional health care response has been an emphasis on primarily increasing the availability and accessibility of health care to address the health needs of persons and communities living with poverty. Despite the enhancement of health care services, a lack of understanding the care-seeking efforts related to the attainment of health needs of persons living in poverty existed in the literature. The purpose of this qualitative research was to explore the structural and relational factors that influenced the effectiveness of the care-seeking efforts of urban persons living in poverty from the perspective of these economically disadvantaged persons.

An interpretive description method that allowed the participants to identify and describe their care-seeking experiences was used for this study. Ten men and women with varied background who lived in one of the four low income neighbourhoods of Community Health Area #2 in Vancouver participated in the study. Thirteen audio-taped and transcribed interviews were accomplished and analyzed for emerging patterns and themes.

The findings of this study focused on the participants' descriptions of living in poverty, receiving and providing lay help, and seeking necessary health or social care and supports. The

study concludes that living in poverty influenced the participants' efforts in seeking help or care for the attainment of their health and basic needs. The participants' care-seeking behaviours and processes were influenced by the structural and relational factors related to the everyday constraints of living in poverty, their experiences of helpful and unhelpful health care, and the infrastructure barriers and gaps within the health and social care systems. An extensive range and types of helpful lay care from the participants' social and community support networks were also described. These findings have implications for nursing practice, nursing education, health care and public policy, and research.

# **TABLE OF CONTENTS**

ABSTRACT
TABLE OF CONTENTS
LIST OF TABLES
LIST OF FIGURES
ACKNOWLEDGEMENTS
CHAPTER ONE: INTRODUCTION
Background to the Problem
The Problem Statement and Research Question
Definition of Terms
Significance of the Study
Introduction to the Method
Assumptions
Summary
CHAPTER TWO: LITERATURE REVIEW
Literature Review
Perspectives on the Phenomenon of Care-seeking
Care-seeking - What is It?15
What Care is Sought and Expected?
How do Individuals Seek Care?
When and Why do Individuals Seek or Not Seek Care?
Care-seeking and Economically Disadvantaged Individuals
Conceptual Perspectives of Poverty
Who are the "Poor"?

# TABLE OF CONTENTS (continued)

A Gap in Knowledge of Care-Seeking by Economically
Disadvantaged Individuals
Conclusion of Literature Review
Forestructure
Personal Experience
Personal Assumptions and Biases
Analytic Framework
CHAPTER THREE: METHODOLOGY
Participant Selection
Sample Criteria
Recruiting Participants
Sample Size, Appropriateness, and Adequacy
Ethical and Human Rights Considerations
Data Collection
Data Sources
The Interview Process
Data Analysis
Rigor
Summary
CHAPTER FOUR: PRESENTATION OF FINDINGS
The Participants
Living with Poverty – Not Belonging to the Same Playing Field
"What Poverty Means to Me"
Needing to "Kowtow" to the Ministries

# TABLE OF CONTENTS (continued)

Managing My Health Day - to - Day	90
Having a Range of Health Conditions	90
The Meaning of Health	91
Managing Health and Basic Needs Living in Poverty	93
Encountering the Multiple Aspects of Care	95
The Meaning of Care	96
Types of Care	96
Having a Community Perspective on Care	98
Experiencing Positive or Helpful Care	99
Experiencing Negative or "Non-Helpful" Care	102
Experiencing Facilitative and Challenging Care-seeking Factors	107
Finding Care	107
"Naturally" Delaying Seeking Care	109
"Caught and Stuck Between Hospital System Rules"	110
Acknowledging the "System" Supports	110
Encountering Challenges Accessing and Getting to Care Living in Pove	rty112
Up Against the System in Getting Funded Health Care or Help	114
Living Through a Time of Transition and Change	116
Summary	118
CHAPTER FIVE: DISCUSSION OF FINDINGS	
Living with Persistent Poverty and Health Inequalities	122
Care-giving Through "Enabling Help" to Facilitate Care-seeking and Health	131
An Enablement Model of Helping	131
Enabling Help at the Social Support Network Level	133

TABLE OF CONTENTS (continue	:d)
-----------------------------	-----

- 6

Summary
CHAPTER SIX: SUMMARY, CONCLUSIONS, AND IMPLICATIONS
Summary of the Study
Study Conclusions
Implications
Implications for Nursing Practice
Implications for Nursing Education
Implications for Health Care and Public Policy
Implications for Research
Conclusion
<b>REFERENCES</b>
APPENDIX A: Participant Information Letter
APPENDIX B: Participant Consent Form
APPENDIX C: Data Documents
APPENDIX D: Sample Interview Questions

# LIST OF TABLES

Fable 1.	. Summary of Culture of Po	verty Behaviour Traits	 42

,

Page

# **LIST OF FIGURES**

1

• 5

	Page
Figure 1. Lauver (1992) Theory of Care-seeking Behavior	

# ACKNOWLEDGEMENTS

To know wisdom and instruction, To discern the sayings of understanding, To receive instruction on wise behaviour, Righteousness, justice, and equity; A wise man will hear and increase in learning, A man of understanding will acquire wise counsel.

Proverbs 1: 2-3, 5

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# **CHAPTER ONE: INTRODUCTION**

This thesis outlines a grounded interpretive descriptive research study that aimed to identify and describe structural and relational factors that influenced the effectiveness of careseeking efforts from the perspective of urban economically disadvantaged/impoverished individuals.

#### **Background to the Problem**

Poverty or low income is endured by some segment of every nation's population (Carney, 1992). In Canada, both the incidence and depth of poverty has risen (Ross, Scott, & Smith, 2000). The gap between the rich and poor continues to widen so that the bottom quintile of Canada's population has earned only 3.6 percent of the total national income while the upper quintile has accounted for 43.3 percent (Hulchanski, Eberle, Olds, & Stewart, 1991; Yalnizyan, 1998). Heightened poverty in industrialized nations is shaped by an integration of macro-level systemic economic, social, and political forces (Carney). In particular, the two pillars of the Canadian welfare system, unemployment insurance and social assistance, do not meet the Statistic Canada poverty line in a single jurisdiction in the country (Hulchanski, Eberle, Olds, & Stewart). The Canadian threshold measure of low income, the low income cut-off (LICO), is expressed as a percentage of pre-taxed income set where families spend 20 percentage points more of their income than the Canadian average on food, shelter, and clothing (Vancouver/Richmond Health Board, 1999). The LICO in 1994 was approximately \$10,000 (Hoog et al, 1994).

The implications of poverty and its associated lower social status on health are undisputed. A vast number of aggregate, epidemiological, and ecological studies has established that poverty unequivocally leads to poor health outcomes and health inequalities (such as Bartley, Blane, & Smith, 1998; Charlton, 1994; Evans, Barer, & Marmor, 1994; Kawachi & Kennedy, 1999; Liao, McGee, Kaufman, Cao, & Cooper 1999; Marmot, & Feeney, 1997;

1

Nettleton, 1995; Prandy, 1999; Soobader & LeClere, 1999; Vagero, 1995; Wallace, 1994; Wilkinson, 1996). Lower income groups have higher mortality, morbidity, and disability rates (Carroll, Bennett, Smith, 1993; Syme & Berkman, 1990). Notably, nearly two thirds of the variation in national mortality rates in developed countries can be accounted for by income distribution (Wilkinson, 1992) and conclusively in every country of the world, the rich are healthier than the poor (Smith, 1990). However, despite the link between health and socioeconomic circumstances, particularly poverty, the nature of the theoretical and empirical linkages between causal variables are ardently debated (Nettleton, 1995).

Nationally, addressing poverty as a socioeconomic determinant of health is identified as an important goal of the health and social care systems (Reutter, 1999). Locally in Vancouver and Richmond, British Columbia, poverty is also identified as a key determinant of health requiring urgent attention of the regional health care system (Vancouver/Richmond Health Board, 1997). The Vancouver/Richmond region has 29.9 percent of its population living below the LICO as compared to 19.6 percent of the British Columbia population (Vancouver/Richmond Health Board, 1998). The regionalization of the provincial health care system has directed the identification of six Community Health Areas in Vancouver and one Community Health Area in Richmond. Community Health Area # 2, consisting of the poorest neighbourhoods in the region (Downtown Eastside, Strathcona, Woodland, and Grandview), has 51.8 percent of its total community health area population living below the LICO (Vancouver/Richmond Health Board, 1998). The Downtown-Eastside/Strathcona neighbourhoods fare the worst in measurement of life expectancy at birth with the highest rate of mortality indicators such as suicide-rate, overdose mortality, AIDS, and smoking-attributable mortality (Vancouver/Richmond Health Board, 1999). Poverty is also identified as a key health issue by three out the six Vancouver Community Health Areas, and specifically by the Aboriginal, Mental Health, Women, Children and Youth Advisory Committees (Vancouver/Richmond Health Board, 1997).

Modern industrialized societies devote very large shares of wealth, effort and attention to maintain or improve the health of individuals and populations through health care systems (Evans, Barer, & Marmot, 1994). Estimates of Canada's total health care expenditure range from 8.79 percent (Roch, 1992) to in excess of 10 percent of the Gross National Product (Canadian Institute for Health Information, 1995; Evans, 1990; Fulton, 1993; McArthur, Ransay, & Walker, 1996). An assumption of the health care system and a result of the socialization of health care providers is the widespread belief that the receipt of available and appropriate health care is the most important determinant of health (Evans, Barer, & Marmor, 1994; Spector, 1996).

The primary focus of health care policies aiming to improve the health of economically disadvantaged individuals and communities is directed at the enhancement of the accessibility of health services (Riessman, 1990). Accessibility of health care services is defined as a broad set of concerns that center on the degree to which individuals and groups are able to obtain needed services from the health care system (Northam, 1996). In fact, equal access to health care is a more common theme in the moral and philosophical literature than attention on the existence of health inequalities (Vagero, 1995). Varied theoretical and public understanding of the relationship of poverty and health has influenced this direction.

One current influential factor directing the enhancement of the accessibility of health services is the application of the population health concept and its underlying premises of health inequalities determinants to health care service planning (Edwards, 1999). The population health model conceptualizes health care services as a key social determinant of population health (Hamilton & Bhatti, 1999; Vancouver/Richmond Health Board, 1997). However, because of its epidemiological roots, a key criticism of the population health model is its reductionist biomedical theory of health that only indirectly and incompletely measures the health of populations by indicators such as mortality, morbidity, and childhood development (Blane, 1985). In fact, Evan, Barer, & Marmor (1994) discern that a definition of health is unfortunately, for pragmatic purposes in quantitative medical research, the absence of disease or injury. Qualitative ways that health is understood and interpreted are also excluded from social representations expressing society's values and conflicts (James, & Eyles, 1999). Therefore, current health care policy development relies almost entirely on research evidence reduced to biological disease instead of understanding class and health relations as embedded in a complex array of status, power, economic and authority relations within political or economic structures and systems (Labonte, 1995).

The materialist/structural perspective of poverty and health likewise influences the health care system emphasis on improving health service accessibility to impoverished individuals and communities. This causal view of poverty and health is predominant in current sociological health and illness literature and in the public health literature (for example, Bartley, Blane, & Smith, 1998; Conrad & Kern, 1990, Freund & McGuire, 1999; Nettleton, 1995; Reutter, Neufeld, Harrison, 1999). It emphasizes that poor health results from decreased access to the material conditions and resources that facilitate health, including the existence of, quality of, and access to health and social care services (Evans, Barer, & Marmor, 1994; Reutter, 1999; Reutter, Neufeld, & Harrison; Robert, 1998; Syme & Berkman, 1990). The emphasis of this perspective is that structural constraints prevent impoverished individuals from having genuine access to quality health care (Riessman, 1990).

A vast amount of literature supports the evidence of the health care policy emphasis on health service accessibility to impoverished individuals. Numerous studies describing enhanced service delivery models to impoverished individuals, including homeless individuals and families, the mentally ill, substance users, and multi-diagnosed HIV/AIDS and mentally ill persons, are evident (Ahmed, 1999; Anderson, Smereck, Hockman, Ross, & Ground, 1999; Berne, Dato, Mason, & Raffe, 1990; Brach, Falik, Law, Robinson, Gillis, & Singer, 1997; Trent-Adams, Ulmer, & Wright, 1994). Outreach health care teams are particularly noted as an essential service delivery approach to impoverished individuals (Greenberg, MacGowan, Neumann, Long, Cheney, Fernando, Sterk, & Wiebel, 1998; Plescia, Watts, Neibacher, & Strelnick, 1997). Locally in Vancouver, there are also a range of reports directing the health care services who provide care to economically-disadvantaged communities to be better coordinated, integrated, and accessible (Vancouver/Richmond Health Board, 1997; Vancouver/Richmond Health Board, 1998; Vancouver/Richmond Health Board, 1999).

However, current evidence does not suggest that differences in health care resources entirely explain social class gradients in mortality and morbidity and other factors must be identified (Syme & Berkman, 1990). The assumption of "building more and better health care services will lead to improved health outcomes of impoverished individuals and communities" is implicit in the current planning and implementation of health services. Despite an enhanced availability and accessibility of health care services, it is argued that there is a lack of local and theoretical understanding of the care-seeking efforts by economically disadvantaged individuals. Specifically, there is a gap in knowledge related to the structural and relational factors that influence the effectiveness of these care-seeking efforts from the perspectives of urban impoverished individuals.

Theory development in relation to individuals engaged in seeking care for health concerns is limited and in its infancy. Care-seeking is described as a process or behaviour (Roberts, 1988; Lauver, 1992). Care-seeking is a multi-dimensional phenomenon related to but separate from the concept of health-related behavior (Butterfield, 1990; Young, 1999), health-related cognition or decision-making (Carver & Scheier, 1994, Schwarzer, 1994), and other concepts such as compliance/adherence (Roberson, 1992) and access to services (Aday & Anderson, 1974; Anderson, 1995). One theoretical frameworks of care-seeking behavior is proposed in the care-seeking literature (Lauver). A related theoretical model pertaining to health-seeking is also noted (Nyamathi, 1989). Both theoretical frameworks require scientific testing to validate the inherent assumptions (Lauver; Nyamathi).

Research related to the care-seeking efforts of specific population groups is also limited. Available research include a quantitative/qualitative study on the role of knowledge and beliefs in care-seeking behaviors for cancer (Sheikh & Ogden, 1998), a qualitative study on postpostpartum women's help-seeking behavior (McIntosh, 1993), a quantitative study on careseeking behavior with breast cancer symptoms in Caucasian and African-American women (Lauver, 1994), a quantitative study on the relationship between physically abused women's care seeking and the level of their abuse (Reidy & Von Korff, 1991), a quantitative study on mental illness and care-seeking behavior among refugees (Portes, Kyle, & Eaton, 1992), and a quantitative study on the characteristics of elderly individuals seeking professional home care services (Frederiks, te Wierik, van Rossum, Visser, Volovics, & Sturmans, 1992). An additional study is Field (1982), who researched adult clients' care-seeking behaviors in relationship to a community health/nursing agency. One qualitative study related to impoverished homeless individuals is found (Shiner, 1995).

On the other hand, literature on the barriers to the utilization of health care services by impoverished individuals is comparatively vast. Specific barriers include negative professional attitudes towards impoverished individuals (Roth, 1990), and the availability and cost of health care (Wheeler, 1979; Wojtusik & White, 1998; Wiecha, Dwyer, Dunn-Strohecker, 1991). The concept of "competing priorities", or the hypothesis that a major barrier to health services utilization is due to the impoverished individual's everyday life centering on meeting his or her basic needs for food, shelter, and safety, is also noted (Gelberg, Gallagher, Anderson, & Koegel, 1997; Gillis, & Singer, 1997). Barriers to health services, defined as the opposite of facilitative conditions by Lauver (1992), are however conceptualized as only one variable related to the care-seeking phenomenon. Furthermore, the prominent and related theoretical construct evident within this body of literature is compliance (Becker, Drachman, Kirscht, 1974; Kiefe & Harrison, 1993). The notion of compliance, or the obligation of patients/clients to follow the

advice given by health care providers, is criticized as consisting of paternalistic overtones by health care providers (Langer, 1999).

Assumptions about the care-seeking efforts of economically disadvantaged individuals and communities are inherent in societal attitudes, including health service providers' attitudes, towards the poor (Carney, 1995; Funkhouser & Moser, 1990; Katz, 1993; Roth, 1990; Zucker & Werner, 1993). Becker (1997) argues that current political factors have diverted attention away from the social policy development process and the social issue of poverty to focus instead on the "subjects" of the policy process, that is, the poor. Academic concerns focusing on lifestyles, living standards, and consumption of the poor also "have unwittingly aided the individualization of poverty, have helped to fuel a political rhetoric which constructs the poor as 'different' and defines poverty in personal, rather than social terms" (Becker, p. 1). An underlying societal belief is that there is an apparent "irrationality" of behaviors associated with the poor (Devine & Wright, 1993). "Blaming the poor", resulting in the stigmatization and marginalization of individuals and communities living in poverty (Hall, Stevens, & Meleis, 1994; Stevens, 1993), leads to the attitude that the poor are socially unworthy and therefore not deserving of assistant services (Becker; Roth).

Presumptive beliefs about poverty and individuals living in poverty influence the shaping of these negative beliefs and attitudes. In particular, while the cultural conceptualization of poverty has been widely criticized (Devin & Wright, 1993; Leacock, 1971), it remains an influential paradigm within the social sciences (Riessman, 1990). Developed using only observational techniques (Carney), the "culture of poverty" viewpoint by Lewis (1969), which identifies 62 behavioral traits of the poor, promotes prevalent beliefs that the poor are crisis-orientated in seeking care, do not use preventative health coping strategies, and are non-compliant with health recommendations (Rundall & Wheeler, 1979).

This writer is currently a community health nurse, who is specifically a clinical nurse specialist within a local community-based multidisciplinary program that provides professional

health services to the poorest communities in the region. Additionally, the writer's experience includes providing primary care nursing as a home care nurse in these communities. Within these roles, this writer has often heard statements which implicitly encompasses these and other beliefs by a variety of health professionals across different health service agencies who provide services to economically disadvantaged individuals and communities. Common comments include, "They (clients of health care services) do not follow through with health recommendations"; "They need more direct support and services to achieve or maintain their health", "They are not home for our visits during welfare-cheque week", and "They do not trust us". These implicit beliefs underpin the orientation of the majority of health care providers and service models to "care for" in contrast to "care with" the recipients of health services (English, 1995). Additionally, these beliefs shape the understanding that building community capacity should occur through the availability and accessibility of health care services as opposed to approaches that follow the philosophy of community empowerment and development process (Chalmers & Bramadat, 1996; English; Stirling & Katamay, 1989).

In summary, whilst poverty is defined as a phenomenon different in modern industrialized societies than in pre-industrial societies and is phenomenologically different in a community where everyone is poor as contrasted to one in which there is a wide range of economic stratas (Spector, 1996; Whyte, 1970), the theory development of poverty is limited. Other concepts of poverty, include those based on the sociological and ideological perspectives of Karl Marx and Max Weber in the late 1800s (Waxman, 1983), the concept of the "value stretch" by Rodman (1963), the "cycle of poverty" (Spector, 1996), and nursing's "interactive adaptional" conceptualization of poverty (Pesznecker, 1984), are atheoretical models that do not present valid representations of poverty (Carney, 1995). Yet, varied conceptualizations of poverty and resultant assumptions about care-seeking efforts by economically disadvantaged individuals and communities directly shape the design of health care service delivery models. Increased and comprehensive understanding of the care-seeking efforts of economically disadvantaged individuals is also critical given the current change in the context of service delivery from institutional health care delivery to one that is administered in the home and community settings (Rachlis & Kushner, 1994; Wearing, 1991). "Quicker and sicker" is a term that is frequently applied to individuals currently discharged from hospitals (Dela Cruz, 1994). This trend has critical significance for economically disadvantaged individuals, who are high volume users of hospital services (Sharpiro, 1994). An inherent assumption of current service delivery context is also that individuals are able to participate in self-care activities related to their health issues and to take on the role of care-giving (Anderson, 1990; Brogna, 1996; Matthis, 1992; Wearing, 1994). However, individuals living with poverty may experience structural factors that hinder the effectiveness of their self-care abilities and care-seeking efforts. Increased understanding of a comprehensive range of factors that enable and inhibit care-seeking efforts from the perspectives of these individuals will therefore enhance the quality and effectiveness of health care services and provider activities towards the strategic engagement of impoverished individuals in illness recovery and health promotion.

#### The Problem Statement and Research Question

A lack of theoretical knowledge and research data regarding the experience of economically disadvantaged/impoverished individuals in seeking care for their health needs existed. Therefore, the main purpose of this study was to identify and provide an in-depth description of the structural and relational factors that influenced the effectiveness of careseeking efforts from the perspective of varied persons living in poverty. These influential factors were social, psychological, geographical, temporal, affective, economical, and political in nature. The question guided this research is:

From the perspective of economically disadvantaged or persons living in poverty, what are the structural and relational factors that influence the effectiveness of their care-seeking efforts?

#### **Definition of Terms**

Economically disadvantaged or impoverished persons - This term refers to individuals who live in poverty. For the purpose of this study, poverty is defined as the chronic, subjective, and objective experience of living with relative deprivations of life resources and necessities. The phenomenon and definition of poverty is multifaceted. Poverty is defined as "the state or condition of having little or no money, goods, means of support" (Webster, 1997). and a variety of conditions involving differences in home and environment, material possessions and educational and occupational resources as well as financial resources (Ferge, 1987). It is relative and not absolute poverty that primarily influences health inequalities in developed nations (Dean, 1994; Marmot & Feeney, 1997). Poverty is also therefore described as relative deprivation related to the denial of various choices and opportunities basic to human development, including the ability to lead a long, creative, and healthy life, self-respect (Becker, 1997; Devine & Wright, 1993; United Nations Development Program Poverty Report, 1998). "Relative deprivation implies a social context and a set of normative standards which serves as a basis comparative evaluation" (Mann, 1970, p. 6). Poverty is subjective in the sense that those who are impoverished experience general deprivations such powerlessness and lack of capabilities resulting in the lack of political freedom, lack of personal security, and treats to sustainability (Mann; United Nations Development Program Poverty Report). In contrast to episodic circumstances of deprivation, poverty is an extreme, concentrated, chronic experience and condition whereby the poor are increasingly "ghettoized" in urban poverty areas and poverty persists across time and over generations. (Devine & Wright). Objective measures of poverty. "poverty threshold", "poverty line", "poverty level" and "poverty rate", consists of the common element of the dollar amounts below which a family or unrelated individual is considered in the state of income deprivation (Canadian Institute for Health Information, 1995; United Nations Development Programme, 1998; U.S. Census Bureau, 1999).

**Care-seeking efforts** – For the purpose of this study, the term "care-seeking efforts" is defined as the thoughts and actions of an individual in response to a threat or troublesome event related to perceived alterations in health, and the realization that external supports are needed to attain or retain optimal health functioning. External supports include lay and professional assistance. Care-seeking may also be considered as the process of seeking help for health-related matters comprising of the thoughts and actions individuals engage in to overcome threats to health, and cope with life crises encountered in order to attain or retain optimal health and functioning (Nyamathi, 1989; Roberts, 1988). The definition of care-seeking is varied in the literature and is complicated by the term care-seeking being synonymous with the terms "help-seeking" and "health-seeking". Effort is defined as the exertion of physical or mental power; an earnest or strenuous attempt; and action undertaken by a group for a specified purpose (Webster, 1997).

Effectiveness: Effectiveness pertains to the "adequacy in accomplishing a purpose; the production of an intended or expected result" (Webster, 1997). Identifying and describing the factors influencing the effectiveness of care-seeking efforts implies that individuals' perception of intended or expected results related to the purpose of seeking care for their health concerns are met.

Structural factors: For the purpose of this study, structural factors are multifaceted, interrelated, and systematic elements that contribute to the effectiveness or ineffectiveness of care-seeking efforts by impoverished individuals. "Structural" is defined as "resulting from the existing political or economic structure", and "pertaining to or based on the assumption that the elements of a file of study are arranged in a systematic manner" (Webster, 1997). The word "structural" is the adjective form of the word "structure (Webster). A factor is "one of the elements contributing to a particular result or situation (Webster).

Relational factors: For the purpose of this study, relational factors refers to the elements that are significantly associated or connected (Webster, 1997) with the effectiveness of

care-seeking efforts by impoverished individuals. This study will explore a range of relational factors, including those that are social, affective, psychological, temporal, political, geographical, and economical in nature, in order to research their association with the effectiveness of care-seeking efforts by impoverished individuals.

#### Significance of the Study

An in-depth understanding of what are the influential structural and relational factors affecting the care-seeking efforts of economically disadvantaged persons facilitates the effectiveness and sensitiveness of health care services and nurses in assisting these individuals in health promotion and illness recovery. A goal of this study included the validation or invalidation of assumptive beliefs regarding the care-seeking process of economically disadvantaged persons. Local and conceptual knowledge of the care-seeking process of economically disadvantaged individuals is also developed. The findings have application potential in service structure reform and development of health professional, particularly nursing, practice standards and education.

#### Introduction to the Method

This study applied a grounded interpretive descriptive method to address the research question. Interpretive description is a noncategorical qualitative research method that draws on principles grounded in nursing's epistemological mandate (Thorne, Kirkham, & MacDonald-Emes, 1997). This approach is relevant to the development of knowledge about human health and illness experience phenomena. It utilizes the building of an analytic framework constructed on the basis of critical analysis of existing knowledge through the identification of theoretical assumptions, biases, and preconceptions that is considered the foundational forestructure. Directed by the foundational forestructure, research design processes include the inductive analysis of both data and the analytic framework to permit thematic explorations of patterns and commonalities within the available data. A grounded interpretative descriptive method serves

the purpose of making inductive sense to develop new theoretical knowledge and practical nursing principles.

### Assumptions

The researcher of the study acknowledged four key assumptions:

- 1. Economically disadvantaged individuals employ care-seeking actions that are influenced by the meanings they attribute to these efforts.
- The meanings of care-seeking efforts by economically disadvantaged individuals are affected by their experiences with living in poverty.
- Economically disadvantaged individuals experience factors that enhance and impede their care-seeking efforts.
- 4. Economically disadvantaged individuals who participate in this study are able to articulate clearly, accurately, and candidly their perceptions and experiences of their efforts to seek care for their health.

#### Summary

There is a critical need to understand the lay person's actions in terms of their own logic, knowledge, and beliefs which are grounded in the context of peoples' daily lives (Williams, 1995). Qualitative research methods that incorporate the "insider' perspective are crucial to the knowledge development of issues related to poverty (Carney, 1992; Evans, Morris, & Marmor, 1994). In addition to systematic differences in access to health care services and in the factors that influence the effectiveness of care, inequalities in health status may result also in differences in care-seeking behaviors (Evans, Barer, & Marmor, 1994). Researching the structural and relational factors that influence the effectiveness of care-seeking efforts from the perspective of economically disadvantaged individuals is critical to the development of quality and productive health services planning and practice that optimally meets the health care needs of impoverished individuals and communities.

### **CHAPTER TWO: LITERATURE REVIEW**

The qualitative approach of interpretive description acknowledges the shared reality of the constructed and contextual nature of the health and illness experience of individuals and directs this interpretation to be located within existing knowledge (Thorne, Kirkham, & Macdonald-Emes, 1997). Interpretive description research is also grounded in the epistemiological orientation of nursing with the goal of better understanding of how nurses can make a differences in individual's health and illness experiences. To this end, this chapter includes a summary and critical analysis of scholarly and multidisciplinary literature, particularly nursing knowledge, and anecdotal experiences that develop the foundational forestructure of researching the phenomenon of care-seeking by economically disadvantaged individuals. The purpose of the forestructure is to orient the inquiry, provide a rationale for its anticipated boundaries, and make explicit the theoretical assumptions, biases, and preconceptions that will drive the design decisions that are outlined in chapter three of this research proposal (Thorne, Kirkham, & Macdonald-Emes).

#### **Literature Review**

Health is conceptualized and broadly accepted as a basic resource for living (World Health Organization, 1984). Thus, a key interest in attempting to describe, explain, and predict how individuals promote and maintain their health, or respond to alterations in their health is readily evident within the vast amount of multi-disciplinary literature, including sociology, psychology, medicine, and nursing perspectives, related to the health and illness experience. The conceptualization of care-seeking further serves to promote knowledge development in this domain (Lauver, 1992).

Literature that is relevant for the purpose of this study will first be reviewed. The following literature review is divided into two major sections: perspectives on the phenomenon of care-seeking, and factors linked with care-seeking by economically disadvantaged

individuals. Non-research and research-based literature are integrated within these two major sections. The first section of the literature review, perspectives on the phenomenon of careseeking, will focus on summarizing the key structural and relational factors related to the following interrelated questions: 1) what is care-seeking? 2) what care is sought and expected? 3) how do individuals seek care?, and 4) when and why do individuals seek and not seek care? The first section will also provide the framework to analyze the literature related to care-seeking by economically disadvantaged individuals.

### Perspectives on the Phenomenon of Care-seeking

#### Care-seeking-What is It?

Varied theoretical perspectives of care-seeking in the literature emphasize numerous dimensions of this phenomenon. Clarification of care-seeking begins with an exploration of what is meant by "care". Care as a verb is broadly defined as "to provide for or attend to needs or perform necessary personal services, and to be concerned about" (Webster's, 1993). In contrast, from the perspectives of health service providers, Dorland's Medical Dictionary (1994) states that care as a noun is "the services rendered by members of the health professional for the benefit of a patient" (p. 269). Health care is thus the provision of services to assist an individual or group in increasing physical capacities, social, and personal resources to realize aspirations and safety needs, and to change or cope with the environment (World Health Organization, 1984). Furthermore, medical care is only one component of health care (World Health Association) and health professionals must avoid viewing health as something that only they can provide (Mhatre & Deber, 1992).

Derived from a theory of general behaviour by Triandis (1977), Lauver (1992) proposes a theoretical model of care-seeking with the perspective that care-seeking is intrinsically linked with the concepts of preventive and illness behaviours. Kasl, Cobb, and Arbor (1966a) define preventive behaviours as any activities undertaken by an individual with the belief that he or she is healthy, for the purpose of preventing disease or detecting it in an asymptomatic stage. Preventive behaviours include either the goals of primary or secondary prevention (Lauver). Illness behaviours, on the other hand, are defined as any activities undertaken by an individual by a person who feels ill, for the purpose of defining the state of his or her health, and to discover a suitable remedy (Kasl, Cobb, & Arbor). The underlying assumption of health and illness behaviours is that they involve the ability of individuals to act on the basis of personal judgment and can be conceptualized as the outcome of a decision process (Lenz, 1984). The phenomenological model of social action, however, emphasizes the habitualized nature of human nature and argues that choice only occurs in relatively rare situations and almost never in the routine context of everyday life (Shiner, 1995).

Specifically, Lauver (1992) conceptualizes care-seeking as a category of preventive health behaviour. Lauver suggests that care-seeking involves the engagement of secondary prevention behaviours, the goals of which are "to diagnose disease, detect disabilities in early stages, and treat diseases to prevent sequelae" (p. 282). Care-seeking involves individuals seeking screening tests in asymptomatic states as well as seeking care with symptoms for diagnosed diseases. Although Lauver theoretically identifies care-seeking as preventive health behaviour, care-seeking as delineated by Lauver is critiqued to be more conceptually linked with illness behaviour.

Furthermore, with the purpose of better guiding health professionals in the prediction of individuals' health behaviour, Lauver (1992) conceptualizes care-seeking as "the probability of engaging in health behavior" (p. 284). The probability of engaging in health behaviour is subsequently "the function of psychosocial variables (affect, expectations, and values about outcomes, habit, and norm) and facilitating conditions regarding the behavior" (p. 284) (see Figure 1). Facilitating conditions are described as specific, objective, external conditions that enable one to seek care (for example, the availability of health insurance) and are the opposite of conditions, or barriers, that inhibit seeking care. The author proposes that theoretical assumptions of the model are as follows: 1) psychosocial variables influences behaviour in

interaction with facilitating conditions, with the assumption that the presence of the conditions reflected by psychosocial variables are necessary but not sufficient to engage in care-seeking; 2) the selection of the psychosocial variables as the major explanatory variables of care-seeking rests on the assumption that behaviour is influenced by many factors; and 3) variables extrinsic to the theory, such as clinical demographic factors, influence behaviour only indirectly through the theoretically identified psychosocial variables. Lauver's model of care-seeking is also critiqued to implicitly assume that the care sought by individuals is exclusively to be health care services.

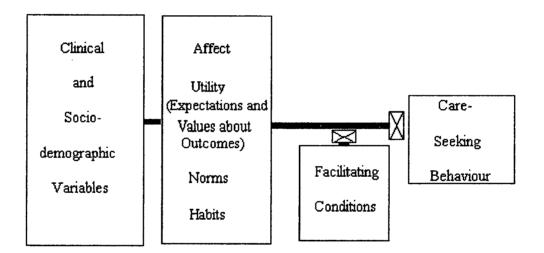


Figure 1. Lauver (1992) Theory of Care-seeking Behaviour (Permission received)

Conceptualization of care-seeking is also theoretically linked to the construct of helpseeking located in the anthropological, sociological, psychological, and health-related disciplinary literature. For example, Gourash (1978) notes that psychologists and sociologists, concerned with the primary constructs of stress and adaptation, conceive help-seeking as one of many coping mechanisms whereby individuals, when confronted by problems or troublesome events, seek out more resources than they alone can provide. Gourash defines help-seeking as "any communication about a problem or troublesome event which is directed toward obtaining support, advice, or assistance in time of distress" (p. 414). Gourash proposes that help-seeking is an inclusive term that encompasses requests for assistance from the social network (family, friends, and neighbours) as well as professional helping agents.

The term "help-seeking" is noted to be often interchangeably used with the term careseeking in the literature reviewed, particularly when the help sought is directly or indirectly referred to as professional assistance and services. This observation is supported by various authors (Freund & McGuire, 1999; Gourash, 1978; Gottlieb, 1976; Nettleton, 1995) who point out that medical sociologists and social service administers have emphasized the use of medical and health services as the primary type of resource sought. This perspective distinguishes helpseeking, which is the search for professional assistance or care, from communication with the social network. The bias of this perspective is suggested to be as result of the dominant paradigm of Western health care, the biomedical model (Freud & McGuire; Nettleton). An additional influential factor related to the health professional bias in the help-seeking literature is a behavioural model of health service use by Anderson and his associates (Aday, & Anderson, 1974; Anderson, 1968; Anderson, & Newman, 1973). The Anderson model is referenced in a number of the literature sources reviewed. This model portrays the causal structure of helpseeking as a complex of three interrelated sets of determinants: predisposing factors, such as age, sex, and education; enabling factors, such as knowledge of the location of health care services; and the need for care.

The professional help bias is also evident in a number of care-seeking research studies. In both descriptive quantitative and qualitative studies, care-seeking is operationalized as a delay in seeking medical care or professional health services. For example, Reidy & Von Korkk's (1991) quantitative study researching the relationship of battered women's help-seeking and the level of abuse focus on the "relationship of categories of physical abuse and delay before contact with battered women's support agencies" (pp. 360-361). McIntosh's (1993) quantitative investigation of depressed post-partum women's help seeking behaviour asserts that women who

18

did seek professional help frequently did so only as a last resort. Ravies, Siegl, and Gorey's (1998) qualitative study of HIV-infected women analyze themes related to the reasons or circumstances offered by these women for their delay in seeing a physician. Using the variables of the care-seeking theory, Lauver with her colleague (Lauver & Ho, 1993) also research the aspect of care-seeking delay with women with breast cancer symptoms related to health professional services.

The term, "health-seeking", is also an associated perspective of care-seeking in the literature. "Health is a state of complete physical, mental, and social well-being - and not merely the absence of disease or infirmity..." (World Health Organization, 1978, p. 2). The definition of health must also consider the inclusion of social and economic contexts and integration of the concept of empowerment in its meaning (Jones, & Meleis, 1993) from the perspective of laypersons (Haggman-Laitila, 1997; Kenney, 1992; Saltonstall, 1993). Health-seeking is also conceptually integrated within the concept of health-promotive behaviour, which encompasses health and wellness as an actualizing concept beyond the prevention of illness (Palank, 1991). In nursing, Schlotfieldt's health-seeking model defines health-seeking behaviours as the range of acquired physiological, psychological, social, cultural, institutional, philosophic, and spiritual activities of the client that are necessary in achieving optimal health (Schlotfeldt, 1978, as cited in Glazer & Pressler, 1989). These behaviours may be voluntary, involuntary, conscious, or subconscious, and requiring the individual to have some knowledge, ability, or desire to pursue them (Glazer & Pressler). Health-seeking involves health-enhancing or preventative measures, and health maintenance activities (Freund & McGuire, 1999; Nyamathi, 1989) within which seeking external resources (that is, help-seeking or care-seeking) is among the range of activities people engage in to keep well. Therefore, advanced knowledge of care-seeking requires the understanding of the individual's definition of health and wellness, core concepts within the conceptualization of health-promotive or enhancing behaviour (Palank).

The concept of self-care is also theoretically related to the phenomenon of care-seeking. Woods (1989) defines self-care as:

"a person's attempts to promote health, prevent illness, detect symptoms at an early date, and manage chronic illness. Self-care also include processes of self-monitoring and assessment, symptom perception and labelling, evaluation of severity, and evaluation and selection of treatment alternatives, such as self-help, lay helping resources, or formal health services" (p.2).

Dorothea Orem (1985) proposes a theory of self-care and nursing that defines self-care as "the practice of activities that individuals personally initiate and perform on their own behalf in maintaining life, health and well-being" (p. 13). Denyes' (1988) quantative study of the significance of Orem's model for health promotion in a sample of adolescents concludes that the analysis of general health state, self-care agency (or the ability to engage in self-care), and self-care does offer important direction for health promotion. Self-care directed at care-seeking, or "health-deviation self-care requisites" in Orem terminology, include: seeking and securing appropriate medical assistance, being aware of and attending to effects of pathologic conditions and states, and modifying the self-concept by accepting oneself in a particular state of health (Orem). Self-care and dependent care are behaviours learned within the context of social groups by human interaction and communication (Johnston, 1989). Woods notes that in addition to nurse scientists, social and behavioural scientists have proposed theoretical models that have guided investigations of help-seeking for illness, but few have used the term "self-care" in their work.

Lauver (1992) critiques classical theoretical models of health behaviour, the Health Belief Model (Rosenstock, 1974; Becker & Maiman, 1983), the Theory of Reasoned Action (Ajzen & Fishbein, 1980), and Triandis" Theory of Behavior (Triandis, 1977; Triandis, 1982) as limited in their explanation and prediction of people's engagement in health behaviours. Other authors (Abraham, Sheeran, & Johnston, 1998) also comment that "accumulated research has produced a series of overlapping social cognitive models which propose a variety of modifiable cognitions as the antecedents of individual motivation and readiness for action" (p. 569). The theoretical bias of these models, including the concepts of care-seeking, help-seeking, healthseeking, and self-care, is the behavioural emphasis on the promotion of health status. The bias results in the theoretical assumption that positive changes in an individual's health are modifiable and can be particularly influenced by health practitioners through specific intervention design (Abraham, Sheeran, & Johnston). The behavioural emphasis of health promotion is also further criticized for its individual and not more "upstream" or societal orientation shaping health status (Butterfield, 1990).

In contrast to the predominant conceptualization of care-seeking as a behaviour, a smaller number of literature sources conceive care-seeking as a process (Field, 1982; Russell, 1996). Field's grounded theory study aims to identify the characteristics and processes inherent in client-care-seeking behaviour in a community health setting and identified dimensions, behaviours, and activities related to three distinct phases of care-seeking. Russell (1996) uses an ethnographic approach to describe the care-seeking process used by elders in a continuing-care retirement community to elicit care from care-givers and engage care-givers in care interactions. Russell identifies two phases of care-seeking and the stages within these phases. Additionally, Lenz (1984) analyzes the concept of information-seeking, an inherently related concept, within the framework of a six-step decision-making process related to health behaviour. Processes are more complex theoretical constructs than are concepts by covering much more comprehensive data observed over a longer period of time (Peplau). Advanced knowledge development of the care-seeking phenomenon thus involves the consideration of temporal and relational factors related to the conceptualization of care-seeking as a process, which may assist in answering the questions of how and when individuals seek or do not seek care.

In contrast to viewing care-seeking from the perspective of the individual, the systems approach of understanding access to health care lends another perspective of care-seeking. Gulzar's (1999) concept analysis of health care access proposes that access to health care is conceptually defined as "the fit among personal, sociocultural, economic, and systems-related factors that enable individuals, families, and communities to have timely, needed, necessary, continuous, and satisfactory health services" (p. 17). Gaultzer states that access to health care is aimed at increasing physical capacity, social, and personal resources to realize aspirations, and safety needs to change or cope with the environment with the goal of improved health, better health outcomes, and improved quality of life. The author furthers proposes that the operational definition of health care access need to consider several dimensions:

"The ability of people to access health care is influenced by health care system and userrelated aspatial characteristics including need for services, sociocultural, psychological, financial, and attitudinal variables and geographical or spatial characteristics such as distance, architectural, and transportational variables which may be barriers or facilitators" (p. 17).

Similarly, Anderson's (1995) behavioural model of health services use includes the health care system as one of three primary determinants of health behaviour. It is argued, therefore, that advanced theoretical understanding of care-seeking, which involves the seeking and use of resources external to the individual, requires the additional exploration of structural and relational health care services and system-orientated factors.

In summary, from the perspective of the individual, care-seeking is conceptualized as a process and behaviour in the literature. Care-seeking consists of the process of seeking help for health-related matters (Field, 1980; Roberts, 1988) comprising of "the thoughts and actions individuals engage in to overcome threats to health, and deal with life crises encountered, in order to attain or retain optimal health and functioning" (Nyamathi, 1989, p. 284). Care-seeking includes self-treatment such as self-dosing with non-prescription drugs and following a balanced diet or regular exercise regimen (Freud & McGuire, 1999; Zola, 1973). Care-seeking behaviour also involves both identification of an individual, people, or agency to provide help in the solution of an identified health problem or goal (Field, 1982). A comprehensive theoretical perspective of care-seeking involves consideration of elements related to the concepts of help-seeking, health-seeking and self-care. Care-seeking also includes the development of an expectation of care (Field). Researching the phenomenon of care-seeking requires the

consideration of individual's consultation with both lay and professional help. The knowledge development of care-seeking is further advanced through the examination of health care system and other contextual variables that systematically and structurally influence care-seeking by individuals.

#### What Care is Sought and Expected?

Enhanced understanding of care-seeking encompasses the awareness of the nature or characteristics of care that is sought and expected by individuals when faced with a health issue. In general, people who seek help are usually looking for comfort, reassurance, and advice Gourash (1978). Help from family and friends is reported to be the initial type of care sought and contact with professional services is only undertaken as a last resort (Gourash). The sole use of professional services occurs much less frequently than either exclusive reliance on family and friends or help-seeking from both the social network and professional sources (Rosenblatt & Mayer, 1972). This point is illustrated in McIntosh's (1993) investigation of depressed postpartum women's help-seeking behaviour. The study concludes that those women who did seek professional help frequently did so as last resort, and only when the severity of symptoms and the perception that normal functioning had become impaired to an unacceptable degree. The study also discovers that less than half of depressed mothers sought help from anyone, and the support is divided approximately equally between professionals and family and friends.

Gottlieb (1976) identifies the lay treatment network, or the nonprofessional modes of interpersonal helping which occur in an individual's natural environment including family members, nonprofessionals in the community, and self-help groups. Four types of informal help are identified: 1) self-help groups, composed of persons who share common problems, 2) social networks, comprised of an individual's personal community of associates with whom one interacts on a face-to-face basis, 3) "community gatekeepers", consists of a person's informal helping resources that positively or negatively influence the use of further help, and 4) neighbourhood-based support systems, composed of residential associates who influence the volume, content and sources of help utilized in the neighbourhood. The author also suggests that a further direction for research is the analysis of existing forms of lay service delivery which may indicate what alternatives to professional means of support are available to aid the coping process.

Gottlieb's (1976) notion of the lay treatment network is congruent with Kleinman's (1978) conceptualization of health systems comprising of professional, popular, and folk sectors. Kleinman's (1978) premise is that health, illness, and health care-related aspects of societies are cultural systems that are like other symbolic systems (for example, kinship and religious systems) built out of meanings, values and behavioural norms. Specifically, the popular sector comprises of the individual and family context of sickness and care, the social network, and community-based activities. Comparable with Gottlieb's (1976) suggestion that the vast majority of care is given by the lay treatment network, Kleinman notes that in both Western and non-Western societies, approximately between 70 and 90% of illness is managed within the popular domain. Moreover, in relationship to care-seeking, Kleinman contends that "most decisions regarding when to seek aid in other arenas, whom to consult, and whether to comply, along with most lay evaluations of the efficiency of treatment, are made in the popular domain" (p. 86). Freund and McGuire (1999) agree that the "hidden health care system" or laypersons are often the real primary health care providers.

Despite the predominance of care in the non-professional domain, a key focus found in the care-seeking research literature is related to the utilization of health care services. A gap in available research is the description of care-seeking processes and behaviours in the lay or nonprofessional realm of care. In contrast, despite the common misconception that professional services are the primary type of care sought (Freund & McGuire, 1999; Gottlieb, 1976), a vast number of literature that research care-seeking through the health service lens is noted. An example is the large number of studies interested in the identification and explanation of the utilization rates of professional services (Frederiks, te Wierik, van Rossum, Visser, Volovics, & Sturmans, 1992; Gelberg, Gallagher, Anderson, & Koegel, 1997; Kiefe, & Harrison, 1993; O'Toole, Gibbon, Hanusa, & Fine, 1999; Padgett, Struening, & Andrews, 1990; Portes, Kyle, & Eaton, 1992; Sharp, Ross, & Cockerham, 1983: Rundell, & Wheeler, 1979; Wiecha, Dwyer, & Dunn-Strohecker, 1991). For instance, researching help-seeking behaviour among mentally ill Mariel Cuban and Haitian refugees, Portes, Kyle, and Eaton (1992) define seeking help as " the total number of visits to a general medical provider or mental health specialist for mental health reasons during the prior six months" (p. 292). The investigation of health-related utilization patterns that focus on how or why health services are used by a specific group is also noted. This is evident in a number of studies in the help-seeking literature (Padgett, Struening, & Andrews, 1990; O'Toole, Gibbon, Hanusa, & Fine, 1999). As previously noted, a possible influential factor is Anderson's model of health services utilization (Aday & Anderson, 1974; Anderson, 1995), which is mentioned in several of the research studies examined.

There are also identified characteristics of professional services expected of individuals in seeking health care services. Client expectations is a key determinant to satisfaction with health care (Greeneich, 1993). Expectations are those responses that are situation specific, influenced by environmental factors, past experience, and properties of the situation (Greeneich). The field of market research proposes that consumers expect equitable treatment in the service setting (Arenson & Evans, 1978). Equity theory advances the concept that an exchange between partners and fair treatment is part of this exchange of goods and services, which is judged against existing societal norm of behaviour (Greeneich, 1993). The extrapolation of this expectation to health care services, then, is suggested to be that clients expect to be treated equitably and fairly by health care providers.

Expediency is another client expectation and is also an important dimension of careseeking that was found by Field's (1982) care-seeking study of community health nursing services. That is, clients look for a facility which is close to home and where they would receive prompt service. Furthermore, all clients who identify their health issue as an emergency are concerned with expediency. Ingram (1978) discovers that in an emergency, clients utilized the nearest service whether or not the facility is appropriate.

Exploring community nursing services, Field (1982) also identifies three major activities clients expected community nurses to perform. First, expected nursing actions related to physical care include weighing, assessing blood pressure, and wound dressing. Second, providing support includes nursing actions such as listening and reassurance and are those activities that sustain clients in endeavours which promote them to more likely succeed in solving their own problem or reaching their perceived goal. One critical function of the nurse in supporting the client is to listen to the client's feelings, fears, and ideas. The nurse is an informed listener and it is this knowledge base that differentiated his or her role from that of a neighbour. Reassurance further includes reinforcement of the client's own observations and decisions. Guidance is the third major nursing activity, involving the provision of direction, mainly through information, so that individuals can select their own course of action. Additionally, Field concludes that a small group of clients who show a lack of external control in their lifestyle expect the nurse to impose controls or limits within which the clients would have to function. Moreover, Field concludes that clients who did not have a clearly defined health goal or purpose did not see nursing activities as relevant even when nurses addressed the problem identified by the referring agency.

Similarly, Cronin and Harrison (1988) research the importance of nurse caring behaviours as perceived by patients after myocardial infarction. The authors conclude that nursing behaviours that focused on the physical well-being is a minimum care requirement that must be met before more qualitative aspects of care, which are those traditionally valued by nurses themselves, can be addressed. The authors concur that this result is consistent with the hierarchy of human needs advanced by Maslow (1943).

Roberson's (1992) qualitative study on clients' meanings of compliance also offers insight into expected outcomes of care. The study findings include that clients and health 26

professionals assume different definitions of compliance and have different treatment goals in mind. Clients define compliance in terms of apparent "good health" and seek treatment approaches that are manageable, liveable, and effective, thus develop systems of selfmanagement which are suited to their lifestyles, belief patterns, and personal priorities. Health professionals believe, however, that compliance is necessary for the success of their treatment plans, the prevention of complications, and the evaluation of the effectiveness of therapeutic regimens. Roberson also notes that the standard medical definition of compliance is implied to be 100% compliance, which fails to consider the implications of the prescribed treatment in the context of people's lives. From the client's point of view, "noncompliant" health-seeking behaviour such as seeking advice from more than one doctor and/or tailoring of the doctor's advice is rational, and it preserves for clients some element of control (Freund & McGuire, 1999).

Additionally, Freund and McGuire (1999) contend that western society in general and medical professionals in particular hold an ambiguous norm for health care consumers. That is, it is expected that responsible persons should get professional medical care for all serious, medically treatable ailments and, at the same time, should not bother doctors or use medical facilities for unimportant or non-treatable ailments. This norm also assumes that people share the professional definition of which ailments are serious or treatable and able to assess their own situations adequately to determine which category they fit. For example, Calnan (1980) suggests that the problematic overuse of emergency departments can be portrayed in terms of a typical conflict between professional and lay needs.

To seek care may also imply the expectation of a caring response. This point is particularly relevant when considering seeking care from health professional services. In relationship to nursing services, Morse, Solberg, Neadner, Bottorff, and Johnson (1990) identify that it is difficult to discern the differences between the terms "care", "caring", and "nursing care". Care or caring may specify the actions performed (for example, "to take care of") or the concern exhibited (for example, "caring about") or in some circumstances "care" encompasses both meaning. Content analysis of caring in the nursing literature by these authors resulted in the identification of five categories of caring: caring as a human trait, caring as a moral imperative or ideal, caring as an affect, caring as an interpersonal relationship, and caring as a therapeutic intervention. Two identified outcomes are caring as the subjective experience of the patient and caring as a physical response. The authors note that numerous studies find that clients repeatedly report that they feel cared for when they are treated as individuals, when they receive help in dealing with illness experience, when nurses anticipate their needs, when they believe that nurses are available, and when nurses appear relaxed and confident.

Three major theories of caring have been developed for nursing (Morse, Solberg, Neadner, Bottorff, and Johnson (1990), including Orem's Self-care Deficit Theory of Nursing (Orem, 1985). Caring functions of nurses related to client care as identified by Orem are related to the 'helping system'', and include doing for or acting for another, guiding another, supporting another (physically and psychologically), providing environmental conditions that support personal development and teaching. However, the values inherent in this self-care theory reflect those of western society and may not be appropriate in multi-cultural societies (Morse, Solberg, Neadner, Bottoroff, & Johnson). Morse, Solberg, Neadner, Bottorff, and Johnson conclude that three nursing care actions – maintenance, negotiation, and restructuring – assist the client to change health, life patterns, or "life ways".

Marck (1990) identifies and operationalizes therapeutic reciprocity as a caring phenomenon to provide direction for nursing practice in the nurse-client relationship. Similar to elements within equity theory (Greenich, 1993), shared control is a critical implication of therapeutic reciprocity that empowers the nature of mutual responsibility for the nurse-client relationship. Shared control assists the client to gain "efficacy in coping with the concerns underlying help-seeking, and the nurse experiences efficacy in the provision of care that genuinely helps" (Marck, p.52). Similarly, Ashworth, Longmate, and Morrison (1992) assert that client participation, encompassing features of self-care, involvement, collaboration, and partnership, clients being listened to by health care professionals, and having the right to speak regarding health care, is essential to client-health care provider relationships. Marck contends that consequences of therapeutic reciprocity include the nurse and the client gaining trust, both in their ability to relate effectively in the help-seeking situation, and in each other as fellow human beings. Watson (1985) further proposes that effective caring promotes health and individual/family growth and that a helping-trusting, human care relationship between nurses and their clients is one of ten "carative" factors that nurses use as a framework for the caring process. The concept of trust is prevalent in numerous literature sources related to community health nursing, and particularly in home care nursing practice (Giordano, 1997; Morse, 1991; Repper, Ford, & Cooke, 1994; Richardson, 1987; Trojan, & Yonge, 1993). Other consequences of therapeutic reciprocity according to Marck consist of the nurse and client being empowered to cope more effectively with the help-seeking situation, and the probability of positive outcomes for both parties is increased.

Furthermore, Brown's (1986) qualitative study of client's perspectives of the experience of care by nurses following hospitalization of a medical or surgical condition identifies eight themes that reflected the clients' perspective of being cared for by a nurse. The care themes are: (1) recognition of individual qualities and needs, (2) reassuring presence, (3) provision of information, (4) demonstration of professional knowledge and skill, (5) assistance with pain, (6) amount of time spent, (7) promotion of autonomy, and (8) surveillance. The theme of surveillance, in particular, consists of interactions in which nursing activities were experienced by the client as keeping him or her under watch for the purposes of monitoring the physical condition and safety of the client.

Some insight about the nature of care sought and expected is offered through the literature. The initial type of care sought is from family and friends. Themes related to expectation of comfort, caring, reassurance, support, and advice are evident in both lay and

professional care. The nursing literature offers, in particular, the expectation by clients of a reciprocal relationship between client and nurse that supports a helping outcome. A gap in the literature is noted to be how is care-seeking behaviours and processes are affected when expectation of care are not met. Advanced understanding of care-seeking requires researching individual's structural and relational expectations of the nature of care sought.

#### How do Individuals Seek Care?

Relational and structural factors impact how individuals seek care. Lauver's (1992) care-seeking model includes "norms" or normative influences as a psychosocial variable that influences care-seeking behaviour. Normative influences include personal norms, which are one's own beliefs about morally correct behaviour regarding care-seeking. Freund and MacGuire (1999) concur that people's belief systems inform their decisions as to when they need help and which kinds of help are appropriate. Normative influences according to Lauver also include social norms, which re defined as others' beliefs about care-seeking. The author does not elaborate on this latter concept. Literature on the relationship of social support and help-seeking provides more information pertaining to how social norms influence care-seeking behaviours and processes.

Research on social support/networks and help-seeking can categorized into two areas: the transmission through the social network of values and beliefs that influence health and illness-related behaviours of the individual, and the relationship of stress to help-seeking and the buffering influence of social support on the stress (Roberts, 1988). The former domain is illustrated by Friedson's (1960) identification of the "lay referral structure", which is described as "the whole process of seeking help involves a network of potential consultants, from the intimate and informal confines of the nuclear family through successively more select, distant, and authoritative laymen, until the professional is reached" (p. 377). Shiner's (1995) qualitative study on homeless men concurs that the decision to seek medical (health professional) care is a socially bounded phenomenon. Although not explicitly identified in previously mentioned careseeking research studies, the factor of the lay social support network on care- seeking as described by Friedson appears to be a plausible causal factor related to the numerous studies' findings that professional help is the last resort.

Lenz (1984) assists in the clearer understanding of the influence of the social network in care-seeking. Lenz proposes the concept of information seeking as an important theoretical antecedent of health-related decisions and behaviour that serves as an intervening process between the perceptions of symptoms and receipt of health care. The author argues that the importance of considering information-seeking is demonstrated by studies which document relationships between information search behaviour, the extent and content of information received, and the choice of provider from among those potentially available. Health care seeking therefore involves a patterned sequence whereby individuals perceiving an actual or potential health problem consult others in their social network, receive information and advice, and are referred to lay and professional persons for information and help. The information acquired during the information search process therefore constrains and helps dictate the searcher's choice of possible health care resources. Moreover, the information search process is an integral part of the decision process model. The decision process model postulates a sequence of steps that involve identifying a problem to be solved or goal to be achieved, gathering information about alternative courses of action, evaluating and weighing options, choosing the optimal alternative and taking action to solve the problem or achieve the goal (Lenz). Increased knowledge of careseeking therefore requires the consideration of what information is sought and received by individuals in regards to care-seeking decisions. Furthermore, the cultural and social meaning of the information gathered, that is, the "rules of thumb" regarding appropriate responses to illness (Shiner, 1995) must also be considered.

The perspective of care-seeking as a decision-making process is evident in findings of Field (1982)'s qualitative study of individuals seeking community health nursing care. The author identifies three phases of care-seeking: preactive, interactive, and post-active. The

dimensions, behaviours, and processes of care-seeking are identified within these phases. For example, problem identification is a second stage in the preactive phase of care-seeking (Field,

1982). Processes involved with problem identification include:

"1) Having perceived a need for help, the individual identified a problem or goal with which to approach a health care agent or agency2) A dominant problem was selected but the presenting problem might be only one symptom of a more complex situation" (p. 21).

Similarly, the perspective of care-seeking as a process is also demonstrated by McKinlay (1973). McKinley describes the "notion of help-seeking career", or the transition from person to patient and back. The help-seeking career includes the following stages: onset of the problem, the response to the symptoms, the lay consultation and referral and self-medication, entry into the medical system, and coming from the encounter that leads to rehabilitation or death.

A relationship also exists between the buffering influence of social support and the social network and the stress related to help-seeking (Roberts, 1988). Gourash (1978) notes that the social network can affect help-seeking in four ways: 1) by buffering the experience of stress that might lead to help seeking; 2) by providing tangible and emotional aid needed, thus not making professional help necessary; 3) by acting as a screening and referral agent to professional services; and 4) by transmitting attitudes, values, and norms about professional help-seeking.

Roberts' (1988) review of the literature related to social support and help-seeking also notes the relational factor of chronic lack of social support. For example, isolated groups have long-term problems with attachment that influences the effectiveness of short-term supportive interventions. Ainsworth (1985) in a review of the developmental evolution of attachment, suggests that the most important element in social networks is "relationships that constitute affectional bonds, and particularly those with attachment components that provide a sense of security" (p. 811). Nurses and other health care providers often, however, become the support networks for individuals with a chronic lack of social support. Research is lacking in the health care literature on the effect of this chronic supportive therapy by professional (Roberts). The individuals with lack of social supports may benefit from interventions that either set them up with a trained lay network on a long-term basis to replace the professionals or that, if possible, work with them to develop an ability to develop or maintain a network.

How individuals seek care is complex. Interrelated factors affecting how individuals seek care include personal and social norms or beliefs. Individuals' social supports and networks are an important structural and relational factor that influence individuals' care-seeking processes and behaviours. How individuals seek care can also be conceptualized as a decision-making process. An information-seeking process is inherent within the decision-making process and which includes seeking information about alternate courses of actions to meet the health problem or goal. The processes and outcomes of the information search is intensely shaped by the social network.

### When and Why do Individuals Seek or Not Seek Care?

There are varied factors in the literature that either theoretically or empirically describe and explain when and why individuals seek or do not seek care. To begin, Lauver's (1992) careseeking model suggests that the theoretical psychosocial variables, "affect", "utility" (which consists of "expectations" and "values"), "norms", and "habits", influence and predict careseeking behaviour. Affect refers to feelings such as anxiety and embarrassment about diagnostic procedures and their results. Utility is the degree of perceived worth of care seeking, such as the worth of detecting cancer early. The concept of utility further consists of the variables, "expectation" (beliefs about the likelihood about positive outcomes of care-seeking), and an individual's "value rating" or perceived importance of the desired outcomes of care-seeking. Norms reflect personal and social beliefs about what one ought to do about care-seeking, and include one's personal obligation to seek care and other's beliefs about the appropriateness of care seeking (Lauver & Ho, 1993). Habit refers to one's usual pattern of seeking health care. Lauver (1992) proposes that the psychosocial variables are mediated by facilitators. Facilitators are those objective conditions that make it easier to seek care, such as having a regular health practitioner. Thus, facilitators are suggested to be structural factors that enhance the care-seeking process. Therefore, according to this care-seeking model, care-seeking is most likely to occur if the psychological variables are conductive to care-seeking and the facilitating conditions are present. Moreover, when the psychosocial variables are not conductive to care-seeking and facilitating conditions are absent, then care-seeking would be least likely to occur (Lauver & Ho, 1993).

Lauver's (1992) psychosocial variables are interrelated with other health and illness behaviour constructs in the literature. For example, the variables, affect, expectation, and valuerating are interrelated to Abraham, Sheeran, and Johnston's (1998) description of motivational constructs. Motivational constructs refer to a health threat, or beliefs related to the perceived severity of, and susceptibility to, a health condition. Individuals seek care, then, when they perceive or believe that the severity of their health condition is high or that they are susceptible to a health condition.

Motivation is also the central construct within the Health Belief Model (Rosenstock, 1974). The model proposes that motivation to engage in a certain behaviour is a function of the reward obtained for engaging in the behaviour minus the perceived cost and barriers associated with the barrier (Cox, 1982). The Health Belief model therefore hypothesizes that people seek care only if they perceive themselves as potentially vulnerable, if existing health conditions are threatened, and if they perceive certain cues to actions with no barriers to the reduction of the health threat (Cox; Woods, 1989). Furthermore, Becker, Drachman, and Krischt (1974) suggest that ones' perception of the threat represented by a disease is influenced by cues to action and modifying factors such as age, social class, and knowledge about the disease

Field's (1982) grounded study offers more detailed support of threat as a factor that affect community health setting clients seeking nursing care. Field identifies that threat to

lifestyle and effect on self-esteem (for example, psychological threats to self-image and social image) are two significant situations that precipitated care-seeking behaviours. The following care-seeking processes emerged in the study:

"1) When factors in the individual's lifestyle exerted sufficient force on his self-esteem so that he perceived himself as helpless to resolve the problem unaided, care seeking behaviour was initiated.2) When an individual perceived that a change in lifestyle would be beneficial to his health but did not believe he had adequate resources to create this change, care-seeking behaviour was initiated" (p. 21).

Numerous literature sources focus on the importance of understanding the role of presenting symptoms in the decision to seek professional assistance. Kasl, Cobb and Arbor (1966b) sought to understand under which conditions an individual will visit a physician and concludes that they must become aware of a symptom as a threat before they will seek professional medical care. Shiner (1995) further suggests that medical sociologists have argued that care-seeking behaviour may be influenced by: 1) the nature of a person's symptoms (visibility, recognizability, perceived seriousness, and persistence); 2) the extent to which they interfere with functional abilities (such as fulfilment of physical, vocational, and social roles); 3) individuals' tolerance thresholds; and 4) the presence of competing interpretations that may be assigned to symptoms once they have been identified (Mechanic, 1972; Zola, 1973). The emphasis on the role of symptoms implies illness behaviour, which requires the consideration of social and cultural definitions of illness (Mechanic, 1972).

Lauver (1992) identifies "habit" as the fourth psychosocial variable directly influencing care-seeking behaviour. Habit refers to how one usually acts when one has symptoms (for example, the promptness of seeking care) and reflects one's usual care-seeking behaviour and past experience with care-seeking. Whilst the author does not elaborate on this variable, Mechanic (1972) suggests that the tendency to attend to symptoms and to seek care for them is a function of the learning that has taken place in the family or the culture. The person's behaviour is therefore a function of the experiences and responses of his or her childhood regarding how to attend to symptoms, what is the proper response, and when to seek help outside the family. Furthermore, Milio (1976) proposes that behaviour patterns of populations are a result of habitual selection from limited choices, and these habits of choice are related to actual and perceived options available, and beliefs and expectations developed and refined over time by socialization, formal learning, and experiences.

Zola's (1973) notes that although the decision to seek help for presenting symptoms may seem obvious, the process is often complex. The importance and frequency of episodes of illness in an individual's life, the seriousness and frequency of those episodes of illness which come to professional attention, and the process by which an individual decides that a series of bodily discomforts is labelled "symptoms" and become worthy of professional attention are three dimensions of presenting symptoms that need to be examined. From an anthropological perspective, symptoms are also evaluated differently in different cultures by delineating the fit or lack of fit of symptoms into a larger cultural pattern that helps to explain why the symptom is or is not abnormal (Zola).

Zola (1973) also notes that an inherent assumption needs to be acknowledged in studying why an individual seeks professional medical help. The general assumption is that in the face of symptoms, a rational individual, after an appropriate amount of caution, would seek aid. When the person does not seek care or delays excessively, the individual's rationality is questioned, particularly by health service providers. Furthermore, the author points out that numerous studies have found that the reasons for delay to seek medical attention are considered a range of "faults" by health professionals, including the patient has no time, no money, no one to care for children, or take over other duties, dislikes physicians, nurses, hospitals, or needles, or has lower education level, is lower socioeconomic status, or an ethnic or racial minority. Zola asserts, however, that given the voluminous number of studies on delay in seeking medical aid for almost every conceivable disorder and treatment, the norm for any population is actually to delay seeking professional attention. Therefore, the evidence that every day people's lives are subject to a vast array of bodily discomforts and only an infinitesimal amount of these discomforts get to a physician must be recognized.

Additionally, Zola's (1973) study concludes that it is very likely that people have their symptoms for a long period of time before ever seeking medical aid. The reason for this delay is found to be a physical, personal, and social accommodation to the symptoms and it is when this accommodation breaks down that the person seeks, or is forced to seek medical aid. Therefore, the "illness" for which one seeks help may only partly be physical relief from symptoms. This observation concurs with Field's (1982) study that concludes individuals select a dominant problem which to approach a health professional, but the presenting problem might be only one symptom of a more complex situation. The author concludes that a set of "nonphysical" variables "triggers" the decision to seek medical aid for a symptom: 1) the occurrence of an interpersonal crisis, 2) perceived interference with social or personal relations 3) sanctioning , or pressure, from another person to be seen, 4) perceived interference with vocational or physical activity, and 5) temporalizing of symptomatology, or setting a time to seek help if "it is not better".

Similarly, Molde and Baker (1985) note that clients visit primary care clinicians for a variety of medical and nonmedical reasons, many of which are not obvious so that the presenting symptom or "chief complaint" (Feinstein, 1967, as cited in Molde & Baker) is only one of several reasons that people seek care. Eisenthal and Lazare (1976) agree that the client has initiated problem-solving in the self-help phase prior to seeking professional help, and where the individual develops and tests concepts of how he or she hopes to be helped. The authors propose that the "request" made of the professional help has thus developed over time and needs to be conceived to be a complex resultant of the client's problem, resources, habitual style of coping, and patient's expectations regarding treatment and the treatment setting.

Accordingly, Molde and Baker (1985) research the reasons motivating people to initiate visits to a primary care clinic staffed by physicians and nurse practitioners. In this quantitative

study, the authors discover that 30% of the sampled clients had "hidden agendas" or care requests that were unrelated to the presenting chief complaint. Significantly, clients with hidden agendas tend to ask about specific causes for their symptoms and to have definite ideas about how these symptoms should be evaluated and treated. In contrast, clients without hidden agendas more often simply ask for a diagnosis or for relief or symptoms without specifying how they thought this should be accomplished.

The relational factors of motivation, health threat, beliefs, role of symptoms, and an individual's habit in care-seeking are additionally suggested to be inherent elements within the concept of risk. Risk is defined as "the probability that a particular adverse event occurs during a stated time period, or results from a particular challenge" (Heyman, Henriksen, & Maughan, 1998, p. 1296). Lauver (1992) notes that individuals engaging in care-seeking behaviours, especially for the goal of screening or evaluating symptoms, warrants individuals inherently expose themselves to the threat of learning that something is seriously wrong. Lauver implies that the risk of confirming a negative health outcome is a deterrent to seeking health care.

Risk is also proposed to consist of the interrelated complex risk elements: events/categories, adversity/value, stated time frames/time frames, and probability/expectations (Heyman, Henriksen, & Maughan, 1998). For example, disease and illness are generally regarded as adversity, but value conflicts arise when efforts to prevent one negative consequence cause another consequence resulting in individuals arriving at their own personal balance between the costs and benefits of risky activities. The authors further state that the negativity of an adverse health event depends upon when it occurs so that the calculations individuals make are situated in their social circumstances. Therefore, risk behaviour is conceptualized as the product of individual cognitions, decisions, and associated actions as well as the product of an interplay between individuals, the actions of other individuals, their communities, and social environments (Plumridge & Chetwynd, 1999; Rhodes, 1997). Plumridge and Chetwynd further studied the relationship of self-identity and the social construction of risk with a population of injection drug users and conclude that more knowledge is needed in how identity is tied to social practice.

The body of literature on access and barriers to health care also offer structural and relational factors pertaining to when and why individuals seek or not seek care. Access and barriers to health care is implied with Lauver's (1992) theoretical model of care-seeking which identifies facilitating conditions as a key variable influencing care-seeking behaviour. Gulzar (1999) identifies that definitions of access to health care are varied, including the consideration of barriers to health care as indirectly defining access (Aday & Anderson, 1975). Access may be defined as factors that affect entry into the health system and is a measure of the fit between characteristics of providers and clients, and characteristics and expectation of clients (Penchansky & Thomas, 1981). Five interrelated dimensions of access are: availability (relationship of volume and type of existing services and resources to a person's volume and type of need), accessibility (the relationship between the location of a health care supply and the location of clients, taking into account transportation resources, travel time, distance, and travel cost), accommodation (the relationship between the organization of resources to accept clients and client's ability to adjust to these factors), affordability (the relationship of the price of services to people's ability to pay for services), and acceptability (the relationship of clients' attitude about personal and practice characteristics to actual provider characteristics) (Penchansky & Thomas). Barriers related to these dimensions of access, therefore, inhibit careseeking.

Care-seeking is also affected by the fit between health care services provider and clients characteristics as perceived by the client. Health care "clinicians in almost every setting are exposed to, and unfortunately become part of, the contexts that distances patients from care" (Moore, 1997, p. 42). Particularly, clients' expectation of health care services is intricately related to client satisfaction of the quality of care received, even that related to a single health care episode (Greeneich, 1993). The assessment of the quality of care within a health care

setting that is expected by clients needs to include the elements of structure, process, and outcome (Donabedian, 1966). Structure is described as the fixed part of the practice setting and consists of providers, resources, and tools. Process is the relationship between activities of care and consequences of these activities for the health and welfare of the client. For example, a discrepancy between the layperson's and the professional's understanding of the sickness, as evidenced in the gap between people's cultural beliefs and folk-illness models and the professional orientation to health and illness, influences individuals' decisions to seek or not seek professional help (Freund & McGuire, 1999). Outcomes are changes in the client's condition secondary to the administration of health care. Poor client outcomes are related to the failure of health clinicians in discovering and addressing all clients reasons for seeking health care that has been previously mentioned. That is, both the overt presenting symptom or "chief complaint" (Feinstein, 1967) and the less obvious "hidden agendas" (Barsky, 1981) that result from the client's failed self-help and other help strategies must be discovered and addressed. Failure of this can result in client dissatisfaction with health care. Client satisfaction is a critical outcome associated with "new and return business" in the health care service setting (Greenich).

Conceptually, the consideration of the environment as a relational factor influencing health is evident in numerous models of individual-orientated and population-focused health and health-related behaviours. Lauver's (1992) care-seeking model proposes that the environmental factors related to socioeconomic status and demographical indicators indirectly influence careseeking. Lauver does not elaborate on how this occurs.

Some insight into how an individual's environment affects care-seeking is gained by consideration of some conceptual perspectives of what is meant by the term "environment". Lindheim and Syme (1983) define the environment as the "result of the constant interaction between natural and man-made spatial forms, social processes, and the relationship between individuals and groups". Chopoorian's (1986) advocates the conceptualization of the environment as "the landscape and geography of human social experience" (p. 47). Similarly,

Curtis and Rees Jones (1998) suggest that the environment involves the complex geographical ideas of space and place, which in turn involves the notions of location, locale, locality, and a sense of place. These descriptions of environment suggest that environmental factors structurally and relationally affect when and why individuals seek or do not seek care.

Psychological variables, including expectations of care, motivation, perception of vulnerability or threat to health conditions, and risk, are suggested to be relational factors that influences the care-seeking. The role of presenting symptoms and individuals' habits related to care-seeking patterns, shaped primarily by cultural and social factors, are also suggested to be important relational factors. Structural factors that influences the effectiveness of individuals' care-seeking efforts includes health care system factors such as accessibility and geographical space or location, differing perspectives about health care given and expected by laypersons and health care professionals, and the individual's environment. Overall, an individual's social environment also affects care-seeking via structural determinants, social processes and relationships, and geographical elements.

#### Care-seeking and Economically Disadvantaged Individuals

Behavioural patterns of populations are proposed to be the result of habitual selection from limited choices (Milio, 1976). Furthermore, these habits of choice are related to actual and perceived options available, and beliefs and expectations developed and refined over time by socialization, formal learning, and the immediate experience (Milio). Theoretically, unique patterns of response to environmental stimuli in person-environmental interaction are needed to understand integrated human functioning (Johnston, 1989). An assumption of this proposed study is that the meanings of care-seeking efforts by economically disadvantaged individuals are affected by their experiences with living in poverty. Thus, increased understanding of the careseeking behaviours and processes of economically-disadvantaged/impoverished individuals first requires the understanding of the scholarly literature on the phenomenon of poverty in order to better understand the contextual influence of poverty on health.

# **Conceptual Perspectives of Poverty**

Carney (1992) asserts that although poverty is one of the most familiar and enduring conditions known to humanity, it is an extremely complicated concept to understand and its meaning is difficult to delineate due to social, political, economic, and cultural forces that influence the concept over time. Various ways that the phenomenon of poverty has been conceptualized or understood and the inherent issues within the specific perspective are now discussed.

The cultural concept of poverty or the "culture of poverty" was developed by Lewis (1966), an anthropologist. Lewis claims that the poor are so alienated from the rest of society that they develop and pass on to their children coping mechanisms so intensive that a culture exists within a culture. The coping mechanisms also enable impoverished people to be resigned to and live with poverty as opposed to the resenting of poverty conditions. Sixty-two behavioural traits are identified and can be categorized as economic, social, and psychological (Table 1).

Classification of Traits	Summary Description
Economic	Unemployment and underemployment, low wages and unskilled occupations, absence of saving; chronic shortness of cash, pawning and/or borrowing at inflated interest rates, use of second-hand clothing and furniture, frequent daily food purchases in small amounts
Social	Crowded quarters with lack of privacy, free unions, with early initiation into sex, abandonment of women and children, maternal-centered families, political apathy and cynicism about government, low level of education and literacy, marginal relationships to organizations of the larger society, critical attitude toward beliefs and values of dominant social class
Psychological	High frequency of alcoholism, violence toward women and children, strong feelings of marginality, helplessness, dependency, inferiority, and fatalism, high tolerance for psychological pathology
Other	Strong present-time orientation with little ability to deter gratification, attempts to use and integrate into a workable way of life the remnants of beliefs and customs of diverse origins.

Table 1. Summary of Culture of Poverty Behavioural Trait

From Lewis (1969). Adapted from permission of the University of Kentucky Press and Mrs. Ruth M. Lewis, University of Illinois as cited in Carney (1992).

A review of the original research report (Lewis, 1963) reveals that the study was limited in several ways. The population that Lewis studied was limited to only Puerto Ricans in both Puerto Rico and New York. The method is stated to:

"combine the traditional techniques of sociology, anthropology and psychology. This includes a battery of 19 questionnaires... Open ended interview and psychological tests (such as thematic apperception test, the Rorschach test, and the sentence completion test) are administered to a sampling of this population" (p.20).

The "naturalistic observation" (p. 21) of families studied (including those of the two assistants) were also included. Despite the claim for a cultural orientation to his study, explicit evidence of an ethnographic research approach or theoretical model is not readily evident in this report. Carney (1992) notes that Lewis' work can not be considered as a theoretical framework, has not been intensely studied scientifically, and only represent sets of observations about people living poverty. All of these limitations indicate that Lewis' findings are not generalizable, yet the predominance of the culture of poverty perspective is noted in a number of literature sources.

The works of Karl Marx and Max Weber in the late 1800s contributed to the development of the situational or structural concept of poverty (Carney, 1992). This perspective maintains that in a stratified society the poor's position at the bottom is maintained by the upper strata as characterized by social, economic, and political inequities among the classes, with the pathology of the poor being due to the structure of the systems rather than the subculture of the people (Carney). Thus the values and behaviours of the impoverished or lower class are generated from external rather than internal influences.

More recently, expanding upon Marx's social class theory, the term and concept of the "underclass" is noted to enter the vocabulary of public policy debate, particularly in the United States (Devine & Wright, 1993; Katz, 1993). Individuals of the underclass are members of the new structural, economic, demographic, and ecological picture of urban poverty concentrated in certain extremely low income central city neighbourhoods (Katz). In class terminology, the underclass refers to the group of the population "under" or beneath the lower class or poor, and

in general comprises those individuals who are at the bottom of the economic and social barrel (e.g. persons with urban criminal and drug dealing elements (Devine & Wright; Katz). The authors further suggest that the meaning of the term underclass is closely associated with the notions of social merit or worth that requires the distinguishing of the "deserving" (i.e., the victims of circumstances or unfavourable economic trends who deserve sympathy and assistance) and "undeserving" poor (i.e., the lazy and shiftless who could "do better" for themselves if they wanted and who therefore merit contempt). The assumption is that the roots of poverty lie in individual misbehaviour (Katz). Similarities between these dimensions and Lewis' (1966) culture of poverty identification of behavioural traits of the poor are noted. Furthermore, parallel with the cultural perspective of poverty, labels such as the underclass impose simple and misleading stereotypes ignoring the complex nuances of individuals and families surmount, as well as succumb to, the environment of the modern inner city (Katz).

An integration of the cultural and structural perspectives of poverty is the adaptational concept of poverty by Rodman (1963). Rodman proposes that in addition to the social strata issues externally oppressing impoverished groups, some behaviour of the poor develop internally as adaptive responses to the condition of poverty. In contrast to Lewis (1966), Rodman postulates that impoverished individuals do share values of the larger society, but however stretch or revise their middle-class value system in order to adapt to the barriers experienced in attempting to reach their goals. Rodman defines this adaptational concept as "the value stretch". This stretch is suggested to prevent the economically disadvantaged individuals from feeling continually frustrated in their attempts to live up to unattainable goals.

Based on a synthesis of Rodman's (1963) adaptational model of poverty and the stress and coping literature, Pesznecker (1984) develops an interactive nursing model of poverty. Pesznecker identifies specific stressors that impoverished individuals experience in their day-today lives and theorized that therefore the poor develop health-promoting or health damaging behaviours in response to these stressors. The model assumes that economically disadvantaged individuals' behaviours are shaped by interactions between individual or group factors and the environment that are characterized by the erratic and constant accumulation of stressors, and which are further mediated by public policy and social support.

Poverty is also defined as a phenomenon. Spector (1996) proposes that one way of analyzing the phenomenon of poverty is to observe the effects of the "cycle of poverty". Elements of this cycle include the poor person living a situation that creates poor physical development and poor economic production. This living situation in turns causes a subsistence economy that often forces the person to reside in densely populated areas where shelter and other amenities are scarce in an unbroken cycle from generation to generation.

Other authors such as Becker (1997) offer the perspective that "poverty is a political issue" (p. 1) socially constructed and specifically framed in political and policy debates. Poverty is asserted to be "experienced as a reflection of attitudes and beliefs held both by those enduring deprivation and by those in the wider society" (Golding, 1995, p. 213). Pivotal to the political debate is the acceptance of poverty as relative or absolute subsistent deprivation. Poverty is relative as a result of the comparison of impoverished individual against the standard of living to other people (Reutter, Neufeld, & Harrison, 1999) as opposed to being defined as absolutely related to income and material deprivation as the primary element. The definition of relative poverty or income inequality has four elements: a comparison between persons, concern with contemporary standards in a social environment, recognition of inequity in society, and dependence on value judgments of what is right or wrong (Carney, 1992). In contrast, absolute poverty is defined as income inadequacy or material deprivation (Marmot & Feeney, 1997; Reutter, Neufeld, & Harrison), which comprises the following three elements: "a focus of physical efficiency rather than enjoyment of life or intellectual development, stringency in calculations with the mode of life this implied, and a view of poverty that was unrelated to the income of society as a whole" (Carney, 1992, p. 76). Additionally, the major issues in the debate on urban poverty include: (1) The extent to which individuals are responsible for their

45

own poverty, or the balance between individual agency and structural forces; (2) The role of culture (defined as the influence of set of attitudes, values, and group behaviours) on perpetuating poverty and dependence; (3) The contribution of family structure, organization, and modes of child rearing to developing and reproducing social pathologies; (4) The influence of ecology, or environment, on behaviour, (5) The capacity of institutions to counteract the influence of family and neighbourhood, and why institutions so often fail to fulfill their missions; and (6) Why poverty persists despite public policy and whether policy has, in fact, mad matters worse (Katz, 1993).

The emphasis that poverty is relative to the structural nature of the society within which individuals live at a particular time, as opposed to the notion that poverty is absolute, is based on the different ideological ways that society perceives people's needs (Reutter, Neufeld, & Harrison, 1999). An illustrative example of the debate related to societal beliefs about poverty is located in a current Canadian newspaper editorial:

For many years, the debate on poverty in Canada – what is it, how much of it is there, and what we can do about it – has been trapped between two poles. The right defines poverty in terms of absolute deprivation; finds, on investigation, that few people are actually starving in Canada; so concludes that nothing much needs to be done. The left defines poverty in terms of relative inequalities; proves in repeated surveys, that some people are poorer than some others; and so concludes nothing much has been done (Coyne, 1999, p. A15).

Hence, political and social ideologies shape public policies, which in turn either address or deliberately not address consequences of poverty in society (Chavin, 1999; Reutter, 1995; Smith, 1990; United Nations Development Programme Poverty Report, 1998).

The challenge of understanding the state or condition of poverty is exemplified by the encounter of numerous allied terms evident in both the academic literature and popular realm. These terms include "poverty line", "poverty threshold", "poverty level", "poverty guidelines", and "poverty rate". The primary element common to each definition is the dollar amounts below which a family or unrelated individual would be considered in the state of income deprivation (U. S. Census Bureau, 1999). The purpose of these definitions is to quantify or

objectively measure poverty for statistical purposes in policy development (Institute for Research & Poverty, 1999). The Canadian, American, and British dissimilar measurements of the poverty lines illustrate the complex social and political implications related to the inclusion criteria of poverty definition (Carney, 1992; Devine & Wright, 1993).

In contrast to the primary focus of income as the definitional criterion for poverty, the moral and ethical perspectives of poverty are envisioned in the United Nation's address of "poverty as a denial of human rights" from a sustainable human development perspective (United Nations Development Program Poverty Report, 1998). Poverty is thus the denial of various choices and opportunities basic to human development, such as the ability to lead a long, creative, and healthy life, self-respect, and the access to the resources needed for a decent standard of living. Subsequently, the concept of human poverty is derived from the understanding that the root of poverty originates from general deprivations such as powerlessness and lack of capabilities resulting in the lack of political freedom, inability to participate in decision-making, lack of personal security, and treats to sustainability and intergenerational equity. This perspective of poverty emphasizes the subjective experience of poverty (Mann, 1970; United Nations Development Program Poverty Report).

The term poverty is a complex, changing entity that is "relational, shifting in meaning and content, to be interpreted in terms of time and place" (Katz, 1993, p. 23). Impoverished persons live with economic, spatial, social, and cultural isolation (Katz). Dominant social attitudes towards poverty, and political ideologies, help to shape the construction of and responses (or lack of responses) to poverty and the poor (Becker, 1997). Consequences of impoverished groups being subordinate by larger and dominant societal groups include inherent oppressed and marginalized group behaviours (Roberts, 1983). Varied conceptual and philosophical perspectives of poverty result in different issues identified that identify and describe causes of ongoing poverty.

#### Who are the "Poor"?

Individuals who are economically disadvantaged or "poor" do not comprise of a homogeneous group. Rather, broad characteristics of individuals living in poverty are associated with ethnicity, age, single parenthood, homelessness, and gender (Nelson, 1995; Reutter, Neufeld, & Harrison, 1999; Takahashi, & Wolch, 1994). Currently, the term "new poverty" refers to such groups within the poverty population as the working poor, children, welfare mothers, undocumented workers, and the homeless (Devine & Wright, 1993). Each of these groups has always been found among the poor, but not in today's numbers or concentration. The new inequalities center more on the young (in the United States, particularly minority youths), females, single-parent families, and the elderly (blacks) (Devine & Wright, 1993).

In Canada, the poverty rate increased to 7.8% in 1996 from 6.2% 1988 and characteristics associated with the poor mirror the above descriptions (Canadian Centre for Policy Alternatives BC Office, 2000). Locally, 29% of the Vancouver/Richmond population live below Statistics Canada' Low Income Cutoff point, compared to 19.6% of the total British Columbian population (Vancouver/Richmond Health Board, 2000). Females, particularly female seniors, seniors in general, and children, particularly those in female single-parent families, are associated with the highest percentage impoverished groups (Vancouver/Richmond Health Board, 2000).

In a market economy, an individual's freedom and opportunities, including participation in community and social life, is severely limited by the amount of accessible cash (Canadian Centre for Policy Alternatives BC Office, 2000). Persons living in poverty are also associated with enrollment in income assistance programs, rental versus ownership of housing, homelessness or use of emergency shelters, residence in unsafe neighbourhoods, high uses of food banks (or occasionally "skip a meal"), purchases of clothes and footwear second hand, reliance on free dental work and eyeglasses, and economic difficulties in meeting needs related to household operations, personal care, and recreation, education, and reading (Bunting, Bevier, & Baker, 1999; Canadian Centre for Policy Alternatives BC Office).

Living with poverty is highly associated with poor health status, including having a range of acute and chronic disease such HIV positive status, cancer, and substance use (Bunting, Bevier, & Baker, 1999; Vancouver/Richmond Health Board, 2000). There is a strong linkage between social conditions, which is defined as factors that involve a person's relationships to other people including relationships ranging from individuals' support networks to positions occupied within the social and economic structures of society, and disease (Link & Phelan, 1995). A fundamental feature of the linkage between social conditions and disease is the lack of resources available to impoverished individuals that can be used to avoid risks or to minimize the consequences of disease once it occurs. The term "resources" is broadly defined to include money, knowledge, power, prestige, and the types of interpersonal resources embodied in the concepts of social support and social network (Link & Phelan).

#### **Poverty and Health Inequalities**

A limited number of literature sources that directly relates to the care-seeking behaviours and processes of economically disadvantaged individuals is found. In contrast, a vast number of scholarly research literature on the theoretical causality of poverty and health inequalities is evident. Health inequality refers to the existence of substantial variations in health that is contingent on socioeconomic position (Smith, 1993). The poverty and health inequity literature indirectly suggests structural and relational factors related to care-seeking of impoverished individuals and therefore a review of this domain of literature is presented before directly exploring the care-seeking literature of impoverished individuals.

A core premise is that it is not absolute poverty but relative poverty that influences health (Reutter, Neufeld, & Harrison, 1999; Wilkinson, 1990). The concepts of social hierarchy and health inequality are intricately linked with the implications of relative poverty. That is, comparing life expectancy between nations, Wilkinson (1986) was the first researcher to report that the distribution of income in countries is more strongly related to life expectancies than the average amount of income available to each member of a population in these countries. After 20 years of researching comparative health trends globally, Wilkinson (1986) demonstrates that a slow down in declining mortality and morbidity rates for infants, children, and young adults in Britain coincided with the stark widening of income differential (Dean, 1994). Furthermore, Wilkinson (1996) strongly demonstrates that the countries with the longest life expectancy are not the richest, but the states with the smallest spread of income. In other words, " in the developed world, it is not the richest countries which have the best health, but the most egalitarian (Wilkinson, 1996, p. 3). Therefore, it is not income alone but also the degree of income inequality that matters for health status (Lomas, 1998). Blaney, Blane, and Smith (1998) indicate that several research studies now confirm Wilkinson's relative income distribution (or income inequality) hypothesis.

Abundant research studies have given strong evidence that rates of all-cause mortality, premature mortality, cause-specific mortality are consistently found to be lowest among the highest income members of a poor population and highest among those with the lowest levels of income (Mustard, 1998). Specifically, poverty has been linked to increased exposure to environmental hazards (Blane, Mongomery, & Berney, 1998), shorter survival following HIV infection (Hogg et al, 1994), and higher rates of cancer, birth defects, infant mortality, asthma, diabetes, and cardiovascular disease (Olden, 1999). The research evidence is summarized well by Mustard:

The incidence of infectious disease, the prevalence of chronic disorders, and the prevalence of disability are also distributed inversely to income in developed economies. These broad patterns have been invariant over time, and seem to be unrelated to international differences in both the GNP share allocated to health care services and the mechanisms of finance, organization, and the delivery of care (p. 2).

In Canada, the health inequality gradient is also evident (Vancouver/Richmond Health Board, 2000).

Although there is a link between health and socioeconomic circumstances, particularly poverty, the nature of this link widely debated (Nettleton, 1995). The complexity of the linkage is indicated by the vast number of variables inherent in people's socioeconomic status and social circumstances: social class, unemployment, gender, ethnicity, geographical location, which all impact upon a person's access to material resources (e.g. housing, education, transport, and income) (Nettleton).

A classical British study, <u>Inequalities in Health</u>, or more commonly referred to as the Black Report (DHSS, 1980, as cited in Blane, 1985) first delineated four plausible mechanisms or pathways for socioeconomic status affecting health. The first pathway, the artifact or myth explanation, maintains that the observed relationship between socioeconomic health results from biases in measuring both the variable of socioeconomic status and health (Blane, 1985; Nelson, 1995; Reutter, Neufeld, & Harrison, 1999). The literature generally agrees that the artifact explanation is inadequate to explain the observed relationship between socioeconomic status and health (Reutter, Neufeld, & Harrison).

The second pathway of the Black Report, the natural or social selection, or drift hypothesis, suggests that individuals suffer from ill health first, and due to the resultant disability and reduced employment in adult life, drift down in social position or become poor (Carroll, Bennett, & Smith, 1993; Nelson, 1994). An individual's health, then, influences social mobility (Blane, 1985). There is moderate evidence for the explanation between poverty and health for some sub-populations, but the impact of ill health on downward mobility is considered to be limited (Carroll, Bennett, & Smith; Reutter, Neufeld, & Harrison, 1999).

A different version of the selection hypothesis, or indirect selection, contends that people bring with them the results of genetic, biological, educational, cultural, psychological, and social influences from their earlier days (Marmot & Feeney, 1997). A body of current literature (McLead, & Shanahan, 1996; Sadowski, Ugarte, Kolvin, Kaplan, & Barnes, 1999; Van de Mheen, Stronks, & Mackenbach, 1998) has been devoted to the exploration of this perspective. The lifecourse view proposes that the accumulation of adverse socioeconomic circumstances and selection are important mechanisms, which successively may cause a downward spiral (Van de Mheen, Stronks, & Mackenbach). Specific categories of social influences that originate in childhood and which indirectly select individuals' health include poor physical care child and home, social economic dependence, and physical and family overcrowding (Sandowski, Ugarte, Kolvin, Kaplan, & Barnes).

The cultural/behavioural explanation, the third mechanism of causality in health inequalities that is highlighted in the Black Report, distinguishes health as the dependent variable in the causal relationship between social class and health (Blane, 1985). This perspective views class gradient in health as the result of social class differences in healthinhibiting behaviours such as the consumption of harmful commodities including tobacco and alcohol, decreased exercise, and the frequency of use of preventative health care (Blane). Elements similar to the previously mentioned Lewis'(1966) concept of the culture poverty and Black's cultural/behavioural explanation of health inequality are observed. The cultural/behavioural explanation implies that these behaviours are the result of individual lifestyles or free-choice decisions based on personal attitudes toward health (Carroll, Bennett, & Smith, 1993; Reutter, Neufeld, & Harrision, 1999). This assumption is also the core tenet of the current health psychology mission and public health promotion strategies (Carroll, Bennett, & Smith, 1993), which in turn has been criticized as leading to victim-blaming (Black, 1991; Lynch, Kaplan, & Salonen, 1997). The evidence for this causal explanation is far from compelling (Carroll, Bennett, & Smith).

The fourth explanation, the materialist/structural explanation, has received the most empirical support (Reutter, Neufeld, & Harrison, 1999). The emphasis in this pathway is that poor health results from material conditions and resources that facilitate health. Particularly, materialist explanations are concerned with the effects of social structure on health, such as a capitalistic society, poverty, access to education, inadequate diet, and poor housing (Blane,

52

1985). The result is that individuals with less purchasing power are more likely to be exposed to the ill effects of inadequate housing, inadequate nutrition, unsafe neighbourhoods, and occupational/environmental hazards (Reutter, Neufeld, & Harrision). Additionally, Curtis and Rees Jones (1998) propose that the consideration of geography, particularly the elements of space and place, is helpful to theoretical discussions is helpful on health inequalities.

Lillie-Blanton and Laveist (1996) also argue that an individual's socioeconomic status must instead be considered as an expression of the educational and economic opportunities available in the social environment, which results in the ability to compete in his/her social environment. The authors propose that the term "social environment" therefore better reflects the root of the problem than the term socioeconomic. Social environment refers to socioeconomic factors (e.g. employment, education), physical surroundings (e.g. neighbourhood and work conditions), social relations (e.g. within a community), and power arrangement (e.g. political empowerment, individual and community control and influence) that are potential determinants of health status. Similarly, Williams' (1990) model of pathways through which socioeconomic status influences health, views the variable "psychosocial factors" as "the patterned response of social groups to the realities and constraints of the external environment" (pp. 81-82).

Examples of public policies that reflect a structural approach in reducing the extent and conditions of poverty include improved welfare benefits, prevention of further cuts to the social safety net, an increase in the minimum wage, progressive taxation aimed at equitable income distribution, and adequate affordable housing (Reutter, Neufeld, Harrison, 1998). Evidence for the material/structural explanation is perhaps the predominant amount of current sociological theories and literature related to health and illness (e.g. Bartley, Blane, & Smith, 1998; Conrad, & Kern, 1990; Freund, & McGuire, 1999; Nettleton, 1995), which contend that explaining health-related behaviors must consider contextual and environmental factors. The

material/structural explanation also highlights the complex interplay between the numerous confounding factors affecting health inequalities.

The poverty and health inequality literature offers a theoretical framework to study causes of health inequalities. In particular, the social selection, cultural/behavioural, and material/structural approaches may offer some theoretical insight to why economicallydisadvantaged individuals generally have poor health status. A relationship between this body of literature and the "determinant of health" framework (Mustard, 1991), which focus on several interrelated spheres of influence on health: prosperity, social environment (social support, work environment, unemployment), physical environment, early childhood development, psychoneuroimmunology, genetic predispostion, cultural values, and access to or over-provision of health care (Browne et al, 1995), is noted. The poverty and health inequality literature also provides contextual knowledge and insight into the research of the effectiveness of care-seeking efforts by impoverished individuals.

A Gap in Knowledge of Care-Seeking by Economically-Disadvantaged Individuals

Both theoretical and research-based literature related to care-seeking by economicallydisadvantaged individuals is limited. A theoretical model of care-seeking by impoverished persons is lacking in the literature. Therefore, a specific theoretical model that identifies and describes the structural and relational factors that influences the care-seeking efforts of impoverished individuals is lacking. Previously mentioned models related to care-seeking include only socio-demographic variables, such as marital status and education, and exclude a theoretical concept of poverty and the consideration of the poverty social environment and experience on care-outcomes and care-seeking processes and behaviours.

In particular, Lauver's (1992) theory of care-seeking behaviour proposes that sociodemographic variables (which are not explicitly identified other than age and education) along with clinical factors "do not influence behavior per se. These factors could influence the theoretical variables (e.g. expectations, values, norms) which in turn, influence behavior" (p. 284). However, Lauver's evidence for this proposition is only studies related to cancer screening or care-seeking for cancer symptoms.

Based upon an integration of Scholfeldt (1981) Paradigm of Health-Seeking Behaviours and the Lazarus' (1966) Theoretical Schema of Coping and Adaptation, Nyamathi's (1989) model of health-seeking and coping also maintains that socio-demographic variables affect the way individuals cope with health issues. The socio-demographic variables are identified as age, education, marital status, employment status, and social class. Again, how and why these variables influence health-seeking and coping is not described and the evidence for inclusion of socio-demographic variables in Nyamathi's model is only from two sources related to clients with cardiac conditions. Additionally, Nyamathi identifies situational factors or variables that characterize the environment for every individual and influence health-seeking and coping, as an important component of the model. The term "environmental constraints" is not clearly defined and the inclusion of living with poverty is not explicit. As well, Nyamathi's proposed model of health-seeking and coping is only hospital-orientated and a community perspective is not reflected in how individuals seek and cope with health issues.

From a medical sociological perspective, Williams (1995) reviews the relationship between class, health, and lifestyles. Evidence for this relationship includes individuals living in poor economic circumstances adapt "low" norms regarding health due to the relatively greater experience of illness suffered by this group (Blaxter & Patterson, 1982), and middle class women's emphasis upon a "balanced diet" and "everything in moderation" whilst working-class women were more concerned about meals being more "substantial" and "filling" (Calnan, 1990). Williams identifies that despite a wealth of empirical material, there is a lack of theoretical knowledge to identify, describe, and explain the relationship between class, health, and lifestyle and the associated issues of structure and agency, and proposes that Bourdieu's (1990) theoretical model of social practice that is framed within the broader structures and patterns of social life is relevant to the class, health and life-styles debate. Research-based literature describing and explaining care-seeking by impoverished individuals is similarly lacking. Numerous quantitative studies (Becker, Drachman, & Kirscht, 1974; Gelberg, Gallagher, Anderson, & Koegel, 1997; Kiefe, & Harrison, 1993; Leenerts, 1998; O'Toole, Gibbon, Hanusa, & Fine, 1999; Pagdett, Struening, & Andrews, 1990; Portes, Kyle, & Eaton, 1992; Raveis, Siegel, & Gorey, 1998; Rundell, & Wheeler, 1979; Sharp, Ross, & Cockerham, 1983) focus only on explanatory factors related to the lack of health services utilization by specific low-income populations. Varied factors are explored, including financial constraints of impoverished individuals, the culture of poverty explanation, and systems barriers to use of service (Rundell, & Wheeler), competing priorities related to meeting basic survival needs as opposed to health and illness needs by impoverished individuals (Gelberg, Gallagher, Anderson, & Koegel,), and selected elements with a compliance model in explaining sick-role behaviour in low income populations (Becker, Drachman, Kirscht,). Additionally, a quantitative study exploring the personal characteristics and health and health-related concerns as reported by members of a Nebraskan homeless population is noted (Reichenbach, McNamee, & Seibel, 1998).

Numerous studies focusing on barriers to health and health care are noted. Studying lowincome white women with HIV disease, Leenerts (1998) identifies that five conditions at diagnosis emerge as barriers to self-care: (1) health care provider failure to mobilize resources, (2) health care provider devaluing of women, (3) social devaluing, (4) economic problems, and (5) legal problems. Harris, Luft, Rudy, and Tierney (1995) conclude that barriers to effective health care are potential contributors to the increased prevalence of hypertension and chronic renal insufficiency observed in black inner-city clients. Northam (1996) concludes that 41 % of the variance in chronic health problems of impoverished Texan individuals was accounted for by barriers, mental health needs, educational needs, and use of social services and 17% of the variance in health status was explained by mutable barriers to access. A model of emergency care that addresses common barriers to health care for the homeless is described by O'Toole and Withers (1998). Studies addressing barriers pertaining to the homeless population are also noted (Gillis, & Singer, 1997; Shiner, 1995; Wojtusik, & White, 1998).

Research-based knowledge answering the questions related to what is care-seeking, what is care is sought and expected, how is care sought, and when and why care is sought from the perspectives of economically disadvantaged individuals is lacking. There is a need to identify and describe the multi-components of care-seeking by impoverished individuals from the individuals' perspectives. The theoretical and research literature that indirectly and directly relate to care-seeking by economically does offer, however, a foundation for appropriate comparisons and contrasts for the new knowledge gained through this proposed research study.

#### **Conclusion of Literature Review**

A review of the care-seeking literature, including conceptual perspectives and related elements, was first explored to provide an initial understanding of associated variables or elements related to behaviours and processes inherent in this phenomenon. The review of the literature related to the care-seeking phenomenon of economically disadvantaged individuals reveals that there is a gap of knowledge in this area. Themes derived from the literature review contribute to an analytic framework for assessment, evaluation, and interpretation of data collected from this proposed research study.

#### **Forestructure**

## Personal Experience

As previously mentioned in Chapter One, I am currently a clinical specialist in Community Health Adult and Older Adult Services in Vancouver and was previously a home care nurse providing nursing care to clients in some of the poorest neighbourhoods in Vancouver. In order to be cognizant of the factors that influence me, I present three "vignettes" that are inherently reflective of my assumptions related to the care-seeking behaviours and processes of economically disadvantaged persons.

As a novice home care nurse in 1993, one of the most challenging and poorest client whom I nursed was a young severely emaciated male client with AIDS. He lived in tiny, dark 12 by 12 foot single room occupancy room in a Downtown Eastside hotel in the direct of living conditions. He had no food or money in his place, his clothes were in tathers, and he was constantly victimized by robbery and vandalism to his room. I visited him for about a week post hospital discharge for medication management and my role included supportive activities such as liaisoning with his financial aid worker for crisis cheques. Why I singly remember this client is because I think that the most helpful "care" I had given him was the five dollars that I granted him upon his request that helped him view a movie to momentarily escape from his life. As a nurse newly exposed to this client population, I wondered if physical health should be the primary focus of care or was physical health even considered a priority by impoverished individuals? I also wondered if I applied a broader conceptual definition of health into my practice, was the actual question: "What is the meaning of health or life to this client group?". Nursing other similar clients, I also subsequently learned that in general, I needed to first address the client's "basic needs" and demonstrate from the client's perspective that I cared and could be trusted in order to then be able to implement health care pertaining to physical health.

Additionally, Orem's theoretical model of self-care is the one of the primary conceptual models used in practice by home care nurses in my agency. A significant element of this self-care model is the assessment and intervention with care-seeking efforts of clients by nurses. As a new home care nurse, I reflected upon my lack of knowledge specific to the care-seeking phenomenon and also upon common client responses such as, "Why go see '(name of doctor or hospital)"? He/They don't help me anyway!" Nurses were sometimes also included as "non-helpers".

As a clinical nurse specialist, I also observe assumptions by staff related care-seeking behaviours of economically-disadvantaged clients. A recent example involves the home care nursing staff making the decision that it was intolerable risk for them to visit an elderly and single gentleman living in a Downtown Eastside rooming house because the building's manager was very threatening to nurses when they tried to access the building. Because of this staff safety situation, the nurses subsequently became aware that the client was actually very well connected to a nearby clinic where he was very willing to go for his medication management. I believe that the nurses, as well as many other staff and disciplines, share the assumption that certain clients, particularly those living with poverty, cannot be trusted to reliably seek meeting their own health care needs.

Similarly, through a health care system perspective, I wonder about the assumptions about care-seeking by clients that underlie health care services emphasizing case management and care coordination services. I observe that a large number of varied agencies and professional and "nonprofessional" health care providers, including outreach workers and supported housing workers, particularly in the Downtown Eastside, <u>all</u> identify that they refer, care coordinate, and link clients to services or case manage clients. Up to about three years ago, I also believed that optimal health care services provided these critical functions. What changed my belief was the result of my involvement in a program review of the care delivery model used in community health services. During one meeting, a Registered Nurses Association of British Columbia representative firmly stated that as a consumer of health care services, she could <u>and</u> wanted to case manage and care coordinate her own care. I remember how the "light bulb turned on" for not only myself but also for all the committee members, and subsequently the principle of respecting client's strengths and abilities was incorporated into our vision of the revised care delivery model.

### Personal Assumptions and Biases

- 1. In general, individuals are capable of seeking care for their identified health needs.
- Individuals seek information and advice on the need for health care and on optimal resources to meet their health needs from a number of resources, including lay and professional help.

- 3. The role of the health care professional in relationship to the care-seeking efforts of the client is to assess the effectiveness of the client's efforts in meeting client's health needs and to intervene only if the client's is not capable of initiating or maintaining these efforts.
- 4. From a societal-level perspective, the effects and consequences of living with poverty are not only the objective lack of material resources but also the subjective experiences that result from deprived material/social resources and imbalanced power structures that disempower impoverished individuals' lives.
- 5. The meaning of health to people, particularly economically disadvantaged individuals, consists of the broadest understanding of health, including well-being and wellness, and not only the absence of illness.
- Increasing community capacity is achieved by empowering community with resources, control, and decision-making, and can not only be achieved by increasing community health care services.

### Analytic Framework

The qualitative research method of interpretive description is grounded in an interpretative orientation that acknowledges the constructed and contextual nature of the healthillness experience as well as allows for shared realities (Thorne, Kirkham, & MacDonald-Emes, 1997). The literature review and personal experiences and assumptions presented form an analytic framework to examine the structural and relational factors that influence the effectiveness of care-seeking efforts by economically disadvantaged individuals. Four themes arise from the critical analysis of the literature: (1) a complex set of interrelated structural and relational factors are inherent in the care-seeking behaviours and processes of individuals; (2) individuals' social networks are involved in the care-seeking process and influence care-seeking behaviours; (3) the subjective and objective consequences of living in the social environment of poverty influence how economically disadvantaged individuals manage their health and health needs, including seeking of care resources; and (4) structural and relational factors related to the health care system affect the effectiveness of individuals' care-seeking efforts.

Thus, building upon these themes, the analytic framework consisting of knowledge derived from the literature review, personal experience, and personal assumptions is now presented. Major areas of common agreement from the literature are first identified. First, the literature generally supports that the care-seeking phenomenon involves inherent processes and behaviours. Moreover, the related constructs of help-seeking, health-seeking, self-care, health, and prevention/illness behaviours are relevant to research on care-seeking. Second, both non research-based and research-based literature related to care-seeking agree that health care services factors such as access and barriers particularly influence how, when, and why individual do or do not seek care. Furthermore, the quality of the relationship and the existence of a common framework of understanding between client and health care provider also influence care-seeking processes, behaviours, and care and health outcomes. Third, the value and belief systems of individuals, both lay and professional persons, affect care-seeking. Client and health provider expectations, including aspects of caring, helpfulness, trust, and therapeutic reciprocity, are also integrated within values and beliefs systems. Fourth, consideration of the social environment, including interactions with other individuals, communities, and society, is a critical element in the exploration of care-seeking. Last, poverty conditions unequivocally result in inequality in health status and economically disadvantaged individuals have comparatively poor health status.

Different perspectives of both care-seeking and poverty are evident in the literature and in the popular and clinical health services realm. The sociological, psychological, and anthropological disciplines primarily focus on the domain of help-seeking, thus, emphasizing the role of the social support and network in help-seeking behaviours and processes. This perspective also identifies the helping and treatment functions or the nonprofessional modes of interpersonal help of the lay network system and asserts that people naturally delay seeking help or health care for their health concerns. In contrast, disciplines within the health care field stress the bias that the care sought and expected falls within health care services. For example, the issues of compliance with recommended health care and delay in seeking health care are illustrative of conflicting perspectives between lay and professional individuals. The professional services perspective also highlight care-seeking in terms of delay in care-seeking and health care services utilization. Furthermore, different perspectives of care-seeking, including the domains of help-seeking, health-seeking, self-care, prevention/ illness behaviours, health-related behaviours, and health care system/services, emphasize either the concepts of health or illness.

Varied disciplinary perspectives on care-seeking also identify and describe different structural and relational elements on when and why individual seek or do not seek care. For example, the health care perspective emphasizes triggers such as physical symptoms that advance care-seeking. In contrast, sociology and anthropology, or disciplines that are interested in the influence of the social environment and social processes, focus on the impact of the symptoms on social roles and the cultural and social meanings of the symptoms from the social network. A gap of knowledge related to the roles, processes, and relationship of economically disadvantaged individuals' social support and networks and the care-seeking phenomenon is also noted in the literature.

Different perspectives of poverty also lend to differing opinions on the causes and ongoing existence of poverty experiences and states. Different conceptual and philosophical perspectives of what is poverty and what causes generations of people to exist in ongoing poverty are readily evident in the literature. Varied perspectives of poverty include the acknowledgement of the subjective experience, the objective lack of material and social resources and opportunities, the political, ideological, and social policy implications of poverty, and the linkage of poverty to human rights. Different approaches in the analysis of the causes of poverty and the affect of poverty on health inequalities, including cultural/behavioural and materialist/structural views, also result in different perspectives of the same phenomenon.

Different perspectives on the analysis of the phenomenon of care-seeking also result in the identification of varied elements within the care-seeking processes and behaviours. To illustrate, the focus of care-seeking as a process identifies that there is an inherent information seeking process located within a decision-making process framework. Care-seeking as a process also identifies the role of presenting symptoms, including elements of threat, risk, vulnerability, and the impact of these symptoms on individuals' lives, to both the client and health service provider. Care-seeking as a behaviour identifies and describes client-specific and health care system-related cultural, habitual, social, and geographical factors that are relational to the behaviour. Care-seeking analyzed from only the health care system perspective highlight structurally related factors such as health care access and barriers that impact care-seeking by individuals, particularly economically disadvantaged clients. Care-seeking as analyzed from the perspective of the social environment of poverty focuses on the societal-level factors that also interplay with the care-seeking elements that are associated with the individual, the individual's support systems, and the health care system.

A critical synthesis of the literature review, personal experiences, and personal assumptions has formed the analytic framework. The framework guided the data collection plan and data analysis. As well, the framework evolved as the study progressed and the validity and applicability of the framework was tested. The following chapter incorporates the analytic framework into the research study methodology plan.

## **CHAPTER THREE: METHODOLOGY**

"Revolutions begin when people who are defined as problems achieve the power to redefine the problem" (McKnight, 1995, p. 16).

Qualitative research involves an interpretive, naturalistic approach to its subject matter with the goal of attempting to interpret or make sense of the phenomena in terms of the meanings people bring to them (Bailey, 1997; Denzin, & Lincoln, 1994). Qualitative methods are characterized by inductive reasoning, subjectivity, discovery, description, and process orienting (Munhall & Boyd, 1993). An analytic framework derived from a critical analysis of existing knowledge within interpretive description methodology provides the foundation for qualitative research design (Thorne, Kirkham, & MacDonald-Emes, 1997). Furthermore, an interpretive description design is ideally suited for the development of nursing clinical knowledge with significant nursing science application.

Interpretive description is grounded in the epistemology of nursing. Nursing's epistemological interests are aligned with Carper's (1978) framework of four fundamental patterns of knowing: empirics, esthetics, personal knowledge, and ethics (Munhall & Boyd, 1993). Moreover, Fawcett (1984) identifies a metaparadigm for nursing that comprises the central concepts and themes that represent the phenomena of interest to the discipline. These central concepts are defined as:

1. Person - the recipient of care.

2. Environment - significant others and the surroundings of the recipient of care; the setting in which nursing care occurs"

Health - the wellness or illness state of the recipient at the time when nursing occurs.
Nursing - actions taken by nurses on behalf of or in conjunction with the recipient of care" (Munhall & Boyd, p. 52).

The goal of this interpretive description study was therefore to develop knowledge through accurately perceiving and presenting the meaning of impoverished individuals' experience with the structural and relational factors that influence the effectiveness of their careseeking efforts from the perspective of these economically disadvantaged persons. The goal of interpretive inquiry is to understand meaning not "truth" (Bailey, 1997). This goal was achieved by the researcher being involved with (1) theoretical sampling of subjects who can articulate their experiences of a range of factors that influence the effectiveness of their care-seeking efforts, (2) ongoing and concurrent data collection, categorization, and interpretation, and (3) the use of qualitative research strategies to ensure the rigor or trustworthiness of the study (Morse & Field, 1995; Sandelowski, 1993).

### Participant Selection

The principle of theoretical sampling is integral to the design of an interpretive description for the purposes of nursing knowledge development (Thorne, Kirkham, & MacDonald-Emes, 1997). Theoretical sampling is defined as purposeful participant sampling based on concepts that have proven theoretical relevance to the evolving theory whereby this researcher jointly collects, codes, and analyzes her data and decides which data to collect next in order to develop the theory as it emerges (Morse, & Field, 1995; Strauss, & Corbin, 1990). Furthermore, theoretical sampling for the interpretive description research design must integrate obtaining maximal variations of themes that emerge from the inductive analysis (Thorne, Kirkham, & MacDonald-Emes). A goal of this study was to strive for the greatest variation of themes possible within the confines of this study. The application of theoretical sampling attains the goal of developing a rich or dense description of the phenomenon studied (Streubert & Carpenter, 1995).

Participants were deliberately selected according to the theoretical needs and direction of the research (Strauss, & Corbin, 1990). The ten participants in this study are a diverse group of individuals in terms of age, health status, functional ability, mobility level, ethnicity, family status, and personal background. Morse (1991) further suggests that initially the researcher may choose to interview participants with a broad, general knowledge and experience of the topic and then as the study progresses, the description is expanded with more specific information, and

participants with that particular knowledge are deliberately sought. I selected the participants with this principle in mind throughout the research.

In the first phase of the sample selection, I purposively selected a participant in each of the four diversely different neighbourhoods (Downtown Eastside, Strathcona, Woodlands, and Grandview) in Community Health Area #2 in order to gain access to a diverse population of participants. I selected the other six participants as directed by theoretical sampling in response to the beginning conceptual categories that emerged from the initial data analysis. For example, participant #9 and #10 were selected because I was interested in understanding the experiences of single mothers and specifically the factor of living in poverty and having a dependent child. I also purposively sampled for other participant characteristics such as age, ethnicity, the use of home-based or community-based care, experiences of a range of illness and health needs, and residence in a particular neighbourhood.

## Sample criteria

The target population for this study consisted of persons who:

- 1. Are 18 years of age or older
- 2. Are able to speak English at a sufficient level to be understood by the researcher
- Are economically disadvantaged those male and female individuals who considered themselves as economically disadvantaged or living in poverty.
- 4. Are experiencing or have experienced seeking for lay and professional help and care for goals and needs related to health and illness, and
- 5. Live in the geographical area of Community Health Area (CHA) #2 in Vancouver bounded by the following streets: Burrard Inlet to the north, Nanaimo Street to the east, Broadway and Terminal Avenues to the south, and Cambie Street to the west. This geographic location has the highest concentration of individuals living with poverty and also has a high concentration of health and social services (Vancouver/Richmond Health Board, 2000).

I had intended to sample participants who lived with the most economically disadvantaged circumstances. For the purposes of this study, I had defined persons who are economically disadvantaged or living with poverty as lacking in material and financial resources, and lacking in choices and opportunities basic to human development relative to higher socioeconomic individuals or communities (United Nations Development Programme, 1998). I understood that these economically disadvantaged persons living in poverty experience threats to everyday human security and sustainability and those individuals who perceive themselves as experiencing severe difficulties in meeting everyday needs such as adequacy of income, meals/food, housing/shelter, safety, personal care, clothing, transportation, household operations, and recreation. As sample selection and data progressed, I quickly learned about the complexity of the concept of poverty from the emerging categories and themes. I will elaborate upon this discovery in following chapter.

### **Recruiting participants**

I have a number of multidisciplinary collegial contacts within community health care services. These colleagues assisted me in approaching potential participants for participation in this research study. If the individual was interested, the collegial contact gave the individual the Participant Information Letter (Appendix A) and asked for verbal permission for the researcher to contact the potential participant to further explain the research study and to be audio-taped interviewed. I did not directly approach any of the participants.

## Sample size, appropriateness, and adequacy

I anticipated interviewing eight to ten individuals for this study. I feel that the ten participants that I interviewed met the criteria of sample appropriateness and adequacy. The appropriateness of the sample is guided by participant characteristics and by the type of information needed by the researcher to facilitate understanding of the research problem (Morse, 1991). Adequacy of the sample refers to the quality, relevance, completeness, and amount of information provided by the informants to ensure the saturation of the resulting theory and the absence of "thin" data areas (Morse). The participant sample obtained is appropriate and adequate because no new themes or patterns emerged from the data, indicating that the sample is complete (Sandelowski, 1995). I describe the ten participants in more detail in Chapter 4.

I experienced some difficulties in accessing two potential participants who were referred to me for this study. One potential participant who lived in a Downtown Eastside women's shelter left a message for me on my voicemail to call her back. However, her name was not clear on the message and because of this, I could not access her at the shelter's phone number that she left for me. As well, I could not obtain the name of this potential participant from the colleague who referred this potential participant because I also experienced difficulties accessing this colleague. I also attempted twice to connect with another potential participant who was described to me as a "dumpster diver" by the referring colleague, but this man did not show up twice at the arranged meeting times. Some of the difficulties in accessing potential participants that I experienced are related to the fact that these two potential participants did not have direct phone access in the places where they lived.

I also attempted to access participants who were living in unstable housing situations. I had hoped that I could access potential participants who were temporarily housed in the emergency shelter. However, I encountered constraints to this plan, such as the colleagues working in these emergency shelters not being available to assist me due to their workload. ' I acknowledge that the absence of participants with this characteristic may be a limitation of the study.

Furthermore, I experienced challenges in interviewing Participant #8. Participant #8 also did not have direct phone access living in a single room occupancy residence in the Downtown Eastside. The other challenge that I experienced is related to her poor health status. I initially met her at a prearranged time at her place as had been negotiated by the nursing colleague in the community health clinic that she visited. At this initial meeting, this participant expressed to me that she was looking forward to our interview time arranged for the following week. However at the following week's interview, I noticed that the participant was looking very pale and fatigued ten minutes into the interview. She agreed with my assessment that it was a good idea to stop the interview because of how she was feeling that day. We made a subsequent interview time for the following week. But again upon my arrival, I noticed that the participant was looking even more pale, fatigued, and ill-looking. I suggested to her that being interviewed by me did not seem to be a good fit for her at this time and she agreed with this assessment.

Despite the challenges and difficulties that I encountered in the sample selection, I am confident of having a strong database upon which to make confident claims about commonalities and differences across all of inherent variables to the phenomenon because of the diverse sample population. I also feel that I met the overall goal of an interpretive description which is to generate nursing practice knowledge that requires purposeful selection of research participants whose accounts reveal elements that are to some degree shared by others (Thorne, Kirkham, & MacDonald-Emes, 1997).

### **Ethical and Human Rights Considerations**

I obtained ethical approval from two sources: (1) the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects, and (2) the Vancouver/Richmond Health Board Research Planning, & Evaluation Department. Informed participant consent was ensured by the clear identification of the purpose and nature of the study, the interview process, the means of maintaining confidentiality and anonymity, and the potential benefits, risks, and outcomes to the participants in the Participant Information Letter (Appendix A) and Participant Consent Form for Interviews (Appendix B). A copy of the Participant Information Letter and Participant Consent Form was given to the participant. The participants had two opportunities to review the Participant Information Letter, once upon initial receipt of the Letter by my referring colleague and then again when I initially met the participant. Prior to each initial interview, I explained using plain language the purpose of the study and procedures to the subject. Each participant was given the opportunity to ask questions about the research study prior to obtaining consent. I also summarized aloud the participant's rights about participating in the study to the participants prior to the participants signing the consent form. I read the Participant Information Letter and Participant Consent Form aloud for the two participants who had impaired vision. I informed the participants that they could withdraw from the study at any point without repercussions and were free to refuse to answer any questions during interviews. I also took care to avoid conflicts with treatments or other activities that the participants had planned.

There were no risks for individuals participating in this study. Additionally, although the researcher holds both roles as a community clinical nurse specialist and a graduate nursing student researcher, the participant were informed that the primary role of the researcher is the participant/researcher relationship. Throughout the study, I anticipated that the participants may present unmet physical, emotional, or spiritual needs. Although this situation did not present itself, I was prepared to give information about appropriate help or services to the individual and/or refer the individual to the appropriate agency services or assistance based on reasonable and prudent professional judgment and with the participant's consent.

The confidentiality and anonymity of participants was ensured by the use of code numbers (e.g. P #4) instead of the participants' names on all written materials and transcripts. I was the only person who could access the list of participant names that matches the names to code numbers located in a locked drawer. Additionally, any information that does or might identify the participants was omitted from the interview transcriptions and research reports. The list will be destroyed and all audio-tapes will be erased upon completion of the study.

### **Data Collection**

## **Data Sources**

I used multiple approaches and sources for data collection in this interpretive description study. In addition to audio-taped participant interviews, field notes, theoretical memoing, and critical reviews of lay print, media literature, and nursing case reports or clinical papers were used to support this research inquiry. I interviewed the participants at a time and place convenient to them, the latter of which was usually at the participant's home or at a coffee shop in the neighbourhood. I was able to interview two participants twice and one participant three times for a total of thirteen interviews. Excluding Participant #8's ten minute interview, the length of the interview ranged from 45 minutes to almost two hours, with the majority of the interviews lasting about 90 minutes. I took care to check in with each participant during the interview about the length of time that they were able to give me. The audio-taped interviews were transcribed verbatim by an experienced research transcriptionist.

Field notes are the second data collection method that I used in this study. Field notes are the researcher's experiences and observation of salient events of interest that are naturally occurring in the field and context of the research's phenomenon under study (Emerson, Fretz, & Shaw, 1995; Morse & Field, 1995). Field notes are comprised of reconstructions of interactions, short conversational excerpts, or descriptions of events that the researcher hears, sees, experiences, and thinks in the course of collecting or reflecting on data (Morse, & Field). I included descriptions of the physical setting, my impressions, or the participants' nonverbal communication in the field notes. I also used field notes to describe the phenomenon of interest by identifying ideas about relationships within the data observed in the field, which then provided a beginning cross-check for later analysis (Morse, & Field, 1995). In addition to writing field notes after each interview, I wrote up two other field notes following two community field visits. One field visit involved spending an evening with a nursing colleague who worked in a newly opened evening community health clinic service. A second field visit was Participant #6 taking me to the different scenes in the Downtown Eastside core, including the back alleys where intravenous drug using was openly taking place.

Theoretical memos also constitute data for analysis. Theoretical memos are written records of the researcher's reflective thoughts and theoretical analysis of the data which show step by step the developing theory (Corbin, 1996). It is in theoretical memos that hypotheses are

recorded, compared, verified, modified, or changed as new data comes in (Corbin). I also used theoretical memoing to explicitly identify and critically analyze my subjective biases and unsubstantiated hunches that occurred in the field observations relating to the setting or phenomenon.

The interpretive description methodology also recognizes the value of lay resources such as lay print and media literature as data sources to complement the data arising from participant interviews and observations. I critically reviewed a number of lay print, media literature, nursing case reports or clinical papers, and health care service documents to better understand the contextual background underpinning the study (Appendix C). Specifically, I reviewed lay print and media literature that focused on public policy debates related to poverty, societal attitudes towards impoverished individuals and populations, and media reports of the daily lives of economically disadvantaged individuals. As well, I incorporated nursing case reports and clinical papers related to nursing beliefs, values, care, and services to economically disadvantaged populations as complementary data sources. Similarly, I included Community Health Area #2 health care service documents to better understand the health care systems structural and relational factors that may influence the effectiveness of care-seeking efforts by impoverished individuals. I looked for information pertaining to service philosophy, mission, mandate, eligibility criteria, structures and processes related to service operations in these health care service documents.

### **The Interview Process**

A social interaction occurs within the research interview whereby the researcher and participant jointly interpret and construct meaning from information arising within the interview (Mishler, 1986). To facilitate this interaction, each participant was encouraged to answer the researcher's questions at his or own pace. Based on existing knowledge derived from the literature review, I used open-ended trigger questions (Appendix D) in the initial interviews in order to stimulate discussion throughout the interviews. I began each initial interview with general questions related to participant's demographic information (e.g. age, marital status, number of family members) and related background information (e.g. how long the participant has lived in the present residence and in the neighbourhood) to help put the participant at ease. I then followed up with opening prompts such as: "Tell me what your health is like" and "Tell me what it is like for you to seek help or care for your health". Overall, the initial interviews with each participants were minimally structured and loosely guided by the set of interview questions in order to permit the informant to determine the general content and pace of the interview (Kvale, 1996).

As the theoretical needs of the study changed, more specific open-ended and clarifying interview questions were used with the study's latter participants and the follow-up participant interviews in order to investigate the emerging commonalities and contrasts of codes, categories, and linkages. For example, latter interview questions focused more on the experience of the participants in dealing with the provincial ministries who provided their income or funded supports. The nature of the later participant interviews also changed as beginning conceptualizations representative of the entire sample were taken back to participants to clarify in the latter set of interviews (Thorne, Kirkham, & MacDonald-Emes, 1997).

#### **Data Analysis**

To manage the data, I followed Knafl and Webster's (1988) description of the data management tasks and data analytic tasks that relate to the qualitative research purpose of conceptualization and theory building. These authors define data management tasks as reductionist activities that prepare the data for analysis. Data analysis tasks are constructionist tasks that facilitate the extraction of meaning from a data set in order to rebuild and present the processed data set in a thematic or conceptually relevant whole. As patterns and themes emerged, tentative conceptual categories were identified and added to help organize and analyze the beginning ideas. Additionally, data analysis was carried out in a systematic manner as guided by the general principles of interpretive description ((Thorne, Kirkham, & MacDonald-Emes, 1997). Data analysis in interpretive description specifically consists of inductive analysis focusing on the challenge of understanding the overall picture or making sense of the data in order to advance more coherent analytic frameworks. To begin, I repeatedly read each interview prior to data analysis to better understand the questions, "what is happening here?" and "what am I learning about this". The immersion in the data prior to beginning coding, classifying, or creating linkages was critical to help me gain a general overall sense of the information and to achieve the goal of identifying patterns or themes by inference through examination of specific instances or events (Morse, & Field, 1995).

Throughout inductive thematic analysis process, I searched for common threads or themes that extended throughout an entire interview or set of interviews (Morse, & Field). Themes are concepts indicated by the data rather than concrete entities directly described by the participants which, when identified, appear to be significant concepts that link substantial portions of the interviews together (Morse & Field). That is, themes are structural meanings units of data which help the researcher cluster information and discover the meanings intended in what is observed and heard (Streubert, & Carpenter, 1995). During thematic analysis, I initially focused on getting a sense of each interview searching for and identifying common threads before attempting comparisons across interviews (Sandelowski, 1995). I read each interview three times in order to apprehend its essential features through critical reflection. Critical reflective thoughts arising from repeated immersions of each interview and the set of interviews were then written in theoretical memos in order to enable me to identify, interpret, and link themes, and to verify findings. In this study, thematic analysis also integrated data from field notes, nursing papers and cases, lay print, and documents related to health care services. Categories and themes were continually formulated and critically reviewed through the entire data analysis process. The nature of the categories changed as the study progressed, including the expansion or merging of the categories and the changing naming of the categories as the emerging concepts became validated and consolidated through the constant comparison process in the data analysis. As well, the thematic framework evolved as the study progressed, resulting in a framework comprising of four major themes which seems to best convey the experiences of the participants.

#### <u>Rigor</u>

Rigor in any research is required to prevent error of either a constant or intermittent nature (Morse, & Field, 1995). Lincoln and Guba (1985) identify four aspects of trustworthiness relevant to qualitative studies. Truth value or credibility includes activities which increase the probability that credible findings will be produced (Streubert, & Carpenter, 1995). Credibility is optimally attained through prolonged engagement with the subject matter and by confirming the credibility of findings through "member checking" or returning to the participants and see whether they recognize the findings to be true to their experiences (Streubert, & Carpenter). The criterion of credibility is accomplished in this study through multiple interviews as permitted by the participants, repeated immersion in the field by visits to community health agencies or participants' homes, and taking the emerging conceptualizations representative of the participant group back to individual participant for verification and clarification. Credibility also refers to the recognition that truth value is subject oriented and is not defined in advance by the researcher as well as the acknowledgement that multiple realities exist (Morse & Field). Theoretical memoing and field about participants' responses was used to explicitly recognize that participants' responses are shaped and constrained by factors such as the nature of the interaction between researcher and participant (Sandelowski, 1993). The researcher's role in this research study is therefore to report the perspectives of the informants as clearly as possible.

Applicability or transferability is a second criterion of trustworthiness. It is the criterion used to determine whether the findings can be applied to other contexts, settings, or other groups or have meanings to others similar situations (Morse, & Field, 1995; Streubert, & Carpenter, 1995). The expectation for determining the fit of findings rests with the potential users of the findings and not the researcher. However, the researcher has a responsibility to provide the data base that makes transferability judgment possible on the part of potential users (Lincoln & Guba, 1985). Applicability in this study is met by providing sufficient information in research reports for readers to follow the analytic reasoning process and to judge the degree to which the analysis is grounded within the data.

Consistency or dependability is the third criterion of trustworthiness. Dependability is met by asking the question: "How dependable are these results (Streubert, & Carpenter, 1995). Dependability of findings in this study is enhanced through the use of theoretical sampling to attain maximum variation of the phenomenon studied until theoretical saturation and theoretical validity are reached.

Neutrality or confirmability, the fourth criterion for trustworthiness, is a process criterion (Streubert, & Carpenter, 1995). Confirmability refers to the freedom from bias in the research procedure and results. As the researcher in this study, I have attempted to increase trustworthiness by prolonged contacts with informants and the application of an audit trail to clearly identify the researcher's biases, decisions, choices, and insights (Morse, & Field, 1995). The audit trail ensures the rigor of the study's findings by retracing the development of abstractions and to ensure that the analytic directions are defensible by illustrating the evidence and thought processes leading to the conclusions (Streubert, & Carpenter; Thorne, Kirkham, & MacDonald-Emes, 1997). The audit trail consists of ordering and dating field notes and theoretical memos to place interviews within context, and the noting of changes in methodological approach, with the rationale, as directed by theoretical sampling in theoretical memos and reflective journaling (Morse, & Field). Additionally, the theoretical memoing of subjective interpretations of events is used to alert me to areas of potential bias. Strongly held professional and personal values and beliefs are included in the audit trail in order to explicitly account for bias upon the research findings.

## Summary

The overall outcome of interpretive description study is the integration of conceptualization and the concrete realities of the practice context to produce sound and usable knowledge for nursing. An interpretive descriptive research design has been used to investigate the structural and relational factors affecting the effectiveness of care-seeking efforts by economically disadvantaged individuals from the perspective of these individuals. The research design comprising of the sample selection and criteria, the data collection procedure, and the interview process, data analysis processes are outlined in this chapter. Research rigor and ethical and human rights considerations are also presented. I believe that this methodology has been appropriate to answer the research question and has enabled me to capture the range and depth of understanding of the participants' experiences and realities.

# **CHAPTER FOUR: PRESENTATION OF FINDINGS**

The findings of the study are presented in this chapter in the form of an interpretive summary of the economically disadvantaged participants' descriptions of the structural and relational factors that influence their care-seeking efforts. This summary is derived from a constant comparative analysis of the data throughout the research process and consists of major themes and constructs that emerged from the participant interviews and data from other sources, including field notes, theoretical memos, lay print, newspaper articles, health authority documents, and clinical case studies and articles. Four major themes emerged from the development of categories from the participants' descriptions of their experiences with careseeking and living with poverty.

This chapter begins with a description of the participants and follows with a discussion of each of the themes. The first theme reflects the experience of living with poverty in contrast to those who do not. The second is concerned with managing health on a day-to day basis. The third theme deals with the multiple aspects of the health and social care systems that confront persons living in poverty. And the fourth addresses the facilitative and challenging factors that influence care-seeking according to these participants. Together, these themes describe the structural and relational factors that influence the care-seeking behaviours and processes of economically disadvantaged persons.

## The Participants

The ten participants in this study are a diverse group of individuals in terms of age, health status, functional ability, mobility level, ethnicity, family status, and personal background. The participants were also purposively selected for their use of a wide range of health and social care services. They live in one of the four low income neighbourhoods of Community Health Area #2. Two participants live in the Downtown Eastside neighbourhood, three participants live in Strathcona, two participants live in Woodlands, and three participants live in the Grandview neighbourhood. The length of time that the participants had lived in their respective neighbourhoods ranged from 18 months to 16 years. Thirteen interviews were completed with these ten participants. Pseudonyms are given to the participants to help make the participants' experiences "more alive" to the reader. General descriptions of each participant are now presented.

Participant 1, "Mary", is a single 63 year old Caucasian female, looking older than her stated age, and has lived in a B.C Housing subsidized bachelor suite in a high rise building in the Woodlands neighbourhood since 1986. She does not leave her building because of her severely limited mobility and vision. She uses a manual wheelchair. She has lay help from friends and extended family members, and formal health care supports coming to her home. I interviewed her in her simply furnished suite.

Participant 2, "Connie" is a 64 year old mixed Portuguese/Aboriginal female living in a low rental housing unit in the Strathcona neighbourhood. She was interviewed by me in her friend's single resident occupancy (SRO) room in the same building, where all her home care nursing visits also take place. She recently retired from being a cook and soon after her retirement, she started "getting sick and have been sick ever since (and) all hell broke loose". She has lived in the neighbourhood for sixteen years and is originally from Pender Harbour. Her mobility is limited by her shortness of breath and fatigue. She has a nurse coming to her home, and she goes out of her home for her other health care. She also has adult children who live in neighbouring municipalities frequently helping her in a variety of ways.

<u>Participant 3</u>, "Stephen" is a 54 year old Caucasian male who lives with his similarly – aged physically disabled wife in a small, crowded one-bedroom suite in a subsidized low-rise apartment building. His wife's elderly father lives with them and sleeps on the living room couch. His wife, "Diane", who moves about in her electric wheelchair, initiated joining in one of the two interviews with Stephen and she is <u>Participant 4</u>. Stephen is legally blind, fully mobile, and works informally as the building's handyman. Stephen and Diane have lived in the Grandview neighbourhood for 10 years. They have a small number of health care providers coming to see Diane's father and them in their home. Otherwise, Stephen primarily uses hospital or general physician care. Stephen and Diane have strong beliefs about what they expect from the health and social care that they receive.

Participant 5, "John", is a divorced 60 year old Caucasian man living in the Strathcona neighbourhood. He lives in a municipal – subsidized housing SRO building, moving into this current place in March 2000. He is very satisfied with his current residence because his previous home was a hotel a few blocks away where the latter was "*full of cockroaches, mice and everything. There's heavy drug dealers sitting out there. There was too much of that going on*". John does not have any home-based care and uses many community-based services, both formal health care and informal neighbourhood-based services. I interviewed him in his room.

Participant 6, "Nancy" is a 42 year old Aboriginal female living in a supported services Downtown Eastside (DTES) hotel. Prior to residing in this hotel, she has lived "*right down and out, laying in the back alleys*". She lives with her husband, and is an intravenous drug user trying to get off drugs. She told me that she had her "*little girl was taken from me (by) her step dad and I haven't seen her since*". She is well-known to people on the DTES streets, and is actively involved with a community intravenous drug users activist group. She walks slowly with painful steps using a cane. Nancy uses a variety of health care services and has strong opinions and moral beliefs about how she is treated as an "*Indian and junkie*" and how her fellow Downtown Eastsiders get treated from health care providers. Our interviews took place in a neighbourhood coffee shop and in the field walking around in the neighbourhood.

<u>Participant 7</u>, "Dean" is a slight 59 year old Aboriginal male living in a Strathcona municipally-subsidized SRO. He came to Vancouver from Northern B. C. because he "got bored with reserve life" and has lived for 20 years in this neighbourhood. He has been a paraplegic since he was 10 or 11 years old when he had to stay in a "stretcher bed in the hospital for three years". He uses a manual wheelchair indoors and a motorized scooter outdoors. Dean is a quiet, soft spoken man and I interviewed in his sparsely furnished physical handicapped – accommodated suite. He receives home-based services and infrequently sees his doctor.

Participant 8, "Robin", is 26 year old Caucasian female living in a tiny SRO in a DTES hotel that recently underwent new management, and which now provides an in-house medication support service and other "minor" health services to its residents. She has been "*in and out of Vancouver since I was thirteen*" and has lived in the Downtown Eastside for a year and a half because of her addictions to intravenous drugs which originated at the infamous corner of Hastings and Main. She was referred to this type of housing after recently "*recovering*" at the community hospice where she was originally admitted after being discharged from the acute care hospital. She is very thin, pale and appears severely fatigued as evidenced by her slow and grimacing movements. She admits that "*my legs do not work all the time so I can't go outside all the time, I can't stand up half the time. I get tired really quickly when I am doing something*". She has home-based care (home support worker and family physician) but still goes to a community health clinic three blocks away. Because of her obvious ill health status, the interview was only 10 minutes and she agreed with my suggestion to discontinue with participating in the study.

<u>Participant 9</u>, "Tarah" is a 35 year old single mother with a sixteen month son living in a small Woodlands neighbourhood, two-bedroom suite in a British Columbia Housing sponsored low – rise apartment building where the interview took place. She is originally from Kuwait where she lived with her family of "good income" and had in the recent past moved to Canada when she "started to have problems with my family". She was a dentist in Kuwait, but is not currently working because her health problems. She has lived in her building for only two years and is finding being a single mom very stressful given her many stressors: mothering an active toddler, living only on her disability income, having no financial support from her son's father, applying for custody of her son, and having no family help and only limited friends/neighbours'

support. Tarah cares very much about her son and is very concerned about her ability to provide better for her son. She uses the word "*struggling*" frequently throughout the interview.

Participant 10, "Karen", is a 20 year old former street youth and mother of a fifteen month old daughter. She lives with her young male partner, who was also a former street youth, in an apartment building in the Grandview neighbourhood. She has been in Vancouver for only two years and was also a street youth in Toronto, leaving Toronto because she had painful memories of giving up her first daughter for adoption. Karen "grew up in a really yuppie (family), my parents belonged to a country club so they were really money oriented", and is very thankful that "If I hadn't ended up on the street and I hadn't had her (daughter) and look the way I do, I would still be that stuck up yuppie snob". She is "goal-oriented", assertive, articulate, and politically-minded. She uses community-based care and services. Our interview took place in a coffee shop in the neighbourhood.

### Living with Poverty - Not Belonging to the Same Playing Field

The first theme, "living in poverty – not belonging to the same playing field" presents the participants' descriptions of living in poverty. The participants described what the term "poverty" meant to them and their management of their daily restrictions living in poverty. They also provided extensive descriptions of their arduous experiences dealing with multiple income assistive government ministries.

## "What Poverty Means to Me"

The participants gave many descriptions of their challenging experiences of living in poverty. I did not directly ask the participants about their income because of my awareness of the participants' potential sensitivity of this topic from my home care nursing experience. Despite this precaution, the majority of participants volunteered information about their income sources or monthly income. The participants' sources of income are varied: provincial social income assistance (welfare), BC Benefits (formally known as GAIN, a provincial disability pension), Canadian Pension Plan (CPP), "widow's pension", or a combination of these sources. Connie stated that her monthly income is \$525 a month. Stephen informed me that his wife's and his combined monthly income is \$1,900 a month. Dean's combined monthly income is about \$800, the majority of which is provided through CPP and "\$132 or so (is) from Social Services". Karen stated that "welfare allows \$650 for rent" which is combined with an additional "\$300 a month support for groceries, diapers, food and clothes" for her family of three.

Interestingly, the participants have a wide range of personal identification with the concept of "poverty". Mary and Robin simply did not associate themselves with the term. Mary commented, "Well, you know, I've never thought that I live in poverty. Because I have so many good friends that I don't consider myself poor. Financially, I'm lousy but I don't care about that. I manage to scrape through." Similarly, Robin did not consider herself living in poverty because "I consider I'm very lucky to be alive" and living in poverty to her meant "a person with no hope". Likewise, John asserted,

Well, I'm definitely below, I'm in the lower class. I wouldn't say poverty because poverty is usually these guys walking the streets and they've got no homes. And that, to me, that's poverty, homeless and all this and that. At least, I've got a roof over my head and, you know, I go down to these pawn shops and things like this.

These three participants philosophically believe that the term poverty is incongruent with their good fortune in having friendships, hope, shelter, and other basic needs meet.

On the other hand, Connie, Nancy, Tarah, and Karen strongly identified themselves as "living in poverty, way below poverty". The term "way below poverty" was actually used by these four women. Connie and Karen directly related the term "poverty" to the inadequate amount of income received. Connie explained that she lived with poverty because "it's very hard to make ends meet because my medications are very, very expensive. (They) cost me \$586 a month and I am getting only \$525 month". Karen commented that the "Poverty level is \$18,000 a year. I bring in about eight, ten thousand a year. So yeah, that's 10,000 below what people in poverty are supposed to make so I wonder what that makes us?" In contrast to poverty meaning inadequate income, Tarah and Nancy described living in poverty as meaning their psychological and practical daily struggles resulting from their inadequate income. Tarah remarked, "It makes me feel miserable, you see. I wake up and I feel, oh my God, my new day is going to be the same as yesterday, so much struggle, so much pain, so much depression. When you live in just the basic and struggle everyday to get the basic things." Nancy described her poverty experience in terms of constantly needing to "stretch out" her food resources, "If I was not taught when I was younger to stretch a meal by my elders, I couldn't do it. Because even if it's a long month, you try and stretch your food."

The participants also described their day-to-day life experiences living in poverty using terms such as having "*limited choices*" and "*restrictions*". Within the context of "*I can't do what I like to do*", the participants felt restricted in attaining every day needs such as housing, recreation, clothing, and nutrition. Dean described his poverty situation simply as, "*I can't go to a movie every week. I can't go to MacDonald's and places like that. I don't like living in low income housing. There's too many restrictions down there in these low income places.*" For Tarah, the limited choices of living in poverty presented additional stressors to being the only provider for her dependent son:

It's very limited choices, very limited income. I'm obligated to do things. It has to be done, you see, but how it's going to be done. I have not many option(s). It just, I have to do it this way because I have baby. He's dependent on me. You go shopping. You have to look for the second hand. You can't buy and just everything expensive. I see drug people from here, prostitution on the street just across from this building. We have drug dealer in this building. I didn't choose. It's city housing. They choose for me. Another thing we don't have a choice.

Some participants described a strong sense of feeling different from and inferior to "*regular people*" as a result of their poverty status. Although the concept of society being comprised of individuals who are "the haves and have-nots" was not directly described by the participants, this concept seems appropriate to describe the context of the participants' feelings. This sense of being structurally differentiated from other individuals in society with a higher income level is noted in Stephen's description: So, in general, I would say that by basically having no money, you don't have the ability to carry on and do things like other people. It means that you do not have the ability to have the same things as anybody else such as driving a car. I don't have a house, a car or job. I don't have credit cards. I get paid by the co-op (as the co-op's handyman), so that makes me feel good because I'm even par with everyone else. It puts me on the same playing field as everyone else. I don't like being on welfare. It's destroyed my whole life as far as I am concerned.

Likewise, Karen compared her severely limited ability to acquire material items to the vastly

greater purchasing power of higher income persons. The wide disparity is illustrated by Karen's

reflection upon her poverty status:

(I feel) crappy. I see so many yuppie parents with their kids in the GAP and Gymboree and all the expensive clothes and stuff. And all the young mums that have their parents helping them out. You know, they were born into rich families and their mums and dads are giving them so much. And they're dressed like Holt Renfrew and all this nice stuff, and I would have loved that chance too. You know, I'm lucky that once every four or five months, I can get myself a new pair of socks or toque or something. My biggest treat is getting something for the house. I get excited if I get a juice jug.

Karen has also directly experienced prejudice against her for being poor and dependent on social

income assistance. She described the following encounter at an attendance at a political

demonstration:

It's usually the people that have the most money that turn around and say that people on income assistance are a waste of time. What was it the Liberal lady said to me? It was something about, "You shouldn't have kids if you're not financially stable". And I said, "Well, what about the women that didn't have a choice?" And she said, "That's what abortion and adoption are for."

The participants also gave specific examples of not being able to meet their "wants and needs" due to the restricted daily choices of living in poverty. Living in poverty meant that the participants had limited choices in recreational activities, housing status, and available means of transportation. Four participants, Dean, Connie, Diane, and Karen, identified the inability "to go out for meals" "for a break". Diane compared herself to the "average person who makes good money can go and have a good time" whereas she and her husband, Stephen, "have to stay home every weekend". Instead of the present housing situation where she and her son are exposed to drug dealing and prostitution activity, Tarah wished that she could afford better housing.

specifically, "Safer and family oriented housing. I don't care about the size and how big it is. The more favourite for me is to be safe and family oriented because it's going to help us emotionally, me and my son." Additionally, for Tarah, living with poverty means struggling to use the bus as her primary means of transportation which in turns puts additional stresses on her physical and mental health:

I take the bus because it's very expense to pay all the time for a taxi to get to my destination. When I get into the bus, I have to carry the stroller. I have to carry my baby. My baby is increasing in weight and I carry the diaper bag. Plus if I'm shopping, I have to carry. So it's a real problem for especially with my fatigue and with my back problem. And the bus driver, some of them are understanding but the majority are not. They just look at you and you have to get into the bus quickly so you don't get other delayed, you see. And it's very stressful like all the time when I want to get into the bus, I am nervous how I'm<sup>2</sup>going to carry all this. How is the bus driver going to look at me and am I going to get help? Am I going to struggle alone? Is my son going to be safe or I'm going to fall down with my baby?

### Needing to "Kowtow" to the Ministries

The participants received their income from a variety of social income assistance programs. Subsequently, they must contend with a range of provincial and federal ministries, including the Ministry of Health Services, Ministry of Human Resources, the Department of Indian Affairs, and the Ministry of Children and Family, and other income-assistive agencies such as British Columbia (B.C.) Housing. Several participants described their realities of living with and being controlled by these organizations' explicit and implicit policies as well as their inherent bureaucratic processes. Connie described her experience with being caught between two government systems, the Department of Indian Affairs and the Ministry of Human Resources, each with their own rules and regulations for gualifying for income assistance:

I went to welfare and they wouldn't touch me with a ten foot pole because I have a couple of RRSPs that I do not want, well, I mean I have to a couple of times take out of them for my medication. I'm working now trying to get my status. When that comes through, I'll be fine. And I'll probably be dead by the time it comes.

Some participants strongly believed that numerous government policies were unrealistic in the expectations they imposed on them. Karen explained the unreasonable food allowance policy that the Ministry of Human Resources has for social income assistance recipients: The Ministry had (the Healthy Food Guide) put out a statement for exactly to judge how much if they did their shopping properly, it would cost a person to live on, for a month on income assistance. And that's where they came up with one ninety-five. They figure it costs you one fifty for groceries and they'll give you forty for toiletries. It's not fair.

Stephen also described his experiences with living with the restrictive rules for food allowance

and for the funding of medical supplies:

They say that, well, food is cheaper for people, but, you know, I really don't think so. Because, okay, so you can buy bigger packages of meat, it still costs you more to get these big packages of meat. So you sort of get screwed. Sometimes I don't know how these people think. I mean, they expect me to have one pair of (orthopedic) shoes. Then you turn around and ask them, "Well, how many do you have? I've bet that you've got more than one pair." The Ministry pays for them so you're entitled to this shoe for four years. So there's once again, there's a lot of restrictions put on you.

In regards to housing, Tarah described the implicit message that she received from B. C.

Housing, a government agency for subsidized housing, "This is what you get. Be happy and try

to survive. You're not in the streets so you have something better than that." Karen provided an

additional example of an experience that she and her partner encountered where the government

policies were not only unreasonable, but they were also inflexible and unsympathetic:

Either me and (partner's name) has to be in school at the same time. He was out of school for a week and a half. And the RTC call us, our training consultant, and told (name) that he needed to get into a program otherwise we would be cut off, we wouldn't be receiving much child allowance. They understood him staying out because of the bus strike, but they just, they wouldn't give him any leniency.

A number of participants gave extensive descriptions of their encounters with lengthy and

difficult bureaucratic processes. Three descriptions are presented in detail to offer insight into

the "rigamarole", "hassling", and "hoop-jumping" processes with which the participants must

comply. Stephen described his experiences as:

You're forced to kowtow to the Ministry. You could go out and buy a ten thousand dollar pair of shoes, sort of thing if you wanted. And I have to go to the Ministry. I have to go through this rigamarole: go to the doctor, see the doctor, and the doctor says this and he writes you a note. And you take it to your worker and then it goes to Victoria, when they say, whatever they say. Then you have to get to doctor to write another letter. So once again, we have to put up with all this crap. You're not on the same place as everyone else. John provided an example of the "hassle" he endured dealing with the Ministry of Human

Resources where he was required to travel to four separate ministry offices to get his application

processed:

So I went up there at (Burnaby street names) to the welfare office there. They say, you'll be going down to (Vancouver Downtown Eastside street names). Your worker is (name) and (number) is his office number. And when I went down there, I had a hassle and I mean it. First of all, you've got to bring in proof of income and you've got to bring in all this and that. Thank, God, I've got all my year 2000 and the year 2001, I've got all my receipts and everything in there in my third drawer. And then when you bring down the receipts, it's still not enough. Well, you'll have to go back to the (Vancouver South neighbourhood street names). And they'll have to stamp this and they'll have to stamp that. And I said, (social assistance worker's name), now when I receive my birth certificate, they've (the welfare office) moved to (Vancouver Downtown South street names). You know, when I received my birth certificate, it must have sat in that office for about at least two months.

Karen described her experience with the unsympathetic qualifying process for social income

assistance:

It's long, it's boring. You have to jump through dozen of hoops and sometimes it doesn't seem like it's worth the benefits. There are times when I made more on the street than I did on the system. At first, you need to go in and make an appointment to have what they call an orientation meeting. And they send you to this course of a Tradeworks. It's an hour long. Tradeworks, it's a building set up for the governmental hoops, I guess. You'll sit there for an hour and they run a film strip telling you what you need to qualify. I thought that it was a load of crap. I thought that it was another waste of money so that they can try and eliminate as many people as possible from going on income assistance. The people who do the orientation don't smile. They stand up at the front of the room. They turn the VCR on and they have you fill out some forms to prove that to your intake worker that you're actually there. It's like, you know, like they're trying to process for the ideal people to fit back into society and the ones that they want to weed out.

Several participants spoke about how government rules on income funding and

bureaucratic systems covertly and systematically keep a person poor and prevent an individual

from "moving ahead". The participants' examples of this experience included descriptions of

bureaucratic rules that keeps an individual's income level to a sub-standard ceiling due to the

funding formulas used. John explained that:

When I got that cash settlement (from Canada Pension Plan), welfare got a pad of paper, and bang, no phone calls, no piece of paper, nothing. When I went to social assistance, I asked them what's going on here? She told me from here on, "You're going to have to make ends meet." And they cut me right down to from five hundred, they cut me down to

one hundred. And at that time I was receiving \$654 dollars and \$100 dollars from social assistance.

Stephen described his strong views with a second example on how the social income assistance

system keeps his wife and him trapped in a poverty situation:

I also think that the Ministry, and I'm gonna use the word, "discriminates". If we were two single people, our income together is more than what we get as a couple by about nearly two hundred dollars a month. People always claim that it's cheaper for two people but that's not necessarily so. So right away, it's more expensive for two people just because of the rent. But you sort of get screwed. Sometimes I don't know how these people think. I get part Canada pension and part welfare and they deduct your Canada pension from your welfare cheque. Now my way of thinking is whatever you're entitled to, you should be entitled to. But they subtract one from the other and you don't get anymore than anybody else. For very long time, I wouldn't claim my Canada pension. They suddenly said, "Well, now you're forced. If you're on Canada pension, then you have to tell us." So we had to but that meant a loss in our wages of nearly four hundred dollars a month.

Stephen further elaborated on how being controlled by an invasive government system drives an

individual to go "underground" in order to get financially ahead in life:

If you want extra money, you have to deceive everyone to make extra money. You have to basically screw the government to have any extra money. They're going to be right down your neck and they'll take that money away from you. Well, I don't agree that it's right. I mean a single person right now I believe gets \$771. I mean this day and age, what kind of crap is that? You're not even getting the same standard of living as other people. Because, now I could be wrong, but the average wage in Canada is \$50,000 a year. So what's somebody like me, seven hundred a month compared to \$4,000 a month basic. That's the way things are designed but I don't think that they're necessarily correct.

To summarize, the participants described their experiences of living in poverty and the

meaning of their experience in the context of their everyday lives. Some participants did not feel that the term "poverty" described their situation while other participants spoke about their strong feelings of having limited choices and restrictions as a result of their inadequate social income assistance. Some participants also strongly believed that that their poverty income status and subsequent constraints separated and differentiated them from persons of higher income, whom they saw as the majority members of society. The participants also provided detailed descriptions of the challenging bureaucratic policies and processes that are inherent in having their income provided by governmental sources.

## Managing My Health Day - to - Day

The second theme presents how the participants manage their health issues and health needs while living in poverty. The participants describe their multiple health conditions and the significance of the concept of health to them. They also present their experiences in attaining their health and basic daily needs.

### Having a Range of Health Conditions

All of the participants lived and coped with a range of physical and mental health conditions. The participants' predominant health conditions were chronic illnesses such as diabetes, hepatitis, HIV/AIDS, substance use, depression, anemia, back pain, and congestive heart failure. The large majority of the participants had a number of co-existing illnesses and associated health problems. An example is Mary who stated, *"I suffer from asthma, angina, epilepsy, a lot of different things. I have a past history of mental illness. I have a lack of balance and lack of vision. I fall down a lot."* Karen was the only participant in the study who did not have a chronic illness diagnosis. Karen was generally a *"well"* young individual who described herself as in good health with her health issues were only infrequent back pain, *"an ulcer from my gallbladder"* that limited her intake of spicy foods, and *"prone to strep throat"*. The majority of participants who had chronic illnesses had their health conditions for an extensive period. Connie is the exception, having her diabetes, asthma, and congestive health failure conditions for approximately only two years.

Most participants felt that their current health status was satisfactory which was described as "I generally feel fine", "I think overall, it's pretty good right now", "It's okay", and "Fairly good". Two participants, Nancy and Robin, described their health status as "deteriorating" or "pretty bad". Nancy described her health as: "Not very good right now. My cirrhosis is getting worse. My HIV is going down, but I try to keep a smile on my face and go on until the end." Robin described her health as: Pretty bad. I'm HIV positive, hepatitis C, and I don't get around too much anymore. My legs do not work all the time so I can't go outside all the time. I can't stand up half the time. I get tired really quickly when I'm doing something. I get sick at night. They took me straight to the hospice where you usually, you used to die there but I recovered. I was very sick, I was near death. I had pneumonia in my lungs and I just wasn't doing so good.

### The Meaning of Health

A number of participants explained what the concept of health meant to them. The participants inferred health to mean having a good health status. Good health is then associated with a feeling of independence and freedom of the body and mind. Mary illustrated this perspective, "(Health is) that I'm healthy enough to function, both physically and mentally. Especially mentally because I have a lot of physical challenges now and I need my mental health to help me through them." Stephen elaborated on this perspective of the meaning of health, emphasizing that having good health is being able to have the freedom to accomplish any desired accomplishments, "Health is that you've got no medical problems. You are able to carry on, you are able to work, run, kill yourself by skiing off a mountain with parachutes."

In contrast, participants who have a poor or deteriorating health status described their

experience of health as a daily struggle. Karen described her psychological struggle and

spiritual coping strategy with her losses associated with decreased physical functioning:

When I was healthy, it meant cleaning after myself, taking a bath, making sure I went to see a doctor. Now I just, sometimes I don't care. All the time I'm lately, I've getting worse, worse feeling. So I'm looking forward, just let me go because it's not easy. But life has to go on, so it's what I do all the time. I try to think the best and go on. I want to be strong and walk with my creator. And that's who I walk with every day is my creator, that's my higher power.

Tarah related how her physical and mental health are negatively affected by the pressures

associated with the role and responsibilities of being single mom:

By the time I get here, my son is very tired and sleepy. So I need to feed him, and also feed myself and cleaning up the kitchen. Pressure by the time, and me not having energy. So there's no time, not enough energy. So it's many things that struggle with, with your health, your depression, the depression affects the health and it's just a circle. I'm just part of the circle"

Connie described her poor health to mean feeling limited in her independence and her daily requirement to be constantly "watchful" of her unstable health conditions, "Health means that I wish that I had my good health. (Before) it meant hat I could go and do just about anything and everything that I wanted to do. And now I'm limited, you know. I can do this, I can't do that. I've got to watch this, watch that." These participants' feelings of stress, losses, and burden associated with coping with their poor physical or mental health are described as separate to yet

also integrated within their struggles associated with living with poverty.

Three participants spoke about a turning point in their lives where they redefined how they viewed their responsibilities in managing their health. John described how he tackled his alcohol misuse to better manage his HIV condition as a result of better understanding of his illness:

There was a guest speaker. They're talking about thousands, and here I am in the hundreds. "Yes, that may be true, but the point is the lower your viral load is, the better for your health, your helper cells." And this is when I had an appointment with Dr. M., and she asked me, "Well, how did you feel when you walked out of that room?" I said that I was confused, mixed emotions. And they also knew that I had a drinking problem so I said to her, "Occasionally, I would come in here half inebriated". And I told them, "There's no more of this coming in and whatever and going back out." And this is the first time that I had ever seen Dr. M. shake and pat my back and she says, "Today is the beginning." Just seems like, alright, there's no cure for HIV and whatever. But the thing to do is, to take the responsibility because nobody else will. And I made that resolution in my mind. It's about time that you, myself, changed your ideas, change your drinking habits, change all this and that, start eating properly.

Nancy described how she made the decision to quit intravenous substance misuse because of her

values and beliefs about her responsibilities to her family:

Well, sleeping on the street, getting sick, dirty, I was like this isn't me. I like being clean. And then when I found out that I was HIV, that's when, I didn't go the other way around. Like when people really go nuts and don't give a sh\*\*, and then they kill themselves because they've got HIV. It went the other way around. I want to stay alive because I got children, grandchildren so that why I did what I did.

Karen explained how her moral values about substance using and its negative effects on her

unborn child contributed her motivation to stop substance use and living on the streets:

I'm probably still be there if I hadn't got pregnant. After I lost (first daughter), I didn't see any point in holding a job, in holding that life and I went back to the street, back to

drugs and, you know, just said, "Screw it." When I found out that I was pregnant and I just stopped, I don't think that it's right to do drugs while you're pregnant.

## Managing Health and Basic Needs Living in Poverty

A number of participants described how they coped with living in poverty and maintaining or trying to improve their physical and mental health and well-being. Several participants associated good health with attaining adequate nutrition. To attain adequate nutrition, Mary and John frequently used community food banks to supplement their food supply. Stephen, Tarah, Dean, and Karen were *"very careful in how you shop"*, *"got to pick and choose"*, or *"bargain hunt"* with food. Karen illustrated her shopping, meal planning, priority setting, and coping strategies required to feed her family on a severely restrictive food allowance:

Well, it's really hard to do balanced books. They always tell you shop around the outside of the supermarket. It's where the healthiest things are. The processed stuff is at the center. Shop around the outside and it costs a lot more money. The cheaper stuff, the processed stuff is cheaper than the fresh stuff and the organic stuff. I always make sure that she (daughter) gets her bananas and vegetables and stuff but I can't afford the real cheese. Real cheddar cheese is way too expensive so she gets cheese slices. It's hard to make balanced meals not so much for her, but for us. Give her a cup of yogurt, and egg, and she's set. But I'm supposed to be on a low fat diet and my partner is on a high fat diet because he just can't gain weight. He's a hundred and forty-seven pounds and he's six foot two so he's a real toothpick. I had to teach him that he gets one big meal a day and he can have like a bowl of soup and sandwich or something for lunch, a couple of bowls of cereal for breakfast. There's been a couple of times when I've had to phone my mum and ask for help. Just like the middle of the month, absolutely broke, no milk in the house.

Some participants also mentioned that they must "scrimp and scrounge" for other

"basics" associated with maintaining and supporting their health. Basic needs included clothing, which is frequently bought second-hand. Karen shopped at thrift stores for herself but made it a priority that her toddler daughter gets "one new outfit every month and a new pair of shoes every three months". She commented on the struggle to meet other daily basic needs with the following two quotes:

It's just the little things, it's a struggle for money for cigarettes. You really don't have much for yourself. It's easier to be pregnant on welfare than being a mother on welfare

because welfare provides you more when you are pregnant. (Money) is the main thing we (her partner and her) only fight about.

(The rent) is going up \$40 to 625. So another year there and we won't be able to afford the rent over \$650. (Because) we're allowed \$650 for rent, where even in the Downtown Eastside, one bedroom is \$900 a month usually.

Connie described that "it's very hard to make ends meet" paying her rent, food, phone, and TV

bills because her monthly medication bills exceeded her monthly income. However, she made it

a priority for her health to "have a cell phone for emergencies for when I'm out on the street. If

anything happens, I can't get to the phone, I can always dial the ambulance". Dean commented

how he obtained funding for phone access, a resource that he otherwise could not afford,

"(My phone) is on restricted use. There's no long distance on it or anything and when I got hooked up, I had a total of something like \$134. So (community HIV/AIDS agency name) gave me a check for \$100 and that's how I got my telephone. And I paid the rest through my income each month."

Tarah remarked how difficult it is to be a single mother being only able to provide basic needs to

her son while grappling with her own health needs at the same time:

I struggle with the money because so many things for the baby have to be done. I mean everything that I get for myself and baby is second-hand. But everything is expensive and nothing cheap. There's no second hand diapers. There is things that you have to buy new. It's expensive, it's costing so much money. So I push myself to do things with all my pain and all my fatigue and all these things because it's very limited choices, very limited income.

Karen provided additional insight into her former street youth life and the hardships faced

obtaining basic needs, including safety and shelter, living with poverty on the streets:

I've met hundreds of really amazing people and I've realized how society treats a lot of under-privileged people. When you go for three days without eating and try panhandling and the police kick you off even though you're hungry and you're tired. You're fifteen years old and you've got no place to go and all the shelters are full. It's Christmas time and nobody will give you money. They don't care. They'll still kick you out of your panhandling spot. The police are sure better than Toronto, but I've seen a lot of kids beaten up by cops. It's scary. I never slept alone when I was on the street. I always had someone beside me.

The participants also spoke about the challenges of meeting their transportation needs.

None of the participants owned or had access to a car. All of the participants have either

impaired mobility because of their health conditions or have transportation needs associated with

having young dependent. Dean, for example, described his mobility level as "I have

neuropathy in both legs. If I was to stand up for half an hour or so, I get out of wind and I have

to sit down." Karen commented on the pressures of relying on and paying for public

transportation on a restricted income:

(1) walk and bus. So the strike really affected me. I was in school then and (daughter) had just started in daycare and the day after she started daycare, the strike started. I was going for my counselling diploma. I tried to walk from my house at (street names) everyday. And then, you have to race. Then like, my partner ended up leaving school so that he could stay home with her so then I could finish it off. A lot of walking especially now the bus price has gone up and it's going up again. Welfare won't pay for a bus pass unless you're in school. It doesn't matter if you're a single mum.

Three participants spoke about collecting pop cans for extra money to help obtain "extra treats" or needs. Stephen and his wife commented with pride that they collected pop cans for a considerate length of time in their neighbourhood's back alleys to pay for their wedding. Connie mentioned that before she become ill:

I used to, well, I went to the parks and stuff like that. I used to for extra money, I used to pick up pop cans and stuff like that and let them build up until I got about ten, fifteen dollars. Then I could maybe treat myself to a dinner or something like that, which of course, was not very often.

Most of the participants described a level of "struggling" or having to cope within their income restrictions to meet their health and basic everyday needs. The maintenance and improvement of their health status are important to the participants. The participants consider attaining good nutrition as an important factor in maintaining or improving their health status. They work hard to be resourceful in managing to get their families' and their essential basic needs by "bargain hunting", "being careful" and priority setting with their money and seeking alternative resources to supplement meeting of their needs.

### Encountering the Multiple Aspects of Care

This third theme identifies structural and relational factors that influence the

participants' care-seeking efforts through an examination of the participants' experiences with the various aspects of care that they have encountered. The meaning of care, the types of care provided by the participants' social support network, and the types of care given by formal health care providers are presented. As well, a perspective of "self-care" at the community network level is discussed. The participants also provided comprehensive descriptions of formal health and social care that they found helpful and not helpful in meeting their health needs.

## The Meaning of Care

The participants generally described care to mean "help" or "helpful care" that contributed to supporting or improving their health status or health needs. This characteristic of care applied to both lay help and formal health care help. For example, Mary described care as help that complemented her abilities or compensated for her lack of self-care and is important to supporting the maintenance of her health, "(Care) means the same thing as help. Help means bathing me, cleaning my apartment, cleaning me up when I've had an accident. With my bath, like I can do the top of me but I need someone to do the bottom part of me. I can't do that now." Connie provided examples of helpful professional care that she received from her home care nurse that directly assisted Connie to optimally manage her unstable and chronically ill health status:

She checks me every week. And once a while, she sends me to the doctor because she says that my lungs are not doing well, and she says I better go and see the doctor. She orders my medication for me especially my pills because I get them mixed up and sometimes I don't take them properly. Reading the labels and understanding what the doctor means (is difficult). She gives me a dossette and doles them out, so many a day, everyday.

Helpful care is also strongly associated with the participants' descriptions of positive care. More detailed descriptions of positive care are provided in a later section in this chapter.

### Types of Care

As a result of having a range of health conditions, the participants received and accessed multiple sources of formal health and social care services. As well, they received care and help from their lay support network. The participants have care provided to them in a range of settings: in their homes, in their communities or neighbourhoods, or in the hospital. Informal lay care was given by family members or friends who provided care or help such as shopping, accessing medical equipment, providing transportation, taking the participant out for meals, providing advice about needed health care, and even paying for the participants' essential health needs such as food and medications. Karen described an example of lay care, health status monitoring, given to her by her friend in the "tight-knit" Downtown Eastside community:

If someone has gotten hurt, they'll come and knock on each other's doors. Though word of mouth, that how it is. I have a friend whose name is Gary. He'll knock on my door real loud and he'll say, "Nancy, are you in there? Are you okay? Do I have to go and get the key again?" And if you don't answer, he will go and get the key. And he'll push this until somebody comes up there to see if I'm okay.

Informal care even took place in the hospital setting. Diane described how she cared for Stephen

when he was in the hospital and nursing care was not timely:

I went and I asked the nurse to come and take his blood sugar and she says, "I'll be there in five minutes". I said, "I haven't got time for five minute." And when he goes down, he goes down real quick sometimes. I ran down and actually got a coke and chocolate bar and I brought them up and the nurse says, "What are you doing?" By the time I got in there, he'd already injected himself. I gave him the chocolate bar and coke.

Informal care was also provided by other community members. An example is the building manager doing room checks. The participants also used a range of community services such as Shop by Phone, church funded services such as food vouchers, community food banks, volunteer services, and support groups.

The participants' formal health care was provided by a wide range of health care professionals, including family and specialist physicians, nurses from home care, public health, or primary care clinic services, nutritionists, pharmacist, case managers, acupuncturists, and family counsellor. Formal health care is also provided through non-professional care providers such as home support workers. The type of services provided through paid health care providers include medical treatment, needle exchange, alcohol and drug rehabilitation, activities of daily living help, and van transportation. The participants described the type of care provided by formal health care providers which included health advice, assessment of the participant's health issue, symptom and illness management, advocacy of the participant's needs to other health care services, personal care, emotional support, and referral to other health care services. Connie described symptom interpretation, an example of care given by her home care nurse, "So (the nurse) said if it happens again, to phone the ambulance, because I was on the verge of collapsing. She said that my heart was telling me you've had enough."

## Having a Community Perspective on Care

Two participants frequently provided descriptions of "community self-care" in their interviews. This level of care is at a broader or more "macro" level than the informal lay help that is given to the participants by their more immediate social support persons. The two participants, Karen and Nancy, strongly identified themselves with their respective community networks. For Nancy, community is the "3 block radius of DTES core" which meant:

In my mind, it's about a three block radius, that' it. Because that's where I choose to live. And I've always lived in the Downtown core and here, this is where I belong. It's where you eat, where you communicate with the people, your friends. That's why I said a three block radius.

Karen still considered herself as belonging to the street youth community despite currently not living on the streets.

Karen and Nancy both described the caring and helping values of their communities. Karen described the "helping community" of the street youths as "*There's a whole family mentality on the streets. Its subculture, everyone looks out for each other.*" Additionally, Karen's caring feelings for her fellow community "family members" are evident in relaying her following story of the current status of street life:

(Living on the streets) has changed a lot. I look at the kids now and I just, I want to pick them up and I want to take them home. They're getting younger and younger and younger everyday. And a lot of society doesn't realize that. We had that big fiasco a couple of months back because they found the eleven year old girl on the stroll. And the media said that she was the first one that have been out there. Well, it's not true. If you go to (street names), it's like two or three girls out there that are not even thirteen.

Equally, a sense of "a community caring for each other" is evident with Nancy's

descriptions of her Downtown Eastside community support network. Nancy commented:

But we're supposed to look after each other. That's what will happen. We people in the Downtown, we look after each other. You see, knock on each other's doors and ask, "Hey, you guys okay in there? Do you need some help? Do you need your sheets done?" (Name) is my street sister and she loves me better than my own family.

Nancy is also a "carer" to her community especially during times when formal health care is not

responsive to her fellow community residents' needs, as evident in her following story:

I think that it was back on Saturday. This one guy had fell over, right, and he hit his head and I know what it feels like to hit a head. Sure, he was drunk, so what. No ambulance came for him because he was drunk. (Someone) did call (the ambulance). But they didn't want to deal (with the call request), "Well, just call Safe Ride." What's Safe Ride going to do for them? Do they have x-ray machines in their detox? They just throw them in the back anyways, and wash him down in the morning and tell him, "Get out." I don't think that's right. When I said, "Do you need help?" And he said, "Yeah." And so I'm calling 911. They didn't come. I called again and they said, "You're being an irritable person. Please don't call." So I sat with him for about four hours. I just talked to him. I had a couple of dollars that day so I got him coffees. That's all they need.

Within her role as a "community care-giver", Nancy also provided community advocacy for

local health care services:

Because I've heard a lot of people saying, "Why don't you guys have more care in the back alleys?" And like because they don't care. I've been fighting with the (health authority) for how many years to get a place that we can go and get clean up, wash up. They just finally are going to give it to us after five years of fighting with the health boards. That's not good, not to me anyway.

**Experiencing Positive or Helpful Care** 

The participants described characteristics of positive or "helpful care" from health or

social care providers or services. These characteristics are relational factors that influence the

participants continuing to use the care. For example, Connie is a participant who had not used

many health care services prior to being chronically ill and was initially determined not to have

health care services in her home after hospital discharge. Connie identified that thorough client

assessment is one characteristic of positive or good care:

I was just looking for a kind of a cure for my cold. Hoping that they help me somehow, advise me as to what the next steps should be. It was kind of good. I mean, they didn't leave any stone unturned. They sent me for x-rays and blood tests, and the whole nine yards.

She also described helpful care included her nurse's knowledge of community health care services hat helped guide her to the appropriate and helpful resources:

I was thinking that I should check it (the neighbourhood health clinic) out and then when it said, "Native." I thought, "Oh, well, you'll probably have to have a card and the whole nine yards." And then when I was telling (nurse's name) about it, she said, "Oh, no. Anyone can go there." So I went and I met two nice doctors.

Other participants described other characteristics of helpful care services or providers.

Mary identified that a collaborative approach taken by her case manager is helpful to meet her

health needs: "And we usually we can get on something to solve the problem". Nancy

considered a direct approach taken by her health care providers is helpful when she is waiting

and anxious for a diagnostic result or required treatment: "I like the direct approach. Well, I

don't like people just p\*\*\* a\*\*ing around, 'Well, jeez. How was your day?' " Tarah described

the availability of professional care services coming to her home is helpful care because home-

based care eliminates the extremely stressful experience associated with taking her son on the

bus to services: "(The family counsellor) comes here which is really great help so I can talk to

her. (The nurse) comes here three times a week and I talk to her. " Nancy described how

advocacy by health care providers on her behalf to other health care providers when she is not

capable of providing self-advocacy is helpful care:

When I really sick and I had to go to (hospital name), the staff that was on that day, she stayed right there for the ambulance (and said to the ambulance staff), "Are you crazy? She can't even sit up here and you're telling her to walk." She said, "You phone me if they're bothering you up (at the hospital)."

The meaning of helpful care by the participants was also associated with numerous relational qualities between the health care provider and the participant relationship. Caring is a predominate quality or factor mentioned by several participants. Mary described her home care nurse as "caring and helpful". Stephen defined caring as timely and responsive help that respects his wishes: "(Caring means) when you tell them you've got a low blood sugar, they should practically, practically jump and be looking after you. They're supposed to be there as nurses caring, and they're not supposed to be arguing with you." Similarly, Nancy appreciated

that fact that her family physician is available at all times when she needs him and he responses

in a timely manner:

You can phone him at home if you get really sick. You can get one of the office staff (in Nancy's hotel) to phone him at home. And if he thinks you're really sick, he will come down and see you right at your home whether he's working or not. Or he'll prescribe something over the phone. And he's been really good.

Nancy provided a second example of her perception of caring actions by her pharmacist, which

included the element of noticing and following up with Nancy about her missed medications:

I've got a really good drug store (Pharmacy name) down here. He notices that you didn't come and get your meds. He'll phone where you're living and say, "What's going on?" And he'll deliver it right to your door. I think that's pretty good service if you ask me. It means that he really cares. He's not just out there trying to make a buck.

Several participants spoke about the element of health care providers taking time to

understand them as a person and their health needs, which is characteristic of caring and positive

care. The understanding and time taken by health care providers were further described within

the elements of "listening" and empathy. Nancy explained how her physician cares for her by

being empathetic to her needs:

He's very caring to the patients (because) he takes more time than a regular doctor. Like the regular doctors, write a prescription and out the door. Him, it's: "How are you going today? I feel," he says, 'I feel that you don't look too good. You're in a lot of pain. Can you tell me why?" He doesn't simply write a prescription. He takes the time to find out what's going on. I like that.

Connie also considered that it is important that her nurse took time to "understand me" and that:

"She doesn't come in and rush into things. Like one of the nurses came in and she was all

business like. She hardly even said hello and chat a minute." Karen associated the element

of understanding to the non-judgmental attitudes and empathetic actions held by the ministry

social workers with the following description:

They'll listen instead of dictating. They'll be non-judgmental. They don't look you up and down and going, "Oh, my God. She hasn't bathed in a week. I'm not going within three feet of her". A lot of their posture, you know. It's sort of a stance thing that you're supposed to have, like open stance and open gestures. Just be friendly and just let the kids bitch if they need to. You're not always going to fix the problem right away. Offer them coffee. Sit down. Stephen further commented that the "understanding" and "honesty" are relational factors that

developed over time within the quality relationship between his family physician and him:

I call it a good understanding we'll say. "How much are you smoking?" And I'll tell him exactly. And I have a little bit of other contraband. He'll say, "How much are you smoking of that?" and I will tell him. So I'm pretty honest with him. (The honesty) developed) through time. After a ten year friendship, you sort of now tell them things that you wouldn't necessarily before. It's just as you get to know them, you open up a little.

Two participants also described a caring element of "tough love" within positive

relationships between health care or social care providers and their clients. Nancy described this

"tough love" factor as "giving me heck": "(The hotel staff) are supposed to be doing my

laundry but they try and make me eat. There's a lunch program, breakfast, lunch. I just don't

feel like going and eating and then I'm loosing weight. And then they're giving me heck but

that's okay." Karen described the range of social workers that she has experienced and the most

helpful ones are those who provided "a kick in the ass":

There's three (types of) workers in field. There's the assholes looking at everything just to shut you up and get off their back. There's the nice ones that stay completely by the rules and will do absolutely nothing for you but give you information and more information and information of where to go and not actually accomplish anything. They're the ones who can be pricks if you don't work with them but can also be the limit. Your best friend (is the third type). If you want to work with them, they'll do their best to help you get through a lot of stuff, get you as much as they can and let you actually know what's out there to help you. Not just throw pamphlets your way. And those are the ones I like because kids do need a kick in the ass. I'm sorry, but, you know, if you're just lashing around on income assistance, not trying to get off, you need a kick in the ass.

## Experiencing Negative or "Non-Helpful" Care

The participants also offered descriptions of their experiences with negative or not helpful

care. Characteristics of negative care included care providers presenting a negative first impression, inadequate time taken for care, lack of continuity between care providers, and negative attitudes held by care providers. The following participants' descriptions provide examples of each of these characteristics.

Mary provided an example of negative care where her home support worker "upset" her in their initial meeting: If someone gets on my bad side, they're out that door and they don't get a chance to come back in again. If they can't help to care for me, then they don't come back again. I had one girl come in, the very first thing she said was, "Smoke, smoke, smoke". Oh, I don't smoke. I had aired the place out at least three hours and I hadn't smoked. So I had her make me a cup of coffee and I threw her out. She upset me.

Despite the availability of health care services in her Downtown Eastside community, Nancy associated "not caring" and "not enough time" taken for care by the care providers with negative and unsatisfactory care: "There's lots of health care and nurses and stuff but they always never have the time for you. It's like, 'Oh, I'm living by a clock and I've got to go'. Like there's no time, they don't have enough time for people who need it. That's not really care." Tarah also believed that feeling "rush, rush, rush" with the time allotted by her physician visits is not helpful care:

I would like to have the best understanding to my problem and give me the time to talk because most of the doctors are very busy. A few minutes, and then you rush, rush, rush. You don't get to talk to them. It adds to my depression and then depression affects my health. My health affects my depression, it's like a circle.

Additionally, both Connie and Tarah commented that the lack of continuous health care providers resulted in a non-helpful situation: "I still feel a little embarassed when I have to expose my bare body to so many different people when they give me a bath" and "New faces every time and I don't' feel that I can talk to him." Lastly, Nancy strongly believed that the reason for the negative care that she received is due to stereotyping by the health care providers towards the community to which she belongs: "Because we're in the Downtown Eastside and no one gives a sh\*\* about us people who live down here. We're just garbage and that's how I feel. And plus a lot of what's happening is the HIV virus and they didn't want to touch it so put your God damned gloves on."

Connie and Nancy provided descriptions of the specific characteristics associated with unsatisfactory or non-helpful physician care. Connie described the lack of thorough care from a community physician and the resulting negative outcomes to her health:

Because some places you to go to and they take one look at you and throw some pills at you and tell you to go home and take them and come back in a week. Well, he just gives

you pills. He didn't take temperatures, and didn't take pulse, and he just didn't check. He just took my word for it. And when I come out of the hospital, he gives me a couple (pills) and they don't work. It was getting worse and worse. And (another time) he decided that he should take some of my pills away from me, like my diabetic pills and some of my heart pills. He kept on saying, "You don't need that. Why are you taking those?" "Because my specialist said I should." So when he took all these pills, there were three different kinds of things he took away from me. I right away thought I better not fool around so I went to see my specialist.

Likewise, Nancy described her two separate experiences with inadequate physician care in the

hospital, describing the judgmental attitudes and lack of caring actions from her physicians in

response to her pain management needs:

I said, "You've made me sit here this long. I tell you what's wrong and what do you do? You don't listen, you don't listen to your patients." Their eyes are somewhere else. Their ears is some. They don't care and they don't give a sh\*\*. That's how I feel with some of the doctors and (hospital name) I don't like. Because there was one doctor when I was in there. I can't remember his name. He come into my room. He says, "How are you? Well, I'd like to get you off the methadone". I said, "I'm not here for that. Would you mind turning around." "Well, then, we can't give you anything for pain." Like, I'm in bad pain. I said, "I don't care. I'll get me pain medication anyway." And I did. And he announced it to me. Why would you want to take me off a medication that was helping me? Use your brain.

I'm always trying to get something for pain. And then the doctors go, "You're on methadone." So I'm looking like, "That's not medic, that's not meant for pain. That's meant to keep you up there. And they get angry at me because I'm trying to voice me my opinion. When you go in (the hospital), it's not because you want to be there, number one. Number two is you go there because you're sick. Number three, you do not like being put down because you are a junkie or Indian or whatever, the nationality, they decide to mark you as.

The above two examples of the physician's judgmental attitudes towards Nancy as "drug seeker"

resulted in an presumptive assessment of her health issue and need, which led Nancy to seek her

pain management needs elsewhere.

Several participants described other encounters with a range of care providers having

presumptive attitudes towards the participants' abilities and health needs. The participants

described this pervasive attitude as commonly resulting from the health professionals' belief that

they are the "authority" on the participants' needs and best interests. Connie provided an

example of how decisions were made for her and "announced" to her by the hospital staff:

When I was in the hospital, because of my condition, they were afraid that it might happen again. And they thought, well, I would be better off in a place where I could be looked after. And I didn't want to go into a home because I figured that I could navigate on my own. So they decided that I should have a homemaker and a nurse. And then I didn't want a homemaker. I figured that I could to do that myself so I let the homemaker go but I keep the nurse.

In our interviews, Stephen provided several examples of the "fights" and "arguments" relating

to his and the hospital staff's conflicting views of appropriate diabetes management, including

this example:

The doctors seem to think that they are the experts on diabetes and I've had a lot of arguments with them. I've told them, "I'm the authority. I've got diabetes longer than you've been alive." I just tell them to go away. And I will look after my diabetes and I will tell you people how much insulin I want. And that's caused some problems. They don't like that. Basically you're bucking their authority when you're really the authority. I have always had big fights with them (doctors and nurses) over my diabetes. They were driving me totally, totally crazy.

Some participants also described how their self-advocacy for satisfactory care resulted in

angry reactions from the health care staff. Stephen remarked:

At one point, they were ready to kick me out because I even went to the hospital administrator. And they said, "Nobody does that." Well, I do this sort of thing and I just won't put up with it, any garbage. I have the right to complain but they didn't like it. They seem to think that they're God and their patients don't know anything.

Nancy also had a similar experience while in the hospital:

I don't like staying in the hospital. They don't give you the proper attention in the hospital anyway. I said, "I need something for pain." But I have to wait at least an hour. Right, there was ways around how we could get what we needed. And if the nurses were just going to make us angry and pissed off, we'll go to the top. And they were angry because we went to the top but I was in pain. What was I supposed to do? "Only another hour." Like they always run everything by a time clock. That's not proper care.

The participants' experiences of other relational factors related to negative or non-helpful

care frequently resulted in the participants refusing to accept or use care or services. Stephen

believed that visits to the Diabetes Clinic were pointless because the clinic's had unreasonable

expectations of blood sugar monitoring by him: "I rarely go to the diabetic clinic because I

believe it's a waste of time. Because if I go to the diabetic clinic, say, every two years, they look

at one page (of his blood sugars levels in his blood monitoring booklet) and that's it."

Tarah mentioned that she also does not frequently visit her physician because the solutions to her

health problems offered to her are unrealistic and not helpful:

He, the doctor, suggested for me not to carry anything. So how am I supposed to not carry? Leave my son home with nobody? Or not do shopping? They give you a solution but it's not realistic because I have to do it. I mean, they don't know how we struggle because they are in a different world than our world. That's why I don't see him all the time.

Nancy firmly stated that the inadequate and non-responsive hospital care that she received is a factor that leads her to:

I won't go to (hospital name). Not the way I've been treated. The doctors and sometimes the nurses, they're sitting there and they're talking, "Who's got a better tan?" I said, "That's what you're getting paid for?" I said I don't need that kind of care. Goodbye.

To summarize, the theme "encountering the multiple aspects of care" represents the various factors and qualities of care that the participants received for their health and associated needs. From the participants' perspective, the help and care that they received from their lay support network is equally significant as the care that they receive from formal health or social care services. Some participants were also involved with caring for their community members and described aspects of "community self-care" that is present within their strong community networks.

The participants described in their interviews numerous characteristics of care providers or services that they considered as positive and helpful care. These characteristics of care are significant factors that influenced the participants' perception of the quality of the services received and contributed to the participants continuing to use the service. The characteristics included care that was timely and available in providing a helpful response to immediate health needs, care that was thorough, and care that was a home-based service when required because of the participants' needs. The participants also expected their health care and help to having a caring characteristics with the health care provider *"understanding me and my needs"*, *"anticipating my health needs"*, *"noticing my needs"*, and providing adequate time for care. For

some participants, it was important that the health care provider "just do their job" and was not providing care to "just make a buck".

All of the participants, with the exception of Robin, experienced negative or not helpful care. Robin did not provide any examples of negative care mainly because her interview was very limited. Predominantly, the negative qualities of these episodes of care can be attributed to the "*authority*" and judgmental attitudes held by health or social care providers. The participants described detailed narratives of care when they felt that they were not listened to, they were labeled because of their personal background, of which substance use was a dominant labeling factor, and they were prejudged as to their abilities to self-manage their health conditions and needs. The participants also described experiences of negative or not helpful care when they encountered health or social care providers who inflexible and "*lived by the rules*". Many of these characteristics of negative non-helpful care are relational factors that influence the participants' care-seeking experiences affecting the participants' continued use or refusal of services.

## Experiencing Facilitative and Challenging Care-seeking Factors

The fourth theme, "experiences of care-seeking" consists of the participants' descriptions of the range of structural and relational factors that influence their care-seeking processes and actions. Factors at the participant, informal or social network level, and health and social care systems levels are presented.

#### Finding Care

The participants described various means of finding health or social care services. One way is the participants initiating finding care by themselves. This was accomplished by looking at posters on bulletin boards or information booklets at health or social care agencies, noticing service agencies signs while walking in the neighbourhood, and phoning neighbourhood resource agencies for information. Stephen described the latter: "I would get the information somehow, whether, I can phone the Neighbourhood House to find out what's going on. So I'm pretty good at gathering information. "Similar to Stephen, Mary and Karen described their assertive attitude and confidence towards actively finding and seeking care or help as "I've learned not be to afraid to ask for help now" and "I'm really good at networking and I'm really good at asking for help".

Initiating finding care is also by way of "*listening to the grapevine*" or "*by word of month*". Both Dean and Nancy who lived in the Downtown Eastside and Strathcona neighbourhoods identified this means of finding care. These two neighbourhoods are often described by both community residents and local health care providers as a "tight-knit community" where many community members know each other. Dean described how this grapevine communication network operated in relationship to Dean finding out about food banks in the neighbourhood:

Well, first of all, there are people at the (Downtown Eastside hotel name). There are people there who are in desperate needs too. And so they said to me, "Do you go to the Sisters? I said, "Well, who are the Sisters?" "Well, you go to down on (street name) and you know where the church is. Every Thursday, you go there and there's the food bank" Like through the grapevine, people talking that there's this. Just going through all these circumstances and things like that, it's amazing what you hear when you're passing people living in an apartment.

Nancy also described how she is the informal referral consultant using the "word of mouth" process in providing health care information to her friends: "They come to me because they know I've been there and they know what I've been through. And I tell them, "I can't carry you, but I can lead you to the right sources so that you can try and get your own help." Mary, who is homebound to her building in the Woodlands neighbourhood, also provided an example of the informal referral process within the "apartment community" in which she resides: "I found out about that program from my friend, (name) downstairs. She told me that she dealt with (name of service) and she gave me their phone number."

The participants also found health care through their associated health care providers. This is through the health care provider providing information about other health care services and providing formal referrals to other health care services. Tarah explained that she found help and care for her and her son by "asking my nurse. She tells me about some helpful programs". Connie noted that her home care services were "arranged at the hospital".

Connecting to other health care services through the participants' current health care providers can also become the primary means of finding or accessing care for some participants after family or friends initially provided this function. Mary, for example, identified that she finds help in her neighbourhood "through the health unit now" and not through her family and friends because she "didn't (want to) impose on them".

# "Naturally" Delaying Seeking Care

Three participants described their process of delaying seeking health care for their presenting illness symptoms. They presented several different factors for their hesitation in seeking care. For Connie, the factor was related to her learning process in recognizing the significance of her presenting symptoms:

I get congested chest. That's what just about caused my life because I didn't want to go. Well, I just figured that I would get over it because the first time, I did have a cold. I had it for quite a while. And I was in the shower and all of a sudden, I just got so weak. I couldn't move. I climbed out of the shower. I said to my friend, "You have got to phone an ambulance." (I had not been feeling well) for a couple of weeks.

Stephen delayed seeing his physician because he categorized his symptoms as "not that bad",

especially if he has had only one single episode of the symptom. His decision-making process

about whether or not to seek care is evident in the following example:

(Recent dizzy spell is) not that bad that I need to see the doctor or somebody. I mean to say if something like (dizzy spells) happened, say two or three times a week, I obviously go right to the doctors. But not the first time, I will, say, a second time, because I got up too fast or something. But if it happened a third time, I would sort of judge myself, although, I've misjudged a few times over the year. So something minor, I just deal with it myself.

Lastly, Nancy delayed seeking care because of her "psychological fatigue" of being constantly

ill and subsequently being "overloaded" by the large number of health care providers, as

described below:

I go to the nurses upstairs at the needle exchange. I try to stay away from them because I'm sick and tired of nurses. I'm sick and tired of doctors. That's all my life has been for the last five years is nurses, doctors, nurses, doctors, and I'm tired of them. Sometimes I run away

from them just to hide on them. There's been so many appointments. It just gets so much sometimes. Like you don't see nobody for how many months and then, bang, you've got all these people asking the same questions over and over again. Like it's just too much to take in your head.

"Caught and Stuck Between Hospital System Rules"

Two participants described a structural factor that influenced their care-seeking efforts.

This factor is related to the hospital access and ambulance diversion policies. These policies do

not seem be explicitly apparent to the participants until they are negatively caught by these rules.

Connie described her extremely frustrating experience with the unfair ambulance diversion for

which she is personally penalized:

And then on top of that, I have to pay the ambulance. They came to pick me up when I need them. I don't mind paying that but when I have to pay them twice. This is ridiculous. Because all I remember is getting my friend to call them. And he told them to take me to (Hospital 'S") because that's where all my doctors are. And that's where I should have been. (But) they said, "No." That they couldn't take me there, that they wouldn't accept me. So they took me to (Hospital 'M'). So when I got to (Hospital 'M'), they didn't have the facilities to treat me. So they shipped me back to (Hospital 'S') anyway. And they charged me from here to (Hospital 'M'). Okay, I paid that one, but they wanted to pay (Hospital 'M') to (Hospital 'S'). And I refused. So I've been fighting them and they've been threatening to take me to court.

Connie admitted that because of this frustrating experience, she currently felt reluctant to call for

ambulance help unless absolutely necessary.

Nancy provided a second example of being caught between system rules related to

designated hospital catchment areas. She explained that she will not go to a particular hospital because of the negative care that she has received there as described in theme # 3. She preferred to be admitted to another hospital for her care, however: "(Hospital #1) has been good but they won't take you in an ambulance there. They have to take you to (Hospital #2) because of the area you're in. So I suffer or wait till my doctor in the morning."

## Acknowledging the "System" Supports

Despite the limitations of living in poverty, a number of participants identified that they received numerous health and basic supports funded by the ministries once they met the eligibility criteria and followed the required qualifying processes. For instance, in addition to

the Ministry of Human Resources providing income assistance for rent and basic needs such as food and clothing, Karen stated that the ministry also funded training courses for her and her partner, bus passes while she and her partner were attending school courses, and drug prescriptions costs. The Ministry of Children and Families also provided day care for Karen's daughter while Karen attended school and baby formula for Karen's daughter until she reached one year of age. Tarah also mentioned that the Ministry of Children and Families will also pay for day care for her son when he reaches eighteen months of age. Stephen felt that he had advantages over a "*regular*" person with higher income because the Ministry of Human Resources funded health supports such as his motorized scooter and his diabetes medical supplies:

I mean how many normal people that, say, have got diabetes can go in (drugstore) and get twelve boxes of blood sticks that are \$50 a box, say four bottles of insulin, and all their pills? And you may have racked up a bill for \$800 or \$900. And now probably, the normal person couldn't even afford to do that. But I just pick up the phone and say, "Hey, I need a dozen boxes." And it's the taxpayers basically are paying for it. So maybe in that sense, we are better off. We're very lucky in this country.

Three participants in the study, Stephen, Dean, and Robin, believed that their poverty status did not affect their care-seeking effectiveness or health status. They generally felt that they "have all the help I need" through various available funded programs such as the Medical Service Plan, helpful community services such as the food banks, and their resourceful and careful management of their limited income to meet their daily health and basic needs.

For example, Robin's current health supports included her family physician and home support worker coming to her home, funded nutritional daily supplements (Ensure), an in-house medication management services in her hotel, and other basic needs such as shelter. Consequently, Robin did not believe that her low income status affected her health or careseeking. Her belief may be a result of a comparison to her previous "desperate" life situation where she was heavily into intravenous drug use, she had not yet had help to apply for disability pension, her health status was considered end-stage palliative, and her housing status was unstable. She described her "previous life" as: "You had not money. So you wouldn't get the care you needed. You didn't sleep in your own bed. You were just sick." She expressed a strong belief that despite her "very bad" health status, she had "hope for her future" because her health and daily basic needs were met.

## Encountering Challenges Accessing and Getting to Care Living in Poverty

Several participants identified factors that presented as challenges in accessing and getting to health care services. One predominant relational factor in care-seeking and services utilization is limited transportation resources. The predominance of transportation being a primary influential factor for the participants was due to several reasons. The majority of the participants had impaired mobility as an outcome of their illnesses. The two participants who are mothers of young dependent children felt additionally challenged with being limited to using the public transportation. Essentially, the participants in the study felt that living with poverty limited their choices in available means of transportation. Nancy described two examples of her challenges in and decision-making process related to getting to care:

I've got to go up to (names of three hospital clinics). I go to (different hospital name), wherever the doctors are, that's where I have to go. (I have to) beg, borrow, and steal. Look for someone to pick me up because as I said, I can't walk. The bus is too hard for me now because it bumps me around so I try and get someone to take me but it's hard. By cab and that's not cheap. Usually, I have to pay that and then I get reimbursed about three or four days. But it's expensive. One way is twenty dollars. And then if you've lost your receipt, there's big trouble. So sometimes you lose out.

My income is very limited. What's more important? Food or going to see the doctor? Sometimes I've made going to see the doctor is more important than food. I look in my cupboards and see what I have. And if I can manage with what I have and then I go up to the doctor. And then it's really hard. Then sometimes when it's empty I have to go and say, "No, I can't come see you because I couldn't find anyone to take, like, to come there."

All the participants, with the exception of Mary who is housebound, mentioned the impact

of the five month bus strike that occurred during the data collection period of this study.

Descriptions of the impact included Connie's example:

My doctor is up on (name of street about 5 kilometers away from her address). But because of the bus strike, I haven't been able to get up there. So I've been going to (name

of street one block away). I just can't get around anymore. I mean, I used to, if I got bored, I could always get on the bus and go for a ride and shop a little on my own.

John remarked on the impact of the bus strike on him was: "When TransLink was on strike, man, it's difficult walking. I have to go to the next bench and sit down. That's how bad it is." A final example is given by Tarah who expressed that the reason for her choice in visiting a nearby clinic doctor, who in the end did not prove to be of help to her because she was subsequently seen by multiple doctors: "I went there because of the bus strike. It was the closest clinic to me that I can walk or just take the bus not far away. But it's not working. I have to see the same doctor (in the clinic) so I can feel free to talk about my problems."

Having phone access is a second factor that influenced the effectiveness of care-seeking and care received. The participants commonly mentioned the challenges of having phone access funded within their income limitations. Government ministries, particularly the Ministry of Human Resources fund residential phone access under very tight criteria, so individuals like Dean sought alternative and supportive community-based funding resources such as British Columbia Persons with AIDS (BCPWA). In the following quote, Karen described the fortunate changes in the telephone company's (Telus) billing policy for residential telephone lines for single mothers below the poverty level. Some insight of the stresses and dilemmas faced by single mothers without private phone access is also apparent in the example:

I have restricted access for phone. They drop the \$200 deposit, which is good thing from (name of telephone company). I thank God for that everyday. Before you had to pay \$200 deposit if you didn't have credit or good credit. And welfare won't pay for it. So it's pretty much you're sick alone, stuck in a house, no phone, no way to call out if anything happens to you child. You have to leave them in the apartment to go down to use the phone or run across the street to a pay phone. By that time you come back and the kids are dead. Or you could be charged with neglect because you had to call an ambulance. Somebody breaks into your house, you can't call 911. So they've made it mandatory now for anybody that is below poverty level. They pay the forty-five dollar connection fee and then twenty-nine dollars a month. They (finally) decided there needed to be something for parents who were living alone. Furthermore, for an individual such as Tarah who was finding it very stressful to get to services, having private phone access, as a minimum, facilitated her receiving counseling care over the phone. She described the positive outcomes of having her own phone as:

(The pregnancy and guidance centre) are very helpful. They help me with some clothes for pregnancy and some baby stuff and things so. But it's very far for me to go and I have to take two buses. It's one hour to get there and I don't get there much. I go maybe every one year. But I talk to them over the phone and they offer me great emotional support over the phone.

## Up Against the System in Getting Funded Health Care or Help

In congruence with the participants' descriptions of their frustrating experiences working with the government agencies' demanding policies and processes, the participants also spoke about similar experiences in requesting or seeking care or help from these organizations. One challenge is understanding upfront what help or supports are available. Tarah and Stephen both stated that information about eligible help or supports was not provided by their ministry workers to them. Rather, finding out about eligible supports was a trial and error request process initiated by the participants, as evidenced by the following respective examples from Tarah and Stephen: "Yeah, so it wasn't like this is what we can offer you. It was just more you asking and then seeing for things, so, yeah, whether it gets approved or not approved" and "They don't tell you a lot of things. No (explanation), never, no, no. Where you learned all this (is) in the real world. Nobody tells you anything." Karen offered a solution to the gap of ministry workers not informing clients of eligible supports, but because of her experiences working with the Ministry, she didn't have faith in the government changing its attitude in more proactively offering help:

And I think that it's more important to get more info out there than just flyers sitting in the community health office that are the same colour as sixty other fliers. I think that they should hold some sort of seminar for single mums. You know, when you're pregnant, go to the seminar and we'll tell you about all the services that are available to you. It would be a great idea but unfortunately, the government didn't do it.

Other participants frequently mentioned the factor of their ministries not funding necessary health and associated supports due to the ministries' restrictive mandates. For

example, Karen stated that bus passes are not funded by the Ministry of Human Resources unless she attended school. Diane found that the Ministry of Human Resources' mandate excluding housing services and funding was a maddening gap in the provision of help to Stephen and her: *"This is where I find that the Ministry is not really involved in getting a bigger place.* Because there's two wheelchairs in a house now. It's very frustrating."

Connie described her frustration of being caught between two ministerial departments. In order to qualify for more funded care, she had been attempting to qualify for Indian status from the federal Department of Indian Affairs but seeking out the required documents to prove that she is of Aboriginal origin has been a very difficult and lengthy process for her. At the same time, she does not yet qualify for provincial Ministry of Health Services' Pharmacare exemptions for senior citizens because she has not yet reach the qualifying age of 65 years. She is further disappointed to discover that after she qualifies for the seniors' Pharmacare program, she still will have to pay for the hefty prescription costs for her each of her prescribed medications, which will remain a strain on her very limited income situation:

It's a real headache because if I get (Indian status), then they will pay for most of my medical expenses. And then I find out that even after I am sixty-five, I still have to pay for it. I asked them at the drugstore, and they said, no, I did not have to pay for my medicine but I have to pay for the prescription. And I think that I was five dollars or something like that. And I take about thirteen, fourteen different kinds of pills so that means five times that still.

Karen frequently used the term "fight" to describe the difficult process that she is required to undertake in order to self-advocate for needed care and services for her family and her with the Ministry of Children and Families:

You pretty much have to fight to get any of the prevention programs that the Ministry offers like respite and stuff like that. You have to fight. You pretty much have to be hanging your kid out the window by her feet over the balcony before they will do anything, you know. They don't care, you know, you have to fight for something everyday. A lot of advocating for yourself, a lot of having to go from agency to agency, calling and having to say, "Look!" Karen provided more details on what this "fight" looked like in dealing with the drawn out

Ministry processes required to receive available services with two more examples:

You're supposed to get another \$300 top-up from the Ministry of Children and Families. I had to call for probably three and a half weeks, four weeks before I even heard back from a worker to find out whether I could apply for daycare subsidy. It took me another three weeks to actually to get the application through. It was just horrible. Like, my daycare was watching her with no guarantee they were going to get the extra \$300. I would have to pay for it. It finally took like, "You know want? You want me to starve my kid." I get \$300 a month for income for food and stuff and that would have been what it taken to top-up daycare. And they kept telling me, "No, you can top it up yourself." I said, "Yeah, my kid is going to starve!"

I'm really good at advocating for myself. You have to work the system. You have to be conniving. You have to be manipulative. You have be a bitch to get what you want. If I have to fight for it, I fight for it. And you're not going to do it by being polite and saying, "Okay, whatever you feel is necessary." You have to grab for what you want. And if not, you're going to be left behind, hiding in a corner.

The participants also described their experiences of coping with ministries' strict

requirement of the participants having the correct documents in order to be eligible for funded

supports. Karen provided another description of her experience and the consequences of not

having the mandated documents:

It took me about five and a half months to get my birth certificate out here from Ontario. I had to refile it twice. Well, I didn't get any of my prenatal benefits from welfare until probably about a week before she was born, a week after she was born, something like that, because I didn't have all my ID.

## Living Through a Time of Transition and Change

The participants in this study were interviewed during a time of transition and changes at various levels that impacted or potentially could impact their lives. One level is the recent change in a different provincial government and whose "conservative liberal" ideology is vastly different from the previous government's socialist ideology. Since the current government political party became the ruling party in the last six months, the last two participants interviewed, Karen and Tarah already identified the changes in available funded government supports in their interviews. Karen expressed her experience with the Ministry of Human Resources' recent decreased funding of health benefits: *"My partner needs glasses. And since* 

they changed the subject, like they changed bandaid or something, it's one time glasses. Now they won't pay for that." Tarah has particularly felt the impact of less funded supports to her physical and mental health:

I wish that I had more understanding and help from the Ministry (of Children and Family). And now with the new government, they are cutting how it was before. Like before, if I needed to go to important appointment, they could get me a babysitter or someone must stay with him while I get to my appointment or come with me. But now they don't and I have to do it alone. So last time I went for counsellor, I didn't understand anything because he was crying because I'm restricting him in the office. They have computer and things and he can't touch everything. And I have to pay attention to what she's saying and I couldn't. So the new government is really bad for me. The rules changed. Yeah, I talk to my social worker and she said the new government is limiting funds. I have to struggle alone. I stopped asking.

Furthermore, the participants of the Downtown Eastside and Strathcona neighbourhoods were interviewed at time when the initiatives of the Vancouver Agreement were just being implemented. The Vancouver Agreement is a joint municipality and local health authority partnership plan to increase and enhance the availability and range of health care services in these two neighbourhoods. The increased and enhanced health care services are implemented with a harm reduction approach to the population health issues related to high incidence and prevalence of intravenous drug problem in these two neighbourhoods. The impact of these services to the participants are not reflected in the findings because the services were just being implemented as the study ended. The anticipation is that the structural changes in services will affect the structural and relational factors of the care-seeking process and actions taken by the residents in these two communities at the local neighbourhood level.

Throughout the interviews, the participants described structural and relational factors that influenced their care-seeking processes and actions. The participants found care or help by themselves, through their informal support network, and through formal referrals to health care services by health care providers. Some participants described the relational factors of delaying to seek care: the learning process of recognizing the significance of symptoms, labelling their symptoms as "not that bad" at the initial onset of the symptom, and simply being tired of

constantly connected to many health care providers associated with deteriorating health. The participants also spoke about being caught between the structural rules that influence the participants' admission to their preferred hospital for their medical care.

Some participants felt that living at the poverty level did not affect their health and careseeking. This perspective was related to the participants' acknowledgement that they "had all the help that they needed" and that the "system" and community services provided adequate funded supports, and their own "careful" daily management of their limited income was adequate to meet their health and basic needs. Other participants described numerous structural factors that challenged their care-seeking. These factors included transportation requirements to get to care and the ability to access or receive care or support by phone. The participants also described challenges in working with their associated government organizations, including not being funded for certain essential needs because of restrictive "stove-piped" mandates and needing to constantly "fight" with ministry workers to self-advocate for funded supports.

### Summary

This chapter represents a description of four themes and related constructs that emerged from the experiences of the care-seeking efforts by individuals coping with meeting their health and basic needs living with poverty. The participants described a range of personal identification with the term "poverty" that integrated their philosophical, subjective, and political values and beliefs of their personal circumstances and their position within societal structures. Some participants described their strong emotions of how their poverty status differentiated them as being the "have nots" members of society from other persons who are the "haves" individuals.

The participants also talked about the daily challenges living with limited choices and restrictions because of their poverty situation. They spoke about their context of living with poverty as including the requirement to work with and answer to the frustrating bureaucratic rules and processes inherent with their funding ministry departments. The participants also strongly voiced that the "system" confined them to the poverty level or "way, way below the

*poverty level*" with the structural funding rules in place amongst the various ministries. The interviews with the two participants who are mothers, particularly present insights on the impact of this "system issue" on children growing up in poverty.

The context of the participants' experiences included coping with and managing many illnesses and the consequent health needs and problems. Maintaining their overall physical and mental health and well-being was an important goal for the participants because good health was identified with feelings of personal independence and freedom. Good nutrition was a particularly important factor to the participants in that it supported their health, and the participants described numerous strategies in attaining adequate nutrition. Having poor health required that they work with extremely difficult bureaucratic processes to obtain necessary health and basic needs. For these participants, obtaining the support they needed in order to be as healthy as possible presented additional stressors to the struggles of living in poverty.

The participants also described multiple aspects of care that they encountered. They received help and care from their lay support network, their health care providers, and community support networks. Some participants also described incidents where they were "care-givers" to others. In general, all the participants experienced both helpful and not helpful care from health and social care providers and services. At some level, the characteristics of helpful and not helpful care "mirror" each other. For example, helpful care was strongly associated with the health care provider presenting caring actions to the participants such as "*listening*", "*understanding*", and empathetic behaviours that are respectful in meeting the participants' care needs and wishes. In contrast, not helpful care consisted of health care providers possessing the "*authority*" and judgmental attitudes that frequently resulted in the participants' care needs not being met or to the participants seeking alternative sources of help or refusal of available services.

Lastly, the participants described other structural and relational factors that influenced their care-seeking efforts. These factors were associated with the various means of finding care,

including the participant's resourcefulness and confidence in their ability to find and selfadvocate for needed supports. The participants' descriptions of finding care including insight into their immediate and community lay support network helping and communication processes. Transportation and telephone access were two significant relational factors that influenced the participants' accessibility and receipt of care services.

The participants acknowledged that there were many funded supports available for them, but for some participants, these supports were simply not adequate in meeting their health or basic needs. The participants' experiences included detail descriptions of the *"fights"* required for self-advocating for supports in coping with and strategizing against the restrictive funding rules and mandates of unsympathetic government agencies. In the following chapter, a discussion of these major findings will occur, focusing on specific areas for clinical practice and health policy with an emphasis on a community health and social care services perspective.

# **CHAPTER FIVE: DISCUSSION OF FINDINGS**

Every nation that permits people to remain under the fetters of preventable disease, and permits social conditions to exist that make it impossible for them to be properly fed, clothed and housed, so as to maintain a high degree of resistance and physical fitness, and that endorses a wage that does not afford sufficient revenue for the home, a revenue that will make possible the development of a sound mind and body, is trampling a primary principle of democracy under its feet."

> Dr. Charles Hastings Medical Health Offer for Toronto and President of the American Public Health Association (APHA) in his inaugural address to the APHA in 1919

> > (Dieticians of Canada, 2001, p.1)

The findings of this study broaden our understanding of the structural and relational factors that influence the care-seeking behaviours and processes of individuals living with poverty. Collectively, the four themes, "Living with poverty – Not belonging to the same playing field", "Managing my health day -to- day", "Encountering the multiple aspects of care", and "Experiencing facilitative and challenging care-seeking factors", describe the complex issues that influence the care-seeking efforts and health of economically disadvantaged persons. Of the many issues that are reflected within these themes, I will address two in considerable depth because they are of particular importance to an understanding of the larger phenomenon by nurses in the community practice context.

The first of these is the persistence of poverty and the health inequalities that follow. This discussion is particularly important in that it has significant implications for the models and approaches that are or can be used by the health care sector to address poverty and inequality. In this study, it was found that the participants' daily decision-making, actions and opportunities related to the attainment of their health and basic needs were shaped by the constraints associated with living with poverty. The participant's descriptions of seeking resources, help, or care for their health and basic needs were also intertwined with their descriptions of living with poverty. As well, the participants also described their frustrations at how the "system" presents barriers to optimally attaining their health needs and improving their health statuses. Thus, it is informative to consider these findings within the context of the ideas of others as to why poverty and health inequalities persist and what health care sector approaches might be effective in addressing them.

The second major theme within the findings that requires further discussion has to do with the idea that formal care providers or services are facilitators versus "doers" for recipients of care and services. The participants in this study described their experiences of helpful and unhelpful care encounters, suggesting that care providers' attitudes about the participant's capabilities and strengths may be a contributing factor to the decision-making processes and actions taken. In this discussion, the role of care providers and services will be considered in the context of the philosophical beliefs and values intrinsic to the concepts of "enabling help" and empowerment as they have been expressed in the literature pertaining to both individual and population/community health levels of service

## Living with Persistent Poverty and Health Inequalities

Poverty negatively affects the health of individuals, communities, and society. An exploration of the economic and political macro-level factors that foster the persistence of poverty is first provided to advance an understanding of the societal context in which the participant's experiences of living with persistent poverty and subsequent health inequalities are located. The concept of social exclusion and the related concepts of social cohesion and social capital are introduced to help explain how poverty causes poor health to better comprehend how the participants' feelings of social exclusion may affect their health. The role of the health care sector, models of health determinants of health, and strategies to address poverty and health inequalities are then explored to provide community health care providers, particularly nurses, direction in effectively helping to improve the health of communities and populations living in poverty.

The participants in the study provided many descriptions of their experiences of managing their health issues and seeking care within the constraints of living in poverty. Some participants described living in poverty as living with daily struggles, limited choices, and restrictions that impact how they manage to meet their basic needs such as housing, recreation, and clothing. Living in poverty also impacted the participants' attainment of their health needs and how care was sought. For example, poverty influenced how the participants attain good nutrition, and limited the participants' choices of transportation and how they accessed necessary health care supports and supplies. They described their coping strategies in obtaining necessary supports for optimal health such as accessing food banks, being very careful with their money or bargain hunting for quality food, or attempting to qualify for other ministries that can help with income or health care funding. They also provided many descriptions of coping with the difficult bureaucratic processes associated with social care agencies and service providers in order to access necessary health supports and basic daily needs for themselves or their families.

The participants' experiences of daily struggles, limited choices, and restrictions led some of the participants to believe that there were very limited opportunities for them to move beyond their poverty status. They faced systematic barriers within the income support ministries that kept their income subsistent and created a continual reliance on government support. The barriers included the income funding formulas and policies used by various levels of government ministries that persistently provided a substandard level of income and the lack of integrative and coordinated services and supports for optimal help between various ministries.

The participants stated that these systematic income barriers facilitated the persistence of their poverty status. It is therefore important to briefly explore the complex interaction of macro-level economic and political conditions that contribute to the formation of the infrastructure barriers and the persistence of poverty for many populations. Contributing economic conditions include changing market conditions. Market conditions such as changes in both hours of work and rates in pay have resulted in more jobs at or near the bottom of the wage

spectrum and decreased minimum wage that are inefficient to meet basic needs and meaningful participation in society (Yalnizyan, 1998). As well, the failure of the market to generate living wages to all Canadian households have resulted in increased poverty rates especially for working age households (Ross, Scott, & Smith, 2000).

In the political arena, raising poverty rates continue to persist because poverty remains a political issue which in turn shapes how poverty is or is not addressed. For instance, there is intense political debate about the existence and extent of poverty instead on the development of strong national anti-poverty plan.

One of the sillier debates about poverty lines arises because of the federal government's continuing refusal to give any official recognition of the existence of poverty in Canada. As a result, the National Council of Welfare and most other social policy groups simply regard the low income cut-offs as poverty lines. We could call them the not-much-money lines or the cut-off-from the mainstream-of-society lines or the having-difficulty-finding-enough-money-to-pay the-rent-at-the-end-of the months line, but we find it much more direct and much more honest to call them poverty lines (National Council of Welfare, 1999, p. 35).

A consequence is that Canada's anti-poverty performance remains weak (Yalnizyan, 1998) resulting in the continued rise in the range and depth of poverty in population groups including young families, children and lone-parent mothers, and minority groups such as disabled persons (Ross, Scott, & Smith, 2000).

The participants' experiences of living in poverty also include descriptions of living with the consequences of reduced social programs and policy changes to social services. They described the struggles of living within the unreasonable social services policies that dictate their access to and the amount of social income assistance and supports. Some participants also spoke about their subsequent "fights" and "manipulative" coping strategies required to "work the system" in order to seek help and care from the social services ministry. One single mother participant emphasized that she stopped asking for previously available government supports for her son and herself. For example, child care supports were previously available to the participant while she attended counselling care. However, the elimination of this support meant that the participant's counselling sessions included the presence of the participant's active toddler thereby hindering the quality of counselling care provided to her and further negatively impacting her mental health.

The participants' experiences of less available social supports are a reflection of Canada's current political and social environment that consist of reduced funded supports to the country's economically disadvantaged populations. This trend has continued from the mid 1990's when the federal government cut back on social security programs because of its perceived expense and made tax cuts as a greater priority for the country's economy (Canadian Centre for Policy Alternatives, 2001). The result is continued social insecurity as a result of social care policies that are explicitly designed to encourage people to leave income support programs and to deter new cases (Klein, & Montgomery, 2001). The high prevalence of "pull yourself up by your bootstraps" ideologically-driven legislations (Capponi, 1999) supports the trend of reduced funding to Canada's social care programs.

Growing social inequality and enduring poverty result in the deteriorating health of populations living with poverty (Canadian Centre for Policy Alternatives, 2001). Social exclusion is a current concept used to explain how poverty causes poor health. It emphasizes how health inequalities are caused from social environmental factors instead of causal factors at the individual level. This concept orients us to a view that poverty is a matter of relative income by associating the relationship of an individual living in poverty to the broader mainstream social group (Wilkinson, 1996). Social conditions, or factors that involve a person's relationship to other people, are fundamental causes of disease (Link & Phelan, 1995) and, significantly, a relationship between social relationships or feelings of self-esteem, self-worth, control, or powerlessness related to hierarchical position and health exists (Evans, Barer, & Marmor, 1994). Poverty therefore has a major impact on the health of its population by way of the psychosocial causal pathways of illness that result in stress responses through social meanings and implication of social position (Wilkinson, 1996).

The idea of social exclusion builds on the concept of poverty from a material deprivation perspective, which views poverty as the imposition of constraints on the material conditions of everyday life that limit access to the fundamental building blocks of health such as adequate housing, good nutrition, availability of supportive care for children, and opportunities to fully participate in society. The concept of social exclusion incorporates the notion of marginalization or the process by which persons come to be excluded and marginalized from various aspects of social and community life (Shaw, Dorling, & Smith, 1999). The concept refers to the cultural aspects of exclusion and discrimination, the relationship between the included and excluded, and the meaning and identity of the excluded. Persons or populations who are socially excluded experience a lack of participation in common societal activities and the exclusion from societal decision-making and civic participation (Raphael, 2001).

For some of participants in the study, feelings of social exclusion are noted in some of the words that they used to describe their feelings about living in poverty. One single mother participant described feeling "crappy" when she sees "so many yuppie parents with their children in GAP". Another older male participant and his wife placed themselves below the group whom they termed "normal or regular persons". One participant who was an intravenous drug user strongly felt that her acquisition of inadequate health care was due to being "an Indian, junkie, and a Downtown Eastsider". The participants' feelings of their perceived individual and community differentiation from higher income societal members who have greater social prestige support that poverty is a relative phenomenon.

Social exclusion applies to both the individual and community levels (Shaw, Dorling, & Smith, 1999). At the community level, the spatial concentration and segregation of communities can mean that the residents in these geographical areas can become deprived, disadvantaged or stigmatized. The social exclusion processes demonstrate that the depth of social, psychological, and emotional deprivation and stress suffered by the persons and communities in

the bottom of the social hierarchy have greater impact on health than the material deprivation experienced (Wilkinson, 1996).

Large income distribution in societies leads to less social capital and social cohesion which in turn affect the health of population groups and the degree in which societal members feel socially included or excluded (Wilkinson, 1994). Social capital is defined as the features of social organization such social networks, norms and trust that facilitate co-ordination and cooperation for mutual benefit (Harrison, 1999). The concept emphasizes that the most important determinant of health is related to how society is organized, the extent to which interaction between the citizenry are encouraged, and the degree to which there is trust and association of all citizens within their communities (Lomas, 1998). Social cohesion refers to the degree to which people come together to pursue and contribute to broader shared purposes (Wilkinson, 1996) and the existence of mutual trust and respect between different sections of society (Marmot & Wilkinson, 1999). It may also be defined as civic community where members of the community involve themselves in public affairs due to a sense of social responsibility.

The concepts of social exclusion, social capital, and social cohension underscore that poverty and health equalities are social concepts. As such, population health promotion and health care strategies must focus less on the individual and more on the social system's influence on health and appreciate that economic and fiscal policies influence the social cohesion of a society (Lomas, 1998). A common belief of the health care system is that health is a simple biological construct in which health is determined by the provision of health care ignoring the evidence that economic impoverishment or poverty is a health determinant (Durch, Bailey, & Stoto, 1997). The emphasis of health care services as the key determinant of health is exceptionally prevalent and enacted by health care policy makers and planners in response to the health inequalities within the poor populations concentrated in Canada's urban cores. McKnight (1995) defines this approach as the "professional problem". The problem is the predominance of service systems overwhelming communities and dominating social perceptions about who best provides care. The result is the ongoing machine of service-driven care instead of the building of community social cohesion and the community caring for its own members.

Two health determinants of health models offer more appropriate direction for the health care sector to address poverty and health inequalities at the population and community levels. The social determinants of health is one model. The model identifies nine determinants of health: income and social status, social support networks, education, employment and working conditions, physical environments, biology and genetic endowments, personal health practices and coping skills, healthy child development, and health care services (Health Canada, 1994; Canadian Health Network, 1999). Implications of the model for the heath care sector include a more balanced emphasis on all the determinants of health with decisions to be made about reallocation of resources to address the full range of health determinants so that there is a less preoccupation with health care. Complex issues such as poor economic opportunities and social stress also have to be addressed.

The social determinants of health model support the need for increased intersectoral understanding of how their policies, decisions, and actions impact population health. The participants' stories of their negative experiences with the restrictive mandates within a variety of government ministries highlight this requirement. To illustrate, the participants spoke about receiving health care benefits such as prescribed medications and hospital or community health care from the Ministry of Health. However, funded income assistance and other supports such funded transportation to get to care appointments are provided through the Ministry of Human Resources. Child supports such as daycare services are funded by the Ministry of Children and Families. The participants' experiences suggest that the 'system' does not deliver its supports and services with a holistic and integrative view of health thereby contributing to the persistence of health inequalities. Collaboration across many sectors including the health, social services, education, and employment sector is therefore essential for successful population health

strategies that effectively and comprehensively address health inequalities of individuals and communities living in poverty.

The field model, a second determinants of health model, also provides direction for population health strategies for addressing poverty and health inequalities by community health care providers. The model, proposed by Evans and Stoddart (1994), identifies nine components of health and well-being and the dynamic relationships among them. The components are: social environment, physical environment, genetic endowment, individual response (behaviour and biology), health care, disease, health and function, well-being, and prosperity. Behavioural and biological responses of individuals are factors that influences health but are themselves influenced by social, physical, and genetic factors that are beyond the control of the individual. Social, environmental, and economic factors are seen as contributing to differences in health status and therefore present opportunities for interventions (Durch, Bailey, & Stoto, 1997). The field model proposes that the overexpansion of health care system directly has negative effects on the well-being and health of the population because the provision of health care uses up economic resources that could be used for other factors that may also have health effects (Evans. Barer, & Marmor, 1994). Similar to the social determinants of health model, the model also emphasizes that interdisciplinary and multisectorial effects are required to achieve health improvements in populations and communities.

Patrick and Wickizer (1995) have extended the field model of determinants of health. The authors focus on factors in the social and physical environments that operate at the community rather than the individual level. Social and physical environment factors are affected by cultural, political, policy, and economic systems, which in turn influence community response, community activation, social support, and ultimately community outcomes such as social behaviours, community health, and quality of life. This perspective stresses the influence of community-level factors and to the opportunities for community-level interventions to improve the health of populations.

Addressing health inequalities must consider targeting various determinants of health to produce change at an individual level, a community level, or both. There is increasing evidence that the health care sector recognizes that poverty and health inequalities must be addressed from various levels. Williamson (2001) researches the range of Canadian health care sector's poverty initiatives. Williamson concludes that there are a variety of health care initiatives directed at the individual/family, organizational, community, and political levels. The initiatives aim to decrease the negative health consequences of poverty, reduce the economic burden and/or barriers to health experienced by people in poverty, or alter the social and economic conditions contributing to poverty. Individual and family strategies include the development of community kitchens, the provision of free vitamins, and helping impoverished people find housing. Organizational strategies include health regions working with other organizations and agencies that target individuals and families either in poverty or at risk of poverty. Examples of organizational strategies include working with a school to provide stay-in-school programs for teen moms and school snack programs, partnering with community colleges to provide training opportunities in poor communities, and incorporating the broad determinants of health including poverty into strategic, service, and program plans. Community strategies include community education and action regarding poverty and community development in low-income communities. Political strategies by health regions include lobbying government about minimum wage, social assistance, affordable housing, and health ministries working with other government ministries to reduce poverty and its negative effects. Williamson's research offers increased knowledge of best practice strategies to address poverty and its associated health inequalities.

To summarize, the participants described their many challenges living with poverty and their subsequent constraints in managing to meet their health needs and seeking of care. In the broad society context, poverty and health inequalities continue to persist due to macro-level economic, social, and political conditions. Canada's public policies that continually fail to

address the increasingly unequal distribution of wealth amongst its members virtually ensure that the range and depth of poverty and health inequalities will prevail and perpetuate the "cycle of poverty". Health and social care policies that do not have a broad view of health determinants also directly influence the persistence of health inequalities. A lack of coordinated supports between care sectors such as health and social care results in inadequate and disjointed services to the poor thus further constraining poor individuals and communities' abilities to optimally improve their health statuses. Health care strategies that aim to mediate the poverty or socioeconomic determinants of health must comprehensively address poverty at the individual/family, organizational, community, and political levels.

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#### Care-Giving through "Enabling Help" to Facilitate Care-seeking and Health

Professional care providers' attitudes about the client or recipient of care services influence their care-giving actions. An enablement model of helping that recognizes the inherent competencies of clients in managing their health needs is presented as a model of effective helping for professional care providers. The concept of social support is next discussed in recognition of the significance of social support in promoting positive health outcomes and of the role of the social network as an enabling helper. An examination of the enabling help at the community level through the community development process is then presented as a suggested effective strategy for community practice that assists communities living in poverty.

## An Enablement Model of Helping

In the study, it was found that the participants described many coping strategies that demonstrate their resourcefulness and competencies in seeking health care and resources that support their health needs. They described various means of finding health or social care services. They initiated finding care by themselves through such means as actively finding information by word of mouth from neighbours or by phoning or noticing care information posted in their neighbourhood. They assertively self-advocated for their needs when they perceived that they received inadequate or inappropriate hospital or community care and help. The participants also described their use of food banks to supplement their funded food allowance income or being very careful in shopping for quality food to attain good nutrition for themselves and their families.

A philosophical stance towards effective helping by care providers that best promote selfdetermination, decision-making capabilities, and self-efficacy or control in the person who is seeking help or care is therefore needed. Effective helping may be defined as the act of enabling individuals or groups to become better able to solve problems, meet needs, or achieve aspirations by promoting the acquisition of competencies that support and strengthen functioning that facilitates a greater sense of individual or group control (Dunst, 1987). Caring, an essential value of nursing and other health care professionals, may be defined as helping the recipient of care to grow and move toward self-actualization (Smith-Campbell, 1999) and can be seen as a component of effective helping.

The concept of empowerment and its philosophical premises underpin effective helping. Empowerment can be described as a process where individuals are helped to develop a critical awareness of their situations to enable them to master their own environment to achieve selfdetermination (Jones, & Meleis, 1993). Empowerment may also be described as a process through which internal feelings of powerlessness, helplessness, or hopelessness are transformed and actions initiated to changed the physical and social living conditions that create or reinforce inequalities in power (Registered Nurses of British Columbia, 1992). Most importantly, empowerment implies that many competencies are already present or at least possible in an individual or group and poor functioning is a result of social structure and the lack of resources which makes it impossible for the existing competencies to operate (Rappaport, 1981).

An enablement model of helping is proposed by Dunst, Trivette, Davis, & Cornwell (1988). The model is applied to families with children with health impairments but it is argued that it is relevant to any person or group who are help or care seekers. The model has three core

components. The first component, the pre-helping attitudes and beliefs of help givers, refer to the help giver's posture and stance toward help seekers and helping relationships. Positive helpgiver's pre-helping attitudes and beliefs include emphasis on the help seeker responsibility for meeting needs and solving problems, high expectations regarding the capacity of help seekers to become competent, and emphasis on building on help seeker strengths. Second, help-giving behaviours refers to the interactional styles employed by help givers during helping acts. Empowering helping behaviours thus include the use of active and reflective listening skills that help the individual to clarify concerns and needs, and the use of partnerships and collaboration with the locus of decision-making resting with the help-seeker as the mechanism for meeting needs. Post-helping responses and consequences is the third component refer to the ensuing influences of the help-giver's behaviour on the help-seeker. Post-helping responses and consequences include minimizing the help seeker's sense of indebtedness and enhancing a sense of self-efficacy regarding active involvement in meeting needs. Together, the core components facilitate a sense of empowerment and control within help seekers to be more competent in managing their health needs. The enablement model of helping assist help givers to be cognizant of how to interact with help seekers in ways that are accepting and supportive and offers an understanding of what "enabling help" is for care providers.

#### Enabling Help at the Social Support Network Level

The participants in the study provided many descriptions of supportive lay help from friends, families, and community members who are members of their social support network. Types of help included shopping, accessing medical equipment, providing transportation, providing advice about needed health care, and providing financial aid for essential health needs such as food and medications. Help from friends and families included monitoring of the health status of the participants and following up with seeking or providing help and care when the participants could not access care themselves because of deteriorating health. These examples of important informal care or social support from the participants' social support network

emphasize the significant role of social support in contributing to the participants' positive health outcomes. Therefore, it is informative to discuss the role of a person's social support and social support network as a health determinant, particularly because the concept of social support is not explicit in the care-seeking literature. Furthermore, social support frames the assistance that professionals provide as surrogate support which extends the support available and replaces the help that is not available in the person's social network (Stewart, 1993). A discussion of social support and social support network provides a broader understanding of the natural help available to persons living in poverty who are coping with the attainment of health needs.

Social support refers to the assistance rendered by lay persons who are part of a person's social network rather than professionals (Stewart, 1993). Social network refers to an individual's integration into a self-defined community and the degree of connectedness to other individuals and to institutions (Durch, Bailey, & Stoto, 1997) or to the social contacts of a group of individuals (Marmot & Wilkinson, 1999). Specifically, social support is emotional, instrumental, informational, and appraisal assistance provided by their social network, which may include family, friends, neighbours, coworkers, community leaders, indigenous lay helpers, volunteers, and self-help mutual aid groups (Steward). Instrumental or practical support is manifested in many forms, including practical help and financial support. Informational support is where the support sources provide information that may assist the help seeker in problem solving. Appraisal assistance is a component of emotional support that boosts self-esteem and encourages positive self-appraisal. Social support may also be defined as one source of an individual's sense of empowerment that comprises of many different resources that help persons in times of crisis and help them cope with life (Freud & McGuire, 1999). Furthermore, social support at the societal level may be conceptualized as social cohesion, a concept discussed earlier in this chapter.

Both the interactions and transactions between people in the social support network affect the nature of help provided. That is, what a person gives in a relationship may as 134

important for their health as what they receive from someone else. This reciprocity has implications for the maintenance of good social relationships, hence, close social relationships can have negative as well as positive outcomes (Marmot & Wilkinson, 1999).

Social support is beneficial to health and is considered a health determinant (Marmot & Wilkinson, 1999). For example, there is considerable evidence that social support can affect immune system competence and levels of stress hormones (Freud & McGuire, 1999). Social support affects health by way of two mechanisms (Marmot & Wilkinson). The first mechanism is that positive support or the lack of support resulting from social isolation has direct effects on people's health. For instance, support from support persons may encourage healthier behaviours such as giving up smoking or exercising. The second mechanism of social support does not have direct effects on health but helps to moderate the impact of acute and chronic stressors on health. For example, a discussion of a potential threat with supportive person may help to reframe the threat to make it more manageable or facilitate the avoidance of it, and practical or emotional help may moderate the impact or consequences of the stressor. It is therefore important to conceive of social support from the social support network as enabling help and a health determinant in community practice.

#### Enabling Help at the Community Level

The study's four themes, "living with poverty – not belonging to the same playing field", "managing my health day-to-day", "encountering the multiple aspects of care", and "experiencing facilitative and challenging care-seeking factors" collectively describe the structural and relational factors that influences the care-seeking efforts of persons living in poverty. The concepts within the four findings offer some insight for effective helping for community health providers. The concept of community development is one such idea that has been discussed as a community health strategy that best enables communities living in poverty to empower themselves by enhancing their internal resources and strengths to manage the structural and relational factors that influences their care-seeking efforts. Furthermore, models of social determinants of health underscores the relevance of community economic development to the practice of community health care providers working in concentrated poor communities.

An enhanced understanding of community development is also significant because sixty percent of preventable morbidity and mortality are located neither within individual control nor individual behaviour, lifestyle or risk but within social organization (Syme, 1996). Consequently, there is an urgent need for a paradigm shift for public health providers to recognize that most health risk and most determinants of health are systemic, located within complex, dynamic, and interactive social relationships within families, communities, workplaces and the health care system itself (Syme). This view suggests that the main function of health promotion is to develop social system interventions that build health competencies into established social structures such as the community (Grossmanm & Scala, 1994). Community development is a collaborative process that increases community competencies and is a key strategy to promote population health (Chalmers & Bramadat, 1996).

Community development is a collective process that engages and partners with community members in problem-solving process through planning, organization, and action. In this process, communities improve their immediate circumstances and gain strength, knowledge, skills, and power to engage in further challenges and building of its well-being (Wharf & Claque, 1997). The traditional health care systems approach that professionalized service providers "care for" the community stands in contrast to "the caring with" enablement approach in community development. It is therefore important to identify informal processes in the community that may represent strengths far greater than those the formal organization can provide (Lauderdale, 2001). Community development is a deliberate, systematic process that is either organized by the group itself or by a leader who assists the group to become consciously engaged in it. There are three characteristics of community development (Wharf, & Claque, 1997) which may also be characteristics of enabling help at the community level. The first characteristic is the need for those who reside in disadvantaged communities to have the opportunity to realize their potential as productive citizens. Second, residents must also be able to analyze the range of development options available in order to deal with the challenges posted by those options. By virtue of being long-time residents of the area, it is important for care providers to acknowledge that community residents already know a great deal about their circumstances, and about the features that serve them well and those that do not. The third characteristic is that there is continuous learning in community development. This means that there is no firm or static description of desired results, which may be an uncomfortable position for health care providers who are traditionally outcome-focused, but there is a shared vision of the possible plan.

Four models of community development have been identified (Chalmers & Bramadat, 1996), of which community education development is one. It focuses on the development of communities through formal and informal educational processes and partnerships within the community. Its core premise is empowerment of learning for community members who are engaged in the process so that once the population is better developed through education, the community itself will benefit. Community groups explore solutions for the problems that affect the community and actions for change are initiated through coalition building.

Community confrontation is a second community development model. In this model, the community's natural or "insider" leaders within the community churches, unions, and other groups mobilize around a single problem and face the issue. The community, acting as a unified force, then pressures the external authorities to bring about the identified change. Community empowerment is a third model. Empowerment models of community development emphasize human and social development by people, organizations, and communities to gain mastery over their affairs. Empowerment models assume that a sense of community is a requirement to community mobilization and citizen participation.

Community economic development is a fourth model (Chalmers & Bramadat, 1996), and is particularly relevant for community health providers working with communities living in poverty. Community economic development is a comprehensive, multifaceted strategy for the revitalization of community economies with a special relevance to communities under economic and social stress. Through community development, organizations and institutions, resources, and alliances are put in place that are democratically controlled by the community. Local resources (people, finances, technical expertise, and real property) in partnership with resources from outside the community are mobilized for the purpose of empowering community members to create and manage new and expanded businesses, specialized institutions, and organizations (Perry, Lewis, & Fontan, 1992). Social goals are the central priority of community economic development. In short, community economic development is a strategy by which people meet social goals through business means. It directly links economic development to increasing social equality, particularly poverty alleviation (Wharf & Claque, 1997).

This discussion of care-giving through "enabling help" to facilitate care-seeking and health has offered an examination of effective helping that embodies the philosophical position of empowerment. Effective helping may be manifested through an enablement model of helping by care providers, enabling help through social support by the social support network, and community development processes. These models are presented here to create a foundation for considering best practice strategies for promoting the health of economically disadvantaged individuals and communities.

### Summary

In closing, I reflect upon the reason why I initially chose the study's research question. After moving into the community health practice setting after hospital nursing, I realized that I needed to enhance my nursing competency to care for clients living in the community as directed by the fundamental community principle, "I am a guest in the client's home". Additionally, as a nurse for the community health organization that serves the poorest persons and neighbourhoods in Vancouver, I felt an inadequacy in understanding the reasons for the depth of poverty that I witnessed and how health care services best provide appropriate care for these clients.

An integrated understanding of the findings incorporated within the study's four themes and key concepts present within the two major topics in this chapter has provided me a critical understanding of my nursing experiences working with persons and communities living in poverty and with health needs. An understanding of the range of factors that contribute to enduring poverty and health inequalities and health determinant models helps health care providers define their role, the scope and limitations of their role, and effective strategies in addressing poverty and the health inequalities that follow. As well, an understanding of enabling help and empowerment at the individual-care provider, social support network, and community levels provides directions for effective helping by health care providers who recognize the inherent strengths and competencies in individual clients and communities in seeking help and care. Health care providers must continue to understand complex issues such as poverty, health inequalities, population health, and community health within the broader societal context in which these issues are located. A critical "upstream" understanding of these issues facilitates effective helping at the client, care system, and community levels to promote empowered strategies for factors that influence care-seeking behaviours and processes of persons living with poverty for community health care providers.

## CHAPTER SIX: SUMMARY, CONCLUSIONS, AND IMPLICATIONS

An interpretive descriptive study was carried out to explore the structural and relational factors that influence the effectiveness of the care-seeking efforts by economically disadvantaged persons. This chapter begins with a summary of the study. The study's conclusions and implications for nursing clinical practice, nursing education, health care and public policy, and research follow the summary.

### Summary of the Study

Canada's persistent rise in poverty rates and the continual poor health profiles of low income populations have presented the nursing profession with the compelling imperative to reconstruct the model of health to include sociopolitical factors. The traditional response has instead been a primary emphasis on increasing the availability and accessibility of health care to address health inequalities that arise from poverty. The health care system's materialist/structural perspective of poverty and health has stressed that poor health results from decreased access to the material conditions and resources that facilitate health, including the existence of, quality of, and access to health care services. Despite the enhanced availability and accessibility of health care services, there exists a lack of understanding the care-seeking behaviours and processes of persons living in poverty. Specifically, there is a gap in knowledge related to the structural and relational factors that influenced the effectiveness of these careseeking efforts from the perspective of persons living in poverty. Thus, the purpose of this study was to explore the experiences of urban economically disadvantaged persons regarding their descriptions of the structural and relational factors that influence their effectiveness of the careseeking efforts.

The care-seeking, poverty, and health inequalities literature was reviewed as the forestructure to the study. Knowledge development in relation to individuals engaged in

seeking care for health concerns was limited and accentuated a health care system perspective, particularly issues related to health care utilization. An integration of the literature on the related concepts of help-seeking, health-seeking, and self care extended the traditional understanding of the concept of care-seeking to include sociological and psychological viewpoints about the phenomenon. Together, the broader range of ideas within the literature review contributed to an understanding of what care-seeking is, what care is sought and expected, how individuals seek care, and when and why do individuals seek or not seek care. The result was a critical examination of the elements of care-seeking behaviours and processes.

The literature on poverty was varied consisting of diverse conceptual perspectives of poverty that have been influenced by social, political, and economic, and cultural forces over time. Varied perspectives of poverty include the subjective experience, the objective lack of material and social resources or opportunities, the political, ideological, and social political policy implications of poverty, and the moral view of poverty in relationship to human rights.

The vast range of literature on poverty and health inequalities provided persuasive evidence that the unequal distribution of wealth in society produced health inequalities. The extensive literature also presented an empirical understanding of the different causal pathways that link poverty or socioeconomic status and poverty. In comparison, the literature on careseeking by economically disadvantaged individuals was extremely limited.

An interpretive descriptive method was selected to identify and describe the structural and relational factors that influenced the care-seeking experiences of economically disadvantaged persons. Ten men and women of varied personal background, age, health status, functional ability, mobility level, ethnicity, and family status participated in the study. The participants lived in one of the four low income neighbourhoods of Community Health Area #2 and used a wide range of health and social care services. Participants were selected using theoretical sampling techniques and thirteen audio-taped and transcribed interviews were accomplished. Primary data sources also included field notes and theoretical memos. Additional data sources, consisting of lay print, media literature, health services reports, and nursing case reports and clinical papers, were used as contextual information.

Inductive thematic analysis was used to identify patterns or themes that extended throughout the entire interview of each participant and the set of interviews through a constant comparison process. Ultimately, a description of shared thematic categories across the participant sample resulted in four themes that described the participants' care-seeking experiences. The themes were: "Living with poverty – Not belonging to the same playing field", "Managing my health day – to – day", "Encountering the multiple aspects of care", and "Experiencing facilitative and challenging care-seeking factors". Collectively, these themes describe the structural and relational factors that influence the care-seeking behaviours and processes of persons living in poverty.

The findings of this study focused on the participants' experiences living in poverty, seeking necessary health and social care or supports, and receiving and providing lay help. The participants' descriptions of their experiences of care given within their identified community network also provided an expanded insight into the extent of informal care that is significant in positively affecting health outcomes. On the basis of the participants' extensive descriptions of living within the constraints of poverty in attaining their health and basic needs, a discussion of the contextual economic, political, and social conditions was undertaken to better understand the macro-level factors that contribute to persisting poverty and the subsequent health inequalities. Models of determinants of health were examined to frame the role and limitations of a predominant health care approach to alleviating poverty and health equalities, and to explore more effective approaches, including better integration and coordination of the health and social care systems, in helping individuals, populations, and communities living in poverty.

The participants' diverse descriptions of helpful or unhelpful care and supports from care systems, and the facilitative or challenging structural and relational factors that influence their care-seeking efforts guided the exploration of a model of enablement of helping by care providers. An enablement model of helping that recognizes the participants' strengths and competency in managing their health needs was presented as one possible direction for change. Similarly, the concept of social support was explored to better understand the often underrecognized significance of lay help from the social support network of persons living in poverty by health care professionals, and to frame the assistance of care providers as surrogate care. An enhanced understanding of the macro-level factors that influence the persistence of poverty and health inequalities and the participants' own descriptions of their experiences of community selfcare created the context for a more detailed exploration of community development processes and models as a "best practice" population health strategy for community health practitioners.

### Study's Conclusions

For the participants in this study, living in poverty influenced efforts in attaining health and basic needs and seeking help or care. The study's findings suggest the following conclusions:

- Persons living in poverty describe a range of personal identification with the term "poverty" that integrates their philosophical, subjective, and political beliefs and values of their personal circumstances or their perspectives of their social position within society's social structures.
- 2. Persons living with poverty and experiencing health needs describe their struggles associated with coping with their poor physical or mental health and health promotion needs as separate yet also integrated within their struggles associated with living with poverty.
- 3. Persons living with poverty can articulate an extensive range of various types of lay help and care from their own social and community support network, and can explain how these positively influence the attainment of the their health and basic needs.
- 4. Persons living with poverty identify a number of gaps that constrain their attainment of their health and basic needs as a result of the limited income provided by social income programs and the limited and restrictive available social care supports.

- 5. Economically disadvantaged persons describe a number of bureaucratic barriers associated with the health and social care systems that influence their ability to obtain necessary health care and support for their basic daily needs.
- 6. Persons living in poverty employ a number of coping strategies that illustrate their resourcefulness and competency in seeking alternative help and care in response to the gaps in socially funded health and basic supports, the inherent bureaucratic barriers in the health and social care systems, and their experiences of unhelpful health care.
- 7. Persons living in poverty who experience hospital or community health and social care services identify characteristics associated with helpful care that contribute to a satisfaction with and continuation of the service. They also identify characteristics associated with unhelpful care that contribute to a dissatisfaction with service, refusal of service, and seeking of alternative sources of help and care.
- 8. Economically disadvantaged persons describe a number of the factors related to their careseeking process and behaviours that are associated with delay in seeking care.
- 9. Persons living in poverty are able to associate increased barriers inaccess to funded supports from the social care ministries with governmental policy changes.

#### **Implications**

The study's findings summarize the participants' descriptions of their experiences of the structural and relational factors that influence the care-seeking behaviours and processes. The findings of this study have implications that are important for nursing practice, nursing education, health care and public policy, and research.

### **Implications for Nursing Practice**

The study concludes that the constraints of living with poverty influence seeking care and help for the attainment of health and basic needs. Therefore, the findings yield a number of implications related to the health needs assessment and care planning by nurses for clients living in poverty. The implications are relevant to many practice settings where nurses practice, for example, in community health nursing (public health, home care, or primary care), or acute care nursing (hospitals or clinics), from which discharge planning for clients living with poverty is a crucial nursing action.

When caring for persons or communities living in poverty, nurses must assess the client's personal, social support, community, and affiliated health or social care system's resources that help or constrain the attainment of the client's health and basic needs. Elements related to personal resources such as the client's ability and confidence in finding, accessing, and getting to care must be assessed. An assessment of the client's access to transportation and phone is particularly important, because of the requirement of getting to care or services that are located far from the client's residence or community. Nurses must assess the client's social support resources such as the range of care or help given by the client's social or community support network that enables the client to meet his or her health and basic needs. An assessment of the client's community resources includes the client's knowledge of neighbourhood resources such as community-based health care services, community food banks, housing advocacy services, and the distance which the client needs to travel to get to these services relative to the client's health, mobility, and functional status. Nurses must also assess the client's knowledge of the health and social care system resources available for or affiliated with the client and the extent of the client's self-management of the bureaucratic processes to obtain the funded resources. The purpose of this assessment is to identify gaps in the range of resources at the personal, social support, community, and care systems levels to provide direction to the nurse's care-plan that best enables the client to meet the identified health needs.

The nurse's assessment of clients experiencing health needs and living in poverty therefore has subsequent implications for care planning by the nurse. Implications include implementing the care plan that addresses the range of barriers within the client's available personal, social support, community, and care system resources. Implications for care planning include collaboratively negotiating and explicitly identifying the role of the nurse in addressing

145

the barriers and gaps in resources experienced by the client living in poverty in seeking care or help that are needed to meet health and basic needs. The nurse's role in helping may include acting for the client or advocating for the client when the client is not capable because of poor health, or mobilizing supports in the health and social care systems for the client. The nurse's role also includes fostering of the client's self care and self-competence.

The study's conclusion that the quality of the client and care-provider relationship is important for service use also has implications for nursing practice. An implication is that the nurse must be aware of the client's expectations of the care and help provided relative to the health goals of the client and the client's historical experiences of helpful and unhelpful care. Accordingly, the nurse must assess what "caring care" is to the client and be aware that caring actions include exhibiting empathetic and listening behaviours and providing adequate time for care so that the client does not feel rushed or that care was incomplete. A nursing goal is the development of a trusting relationship between the client and nurse so that effective helping occurs. The nurse must also assess the client's historical experiences with care providers to identify if the negative experiences currently affect the continued use of nursing services. Furthermore, the nurse must be self-reflective of his or her beliefs, attitudes, and assumptions towards persons living in poverty that can influence the quality of the caring actions and underestimate the client's competence and resourcefulness in self-care.

### **Implications for Nursing Education**

Nursing education curricula should include opportunities for nurses to better understand nursing actions that effectively help populations and communities living with poverty and meet health needs at the individual, family, organizational, and systems levels. Such insights would be important at both basic and graduate levels. At the advanced nursing practice level in particular, specialized knowledge and skills related to caring for individuals and communities living in poverty must be a part of the curriculum, including advanced competence in health promotion, community and population wellness, ethics, leadership, program development and evaluation, and health policy. To support the acquisition of clinical practice competencies by nurses working with clients and populations living with or at risk for poverty, nursing educational experiences should include the exploration of the political, economic, and social conditions and associated infrastructure barriers related to living in poverty and seeking care. Similarly, in their educational programs, future nurses should be exposed to varied conceptual poverty definitions and models as well as health inequalities pathways so that they will be able to critically analyze the social and historical context of enduring poverty and health inequalities. An enhanced understanding of the social exclusion pathway, for example, can help nurses to reflect on the moral imperatives and social justice issue arising from persistent poverty and health inequalities, and upon that basis, learn to conceptually interpret poor clients' descriptions of their experiences of being structurally differentiated from the larger society.

Nursing educational experiences must expand nurse's understanding that reducing health inequalities at the client and population levels requires a focus on the broad social determinants of health. This perspective fosters the valuing of interdisciplinary, intersectoral, and community-driven partnerships in the health promotion strategies towards health inequalities to enable the self-sufficiency of individuals, families, and communities living in poverty. From a philosophical standpoint, nursing curricula must be designed in such a manner as to avoid generalizing and stereotyping clients and communities living in poverty as "needy" and reliant on formalized formal care and services. Rather, enabling helping approaches must be emphasized and supported. Similarly, the assessment and identification of clients' and communities' strengths must be emphasized in the clinical placements for practical learning experiences that nursing students have in the course of their programs. Community health nursing courses would be an appropriate occasion to educate nurses in community assessment and development skills so that they understand the social structures in which economically disadvantaged persons live, and can therefore plan and develop health or social care services that complement existing community resources, and to optimally empower poor communities to be self-reliant. Within such learning experiences, future nurses might also be supported in developing skills in the political domain so that they can better advocate for people and communities living in poverty and can work more effectively to alleviate the effects of poverty, health inequalities, and the system barriers that affect the seeking of care and resources. Implications for Health Care and Public Policy

The study's findings have numerous implications for health care and public policy development. The study concludes that persons living in poverty face a number of infrastructure barriers that constrain their ability to obtain necessary health and social care. These barriers include difficult bureaucratic processes required by social care clients to undertake to quality and access funded supports, and social income assistance policies with various ministries that systematically prevent persons living with inadequate income from meeting everyday health and basic needs. The barriers in the health care system include such regulations as hospital catchment areas and ambulance diversion policies that inhibit a person from accessing the hospital care of choice and negatively affect the seeking of care by persons living in poverty. Another significant infrastructure barrier is the lack of integration and coordination between the health and social care systems. The lack leads to gaps in supports to the persons living in poverty as a result of narrowly defined ministerial mandates that do not embody comprehensive and health determinants views of health.

Health care policy must include service directions for streamlining the processes by which people qualify for health care and assistance within the health and social care systems. Care systems must have "built-in" client advocacy including dedicated client advocacy roles in staff positions or organizational policies that create a systemic culture of helping towards individuals and families living with poverty. Policies within both health and social care services must be guided by a holistic and health promotion view of health. Health care policy must additionally promote enhanced integration and coordination between the social and health care systems to more comprehensive support poor clients, communities, and populations. In general, the scope of health care policies in addressing poverty and health inequalities requires strategic initiatives at the individual, community, population, and political levels.

Enhanced public policies that address poverty, health inequalities, and system barriers to accessible and available supports or care to individuals and populations living in poverty are also necessary. The study concludes that persons living in poverty experience a number of infrastructure constraints that systematically restrict their income to the poverty level and shape their attainment of health and basic needs, their care-seeking behaviours or processes, and the continuation of their poverty status. It seems urgent to advocate for public policies that proactively and pragmatically reduce poverty rates and the burdens of living with poverty as an important step in creating a more socially just Canadian society that effectively cares for its disadvantaged citizens.

### Implications for Nursing Research

Historically, research by nurses in the area of poverty, health inequalities, or careseeking issues by people, communities, and populations living in poverty is very rare. Several implications for nursing research specifically, and research by other disciplines in general are apparent. A limitation of the study was the inability of accessing participants who experience unstable housing conditions or are homeless. Clearly, it would be useful to have descriptive reports on their experiences to inform our practice and policy understanding.

Research that captures the human aspects of how poverty affects care-seeking will be an important issue in times of health reform, health budget cuts, and structural readjustments. Exploration of the impact of reduced social supports to children and families living in poverty would seem essential whenever these occur so that we can document and vividly describe the long term health and social outcomes of reduced social funding. A variety of qualitative methods, including critical social theory methodology or participant action research, could constructively be used by nurses and other health professionals to document the ways in which poverty functions as a critical social environmental or as a structural factor that becomes a

149

powerful determinant of health. In changing and challenging economic times such as these, it would seem important that nurses begin to document the longitudinal experience of persons living in poverty and to record the ways in which public policy changes have an impact on the everyday lives and health of these individuals.

### **Conclusion**

In this study, the experiences of persons living with poverty and seeking care or help for their health were explored. The study's main findings and conclusions promote a greater understanding of the numerous structural and relational factors that are experienced by persons seeking care or help and living in poverty. The participants' narratives provided powerful insight into their immense capacity and resilience in attaining their health needs, and the range of the care and help provided to them by their social and community support networks. The participants' descriptions of their multiple stresses and struggles of living in poverty expand our understanding of the social context and structural constraints in which economically disadvantaged persons and families live. This research study offers a beginning understanding from a nursing perspective of the complexity of living with poverty and health needs at the individual level. It is hoped that this study contributes as a "spring board" to more research that questions the structural and relational factors impacting health outcomes at the population, community, and societal levels.

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# **APPENDIX A**

## **Participant Information Letter**

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### Participant Information Letter

**Title of Study:** The Effectiveness of Care-seeking Efforts From the Perspectives of Economically Disadvantaged Individuals

My name is Betty Da Silva. I am a student in the Master of Science in Nursing Program at the University of British Columbia and a nurse working in community health in Vancouver. I am interested in researching the experience of how persons living with poverty seek help and care from family/friends and health care professionals for their health and/or illnesses. I am also interested in the understanding what factors help or do not help in seeking professional care. The goal of this study is to help health care professionals, particularly nurses, to better understand what factors affect the effectiveness of care-seeking efforts by economically disadvantaged individuals.

If you decide to participate in this research study, you will be interviewed by me in a time and place convenient to you. The first interview will last about one hour, and I will ask about your experience of seeking help and care. If you are agreeable, I may ask for additional interviews to clarify my understandings of how you obtain the help you need. The interviews will be audio-tape recorded and transcribed. The tapes and transcriptions will be safely stored and locked in my home. The tapes will be erased when the study is completed.

# **APPENDIX B**

# Participant Consent Form

# **APPENDIX C**

## **Data Documents**

### **Data Documents**

Brennan, E., & Giles, S. (1996). <u>Nursing close to the street: Home care nursing in</u> <u>Vancouver's urban core.</u> [Brochure]. Vancouver, BC: Author.

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### **APPENDIX D**

#### **Sample Interview Questions**

The following are a sample of open-ended trigger questions that were used in this study:

- 1. Tell me what it is like for you to seek help or care for your health.
- 2. What does help mean to you?
- 3. What does care mean to you?
- 4. What does health mean to you?
- 5. What does poverty mean to you?
- 6. What does living with poverty mean to you?
- 7. Who do you talk to about getting help or care?
- 8. How do you find help? How do you find care?
- 9. What help do you expect? From your family or friends/people that you know? From health care professionals?
- 10. What care do you expect? From your family or friends? From health care professionals?
- 11. What prompted you to use help or care from family or friends? From health care professional?
- 12. When do you decide to seek help from family or friends? From health care professionals?
- 13. When do you decide to not seek help from family or friends? From health care professionals?
- 14. What are the things that are helpful/not helpful for you in getting the help or care from health care professionals?
- 15. How do you feel about the care that you have received/are receiving from health care professionals?
- 14. How has your decision to use (or not use) help or care from health care professionals change over time?
- 15. How does living in poverty affect your health? Your care-seeking for care/help?