CENTRAL AMERICAN REFUGEE CLAIMANTS' EXPERIENCES ACCESSING HEALTH CARE

by

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ABSTRACT

Recent Canada Employment and Immigration Commission statistics indicate that individuals from Central America continue to claim refugee status at B. C. port-of-entry. No studies have been conducted examining Central American refugee claimants' experiences when trying to access health care services. The purpose of this study, therefore, was to examine from the perspective of the refugee claimants, their experiences accessing health care services in Vancouver.

A conceptual framework developed by this researcher guided the analysis of the data whereby macro political, economic and social domains were depicted as influencing refugee claimants' every day psychosocial/economic realities, their health care seeking experiences and their health status. The policies of the political domain also influenced the health care institutional level.

The research method for this study was a phenomenological approach. Data for the study were derived from unstructured audiotaped interviews conducted by this researcher with the assistance of simultaneous translation by a translator. Interviews with 9 Central Americans, who described their experiences accessing health care, were 50 to 135 minutes long. Participants shared information of their past and present realities which provided a contextual basis for understanding their experiences. The audiotapes of the interviews were transcribed verbatim and were analyzed for emerging concepts and themes. Each concept was comprised of several themes.

The three main concepts that evolved from the data analysis were marginality, health care seeking experiences and the illness experience. These concepts were interpreted in relation to the study's conceptual framework. Fear and suffering, along with unemployment, loss and isolation, and discrimination, are themes reflecting past and present influence on participants' marginality. Participants' health care seeking experiences are understood within this "marginal" context. Health policy and associated bureaucratic processes shaped participants' health care seeking patterns and what transpired at the health care institutional level. Difficulty accessing medical coverage and or comprehensive medical care had repercussions on participants' illness experiences. A number of recommendations have been made that address health policy, nursing practice, education, research, administration and professional associations.
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FOREWARD

Many individuals who provided commentary for the section Background to the Problem (p.1), including social workers, refugee lawyers, public health nurses and individuals working in government institutions, requested that they remain anonymous. Many chose not to release their names indicating the sensitive, political nature of the issue surrounding refugee claimant health care in British Columbia.

Conflicting opinions between individuals working in government settings, social/legal workers and also between interdepartmental government staff were presented in this section, not to illustrate rivalry, but rather, to demonstrate the complexity and confusion plaguing this subject. Conflicting policy interpretations related to refugee claimant health care within government agencies is indicative of the difficulties refugee claimants have in accessing health care.

In order to protect the identity of participants, alterations were made in the data while maintaining the essence of what was disclosed.
CHAPTER 1: INTRODUCTION

Background to the Problem

The number of refugees allowed entry into Canada has increased from 27,000 in 1987 to 39,000 in 1990 (personal communication, August 1991). Individuals claiming refugee status, implying they have well-founded fear of persecution in their country-of-origin, enter Canada either as port-of-entry refugee claimants, or are preselected/sponsored by the Canadian government while still abroad. Upon arrival in Canada, federally sponsored refugees are entitled to medical coverage for one year (Gleave, 1990). Port-of-entry refugee claimants, on the other hand, are not so fortunate and face a number of difficulties obtaining health care in the Province of British Columbia (B.C.). It is this latter group that is being studied.

Limited access to health care jeopardizes the health of refugee claimants. Claimants' difficulties in accessing health care is therefore of concern to public health nursing since the role of the public health nurse is to respond to the needs of given populations (Canadian Public Health Association, 1990). Claimants' difficulties in accessing health care is also a relevant issue for public health nursing, due to the belief that individuals, families and communities have the right to accessible, affordable health care (Canadian Public Health Association, 1990).

Barriers to Health Care: Professionals' Perspectives

Aside from Gleave's work (1990), no literature could be located concerning refugee claimants and circumstances surrounding their access to health care. Thus, in order to gain background information on the problem, prior to commencing this study, this researcher directed questions to social workers, refugee lawyers, public health nurses and individuals in government regarding this issue. Their perspectives are presented in this section. Since this study was conducted before changes to the Canada Immigration Act came into effect on February 1, 1993, the perspectives of professionals relate to immigration legal procedures that existed before this date. Their description of the policies and processes affiliated with refugee claimants accessing health care, however, remain current (personal communication, Oct., 1993).

In B.C., in 1990, 2,069 port-of-entry refugee claims were made primarily by individuals from China and Central America (Immigration and Refugee Board Statistical Summary, 1991). According to a government spokesperson, processing these claims involves initial and full hearings with the Refugee Determination Board and spans a 6-7 month period (personal communication, May 1991). Social workers and lawyers, however,
claim that some clients wait 12 or more months for initial hearings (personal communication, July 1991). During these months while awaiting a decision as to their political status, port-of-entry refugee claimants have limited access to medical services whose cost would be covered by Canada Employment and Immigration Commission (CEIC) (personal communication, July 1991). Securing medical coverage from CEIC involves claimants going to CEIC requesting permission for coverage for whatever services are necessary to deal with their specific health complaints. Medical coverage is issued to refugee claimants in the form of medical authorization letters which stipulate within a given time frame, the health care services (the tests and treatment) CEIC is willing to cover (personal communication, July 1991). Canada Employment and Immigration Commission authorities state the joint policy of Federal Health and Welfare/CEIC is to grant coverage only in emergency situations (personal communication, July 1991). Such a policy limits health care access, discourages preventive care and has the potential to interrupt early diagnosis (Latin American Community Council, 1990). In addition, social workers and lawyers state that what constitutes an emergency situation is not clearly defined. They remarked that some refugee claimants have been denied medical authorization by CEIC employees on the basis that their health care needs were designated as non-emergency concerns (personal communication, August 1991). With no medical coverage and fear of government reprisal associated with not being able to pay medical/hospital fees, refugee lawyers explained that claimants often forego medical treatment (personal communication, July 1991). Furthermore, refugee claimants’ problems in accessing health care also stems from lack of information. An individual working for the government explained that no written information on health care services is available to give to refugee claimants at Canadian ports-of-entry (personal communication, August, 1991).

As well as federal policy limiting access, lawyers and health care professionals who work with refugee claimants informed this researcher that the lengthy procedure of requesting permission for medical authorization from CEIC deters refugee claimants from seeking health care services (personal communication, August 1991). Professionals described that part of the process in obtaining medical authorization from CEIC requires refugee claimants to prove their indigent status to CEIC employees. Proving their indigent status (their inability to pay for their own medical expenses), necessitates refugee claimants going to the Ministry of Social Services and Housing (Welfare) requesting a letter that substantiates their welfare status. Claimants then proceed to CEIC where they endure long waits (personal communication, July 1991). While social workers explained how CEIC’s issuing of Order in Council letters are of benefit to claimants since they allow claimants
direct access to medical care for extended periods of time (i.e. 1 week, 3 months or 6 months, depending on the claimant's health problems), this researcher was informed by a government authority that statistics on the number of Order in Council letters issued to refugee claimants are not kept (personal communication, August 1991). While asking government persons when and to whom Order in Council letters are issued, conflicting responses were given. For example, one person stated that Order in Council letters were issued to every port-of-entry claimant at every port of entry, whereas another individual explained that letters are judiciously issued to claimants who are not likely to abuse the health care system and who require extensive medical follow-up (personal communication, August 1991). Yet, another person commented that Order in Council letters are available on request from the refugee claimant.

Based on professionals' perspectives and government employees' comments, conflicting information surrounding the issuing of Order in Council letters, unclear federal policies regarding what constitutes an emergency situation and the bureaucratic processes associated with CEIC authorization, are obstacles preventing refugee claimants from obtaining health care services. Responsibility for refugee claimants' difficulties in accessing health care services, however, does not solely rest with the federal government. Responsibility also lies with the B.C. provincial government and its policies concerning eligibility for provincial health insurance through the medical services plan (MSP).

Discussions with social workers reveal that unlike Ontario, where refugee claimants when applying for refugee status are granted medical coverage eligibility, claimants in B.C. are not eligible for the province's medical coverage or its premium assistance program (personal communication, July 1991). Discrepancy between the provinces concerning refugee claimants' eligibility for medical coverage exists since health care in Canada remains largely a provincial responsibility with each province determining its own health care programs, including eligibility criteria for provincial medical insurance (Grant, 1988). As a result of the B.C. government's health care jurisdiction, with its own policies governing claimant MSP eligibility, refugee claimants in B.C. do not have the same access as claimants in other provinces such as Ontario. Lawyers speculated that restrictions on claimants' MSP eligibility arise from the provincial bureaucratic belief that refugee claimants are primarily a federal responsibility, justifying minimal provincial health care spending on refugee claimants (personal communication, August 1991). These lawyers also claim that the difficulties refugee claimants have in accessing health care is the outcome of political debate which is embedded in economic concerns between federal and provincial governments (personal communication, August, 1991).
Social workers report that in addition to restrictions associated with MSP coverage, the provincial government also denies refugee claimants' eligibility for premium assistance (personal communication, July 1991). Social workers went on to explain that some claimants who were earning low incomes and were granted MSP coverage because of their employment status, were unable to pay their MSP premiums and thus had to forfeit their medical coverage (personal communication, July 1991). With no MSP coverage or medical authorization from CEIC, they reported that some refugee claimants have occasionally been refused medical treatment by physicians in hospital emergency departments (personal communication, July 1991).

In discussing the issue of refugee claimants and their problems in accessing health care with public health nurses in Vancouver, another difficulty was uncovered. Public health nurses explained that although the local health department has responded to the needs of refugee claimants by allowing them access to free clinics, the limited services offered at free clinics are inadequate to meet their complex health problems (personal communication, Sept. 1991). Thus, the problems refugee claimants encounter in trying to obtain health care also embodies the notion of access to 'adequate', 'comprehensive' care.

The difficulties related to health care access for refugee claimants, as described in discussions with lawyers, social workers, public health nurses and individuals in government, are clearly beyond the domain of one-to-one encounters and are influenced by federal/provincial policies and bureaucratic processes.

**Canadian Health Policy**

Limiting refugee claimants' access to health care services is of concern since it undermines current public health policy. Accessible health care is one of the founding principles of our Canadian health care system, assuring that the basis of access to medical care is not one's ability to pay, but rather, on one's need (Manga, 1981). It can also be argued that with the recent emphasis on health promotion (Epp, 1986), restricting claimants' access to medical coverage only in emergency situations undermines current health policy. Furthermore, it can be argued that since holders of student authorization permits are eligible for MSP benefits after a statutory 3 month waiting period, the criterion for medical coverage appears to be **residence** in the country and not necessarily Canadian citizenship or landed immigrant status. Restricting refugee claimants' access to health care is therefore not only inconsistent with public health policies, but also policies governing non-Canadian individuals' access to health care services.
Advocacy

Advocacy in public health nursing embodies empowering individuals, families and communities to become self-reliant in meeting their own health care needs and concerns (Geoppinger & Shuster, 1988). However, when individuals, families and communities face language and cultural barriers, the role of the public health nurse may require acting on behalf of the individual, family, or community, as opposed to individuals/groups acting for themselves. Since public health nursing recognizes the impact of social, political and economic forces influencing the health of populations (Canadian Public Health Association, 1990), public health nurses advocating for individuals or communities at a system level is an expected function (Geoppinger & Shuster, 1990). The advocate's role at the system level involves changing the system to make it more sensitive and relevant by revealing its injustices and inadequacies (Kosik, 1972) and by promoting accessible health care through policy changes (Rootman, 1987). Public health nurses' involvement in policy change at the system level for improved access to medical care is, therefore, an important act of advocacy, ultimately promoting the well-being of this population.

Rootman (1987) believes that health professionals have an obligation to help those who are disadvantaged. Refugee claimants' limited access to health care qualifies them as disadvantaged. Believing health care is a right for all individuals, restricting refugee claimants' access to health care services warrants advocacy.

This researcher's concern over claimants' dilemma in accessing health care evolved from having contact with public health nurses and social workers who have been working with Central American refugee claimants. With the Central American community largely made up of poorly educated, working class individuals who have only recently sought asylum in Canada (Gleave, 1990), the Central American community has not had the opportunity to develop elaborate informal networks to assist members of its own community, typical of well established communities (Task Force on Latin American Canadians, 1989). Although it can be argued that particular groups within other ethnocultural communities may experience difficulties accessing health care services, the difficulties facing Central American refugee claimants has not been researched and has gained the attention of this researcher.

The Problem Statement

Most individuals emigrating from Central America come to Canada as refugee claimants (Gleave, 1990). With ongoing political unrest, port-of-entry refugee claimants from Central America continue to flow into B.C. (Gleave, 1990). Given refugee claimants' economic difficulties, poor nutritional status and their mental anguish associated with
torture and loss of family (Canadian Task Force on Mental Health Issues Affecting Refugees, 1988), their increased vulnerability to poor health explicitly indicates the need for appropriate access to health care services.

In order to advocate for improved accessibility to health services, understanding Central American refugee claimants' perceptions of their difficulties in obtaining health care is needed. To date, no research has examined the experiences of port-of-entry Central American refugee claimants' experiences in accessing health care in B.C..

Purpose

The purpose of this study is to investigate, from the perspective of Central American port-of-entry refugee claimants, their experiences in accessing health care.

Conceptualization of the Problem

Conceptualization of the problem reveals the perspective from which the investigator views the problem (Catanzaro, 1988). This study draws upon the theoretical perspective advanced by Anderson (1985) who argues that larger political, economic and social structures must be considered when examining an individual's every day realities, including their health and illness experiences.

Anderson's (1985) perspective is based on the premise that an individual does not experience life in a vacuum. Rather, an individual's psychosocial and economic realities are embedded within the "larger social organization and cannot be divorced from the macro sociopolitical and economic context" (Anderson, 1990). Drawing upon this perspective, it could be argued that refugee claimants' experiences in their every day lives are connected to a larger macro system which can dominate and influence their lives, including their psychosocial/economic realities, health status and access to health care, via political, economic and social means. This relationship between the macro and micro level (the refugee claimant) is depicted in this study's conceptual framework (p. 7), developed by this researcher. Furthermore, the conceptual framework illustrates the health care institutional level playing an intermediary role between macro and micro levels. In other words, political policies formulated within the political domain (provincial/federal governments) influence the availability of resources at the health care institutional level, which in turn, has an impact on refugee claimants' access to health services and subsequently shapes their health status.

The macro economic domain pertains to the allocation of provincial/federal financial health resources which control the measure of restraints on refugee claimants' access to health care services. Concerning the macro social domain, predominant
CONCEPTUALIZATION OF THE MACRO LEVEL'S INFLUENCE ON REFUGEE CLAIMANTS' REALITIES, HEALTH CARE ACCESS AND HEALTH STATUS BY DIRECT MEANS AND VIA THE HEALTH CARE INSTITUTIONAL LEVEL.

Figure 1. depicts the macro level's political, economic and social domains' influence over the micro personal level via policies, resource allocation and social attitudes/values of society. While the macro level directly influences refugee claimants' psychosocial/economic realities and their health status, the macro level also impacts at the health care institutional level. The impact at the health care institutional level shapes refugee claimants' experiences within health care settings which bears influence on their health status.
values/attitudes of society may influence health policy. Prevailing societal attitudes can also shape refugee claimants' degree of opportunity, adaptation and personal growth. What the conceptual framework essentially portrays, then, is a complex web of varying domains or forces which bear significantly on refugee claimants' lives.

Research Questions

This study will address the following questions regarding Central American port-of-entry refugee claimants accessing health care: 1) what are Central American port-of-entry refugee claimants' health concerns necessitating access to health care services, 2) what difficulties do they experience while trying to obtain medical care, 3) what consequences arise when claimants and/or their families experience difficulty gaining access to health care services or when they are unable to secure adequate medical treatment?

Definitions of Terms

For the purpose of this study, the following definitions are used:
1) Refugee claimant: an individual from Central America not pre-selected/sponsored by the Canadian government who claims refugee status at a B. C. port-of-entry.
2) Access: refugee claimants' entry into the health care system.
3) Limited access: restricted use of health care services that a Canadian citizen or landed immigrant has the right to.
4) Health care: in this study, health care includes all services offered within the health care system. However, many of the examples described in this study pertain to medical care.
5) Medical authorization: CEIC granting medical coverage for designated health care services affiliated with refugee claimants' specific health complaints. The terms medical authorization and medical coverage are used interchangeably.

Assumptions

In this study, the following assumptions are made about the participants:
1) The participant's view represents reality for that person.
2) Participants from the same cultural background may interpret experiences differently.
3) Refugee claimants have greater difficulty accessing health care services than do landed immigrants or Canadian citizens.

Limitations

1) Participants may not share their experiences of accessing health care entirely due to mistrust or fear, thereby limiting findings.
2) This researcher is unable to speak or understand Spanish, therefore, data may be lost or altered through use of an interpreter.

3) Participant access is through various community based non-profit agencies, therefore, recruitment is limited to those participants using such services.

4) Interpreters involved in this study were agency staff. Their presence during the interview process may have influenced participant disclosure.

Significance of the Study

There tends to be an ongoing influx of individuals claiming refugee status at B. C. ports-of-entry. Federal/provincial policies limiting claimants' access to health care jeopardizes the health of these individuals. Since research is one of the ways in which nursing can shape federal/provincial policy (Brecht, 1990; Hinshaw, 1988), researching claimants' experiences in accessing health care is considered an important endeavor.

Summary

This chapter presented this study's problem, purpose, research questions, its significance and the conceptual framework. A graphic illustration of the conceptual framework depicting the theoretical perspective from which study findings will be analyzed, was provided. As well, definitions of terms, assumptions and limitations were also addressed. The following chapter examines the literature in relation to barriers in accessing health care.
CHAPTER 2: THE LITERATURE REVIEW

Many studies have been conducted on refugees without clear distinction as to whether refugee claimants were included in the studies’ populations. The subject of refugee claimants per se remains virtually unstudied in Canada. The few studies that have been conducted have focused on claimants’ mental/physical health status (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988; Thonneau, Gratton, & Desrosiers, 1990). The only literature found acknowledging problems of access is a brief commentary by Gleave (1990). The review will, therefore, consist of articles and research findings examining barriers to health care. Since refugee claimants have restricted medical coverage in B.C. (Gleave, 1990; Legal Services of B.C., 1989), their difficulties accessing health care mirror some of the difficulties experienced by the indigent and the medically uninsured in the United States. For this reason, American literature is also cited in the review.

A vast amount of literature has examined barriers to accessing health care, equating barriers with a lack of or reduced access to care (Melnyk, 1988). Melnyk (1988) reviewed recent literature and concluded that most literature categorizes barriers as either structural or individual. For the purposes of this study, structural/individual barriers become more meaningful if they are thought of in the context of refugee claimants’ interplay with government agencies, as well as health care agencies where claimants have been denied health care services. Structural/individual barriers will now be examined.

Structural Barriers

Structural refers to the distribution/organization of health services and the health labour force (Grant, 1988). Structural barriers include: health care policies, availability of services, fragmentation of services and discriminatory behaviour of agency personnel (Aday & Andersen, 1974; Daniels, 1982; Melnyk, 1988; Cornely, 1976).

Health Care Policy

Aday and Andersen (1974) claim that health care policy is the most important variable influencing health care accessibility. Supporting this truism were the results of Canadian studies conducted by Manga (1978), Greenhill and Haythorne (1972). They concluded that an increase in utilization of health care services of the uninsured and low income families in Saskatchewan, Alberta, and Ontario was a result of the enactment of the public health insurance policy allowing all citizens, regardless of income, accessibility to health care (Manga, 1987). Similarly, in 1989, the U.S. Congress mandated Medicaid coverage for low income pregnant women, reducing access constraints (Friedman, 1991).
The 1984 Canada Health Act, however, failed to promote accessibility among the uninsured. Accessibility to health care was defined as reasonable access by insured persons to insured services (Crichton, Hsu & Tang, 1990). Wahn (1984) believes unequal accessibility is failure of the government to embrace equity as an objective (Grant, 1988).

**Availability of Services**

Availability of services also predicts service utilization. Wan and Yates (1975), and Jacoby and Jones (1982) found a low provider/consumer ratio, limited office hours and excessive waiting for physician appointments, reduced use of services (Melnyk, 1988). Long distance travel to services was frequently found to be a deterrent by Aday (1975). Snowden, Collinge and Runkle (1982) attribute poor health of rural individuals to lack of available services in non-urban locations.

**Fragmentation of Services**

Canadian health policy analysts consider fragmentation of services an access barrier (Soderstrom, 1983). Sawyer (1982), examining the relationship between the setting where care is received and client satisfaction found fragmented, impersonal care, typical of emergency/outpatient departments, resulted in client dissatisfaction deterring future use. In contrast, Jacoby and Jones (1982) reported clients preferred emergency settings, perceiving staff as more tolerant, flexible and informal than other structured settings (Melnyk, 1988). Soderstrom (1983) identifies poorly coordinated services and lack of primary health care professionals as barriers to accessing health care in Canada. Aday and Andersen (1974) found that in the United States, non-whites and those below the poverty level were more likely to use emergency settings as their regular source of care.

**Discrimination**

Discrimination by race is a barrier suggested by Cornely (1976). He argues racism is one of the most important barriers in our society in the attainment of health care. Racist attitudes prevalent in Canadian society (Report of the Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988) are reflected not only in the health care setting, but also in health policy decisions and programs established by the Canadian government (Frideres, 1988). Frideres (1988) believes that Canadian health care policies are discriminatory since they lack a societal contextual focus explaining why sickness occurs. In other words, the government fails to install policies that effectively deal with etiological societal factors that cause or promote "ill health." For example, Frideres (1988) argues that the ridiculing of Native health practices by medical practitioners of the dominant society clearly depicts racist attitudes and intolerance.
Structural barriers thus involve policies governing access to health services, as well as the organization/distribution of services and the interaction of health professionals with consumers. Consumer satisfaction associated with the degree of accessibility of services and care received influences whether resources will be accessed. Examining discriminatory barriers at the policy, program and client-provider level is needed in order to gain insight as to its prevalence, manifestation and impact on service utilization. Although structural barriers have been examined in relation to ethnic minorities and the indigent, no research has examined structural barriers in relation to refugee claimants.

Individual Barriers

Individual barriers include both predisposing and lack of enabling factors in which the unit of analysis is the health care seeking individual rather than the system (Aday & Andersen, 1974).

Predisposing Variables

According to Aday and Andersen (1974) and Daniels (1982), predisposing factors are attributes of an individual which influence their help seeking behaviour and include such characteristics as age, health status, cultural background and family characteristics.

Age as a barrier is somewhat disputed by researchers. Studies conducted by Antczak and Branck (1985) found the elderly less likely to access dental services, although Veroff, Kulka and Douvan (1981) found no evidence that accessing health services declined with age (Melnyk, 1988; Snowden et al., 1982). Health status, in terms of decreased activity due to chronic disability or an increase in the number of health ailments an individual has, was found to act as a barrier by Gaitz (1974) and Brunswick, Boyle and Tarcia (1979). In contrast, Heinemann, Moore and Gruel (1977) found that the presence of persistent health problems was the impetus for service utilization (Melnyk, 1988).

Cultural background is considered a barrier when language communication problems exist between the health care provider and the consumer (Ginzberg & Ostow, 1991). In a Canadian study conducted by Christensen (1986) examining the help seeking preferences of Chinese people in Montreal, the majority of respondents feared large bureaucratic organizations and did not expect mainstream agency staff to understand their problems due to language barriers and lack of cultural understanding. Kleinman (1978) and Anderson (1985) acknowledge the need for Canadian and American health professionals to understand the clients' cultural interpretation of their illness, thereby fostering quality care and client satisfaction. Studies have shown that dissatisfaction with health services among mainstream and culturally diverse clientele leads to underutilization of health services (Andersen, McCutcheon, Aday, Chiu & Bell, 1983; Zane, Sue, Casto &
William, 1982; Barrera, 1982). Snowden et. al. (1982) argue that increasing the number of mainstream services is not a viable solution to the problem of underutilization of services among culturally diverse communities. Rather, a match between services and the cultural patterns of clients is necessary for improving their utilization of services (Snowden et. al., 1982). Bergin's (1988) report on ethnic minorities accessing health and social services in the Ottawa-Carleton region offers similar recommendations.

Quesada and Heller (1977) also found that ethnic alienation from mainstream society was associated with lack of use of health services (Melnyk, 1988). Supporting this finding is Bullough's (1972) study examining use of preventive health care programs by Black and Mexican-American women. She concluded that minority ethnic identity created feelings of alienation which resulted in underutilization of preventive services by minority women (Bullough, 1972).

With respect to family characteristics, large family size and increased stress associated with family responsibilities were found by Salkever (1976) and Pender and Pender (1980) to deter service use. Researchers Roghmann and Haggerty (1972) also support these findings. In addition, Stewart (1990) states inability to find adequate child supervision often deters Canadian mothers from seeking health care.

**Lack of Enabling Variables**

Aday and Andersen (1974) describe enabling factors as the "means" individuals have available which enable them to access health care services. While they consider adequate income and medical insurance as enabling factors promoting service use, in subsequent research they identify low income and lack of medical coverage as factors deterring service utilization (Aday, 1975; Andersen, Giachello & Aday, 1986). Since other researchers have found lack of knowledge of available services hindering access (Christensen, 1986; Kim, 1986; Bergin, 1988), lack of knowledge is categorized as an additional factor associated with 'lack of enabling variables.'

**Low income**, making health care services unaffordable, is viewed by many researchers as a significant barrier to access (Sawyer, 1982; Andersen et al., 1983; Daniels, 1982; Aday, 1975). Despite Canada's national health service enhancing health care access, a study examining extra billing fees during the 1970's in Alberta and Ontario found that such payment deterred the poor from seeking care (Northcott, 1988). Rootman (1987) claims that socio-economic status has a profound bearing on Canadians' use of health services. Transportation costs and lost work while accessing health care were found to discourage use particularly among lower income groups (Aday, 1975). In the United States, low income restricts access to health care more than any other variable among the
Hispanic population (Council on Scientific Affairs, 1991).

**Inadequate insurance coverage** is also recognized as a significant factor determining health care utilization (Blendon & Edwards, 1991). Aday (1975) found the uninsured poor to have the lowest rates of use, relative to their respective needs for health care than any other group. In the U.S., Hispanics' underutilization of health services was attributed not only to low income, but also to employment in low wage establishments which failed to provide health insurance benefits (Ginzberg, 1991).

**Lack of knowledge of existing health services**, in addition to low income and lack of medical coverage, is another factor inhibiting health care access particularly among ethnic minorities in Canada (Christensen, 1986; Kim, 1986; Bergin, 1988). According to Gore (1989), however, social networks are key sources of knowledge that influence access to formal health care services. Large network size and geographic density of the network are often associated with greater use of services (Gore, 1990). In contrast, Christensen (1986) found use of informal networks delayed individuals from seeking health care in formal institutions.

Individual barriers include an array of factors predisposing/inhibiting individuals from accessing health care. Cultural background and level of income were of particular influence. Labelling these barriers as 'individual', however, is somewhat of a misnomer since it implies the individual has control and power to change one's circumstance. Eradicating individual barriers to health care would require a radical transformation of the health care system, and changes in policies, societal attitudes and in the economic realities in the lives of individuals.

**Summary**

The literature review indicates that potential entry into the health care system is influenced not only by structural characteristics of the health care system, but also by individuals' resources and characteristics. The literature illustrates that no one variable, but rather a number of complex interacting variables determine health care access. It appears, however, that public health policy has considerable impact on accessibility, as well as medical insurance coverage.

Ethnocultural minorities experience greater disadvantages accessing health care when mainstream services are culturally inappropriate to their needs. Their alienation and low socioeconomic status further restricts accessibility. Barriers to accessing health care thus involve political, economic and social factors.

To date, there is no research examining refugee claimants' experiences in accessing health care. Whether access barriers discussed in the literature are applicable to refugee
claimants' experiences, remain uncertain. Research exploring the difficulties refugee claimants have in accessing health care would clarify and provide insight into what they perceive barriers to be.
CHAPTER 3: METHODOLOGY

This chapter describes the research design, sample selection, participant criteria and recruitment procedures, characteristics of the participants, procedures for collecting and analyzing the data, issues related to establishing reliability and validity and, approaches to the protection of the human rights of participants. As well, issues related to participant recruitment, interpreter issues, the emotional aspect of the interviews and this researcher’s involvement with participants are also discussed.

Research Design

This qualitative study used a phenomenological research method. This method was chosen since the purpose of phenomenology is to understand the meaning of human experience as it is perceived by those who have lived the experience (Munhall & Oiler, 1988). Major philosophical differences exist between phenomenology and the natural scientific approach. The natural science perspective requires phenomena to be observable, measurable and verifiable by other observers where the research method involves testing and experimentation (Knaack, 1984). In contrast, the phenomenological perspective views the human not as an object apart from the world, but rather, in the context of his or her surroundings (Knaack, 1984). In phenomenology, the focus is on the processes of understanding and describing, rather than seeking to control or predict behaviour (Knaack, 1984).

Sample Selection

Non-probability sampling was employed because the purpose of the study was to understand a specific reality. Hence, participants were chosen according to whether their experiences offered insight into the difficulties refugee claimants encounter while trying to access health care services. Sample size was determined by the quality, completeness and the amount of information offered by participants (Morse, 1986), as well as by the saturation of conceptual categories. Saturation refers to the point where the investigator finds no new information emerging from the interviews (Guba and Lincoln, 1981). Saturation implies that maximum construction of core categories have been developed from the interview data which is inherent in the qualitative process (Guba & Lincoln, 1981; Morse, 1986; Catanzaro & Olanshansky, 1988). To achieve saturation, a sample size of 8 participants was predicted; in the end, 9 individuals were recruited.

Participant Criteria

The following criteria were used to guide participant selection: that each
participant: 1) be of Central American origin, Spanish or English speaking, male or female, between the ages of 19 and 65; 2) is or has been a refugee claimant in B. C.; 3) has needed to obtain health care services while a refugee claimant out of psychological or physical need, or, has needed to seek health care services on behalf of a family member refugee claimant needing psychological or physical care; 4) has sought health care services but either had difficulty or was unable to obtain the desired care; and 5) is living in the Vancouver/Lower Mainland area.

**Participant Recruitment**

In order to do this study, this researcher needed access into the Central American community. Multicultural, Hispanic and grassroots agencies were approached and asked to assist this researcher with the study. Five agencies were approached and 4 agreed to assist with the recruitment of participants. These agencies are well established within the ethnocultural community and are not involved in the delivery of health care services. These non-profit agencies were established for the purposes of providing interpreters, information and job/language training to refugees and immigrants. In addition, one immigration lawyer agreed to refer participants, however, no participants were recruited from this source since individuals meeting study criteria were not available.

Upon obtaining approval from agencies and the University of British Columbia Behavioural Sciences Screening Committee for Research Involving Human Subjects, recruitment of participants commenced. Agency directors suggested specific agency staff who would be most helpful with the recruitment process. Although networking among multicultural agencies had taken place during previous coursework, staff who assisted with recruitment were unknown to this researcher. This researcher was aware that her demeanor and sincerity was being assessed by agency staff because of their concern to protect their clientele. This assessment process was perceived by this researcher as a protective act symbolizing agency staff's concern for their clients. Upon being appraised by agency staff as "non-threatening and sincere", they began to consider potential participants for this study. Along with recruitment, agency staff were also interpreters for the study. Their involvement as interpreters in the study will be addressed later in this chapter.

Agency staff were briefed about the study and were given the 'Letter to the Agency' (Appendix D) to use as a reference when telephoning or speaking in person to potential participants. When agency staff came in contact with potential participants, these individuals were given a 'Participant Information Letter' that had been translated into Spanish (Appendix A: English and Spanish translation). Taking into account potential participants' possible illiteracy, agency staff orally explained the intent of the study, what
their participation would involve, confidentiality measures, and participants' rights to withdraw from the study at any time. When verbal consent to participate was expressed by potential participants, agency staff arranged the first interview at a time and place convenient to the participants.

The 'Consent Form' (Appendix B: English and Spanish translation) was read in Spanish to illiterate participants before they signed the consent, while other participants were given the Spanish translated 'Consent Form' and were encouraged to ask questions if the consent form was confusing or unclear, or if they were concerned about their involvement in the study.

At the request of one participant, a separate introductory meeting was arranged. This participant had recently arrived from Central America and although he originally declined being involved in the study out of fear that negative comments about the government might jeopardize him from being granted refugee status, he later contacted the agency staff person involved in the study and declared his desire to participate. His interest in participating evolved from his experiences at CEIC during the week following his initial decline. An introductory meeting lasting 10 minutes took place with the researcher and the agency staff person. This individual’s main concern, understandably, was confidentiality. This individual agreed to participate after explicit details were provided describing how his identity would be protected.

This participant’s concern was not unusual. In a survey conducted among Vancouver American Hispanics, only 49% of respondents agreed to be involved in the survey; of those who declined, two thirds expressed concern about their illegal immigration status (Palacios & Sheps, 1992). These concerns reveal the kinds of obstacles researchers encounter when trying to recruit participants whose political status is either illegal or is in the process of being determined by the government. What this researcher found was that gaining participants' trust and ensuring confidentiality were two major hurdles that had to be overcome in order for individuals to participate and be willing to share their experiences in the Canadian system.

A dilemma which surfaced when speaking with participants was that although they wanted their concerns about accessing health care to be known, at the same time, they were reticent to share such experiences because they appreciated being in Canada. While this researcher encouraged participants to disclose only those experiences they felt comfortable in sharing, the researcher also emphasized to participants that they had a right to let others know about the kinds of difficulties they were experiencing when trying to access health care services. In order to encourage participants to share their experiences (positive or negative), the researcher sought to convey the notion that they were important
and what happened to them while living in this country mattered to health care professionals.

Before the first interview began, time was allotted for the researcher to introduce herself, to get to know participants and for participants to ask questions about the researcher. I was keen to conduct interviews as informally as possible in order to diminish the distance inherent in the 'researcher' 'participant' role classification, since distance was perceived as hindering participants' comfort and disclosure. During this time, participants asked questions about my marital status, whether I had children, where I was from and so forth. Such questioning transformed my identity from being somewhat of an enigma to that of having a more human, personal identity that participants could relate to. 'Shaping an identity' of the researcher was an important process for both the interviewer and the interviewee. In addition to supporting a non-hierarchical approach and the diminishing of distance between the researcher and the participant, Oakley (1981) acknowledges that the interview process is enhanced when the interviewer is prepared to invest his or her personal identity in the relationship.

With 9 individuals participating in the study, a total of 20 interviews were conducted. Each interview lasted between 50 and 135 minutes; the total number of interviewing hours was 29.5 hours.

**Characteristics of the Participants**

Nine individuals participated in this study: 6 men and 3 women whose age range was between 23 and 59 years. The majority of participants were in their mid 20's to early 30's. Participants' family/marital status at the time of the interviews were as follows (note: some participants marital/family status changed from the time they experienced difficulties accessing health care to when they were interviewed): concerning male participants, 2 were single, 2 participants lived with their spouse and each had 2 children, while the 2 remaining men were married to Canadian women. One of these individuals had an infant while the other participant's wife was pregnant. Two women in the study were single parents with children living at home. One of these women also had a son who was living in a separate apartment in the city. The account this woman gave concerned her son's injury and his difficulties accessing medical care. The third women, currently living alone with her 2 children, spoke of the difficulty she had in obtaining medical authorization for her husband before he departed for an extended visit to Central America.

Four participants had grade 3 education, 3 had secondary education, 1 had a college degree and the other a university education. Three participants had family
members already living in Vancouver when they arrived at the Canadian border. Two had family in eastern Canada, while 4 participants had no family members in the country. At the time of the first interview, 2 participants had been granted refugee status and gave accounts of their difficulties accessing health care when they were refugee claimants. The remaining 7 were in the process of having their claims heard. Two of the 7 were in the 'backlog', meaning they had applied for refugee status before January 1st, 1989 and had been waiting 2 and 5 years for a first hearing. Participants' residency in the province ranged from 7 weeks to 6 years, with the majority having lived in the city for approximately 2 years.

Concerning participants desire to obtain health care services, 5 sought health care services/medical coverage from CEIC on behalf of family members, while the remaining 4 had personal health concerns. Participants'/family members' health concerns ranged from preventive concerns about immunization, to chronic, acute and life threatening illnesses. Two participants had been hit by motor vehicles, initiating or perpetuating already existing ambulatory difficulties. Two participants' chronic conditions were gastrointestinal in nature and 1 had an arthritic problem. One participant sought medical coverage from CEIC on behalf of her husband's visual impairment. Other health problems were typical of those who live at the margins of society, namely, sexually transmitted diseases and injuries from assault. One child's problem was related to kidney disease which had been asymptomatic, while another participant's family member suffered injury from heavy labour. His injury developed into a life threatening condition as a result of being denied early medical intervention. Lastly, 2 participants' chronic ambulatory difficulties were related to the militia's brutal attacks in their countries of origin.

Concerning participants' mental health, descriptions from 2 individuals indicated that they were suffering from post traumatic stress which originated from past atrocities in their countries of origin. Their stress was manifested either in the form of paranoia, nightmares or painful memories from having witnessed family members being killed or from being physically attacked or tortured. Other participants seemed to be suffering emotionally. For example, there seemed to be a wave of despair among 2 participants that arose from the ongoing strain of trying to adapt to life in Canada. Over the course of the interviews, it became apparent that opportunities that would enrich their lives were few or non-existent. In addition, the majority of participants lacked sufficient support to help them cope with the stresses associated with resettlement. In contrast, however, 2 participants were vibrant. One individual's exuberance stemmed from not having to worry about death threats and his family's safety. The other individual was happy about the turn of events in his life: he had found a wife and was now an extremely proud father.
Procedures for the Collection and Analysis of the Data

Four participants were interviewed in their homes, 2 participants were interviewed at agencies, while 3 participants had their first interview at an agency with the subsequent interviews being conducted in their homes. These arrangements were made according to the wishes of the participants. Subsequent interviews were generally conducted 2 weeks after the first interview, although some participants' circumstances necessitated longer intervals. Data collection was through unstructured interviews with agency staff interpreting. Translated interviews were audio-taped with permission from the participants and later transcribed by this researcher.

'Trigger questions' (Appendix C) were used to initiate the interview process but were rarely used during the interviews so as not to interrupt the flow of participants' descriptions. Two participants, however, were found to give consistently short answers and to get them to elaborate on their experiences was difficult, even when using open ended questions. In these situations, the interpreter was asked to explain the need for more detail, but this process proved futile. In the end, these interviews were very regimented with this researcher having to ask a number of questions instead of participants providing a free flowing descriptive narrative. Although the data from these 2 participants was sparse in content, it was rich in meaning and enabled this researcher to get a clear sense of their experiences accessing health care. In contrast, the other 7 remaining participants were quite verbose and described their experiences at length. When discussing the verbal disparity between the participants, the interpreters remarked that the individuals who failed to elaborate were generally quiet or shy, while those who freely discussed their experiences at length were more outgoing and talkative.

Interviews conducted in the home were sometimes interrupted by children. Interruptions were not perceived as 'annoyances', but rather, offered insight into family life. Family members were also often in the background listening to what was being said. Their presence did not seem to interfere with participant disclosure as the information that was provided by participants was detailed and extensive. Observation of where participants lived, what their homes were like, what they ate, who was visiting (extended family or friends), were observable data that helped this researcher formulate a sense of participants' daily lives. While 2 participants lived or spent the majority of their time in downtown eastside streets, other participants had settled into apartments in less transient areas.

Each interview lasted between 50 and 135 minutes. All participants were interviewed twice, while 2 were interviewed 3 times. Interviews were later transcribed verbatim by the researcher and analyzed according to Giorgi's (1975) phenomenological method of analysis which included the following 4 stages: 1) a reading of the entire script
script to get a sense of the whole 2) another reading to categorize units representing changes of meaning in the data and to identify themes dominating these units 3) analysis whereby relationships between themes were identified; this process of analysis continued until no new themes emerged. Themes were then translated from participant language to concepts, and lastly 4) a synthesis of the themes/concepts was formulated into a comprehensive description which described their experiences. Data collection and analysis occurred concurrently which is congruent with phenomenological research (Lofland, 1971). Analysis of the data was then clarified and/or validated by the participants and confirmed by the interpreters. Lynam and Anderson (1987) acknowledge the interpreter's role in the data analysis.

The Complexity of Accessing and Interviewing Study Participants

How to access potential participants is an issue that confronts researchers. The researcher's limited familiarity with the Latin American community and her inability to speak the language of participants added to the complexity of accessing and interviewing individuals who met participant criteria. This situation necessitated greater reliance on agency personnel for their assistance. Control over access and decisions regarding who does the interpreting became a shared domain between agency staff and the researcher. The notion of 'shared domain' embodies acknowledgement and respect for agency staff wanting a more substantial role in the research process. While the researcher originally planned to use an independent interpreter for the interviews, agency staffs' request to interpret for individuals they recruited was respected. Agreement was based on the fact that agency staff were neither CEIC employees nor health care providers, and their trusting relationship with participants would promote participant comfort and a sense of security. Furthermore, agency staff's involvement in the interview process was perceived as a means of safeguarding their relationships with these individuals.

The above perspective suggests that agency workers, as interpreters, fulfilled the roles of protector and overseer. In other words, it was their way of maintaining 'a handle on the situation'. However, drawbacks exist concerning agency staff involvement as interpreters and in recruitment. It is recognized that agency staff may have selected clients and directed the interviews to create support for their perspectives on issues facing refugee claimants; as such, this creates limits on the data.

Emotional Distress and Researcher Response

As the perspective in phenomenological research emphasizes the relationship
between the participant and the researcher, it is necessary to address issues that emerged in the course of the interviews and how these were managed. The most common issue was participants' expression of emotional distress. During the interviews, 2 men and 2 women expressed emotional pain either from past atrocities in their countries of origin, or, from the difficulties they encountered when trying to access health care services for their family members. The point at which distress began to surface, in the expression of a quivering voice, tears or prolonged staring at the ground, the tape recorder was turned off and time was given to allow participants' emotions to surface, linger and dissipate. At this point, although the interview was still an interview in the sense that participants' emotional expressions revealed the intensity/acute of their feelings associated with past and present circumstances, more importantly, the interview became a therapeutic process whereby participants had an opportunity to vent their feelings and concerns. The researcher acknowledged the intensity of emotion at these times and empathy and compassion were expressed. These moments made it clear to this researcher that these individuals needed to share their experiences, and that their circumstances concerning past atrocities or difficulties accessing health care were very much in the forefront.

Hearing participants' stories of being brutally attacked and witnessing family members being killed in Central America, along with seeing participants' wounds, had a profound impact on the researcher. Although the researcher has cared for the dying whose suffering stemmed from the natural course of disease, the suffering the study participants experienced was of a different kind; one that was rooted in violence towards humankind. As a result of hearing participants' accounts of personal atrocities, the researcher experienced nightmares and felt depressed about their life circumstances. The distress and the emotional content of the information participants shared was perceived by the researcher as a valuable opportunity to grasp more clearly their realities. The results of internalizing participants' experiences was a way of coping with the traumatic data.

Anderson (1991) discusses the notion of reciprocity between the interviewer and the interviewee within the confines of the interview. Anderson's (1991) example of reciprocity is when an interviewer answers an interviewee's health related questions that arise during the course of the interview. In this study, it became clear to this researcher that many participants were needing support that went beyond the confines of the interview. The researcher defined her own boundary of reciprocity and assisted participants once final interviews were completed. Helping these individuals in a concrete way conveyed to participants the researcher's genuine concern for their circumstance.
Issues of Reliability and Validity

The rigor of qualitative research must be evaluated in relation to criteria appropriate for this type of study (Sandelowski, 1986). Because qualitative studies are not designed to test theory, they cannot be judged according to the same tests of rigor associated with quantitative research (Sandelowski, 1986). Rather, Guba and Lincoln (1981) have designed four criteria of rigor pertinent to qualitative study: credibility, transferability, auditability and confirmability.

Credibility

Internal validity in qualitative research refers to whether findings are indeed credible (Sandelowski, 1986). Comparing findings with other sources is a means of achieving credibility (Guba & Lincoln, 1981). Clarification with participants included validation of meaning and this researcher's interpretation of the data. Interpreters' confirmation of the data analysis was also a means of establishing credible findings.

Transferability

Transferability in qualitative research addresses external validity or generalizability of the findings (Guba & Lincoln, 1989). While in quantitative research methods of assuring external validity pertain to tightly controlled environments, in qualitative research, examining phenomena in their natural setting with fewer controls creates fewer threats to external validity (Sandelowski, 1986). According to Guba & Lincoln (1981), a way of assuring generalizability is through 'thick description' where subjects' characteristics, the entity being evaluated, the nature of the community and the culture are described. Such a description facilitates transferability judgment for those who may wish to apply the study to their own situations (Guba & Lincoln, 1989). In this study, extensive description of participants' characteristics, their health care seeking experiences, the context in which these experiences were lived, along with verbatim narratives enclosed in the findings, fosters clarity and comprehension of the findings, thus facilitating transferability.

Auditability

Auditability refers to whether the researcher has achieved a clear decision trail, enabling another researcher or reader to follow the progression of events in the study and understand its logic (Sandelowski, 1986). Steps in analysis included descriptions of the way in which concepts were formulated from the data. Thesis committee members' scrutiny of how concepts emerged from the data assure auditability.
**Confirmability**

Confirmability concerns freedom from researcher bias (Sandelowski, 1986). In quantitative research, while researcher distance from the subject and the data are means of diminishing researcher bias, Sandelowski (1986) states that in qualitative research, the relationship between the interviewer and the participant is a significant part of the research process. According to Guba and Lincoln (1981), the criterion for confirmability is the confirmation that the conceptual analysis of the findings is grounded in the data. A technique described by Guba and Lincoln (1989) for assuring confirmability is an audit of the findings which was described above.

**Protection of Human Rights**

The rights of participants were protected in the following ways:

1) Written approval to conduct the study was obtained from the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects.
2) Agency approval to recruit participants was obtained.
3) Participants signed written consents before the interviews began and only after the nature of the study, their involvement, the study's purpose, how the data would be collected and handled, were explained.
4) The participant information letter and the consent form were translated into Spanish (and then back translated into English) to facilitate understanding among participants who were literate in Spanish.
5) Participants were advised of their rights to withdraw from the study at any time, that they could refuse to answer any questions without adverse effects and had the power to stop the interviews or refuse taping (see Participant Information Letter and Consent Form: Appendices A & B).
6) Participants were told that their decision not to participate or to withdraw from the study would not jeopardize their access to the agency's services.
7) Participants were informed that only this researcher, the interpreter and faculty on the thesis committee would have access to taped materials/transcripts and that their names would not be identified on materials, thus ensuring the protection of participants' identity (see Appendices A & B).
8) This researcher acted in a manner considered to be in the best interests of the participants.
Summary

This chapter addressed the research design used in this study. Sampling method, participant selection, procedures for collecting and analyzing data, and issues of reliability and validity were outlined in congruence with phenomenological research. Participant's rights, recruitment/interpreter issues, the emotional context of the interviews and this researcher's response were also discussed. The next chapter presents the findings from the interview data.
CHAPTER 4: PRESENTATION OF THE FINDINGS

This chapter examines the health care seeking experiences of the participants and/or their family members. From the narratives of the participants, what became strikingly apparent was the complex nature of their circumstances and the degree of hardship the majority of participants encountered while trying to access health services either for themselves, or for their family members. Although this study was originally designed to address refugee claimants' experiences prior to obtaining health care services, understanding participants' health care seeking experiences in a more meaningful way necessitated the inclusion of their experiences within health care institutions. For this reason, participants' experiences in health care settings are also included in the findings.

Three central concepts emerged from the data: marginality, health care seeking experiences and the illness experience. Each concept was comprised of several different themes which will be described below. In the process of analyzing the data, it became evident that participants' experiences in their countries of origin shaped their lives in Canada. Their health care seeking and illness experiences, then, had to be understood in relation to the context of their past, as well as to their present circumstances. A main explanatory concept central to understanding participants' realities is the concept of marginality. The themes—fear, suffering and the journey pertain to participants' past. The themes unemployment, loss and isolation and discrimination describe their present realities.

Themes affiliated with the concept, health care seeking, namely, deciding to seek health care, experiences with CEIC and encounters in health care institutions, reflect the processes participants experienced when trying to obtain health care. Policies and bureaucratic processes were found to significantly shape their health care seeking patterns. Difficulties in obtaining medical coverage or comprehensive medical care had repercussions on their illness experiences. Prolonged physical/psychological suffering, familial consequences and functional decline are themes that capture the essence of such experiences. While participants' health care seeking and illness experiences were shaped by their marginality (see Figure 2, p. 28), participants' narratives also indicate that their experiences were embedded in the realms of larger political institutional structures of society.

This chapter, then, addresses the three main concepts and their related themes. The chapter begins by analyzing participants' marginality which provides the contextual basis for understanding participants' health seeking/illness experiences. Figure 3 (p.28) is an overview of the concepts and themes which emerged from the data analysis.
Figure 2. depicts three major concepts that evolved from the data analysis. The diagram illustrates how the concepts health care seeking experiences and the illness experience are embedded in the concept of marginality.

CONCEPTS AND THEMES (explicating the diagram)

Concept: **Marginality**
Themes:
- The Past: Fear, Suffering and the Journey
- The Present: Unemployment, Loss and Isolation and Discrimination

Concept: **Health Care Seeking Experiences**
Themes:
- Deciding to Seek Health Care
  - information
  - language issues
  - the influence of policy, processes & political status
  - illness/injury symptoms
- Encounters in Health Care Institutions
  - services accessed
  - negative experiences
  - positive experiences
Themes: Experiences with CEIC
- rejection
- fear and perseverance
- powerlessness

Concept: **The Illness Experience**
Themes:
- Prolonged Physical/Psychological Suffering
- Familial Consequences
- Functional Decline

Figure 3. Concepts and themes emerging from the data analysis.
Marginality

The Past: Fear, Suffering and the Journey

When participants spoke of their lives in their countries of origin, one particular emotion surfaced: fear. Participants feared for their own lives and for the lives of their wives, children and extended family members. Because many participants were involved in political activities in their countries of origin, their lives and their families were endangered. Living in constant fear thus became the impetus for leaving their countries.

I had many serious political problems. I belonged to a union. Many enterprises were destroying the workers--they don't pay them enough money. Since we were trying to create unions we automatically became enemies of the government. We got many death threats. The political police were persecuting us, watching us and trying to destroy our belongings. They would come into our home many times. I was afraid for my children and wife. That is why we left our country.

My son worked in a factory. One day the military came and took his friend away. She disappeared. No one ever saw her again. My son got scared and he decided to leave the country.

The police were killing a lot of people in my country. Somebody was persecuting me because of my political activities. There was a murder attempt on me. My brother is also an activist and some people from another party tried to kill him too. That is why I left the country.

Along with fear, the second emotion that surfaced from the interviews was suffering. Although only a few participants volunteered to speak about their personal experiences, one person's comment alluded to the notion of collective suffering when she said: "No one, no one in my country has been spared. We have all suffered." Most participants declined speaking about their personal experiences, motioning that their memories were too painful. Insight into how painful these memories can be for some refugee claimants was triggered by what one individual said:

If I unleash my memories, these things about my past, about my torture--who is going to be there to pick me up when I fall? I may never, never come out of it alive. (pause) I am speaking about suicide.

Embedded in these few words is the sense of unfathomable pain and vulnerability some refugees live with. Thus, when 2 participants volunteered to share their experiences, it was a testimony to their personal strength and fortitude.

I remember when the police squadron killed my sister and father-in-law. As a
consequence, my mother died that night of a heart attack. I too was almost
killed. I have many holes here (participant points to his head). The militia attacked
my head with the end of their machine guns. They shot me. The bullet went
through my liver and stopped here (participant points to his chest). Another
bullet went through my arm. The only reason why I am alive today is because they
thought I was dead. Someone found me lying on the road bleeding. I was taken to
hospital. I was in very bad shape. I had a brain operation. For a long time I could
not even remember my name.

One time my sister and I were helping some peasants in a nearby village from
where we lived. It was a small village with not too many people and the people
were very, very poor. We were outside a family's home when the militia came. In
front of me they killed my sister. I started screaming. They said she was involved
in activities that went against the government. They took me and dragged me
through a field and started beating me up. They kicked me in the stomach many
times. I was pregnant. I thought my baby was going to die. Then they left. I tried
to get up but I was in too much pain. Then I heard shots. A soldier was still in the
field and was shooting at me. It was dark, he could not see well, so I never got hit.
I lived and so did my baby (pause). Four months earlier they killed my husband. I
saw that too (participant starts to cry).

These peoples' experiences unveil profound human tragedy. Yet, rather than
dwelling in the past, these individuals spoke of living for the future. The one individual
explained how he looked forward to one day being granted refugee status and finding
work. The woman recounted how raising her daughter has brought meaning and purpose
into her life. She also explained that her hope in life centered on her daughter's existence.

In addition to participants' experiences in their countries of origin, some
participants spoke about their experiences of coming to Canada. Their stories depict
hardship, compassion and danger.

I came to Canada by jumping on trains. My friend taught me how to jump so I
wouldn't roll under the train and kill myself. It was cold riding the trains and
the smoke from the engines would make my eyes burn....My friend and I survived
by going to churches and asking priests for some money for food. Sometimes we
worked picking fruit or vegetables--but the pay was never good. Once I worked
for a week picking green peppers and the boss took money from our wages for
food and lodging. I had worked a week and only received twenty five dollars!

This one United States Immigration officer didn't like me. He grabbed me by
the shirt and pushed me. He said he didn't like Central Americans. His actions
brought back feelings of me in the war and I had to tell myself not to react. I
was scared. My family and I were told to come back in the morning. They
wouldn't let us stay in the Immigration border office....So there we were, my
wife, our child and me, with our bags, walking to Bellingham along the highway at
one o'clock in the morning.
When coming to Canada, the most beautiful thing happened to us while at the border. Because there was no Spanish interpreter at the Canadian border—it was late at night—my family and I were sent back to the United States side. One Immigration officer who spoke Spanish said we could not stay there for the night but said he would help us find accommodation. He went away and made a telephone call. A while later this older lady in her fifties came in her car and said she would take us to a hotel. She was really kind. She paid our hotel bill and gave us money for a taxi to get back to the border in the morning. She said if something went wrong and we couldn’t get into Canada, I was to call her and she would help us out again. This was a very wonderful moment for me to see people who were so kind.

Participants' experiences of coming to Canada varied. It is clear that what helped participants the most was the kindness and compassion that was offered to them by individuals: individuals in government positions, clergy, and in the community. By the same token, what made participants' journeys difficult was when they were taken advantage of, mistreated, or when there was no compassion for their circumstances.

Participants' accounts of their journeys, fears, and what happened to them in their countries of origin are important to this study. They are important to this study because they provide a greater understanding of who these individuals are. Thus, when these individuals attempted to access health care and encountered difficulties, their experiences were embedded within an entire history of hardship and suffering.

The Present

The present marginal lives of the participants characteristically reflect uncertainty and vulnerability. Their vulnerability and uncertainty stem from the emotional drain of facing life in an unfamiliar culture, with undetermined legal status, while also coping with traumas of the past. Yet, these individuals earnestly strive towards the rebuilding of their lives in hopes of leading peaceful, productive lives. It became apparent from the interviews, however, that the difficulties participants encountered that interrupted their growth, stability and development of positive self esteem were related to social and economic factors that were steeped in political issues. This section of the chapter will therefore focus on participants' life experiences according to unemployment, loss and isolation and discrimination, as they described them.

Unemployment was a major concern that plagued all participants. According to these individuals, their language/educational barriers, policies restricting their access to government-sponsored English/job training, as well as, policies surrounding the issuing of work permits to refugee claimants, were reasons participants gave that hindered employment opportunities. At the time of the interviews, all participants were on welfare
and not by choice. During the course of the interviews, participants talked about the importance of work and how living on welfare was an unacceptable way to live.

In my country, you have to work in order to live. If you no work, you no eat. Everyone must work. It's no good for the people to do nothing and get paid for it.

I want to earn money with my hands and my mind. I don't like to take welfare. I need to improve what I have in my mind—to develop myself—to give something good to society.

We are on welfare. I feel I am not doing enough for my family (pause).... I feel I am not a good provider for my wife and child. (participant begins to cry).

From the above excerpts, it is clear that participants' desire to work was multifaceted. Longing for work grew out of a need to provide for their families, to develop themselves, and to be contributing members of society. It was evident that working was strongly linked to a positive self image and that unemployment fostered feelings of low self esteem. Fathers in this study were particularly vulnerable to feelings of low self esteem since unemployment jeopardized their credibility as providers.

Participants' impetus to work not only evolved out of familial responsibility. Financial hardship was another reason employment was sought. According to participants, even those of lower class standing in their countries of origin stated the amount they received from the Ministry of Social Services and Housing (MSSH) was inadequate to live on. They described having to rely on food banks and other charitable organizations to help them sustain their lives. In addition, economic hardship had an impact on their illness experiences.

I would like to work because not working means I have no money to support my family. The money from welfare is not too much...I cannot buy things for my daughter. This is a big mental problem for me. I think about this very much.... What helps us is the food bank. I bicycle there every week.

When I am sick I worry because I don't know if I will have enough to buy medicine....It is very difficult living on the money Social Services gives you.

I have little money...I could not even afford the bus when I was sick. I had to walk to the hospital. I get little money from Welfare—$62.50 a week, that is all. I am waiting for my refugee papers from Immigration so I can work.

Minimal income from MSSH dramatically hampered the last person's quality of life. He lived in a large rooming house where he shared a bathroom with twenty other occupants living on the same floor. There were no shower or bath facilities. He explained
that his day consisted of going to a charity agency where he had breakfast and a shower. After that, he said, he would walk the streets for most of the day, or, occasionally volunteer to sweep church halls and clean up parks. When his health was better, playing soccer was included in his daily activities. Now, he said, he just sits on the sidelines or doesn't bother going at all and instead, in the evening, goes and drinks beer at a local bar. This man went on to explain that he has been waiting for his refugee papers from CEIC since the mid 1980's and hopes to secure a job once being granted refugee status. He said with refugee status, opportunities for work will be greater.

This individual's life reveals how empty and meager refugee claimants' lives can be. His circumstance stems from lack of employment opportunities, financial hardship and an undetermined legal status. When this man spoke of his life, there was an overwhelming presence of sadness and shame. His situation reflects how policies associated with the issuing of work permits and drawn out legal procedures that determine refugee claimants' legal status can shape the lives of refugee claimants.

The negative repercussions of unemployment and low income influenced the psyche of participants. It also had an impact on their lifestyles beyond creating a marginal existence. For example, a few participants perceived government restrictions on refugee claimants accessing work permits and the work force as having potentiated their vulnerability to alcohol abuse. One participant explained that his vulnerability stemmed from "not having anything to do."

In this study, participants who were living alone and had no family in Vancouver talked of using alcohol as a means of coping with their loneliness and marginality. Their use of alcohol subsided when they entered meaningful relationships which led to marriage and eventually parenthood. The impetus for change, according to these participants, was their desire to become good providers for their families. Despite language and cultural barriers, marriage to Canadian women helped these participants to successfully alter their lives. Ultimately, it seems what these individuals needed was something that would give their lives meaning and direction. Limited opportunities for employment associated with language/educational barriers and the issuing of work permits failed to provide these individuals with the focus they needed; relationships, however, did.

Being unemployed and living on welfare created additional problems for some refugee claimants. The feeling of being dominated by the government was an issue that one participant spoke about in conjunction with living on welfare. Living on welfare not only undermined this individual's economic capabilities, it also created the unwanted feeling of being dependent on the government. The participant explains:
I am not use to being dependent on people—on Welfare and Immigration and being told how I am to spend the money. I was use to managing my own money and spending it how I wanted. I had three jobs. Now I feel like my life is being controlled because they tell me how I am to spend the money.

The difficulty some participants experienced with living on welfare was linked to loss of economic independence. Feelings of domination, which were rooted in the government's control over the spending of their welfare cheques, was interpreted by this participant as loss of personal freedom.

While participants perceived that their unemployment was associated with restricted access to work permits by CEIC, they also explained how their inability to speak English and lack of educational qualifications contributed to the problem. None of the participants spoke English when they arrived in Canada, and 4 of the 9 participants had only grade 3 education. A few participants described how they were denied access to government language and job training programs because of their refugee claimant status and claimed being denied entry to such programs created further delays in their joining the work force. One person, however, with grade 3 education and minimal English, did find assembly type work through the help of a Latin American agency.

**Loss and Isolation** In addition to coping with unemployment, some participants' lives were also characterized by a sense of loss and isolation. Their isolation stemmed partly from loss of family and friends, loss of the milieu of traditional values, cultural transitions, and having experienced atrocities in the past. The following excerpt illustrates one participant's experience of loss and how cultural change fostered isolation.

First you lose your country, your city, your family, your parents. Then you come here where the condition is too fast. The people almost never, never have time to come see you, to stop and say hello, have a cup of tea. Instead they say no, I have no time—I go to work, I go shopping, I have to pick up my daughter, I have to vacuum the house. It's crazy here! It's different in my country. We live more near each other and make time for the people. (pause) We have nothing here. We lose many things here in Canada.

The above narrative illustrates how pervasive the experience of loss can be. This individual spoke of loss in terms of the geographical, the social and the cultural. The greatest loss was that of friendship. When this person encountered the cultural values of Canadian society while trying to maintain his culture's value of friendship, his efforts of extending opportunities for friendship were rejected. The impact of this experience was revealed later in the interview when he said: "We don't have many friends here. We just keep to ourselves."
Participants' isolation was often more acutely felt during their first few months in Canada. As claimants became accustomed to life in Canada, their isolation slowly began to lessen.

It's hard when you first come here. It's so different and so cold. When we took the apartment we did not go outside many times--maybe four times a week.

We didn't know the area if it was good. We kept the children inside. It was very hard for all of us. We couldn't speak no English. We never spoke to anyone. But after a while, we learn a little English and we find what a good country this is. We like it here. Everything is fine.

This individual's sense of isolation was experienced in the context of unfamiliarity. As this person felt more familiar with his surroundings, the boundaries he had set for himself and his family were extended. It appears, then, that the process of familiarity was a necessary step in diminishing his and his family's seclusion. Language ability was an important vehicle in facilitating integration.

Although some individuals experienced isolation more dramatically when they first arrived in Canada, others experienced different kinds of isolation over the years. Past and present circumstances contributed to this one individual's experience of isolation which resulted in loneliness.

I has lived here for some years and I am homesick. I has got no family here. My life I speak of solitude. The country is very big and I am alone here. It is not difficult to make friends here, but these people are not really my friends--they don't really care....It is painful to live sometimes. I remember the police killing my sister (pause). That is why I cannot sleep at night. Sometimes I have nightmares. It makes life very difficult.

For some individuals, their experience of isolation was magnified when they perceived their new surroundings as threatening. Living "underground" in their countries of origin and experiencing torture created an overwhelming sense of fear for their lives even when in Canada. The manifestation of their fear was deliberate isolation.

I was a victim of torture and for many years my life was in jeopardy. Because the militia wanted to kill me, I had to go in hiding. So, when I first came to Canada I was afraid to go anywhere. I could only walk within a few block radius. I was afraid I was going to be killed. It was even difficult for me to go to my friend's home--and this was someone I trusted. It took me a long time to recognize that I was safe and to get over my paranoia. I spent a lot of time in my rented basement room. It only had a bare lightbulb hanging from the ceiling and a bed. That was it! But I felt safe there. It was my home. Whenever I went out, I couldn't wait to get back to my room.
The above narrative uncovers the ongoing psychological trauma some people experience and how fear is manifested in a life of isolation. Insight is gained about the effort it takes for some refugee claimants to rebuild their lives.

**Discrimination**  Along with unemployment and the experience of loss and isolation, discrimination also contributed to participants' sense of marginality. Discriminatory experiences conveyed to the participants that they were neither wanted nor cared for, which left participants feeling they did not belong. All 9 participants described incidents in which they felt discriminated against. Participants described being discriminated against on streets, public transit, educational settings, government institutions, health care settings and in jail. The following narratives are examples of participants' experiences:

When I first came to Canada, I was about thirty. I was on the bus and these guys started to hit me. I have been hit many times since without knowing why. There started my depression. In my country, I am proud of being myself—I can look right at people, but here—I look to the floor.

At school people look at me as if I am stupid. They think I am inferior. People think Spanish people are poor, not only in the material, but also in the mind. One day I will convince them something different.

When I went to pick up my welfare cheque, my stomach was always in knots. My girlfriend and I were always made to wait longer than everyone else before being given our welfare cheques. Sometimes my girlfriend was told to come back tomorrow after having waited many hours. This one person at Welfare would throw the cheque at me as if I was a dog and would say us foreigners were taking money away from Canadian people. I wanted to tell her all that I had been through but I couldn’t speak English.... We were often treated like this.

I felt discriminated against in the hospital because nobody cared for me. They say I need Care Card.

I told police when I was in jail that I needed to see a doctor. Nobody came. Three separate times I asked but no doctor came to help me. I see other people in jail ask and they get help. I felt very bad.

Such actions of others made participants feel that they were somehow different and inferior. This contributed to their feeling of isolation. Their inability to speak up for themselves because of language barriers perpetuated powerlessness.

By examining the present lives of the participants, an understanding of their disadvantaged, marginalized position in society is gained. Thus, when participants encountered illnesses and injuries, their misfortunes were experienced within the context of unemployment, loss and isolation and discrimination. The burden of having to cope with
their illnesses and injuries was accentuated when they encountered hardship while trying to access health care services.

Health Care Seeking Experiences

Participants' experiences of seeking health care involved a series of processes. Themes reflecting such processes include: deciding to seek health care, experiences with CEIC and encounters in health care institutions.

Deciding to Seek Health Care

From participants' narratives, it became evident that deciding to seek health care was a complex process. The sub-themes: information, language issues, the influence of policy, processes and political status, as well as, illness/injury symptoms are variables which had an impact on participants' decisions to seek health care.

Information

Participants' decisions to seek health care services were dependent upon the information they received about services and the processes involved in accessing them. Participants gleaned information about accessing health care from formal and informal sources. Formal sources included Immigration border officials, CEIC central office employees, and agency staff who worked for multicultural or non-profit community based organizations. Informal sources were primarily family members and friends.

Participants' narratives reveal that the information they received from border officials ranged from no information to one participant being explicitly told that he and his family had the right to ask for medical coverage from CEIC; free clinics, however, were not mentioned. It became clear from the data analysis that the information provided by CEIC employees varied and was left up to the employee's discretion. The data, however, did indicate that a steady increase in information was being provided by CEIC. In this study, for example, those participants who arrived in the mid 1980s reported that no information was given, whereas in the late 1980s, participants were given names of Spanish speaking physicians and were told which hospital to go to if they needed medical care. By the early 1990s, some participants were given lists of Spanish speaking physicians and which medical clinics accept refugee claimants. One participant suggested a similar list of dental clinics would be useful. This individual was refused emergency dental treatment at one clinic because this clinic was unfamiliar with the process of billing CEIC.

Non-profit agency workers provided participants with the most comprehensive information. Agency workers informed participants about free clinics and going to CEIC for medical coverage. This researcher observed, however, that some agency workers, in the best interest of their clients, withheld information about services they felt were inferior.
Some non-profit agency workers who were providing information were relative newcomers to the country and/or the city.

As for family and friends, the information they provided to participants was based on personal experiences and preferences and included which doctor, free clinic or hospital to go to. They were also familiar with the process of going to CEIC requesting medical coverage. However, family and friends lacked up to date information about what resources were available for refugee claimants. For example, one participant was unaware that her son could have attended a free clinic.

In the final analysis, it seems that participants never received complete information either from formal or informal sources about the health care system and what health care services different health care facilities provided. This conclusion was drawn when one participant said he was not aware that his children could be immunized at free clinics. Instead, this father went through the trouble of obtaining medical coverage from CEIC in order to visit a family physician. Participants were also unfamiliar with the services public health nurses provided and many were not familiar with the term public health nurse. Participants also wanted to know how they could access specialists. They described how in their countries of origin, they sought specialists directly and thus were unfamiliar with the system of referral.

The information participants received influenced their health care seeking. Their decisions to access services, however, were not always easy, particularly when participants had to seek medical authorization from CEIC. These circumstances arose when participants lacked knowledge about free clinics, or, had complicated health problems that could not be treated at the clinics. Most participants, because of their inability to pay for their own medical expenses, sought medical coverage from CEIC before using health care services. Knowing that requesting coverage from CEIC involved embarking on a bureaucratic odyssey created a certain degree of uncertainty in the participants. For example, phrases such as "I didn't know what to do--whether I should go to Immigration" were iterated by a number of individuals indicating their indecisiveness and the negative influence the bureaucratic process had on their decisions related to accessing health care. Participants explained that accessing health care via CEIC was a difficult, time consuming process involving additional considerations that influenced their decision making.

Language Issues

One consideration participants identified was the issue of language and the problem of finding interpreters who would accompany them to CEIC.

Before you go to Immigration you have to think about interpreters --how you are going to get one. This is a big problem for us. Sometimes you have to wait eight days for an interpreter from an agency. When you are sick, you cannot wait eight
days. That is why I couldn't decide whether to go to Immigration or not, because I didn't have an interpreter.

The only person interested in getting up at five thirty in the morning to go to Immigration is yourself. It is very difficult to ask a friend to come and interpret. You know it is a big inconvenience. It is not easy to ask. It makes you think twice about going to Immigration for medical assistance.

Participants encountered difficulties both formally and informally when it came to finding interpreters. A high demand for agency interpreters and participants' own reluctance to ask friends and family for assistance, prolonged or deterred their decision to seek medical coverage from CEIC. In cases where participants spoke a little English, they ventured to CEIC without interpreters but feared not being able to describe explicitly their health concerns in a way that would render medical authorization.

I think why my husband have to wait so long before Immigration say yes to cover eye surgery is maybe because I no speak clearly--I no explain well to Immigration the suffering he go through because of the eye.

The last few narratives depict problems participants faced in relation to language issues. Participants encountered difficulties or risks when confronted with having to find interpreters or when venturing to CEIC alone. Furthermore, this individual, because of her limited English, blamed herself for not being able to secure medical coverage for her husband. Language barriers, then, not only impinged on their daily lives, they also created barriers for participants when wanting to access health care.

The Influence of Policy, Processes and Political Status In addition to language related issues, participants gave other reasons for hesitating or deciding not to seek health care via CEIC. Many participants' considerations were related to how services were structured and the waiting involved in receiving attention at CEIC.

I decided I would not go to Immigration ever again even when I am sick because of the process. The waiting, waiting, waiting....You wait outside in the cold at six in the morning. At 7:30 they open the doors and then you go inside and wait again. It takes the whole day....It's a very demoralizing process.

You have to wait many hours. It's the worst thing. Sometimes its raining. You have to be there around six in the morning. Every morning you can see the people line up. We ask for a number and you go inside to the third floor and wait again--usually three or four hours. That is why I don't go to Immigration.

It is so difficult to go to CEIC. When one is sick one usually goes to bed and rests. For refugee claimants, we have to spend a day at Immigration.
In addition to having to endure long waits, some individuals referred to CEIC's policy of covering "emergency situations" as the reason they chose not to go to CEIC requesting medical coverage.

Immigration told me very clearly that their policy is only to cover emergency situations. That is why I never ask Immigration for assistance. My problems aren't emergencies. So, I have never received treatment for my condition.

This participant's decision not to seek health care services was directly linked to CEIC's policy of covering only emergency situations. This individual feared that his efforts to gain authorization would be rejected by CEIC staff because they would not consider his health problems to be an emergency. This individual stated, however, that CEIC employees never clarified the meaning of "emergency". During the course of the interview he asked: "Does emergency mean I have to be dying?" He was warned by CEIC staff about the consequences of seeking health care services in non-emergency situations:

Immigration told me if it is not an emergency and I still went to the doctor, I would have to pay the bill--they would not cover the expenses. I have no money to pay. If I no pay, maybe Immigration say I cannot stay in Canada-- they see on my record I didn't pay.

Monetary warnings from CEIC were a powerful incentive for this person not to seek health care. Fear of not being able to pay his medical expenses if his condition was rendered a non-emergency by CEIC staff was embedded within his own financial limitations and fear of possibly jeopardizing his future legal status. This participant's concern about his legal status illustrates how political matters took precedence over health concerns. His situation reveals the power of politics in refugee claimants' lives and how politics influences participants' health care seeking practices.

The complexity of participants' decision making concerning accessing health care via CEIC was related to language issues and the influences of policy and processes. It also extended into the realm of financial and political concerns and fear of government reprisal. Because of these difficulties, participants often delayed their decisions or decided not to access health care services via CEIC. The outcome of their reluctance to seek health care via CEIC was demonstrated by their infrequent requests for medical coverage. Some participants explained that although they had been living in the province for several years, they had gone to CEIC requesting medical authorization only once or twice despite suffering from chronic ailments.

Illness/Injury Symptoms Because of the difficulties associated with obtaining medical coverage, it appears that the impetus for the majority of participants in going to
CEIC was linked to how serious they perceived their or their family members' illnesses or injuries. What helped participants determine the seriousness of their own or family members' conditions was the witnessing or experiencing of illness/injury symptoms.

My daughter's condition was an emergency. She was breathing very fast. She fell to the ground and said she could not breathe....That is why I wanted to go Immigration.

I have ulcer....I would go to the washroom and I would see I am bleeding dark red blood....It's coming too much. My wife told me I need to go to Immigration.

I was still having a lot of pain from being hit by a car. I could not bend. When I breathed, I had very sharp pain....A friend went to Immigration for me.

From the above excerpts, it is clear that participants' desires to obtain medical coverage from CEIC were based on tangible signs and symptoms which created a sense of urgency in wanting to access health care services immediately. Having to obtain permission for medical coverage from CEIC before receiving health care services impeded their ability to seek immediate treatment.

Although the majority of participants wanted to obtain medical coverage because of serious illnesses or injuries, some participant's ventured to CEIC for preventive reasons. For example, one father, who wanted his children to maintain their health and well-being, went to CEIC to secure coverage in order to have his children immunized.

What follows, then, are scenarios describing what happened to 4 participants when they went to CEIC requesting medical authorization. The first account addresses what happened to the father who wanted medical coverage for his children. The other scenarios reveal participants' experiences when they or their family members were confronted with serious health problems.

Experiences with CEIC

Scenario 1.

I went to Immigration at six o'clock in the morning with my wife and children. I wanted to get medical coverage for my family. I needed my children to be vaccinated so they could maintain their good health. My wife was also pregnant. We waited six hours and were then told to come back the next day because they could not serve us because there were too many people. The next day we were there at Immigration at eight thirty and at ten o'clock were told to come back the next day. The third day I was at Immigration at six o'clock in the morning and at twelve o'clock I was finally served. The Immigration officer said she could not give me medical coverage because my legal documents were still being processed even though weeks had already passed by. I came three times to Immigration to be told this! She said she could only give medical coverage for my
wife because she was pregnant but that I would have to come back another day when our papers had been processed.

Scenario 2.
I had to go to Immigration and beg these people to cover my husband’s operation. He has only one eye working and it was his good eye that was causing him much trouble. He was getting really sick. He would have these frequent terrible headaches. Sometimes he couldn’t even see....He needed eye operation but people at Immigration said they would not cover his eye surgery. They said this is no emergency. I went four or five times to Immigration asking for their assistance, but each time they told me no. Even when I told them how he suffers, they said they could not help.

Scenario 3.
The third scenario concerns a participant’s son, who, when arriving in Canada was told by CEIC that he could either do janitorial or construction work. Once having found employment, he was told by CEIC that he could then apply for a work permit. Although the son had a previous hip injury while in his country of origin, he accepted work in heavy labour out of financial necessity. After two months of labor, this individual reinjured his hip. The participant describes what happened to her son.

My son heard this cracking in his hip...He didn’t want to tell his boss in case he would be fired. He still had to get the letter from his boss to prove to Immigration that he was working so Immigration would give him a work permit. With the work permit my son could find another job, a lighter job that wouldn’t give his hip so much trouble....My son was in alot of pain--he needed medical attention. When he went to Immigration asking for medical coverage so he could see a doctor, they said they couldn’t give it to him because he had no legal documents, no passport....

Scenario 4.
Our teenage daughter got really, really sick very quickly. She collapsed. Blood was in her urine and her breathing was very fast. This happened three times in two days. This all started one afternoon when she was visiting with her friend after school. We wanted to take her to the hospital but we couldn’t because we had no medical coverage. Instead, we had to go to Immigration asking for medical assistance. At Immigration they told us there was a new procedure for backlog refugee claimants. They said we had to mail our request for coverage instead of asking for it in person. We felt desperate. We explained that our daughter needed medical coverage immediately. The Immigration person just looked at us and said: "that is your problem not mine." I pleaded to her to help us but she just motioned us aside and said "next person."

I mailed a letter to Immigration the next day. Out of fear for our daughter's life we took her to the hospital. I explained to the doctor everything about her condition. After seeing our daughter, he immediately made a referral to a specialist in another department. Tests started on her right away. The nurse
assured me that our daughter would be taken care of but that we needed to get medical coverage from Immigration. So, I went to Immigration the next day again asking for that letter but was told I had to wait. I was told they could not give me the letter in person and that it would come in the mail. When we received the first bill in the mail, I went to Immigration and asked why we had not received the letter. Many weeks had gone by before we finally received the letter for medical coverage for our daughter. This was a very hard time for us. My wife worried every day that maybe our daughter wouldn't be taken care of because we could not pay and because we did not have the letter from Immigration. This was awful for everyone.

These accounts depict 4 participants' experiences with CEIC. Themes depicting the essence of their experiences are: rejection, fear and perseverance, and powerlessness.

Rejection Three out of the 4 scenarios demonstrate that participants or their family members, at the time of attempting to obtain medical coverage from CEIC, were confronted with medical crises. Participants' accounts illustrate that their initial requests for medical coverage were rejected. CEIC employees denied participants medical authorization because: participants lacked appropriate legal documents, their health problems were considered non-emergencies, their legal documents were still being processed and new mailing procedures applied to the issuing of authorization letters for backlog claimants. The basis for employees refusing to issue medical coverage to these individuals, then, even in the event of medical crises, stemmed from CEIC employees' adherence to policies and processes. For participants, rejection was experienced after having endured long waits, and for some, after having made multiple visits to CEIC.

Participants described feeling incensed by CEIC employees' lack of compassion for their circumstances and their inability to "bend the rules." The following comments reveal participants' shock, their disdain for the process, and their awareness of only refugee claimants being subject to such processes. They also perceived their experiences at CEIC as inhumane.

It's a very bad process for refugee claimants and only refugee claimants. It's not efficient for us to have to wait and wait and then to be told to come back again. It is a big, big bureaucracy. The whole process makes me feel very bad. Because we are refugees doesn't mean we are not human beings. It would be better if people at Immigration could understand our situation better. I didn't think people could be treated like this by a government in a democratic, developed country like Canada.

The people at Immigration don't care about us. I feel frustrated and angry with how I was treated. I was treated as if I was an animal. There was no concern, no concern for my daughter's condition. I felt I was being put aside. These are the kinds of things that happen to refugees [claimants] in this country --it's terrible.
I felt angry with the people at Immigration. I had the impression they did not care about me. I had the impression that they did not care about our health problems. I was very upset that my wife and children were exposed to this kind of treatment.

**Fear and Perseverance** The impetus for participants to persevere with numerous attempts at obtaining medical coverage grew from their emotional ties and grave concerns for their loved ones. Participants described that watching family members suffer created the need to "do something." "Doing something" thus involved the task of having to convince CEIC employees of the realities of their or their family members' suffering. When faced with rejection, participants described situations where they 'begged' and 'pleaded' for medical assistance. According to the participants, the uncertainty as to what could happen to their loved ones if they were unable to secure medical coverage from CEIC was a relentless worry. These participants confessed to fearing their loved ones would die or would succumb to having permanent disability.

I would think about what would happen to our daughter. I worried if we didn't get coverage from Immigration that maybe the specialist wouldn't treat her. We were afraid she might die. This worry wore me down. I couldn't eat. I couldn't sleep. I couldn't concentrate on my studies. I felt as if I was in a fog.

I knew my son was really sick. I wanted him to get medical care but Immigration wouldn't help because he didn't have legal papers. I thought-- oh my God, what if he dies?" (participant starts to cry).

I worried that my husband would lose his vision completely. I thought what am I going to do if my husband goes blind? What will happen to the children? I didn't know what I would do. These thoughts were too strong for me.

These excerpts are important because they indicate the psychological impact being denied medical coverage had on the participants. One individual, while trying to convey what it was like being denied medical coverage when her daughter faced a life threatening illness stated: "Although I have been through torture, with my child being critically ill and not getting support from Immigration, is the worst experience I have ever gone through."

**Powerlessness** Experiences with CEIC were disempowering and increased participants' feelings of marginality. The vulnerability they experienced from facing medical crises was heightened by the fact that government employees controlled their access to insured medical care. Participants, therefore, lacked control over the outcomes of their medical crises. Going to CEIC and being refused medical coverage at a time of need created in the participants an awareness of their powerlessness. Participants linked their powerlessness to government control, their lack of status and their inability to effect change. Their powerlessness was increased by their inability to express themselves.
We have no control whether we get coverage or not—we are refugee claimants. We have no rights.

There is no other way—you need that letter from Immigration so you go and wait.

We didn't have a choice about what would happen with my husband's eye. I knew he could go blind, but there was nothing we could do about it.

Not being able to speak the language, I could not even express how angry I felt with the people at Immigration. This really affected me.

Submission to their circumstances conveys the extent to which participants felt a sense of helplessness. Along with feeling controlled by CEIC, another participant described occasions where she felt humiliated by government employees during the questioning process. She recalled situations whereby employees would take the liberty to ask questions that had nothing to do with the issue of obtaining medical coverage, making her feel humiliated when they asked her when she was going to start working. She commented: "it's not right to be treated this way—for people to make you feel low." This same individual also referred to the difficulty she had in telling government employees about medical problems that were of a personal nature.

I had to tell that I needed______, fortunately, to an Immigration lady. But she kept saying 'I can't hear you, speak up, speak up.' So, I was made to speak up so everyone could hear....She spoke to me rudely....The way she looked at me, I could tell she didn't care.

The people at Immigration would say 'what do you have--what's your problem?' It was like telling Immigration point by point details of how I was tortured every time I went to get that letter.

This person's experience addresses confidentiality issues and the kinds of problems refugee claimants encounter when they are forced to reveal to a CEIC staff medical concerns that are highly personal. According to this individual, difficulty in relaying personal information stemmed not only from the public, impersonal setting, but also from the insensitivity of a non-medical government employee receiving the information.

Encounters in Health Care Institutions

In addition to participants' problems with CEIC, many participants experienced difficulties in health care settings. What surfaced from the data analysis was that participants faced situations where they were denied health care services at hospital emergency departments because they lacked medical coverage. In these instances, their difficulties were directly related to government policy. Receiving inadequate care from
health care professionals when they were insured, or accessing clinics which only could provide minimal care were other factors that hindered participants ability to secure comprehensive care. According to participants, their experiences in health care settings were also hampered by problems with language and discrimination, and a few participants encountered pursuit for payment by health care facilities or collection agencies.

To promote understanding of their difficult situations, participants chose to focus on health care experiences they deemed negative, although they also recounted positive experiences. While this section of the chapter will focus largely on participants' negative experiences, participants' positive experiences will also be included, providing a more unbiased view of their encounters. Examination of place and person to whom participants went for health care and their presenting concerns will first be discussed. Such an introduction provides an overview of participants' health care seeking patterns.

**Services Accessed** Participants' experiences in health care settings involved interactions primarily with physicians in free clinics, hospital emergency departments and family practitioners' offices. In addition, some participants were referred to specialists by family or emergency physicians. Two participants described situations where public health nurses played a dominant role in delivering health care services. These situations were associated with home pre and post-natal visits. No other mention of interactions with public health nurses were made. The visibility of public health nurses within the refugee claimant population is addressed in Chapter 6. Although the remainder of this analysis deals with participants' encounters with physicians, these findings are informative for public health nurses working with the refugee claimant population. Figure 4. depicts where or to whom each participant went for health care services.

**HEALTH CARE SERVICES ACCESSED**

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<tr>
<th>Participant#</th>
<th>Free Clinics</th>
<th>Family Physicians</th>
<th>Hospital Emergency</th>
<th>Medical Specialists</th>
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Figure 4. illustrating the medical professional/ health care setting participants accessed. Note: This figure does not depict the frequency of visits.
Seven out of 9 study participants visited more than one health care provider or health care agency. Free clinics were the most accessed health care service. Of the 7 participants who visited free clinics, 5 were using them as primary sources of health care. According to the participants, free clinics were appealing not only because they provided a free, direct means to health care, but also because the clinics provided Spanish interpreters or had rotating nurses or doctors who could speak Spanish, thereby relieving participants of the responsibility of finding interpreters. Participants also spoke of accessing clinics because of proximity to their domicile/residence.

Participants used free clinics primarily for treatment of common gastrointestinal/respiratory infections and for problems typical of those who live at the margins of society, namely, sexually transmitted diseases and injuries from assaults. Since CEIC covers refugee claimants' medical emergencies, free clinics were particularly beneficial for participants' uncomplicated, easy to treat problems.

The 4 participants who attended hospital emergency departments did so for acute or life threatening conditions resulting from car accidents or work related injuries, as well as for ambulatory difficulties and diagnosis/treatment of symptoms thought to be associated with hepatitis. All participants were medically uninsured at the time of visiting hospital emergency departments. Four participants were referred to physicians specializing in nephrology, ophthalmology and orthopedics. Two out of 4 cases were deemed emergencies by family or emergency physicians.

Although 5 participants had visited family practitioners, 3 were on a once only basis. The remaining 2 individuals who maintained contact with their family doctors were participants with children. They described going to their doctors when their children encountered emergencies or contracted childhood communicable diseases, as well as for their own health problems, including post traumatic stress. Both family physicians were Spanish speaking.

Participants were aware that lack of medical coverage meant they were either going to have to pay for physicians' services, or that physicians were not going to be paid. Hence, most participants attempted to obtain medical coverage from CEIC before visiting physicians. Participants' lack of coverage was associated with having been denied medical coverage by CEIC or when the nature of their illnesses or injuries warranted immediate medical attention. Such was the case when two participants were hit by motor vehicles. As well, participants explained that it was impossible to obtain medical coverage from CEIC when medical 'emergencies' occurred on weekends when CEIC was closed. Furthermore, one father described the dilemma about obtaining medical coverage for his daughter. He explained that although he and his wife and son were refugee claimants and could
potentially obtain medical coverage from CEIC, their daughter, being Canadian born, could not. The participant stated that while CEIC advised him to seek provincial coverage, his refugee claimant status made him ineligible for premium assistance. Unemployment made it impossible for him to pay the premiums. As a result, for over a 2 year period until the family was granted refugee status and were then eligible for premium assistance, whenever the participant took his uninsured daughter to their family physician, the doctor went unpaid for services rendered. The participant perceived himself as being trapped between federal and provincial institutions who declined responsibility for payment. This participant’s situation depicts how provincial/federal policies create situations that make it difficult for some refugee claimants’ family members to be medically insured.

**Negative Experiences**  
Inadequate care, being denied medical treatment and pursuit for payment are themes that reflect participants’ negative encounters in health care settings. According to participants, inadequate care was linked to health care professionals’ lack of concern, as well as to limitations of health care settings. The following excerpts are accounts of participants’ experiences.

```
I told the doctor it is hard for me to eat, that sometimes I have no appetite. He then asked me if I ever had a mammogram. He didn’t even look into my problem about my loss of appetite. I don’t know why he didn’t ask.... I don’t know if that’s the way doctors treat people here, or if it’s a deficiency....they don’t research more into the problem...(pause). I worry I might have cancer.

I didn’t tell the doctor about my problems. He is there only for small problem. My problem is more difficult...I need more information about _____, but I don’t feel comfortable talking because there are too many doctors at the clinic. I need one doctor to tell all my problems to; one doctor who would know my problems well.

I explain my problem to the doctor but the doctor didn’t even check me. The only thing is we talked. He gave me a prescription....I went home and took the medicine but a week later I still had the infection. I didn’t know what to do.

At______, they only help you for medicine. I told the doctor that I was really sick with the ulcer--that I have no check for this. He say I need Care Card or to go to Immigration. He gave me a bottle of maalox and that was all.

I told the doctor about my problem walking. He said he had no equipment, no technology to diagnose my problem. He told me I need to go to hospital--there they could do tests and x-rays. He say he can make no referral to specialist because I need paper from Immigration (medical authorization). So, he didn’t pay much attention.
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Participants' accounts of receiving inadequate care stemmed partially from their perceptions of health care professionals not adequately addressing their concerns or failing to explain why some problems were dismissed. It was found that lack of information or explanation led participants to worry about unresolved health concerns. Although one participant had negative feelings about the care he received, lack of alternatives left him continuing to use the same facility.

At the time of the interviews, 4 participants were living with deteriorating chronic conditions for which they were not receiving medical care. Participants indicated that they did not pursue further assessment or treatment because they felt their chronic conditions made them ineligible for medical coverage from CEIC. Without coverage, these participants explained they had no access to comprehensive assessment or treatment. In addition, 2 of the 4 individuals admitted that their fear of government institutions made them reluctant to seek coverage.

According to participants' narratives, receiving inadequate care also involved situations where they received inappropriate care or were treated in a degrading manner.

My husband found this family doctor through his sister. We went to this doctor but he was very bad. He didn't have good feel to be doctor. He's like radio technician—he's the same. My husband explained about his problem and that he needed his help. This doctor didn't even check my husband. He seemed totally disinterested. He told my husband he could wait till next year for an operation. We left feeling very discouraged.

I had to have my stitches out. I went to Immigration to get medical authorization and they told me of a doctor I could go to. I went but the doctor didn't want to treat me. I think he didn't like the way I was dressed or how I looked or something. He said he didn't want to help me. I told him: 'You are a doctor, why don't you help me?' He just looked at me and then took out my stitches.

My husband and I went to this private clinic....We waited long time before we got attention. My husband say 'look how people who came one hour after us get first attention?' We were there three hours and only three people we waiting ahead of us....I think this is discrimination. They know we are Spanish—they think we are stupid so they don't give us good attention—they think we are different.

While participants experienced marginality outside the health care context, the above narratives reveal that such experiences also occurred within health care settings. Being denied medical care in the presence of acute suffering and life threatening illnesses was another way in which participants' lives were marginalized.

I had a lot of pain—a lot of pain....I couldn't even walk. Although I have very little money, I took a taxi to the hospital....I didn't get any treatment. I was asked to
show paper from Immigration (authorization letter). I have not any papers. I had none to show. So I did not get help. There was no one there I could speak to in Spanish and I could not explain my problem well (pause). I think, I think the doctor in emergency should be there for all, all the people. I left feeling very, very bad, very disappointed. Because of this and other complications in my life—my health is bad, I cannot work, I cannot walk, I have difficulty sleeping because I think of my sister being killed— I think of throwing myself at a car (pause). I think of suicide.

My son was in a lot of pain. When my son went to the hospital, the doctor didn’t treat him. My son told him that there was too much cracking in his hip but the doctor said it was nothing. My son asked him to take x-rays but the doctor wouldn’t because he said he needed that letter from Immigration (medical authorization). I don’t think it’s right that my son was turned away. He had fever, but the doctor just gave him pills for pain....He didn’t even check him. My son went home and cried. Later he got very, very sick.

These narratives uncover situations where participants chose to go to hospital emergency departments when they were in great need of medical care. When participants were refused care because they had no medical coverage, rejection was experienced within the context of accumulated past and present suffering and marginality. The despair they experienced lay in their philosophical beliefs that hospitals were places of compassion and were a resource to all human beings in need. This notion was rooted in past experiences where they described having never been refused treatment either in their countries of origin or while living in the United States. In contrast, their present reality, according to the interview data, reveals that without the appropriate bureaucratic paperwork associated with medical coverage, it was difficult to get the help they needed.

The tragedy for the participant and the participant’s son went beyond the hospital setting. When this researcher asked the participants what happened after they or their son had left the hospital, their responses uncover the marginality in which their illness experiences were lived.

If you have a house, you go to your house. I didn’t have a house. I was living in a tent. I found this tent by the docks. I could not afford rent because Welfare didn’t want to give me money...I walked back to the tent even though I was in a lot of pain. I didn’t have anybody to help me. That is like that here. In my country, friends and family could help me.

My son left his wife and children. Something went wrong between them....When my son left the hospital, he went back to his apartment where he lives mostly alone. He didn’t come to my house because he would drink a lot to take the pain away. He didn’t want me to see him like this....My son has much pride.
In addition to participants' negative experiences where they were denied medical care or received inadequate treatment, they were also confronted with pursuit for payment by health care facility administrators or by collection agencies. Weeks or months after being hospitalized or after visiting emergency departments or non-free clinics, participants were notified they owed money. According to the participants, they assumed when CEIC granted them medical coverage, expenses were covered. Participants were shocked when they had to pay hospital/clinic fees that ranged from hundreds to thousands of dollars. A few participants described their experiences.

Immigration say they pay for all of my medical expenses....Months after I received treatment, I received a call from the health care facility saying I owed money and that Immigration didn't pay all the bill....A week later I received a letter from a collection agency saying I have to pay even a larger amount in forty-eight hours. If not, I should contact a lawyer....They call again and again.

A relative of ours had the impression that Immigration was going to pay for everything. Somehow the health care facility found our address and charged us with our relative's medical expenses. The health care institution kept calling and calling saying, 'you must pay, you must pay' because our relative could not pay. We were told to sign a number of cheques. I made an agreement to pay little money each month. I don't think we should have to pay—it wasn't us who got treatment and besides, Immigration said they were going to cover everything.

Participants or their family members were never told that CEIC's medical coverage pertained to physicians' expenses and not health care facilities' operating costs. Receiving notices or phone calls stating they owed money were perceived as threatening for political and financial reasons. Some participants were disadvantaged when they negotiated monthly payments without interpreters or legal advice.

Positive Experiences In addition to participants sharing their negative experiences, they also spoke of positive experiences in health care settings. From participants' perceptions, positive experiences were linked to 4 recurrent themes: the caring nature and communicative manner of the health care professional, information giving, and treatment and cure. Perhaps the most meaningful "caring nature" participants spoke of was when family practitioners, specialists and emergency physicians agreed to treat them when they lacked medical coverage. The following comments reveal their appreciation of the physicians who were willing to treat them despite their financial hardship and their uninsured status.

I told my doctor about the problem with Immigration--that they would not cover my daughter and that she was really sick. The doctor told me to bring her in and told me not to worry. She was very kind. This happened four or five times.
The doctor told us that under any circumstance, if my wife gets sick, I am to call day or night and he will come, even if we don't have medical authorization from Immigration...I finally found someone who was a real humanist.

After my son was refused treatment at the hospital my son got very, very sick. He went to another hospital a number of days later and when the doctor there saw him he said 'Quick, you must have surgery immediately. This doctor arranged everything for my son. My son was soon operated on.

Such actions by physicians conveyed the message that someone did care, that their health problems were of priority and that payment was of secondary concern. Seeking physicians' assistance when they were uninsured, however, was a difficult process for the participants. The father whose daughter was uninsured described "losing face" every time he had to take her to the doctor. He stated: "How I face my doctor? I know I cannot pay her--but what can I do? My daughter is sick. Every time I see her I have not a good face."

Other characteristics attributed to be caring by the participants were when physicians gave out free medicine, vitamins, infant formula or assisted participants in obtaining welfare. These actions were interpreted as additional acts of support and demonstrated to these individuals that physicians were understanding about their financial plight. One person commented that without the free medicine she received from the clinic, it was unlikely she would recover from her illnesses because she was unable to afford prescriptions. This individual's financial hardship reveals the kinds of services she needed from the health care agency and the magnitude of her dependency on such services.

What was also important to these individuals was when they perceived physicians as making a "reasonable effort" in diagnosing and treating their illnesses and injuries. "Reasonable effort" was based on tangible actions of the physician such as: physical exam, carrying out treatment procedures such as draining or suturing wounds, ordering laboratory tests and x-rays, prescribing medicine, or getting second opinions. In addition, these individuals judged the care they received according to whether they had been cured. One person commented: "...the service at the clinic is good because they cured me of my bronchitis." Another, however, stated: "I am dissatisfied with the care I received at the hospital because they did not cure me. I still have difficulty moving. I am always in pain."

Information giving and the health care professional's manner of communication was important in fostering positive experiences. From the data analysis, it appears that when nurses and physicians provided health care information, participants interpreted such behaviours as showing interest and concern. What facilitated communication was when health care professionals conveyed a non-threatening, friendly manner. Although health care professionals' abilities to speak Spanish fostered communication and was greatly
appreciated by participants, it was found not to be a determinant of positive experiences. What was more essential to the participants was the demeanor of the health care professional and whether they cared about their and their families' well-being. It was also meaningful to participants when health care professionals provided positive feedback about the state of their children's health. Being uprooted and encountering cultural transitions created additional worries for parents, hence, they found positive comments from health professionals reassuring. The following excerpts illustrate the importance of positive feedback, information giving and physicians'/nurses' non-threatening manner.

I like the care at the clinic because they speak Spanish. They have good communication manner and people are friendly and show concern for you....The doctor explain things about infection and nutrition. He tell me my children are healthy....I was pleased to hear that....My wife and I worry about our children because they have been through so much.

The nurse who came to visit my wife was wonderful. She could speak Spanish and was very easy to communicate with. She help my wife with many things. She explain about how the baby grows and she made a referral to the doctor because my wife have problem with her pregnancy.

The nurse came to see my wife soon after our son was born. She talk to us about nutrition and immunization. She showed real concern for our son. My wife was very impressed with this nurse [the participant acted as interpreter during the nurse's home visit].

In contrast to participants' negative experiences, positive encounters in health care settings were situations where participants felt accepted. Positive experiences evolved when participants were medically covered, when language differences were less of a problem and when health care professionals acted out of compassion and concern.

The Illness Experience

From participants' narratives, it is clear that delays or being denied medical coverage/medical services and receiving inadequate care had an impact on participants' lives and illness experiences. Themes that evolved from the data analysis which reveal this impact are: prolonged physical/ psychological suffering, familial consequences and functional decline.

Prolonged Physical/Psychological Suffering

Physical suffering was common to all participants' family members' illness experiences, whether they had acute, chronic or life threatening illnesses. Their suffering
was typically endured for long periods of time and often increased in severity. The following narratives illustrate the duration and increase in severity of symptoms.

In October, my husband get headache four or five times a week. In April it’s continuous—everyday—very big headache all the day....Over a year went by before he get eye operation.

At first there was just this cracking sound in my son’s hip. Later, this infection started to grow. There was much much pus. It was horrible to look at. My son got very high fever. When he moved he would moan. He was in so much pain. (participant starts to cry).

I have ulcer. At first, I just have pain in the stomach. I like this for 2 years. Now when I go to the bathroom I see sometimes dark red blood....I feel scared. It’s coming too much.

The above narratives reveal prolongation of participants’ suffering. They also reveal the development in the severity of symptoms which were often frightening to experience or witness. All of the above individuals attempted to secure medical coverage or adequate medical care. Two eventually did receive the necessary medical intervention required, although it was only after their lives had been jeopardized or after having endured prolonged suffering.

Physical suffering perpetuated psychological pain. Psychological pain stemmed from the hopelessness of their situation and fear of what the outcomes might be should they never access adequate medical care. In some cases, participants or family members feared disability, the inability to care for their families and even death.

I had too much depression....I cry too much. I felt worry for my son and my daughter. I feel maybe my husband lose his vision 100% and don’t see anything anymore. I was very afraid....I used to think about my children and that he was going to be unable to work and take care of us....I was worried he was going to be disabled.

I worried too much. I thought my son was going to die.

What is going to happen? Is my daughter’s pain going to go on and on and on? This worries me. There is nothing worse than what I am going through now.

My children suffered too, especially my son. When he see his father cry he would ask me, ‘mommy why is daddy crying?’

Familial Consequences

According to some participants, prolonged physical/psychological suffering sometimes led to family disruption. For one particular family, tensions often flared. The
wife's insight, however, made the tension a little more tolerable. For another participant, his ulcer pain led to loss of intimate desire with his recently married wife.

I feel every morning too hard in the stomach. My wife I can't kiss or anything. I feel bored; I don't want my wife to touch me....My ulcer too much pain.

Because my husband was so afraid to lose his sight and was sick all the time with headache, we were having a lot of problems--we fight a lot because it was an outlet for my husband to express his anxiety for the situation...even something small like economic made him feel very upset.

The illness and injuries these people experienced eroded a life they were trying to build, including relationships. As well, their desires to move ahead were hampered by illness and a bureaucratic system that prevented early access to treatment.

**Functional Decline**

All participants, those suffering from acute, chronic or life threatening illnesses or injuries experienced a decline in functioning. The impact of their decline, understandably depended on how incapacitating the symptoms became. Compromised mobility, as well as pain, had an impact on participants' ability to interact with their families, participate in sports and was the reason 2 participants were forced to leave their work and rely on social assistance and charity.

I could not even pick up my daughter....It became very painful for me to work. I had to leave. I could not lift things or stand for long periods of time. I would like to work every day but I cannot because of the pain. Now, I don't have money....we live miserly and have to go to the food bank.

Last year I was able to play soccer well. Now, I cannot anymore. My health is deteriorating. The only thing I can do is walk, walk, walk. I feel very bad to stay in my room....I feel very depressed as if I were in jail. I cannot do the things I used to do and I am only in my early thirties.

The above narratives reveal how participants' lives were compromised because of their illnesses or injuries. If these individuals had received timely treatment, their progression of disease or injury might have been arrested. At a time when participants were trying to rebuild their lives, they were faced with having to cope with chronic pain and disability. Participants' experiences demonstrate how untreated illnesses or injuries had physical, psychological, social and economic repercussions.
Summary

This chapter has explored 9 Central Americans' perceptions of their experiences in accessing health care while refugee claimants. Their experiences in seeking health care are located within the context of their marginality. The difficulties they faced when accessing health care increased severity of symptoms and distress associated with the illness experience.
CHAPTER 5: DISCUSSION OF THE FINDINGS

Concepts presented in Chapter 4 were marginality, health care seeking experiences and the illness experience. How can these concepts be understood within the context of the conceptual framework's macro political, economic and social domains? As a means of addressing this question, this discussion will focus on how social and health policy, limiting participants' access to the work force and to comprehensive medical care, perpetuated participants' marginality. Incorporated into this discussion, addressing the conceptual framework's social and economic domains, is an examination of the social and economic forces underlying such policies. While Chapter 4 focused on participants' health care seeking/illness experiences within the context of marginality (Figure 2, p. 28), the emphasis in this chapter is policy and its influence on marginality. A graphic illustration of this relationship is depicted in Figure 5 (p. 58). In relation to the literature review presented in Chapter 2, discussing policy is an appropriate focus for according to Aday and Andersen (1974), policy is the most important variable influencing an individual's access to health care.

Crucial to this discussion on policy is the notion of power and powerlessness. While powerlessness is an inherent characterisitic of participants' marginality, power is what underlies policy. Pappas (1990) recognizes power as having repressive, destructive potential and argues that when asymmetry of power exists in a relationship, domination can occur. Pappas' (1990) perspective on power is significant to this study since it facilitates comprehension of how governments' omnipotent power, manifested in its policies, perpetuated participants' powerlessness and marginality. While Edginton (1989) acknowledges that societal forces make it difficult for individuals to control conditions that shape one's health status, the policies of the political domain in conjunction with societal/economic forces, significantly shaped participants' health seeking/illness experiences and their every day realities. The enmeshing of social and economic forces with political structures uncovers participants' powerless position.

This discussion begins by examining social policy in relation to participants' marginality followed by an analysis of health policy.

Social Policy/Marginality

At the time participants were interviewed, their difficulty obtaining work was related to policy which stipulated that refugee claimants required work permits from CEIC. Work permits were obtainable after a successful first hearing with the Refugee Determination Board. While some participants waited 6 to 8 months for a first hearing, a
Figure 5. depicts the synthesis of the 3 major concepts in relation to the study's conceptual framework (p.6). The figure illustrates the impact policy has on shaping refugee claimants' marginality, which in turn, influences their health care seeking/illness experiences. Social and economic domains are depicted as forces that influence policy.
few participants caught in the backlog waited 2 to 5 years. Thus, in participants' marginality associated with unemployment, a critical element of their experience is the time span in which they were ineligible for permits. Although work permits were also issued to claimants who found work, according to the participants, language/educational barriers and lack of job skills decreased the feasibility of that occurring. The importance of language in relation to employment is raised by Thomas (1990) who argues that without language skills, there is no real access to the job market.

Participants' opportunities for improving their qualifications for the work force were minimized by policy which excluded refugee claimants from government-sponsored language/work training programs. Daezner (1987) addresses the issue of exclusion.

"Refugee claimants, because of their status, are denied access to [government-sponsored] Job Development programs, which purportedly assist individuals who are employment disadvantaged by minimizing barriers to mainstream employment. Refugee claimants because of their status have no bargaining power within the work force and must begin life in Canadian society as seriously disadvantaged persons" (p.13).

The above quote offers a wider perspective on participants' marginality by linking refugee claimants' disadvantaged position within a larger social context. Policy, which excluded refugee claimants from language and job training programs, perpetuated their marginality and powerlessness by reinforcing and maintaining their disadvantaged position in society by impeding their social/economic mobility and thus their self-reliance.

Social integration into mainstream society is an important means to obtaining employment, for according to Rees (1991), information on jobs is increasingly disseminated through informal networks. Rees (1991) explains that while employers are becoming less inclined to use formal agencies such as Canada Employment Centres and base hiring practices on 'word of mouth', 'hire who you know', and family/kinship ties, minorities with less access to informal channels are disadvantaged when seeking employment. Policies excluding claimants from language training are perceived as diminishing participants' opportunities to benefit from these informal sources of employment information.

In order to fully comprehend the issue of policies limiting participants' joining the work force, examination of the influence social and economic forces have on such policies is needed.

Prevailing negative social attitudes such as those conveyed in a 1989 poll where 36% of British Columbians believed immigrants took jobs away from Canadians (Employment & Immigration, 1989), uncovers the kind of negative social attitudes that
can influence policy. Furthermore, 72% of Canadians believe there are too many refugee claimants in Canada (Employment & Immigration, 1989). The Economic Council of Canada (ECC) (1991) claims that unfavourable societal attitudes towards minorities are likely to increase during high or worsening unemployment which depicts the interrelationship between the social and economic domains. The ECC (1991) also acknowledges that Canadian immigration target levels in previous years were cut back during recessionary periods and interprets such practices as indicating the government's belief that immigration can increase unemployment among Canadians. The same rationale may apply to policies which restrict refugee claimants from obtaining work.

The relevance of examining social/economic forces in relation to participants' unemployment is that it grounds their experiences within the larger contemporary socioeconomic climate. Thus, while participants may blame their inability to secure employment on their own inadequacies, what underlies their experiences are macro political, economic and social forces which shape their employment opportunities.

The negative consequences of participants' unemployment described in Chapter 4 were: decreased self esteem, financial hardship, increased vulnerability to alcohol abuse, dependency on the government and indirectly, deteriorating health. Social policies restricting claimants' access to the work force and to language/job training programs are perceived as fostering these negative outcomes. In contrast to participants' marginalizing unemployment experiences, Anderson and Lynam (1987) found the benefits of employment for immigrant women were: increased self esteem, self worth and reduced stress. In addition, employment "demystified the outside world and provided opportunities for these women to develop social skills necessary to function in everyday life" (Anderson & Lynam, 1987, p. 76). How social policies contributed to participants' marginality is thus understood within the context of negative outcomes and lost opportunity. Furthermore, policies restricting participants' access to the work force also had an impact on the participants' health care seeking experiences: without work permits, participants were not eligible to apply for provincial MSP.

Health Policy/Marginality

Provincial policies limiting refugee claimants' eligibility for provincial MSP and federal policy covering only emergency situations, shaped participants' health care seeking experiences. Difficulty obtaining medical coverage/comprehensive care marginalized participants' lives by perpetuating suffering and decline in health status. Zambrana (1987), Friedman (1991), Ginzberg (1991) and Aday and Andersen (1974) consider lack of medical coverage a serious barrier to health care.
Singer (1989) argues that the starting point for comprehending individual troubles is careful analysis of the structural transformations that usually lie behind them. Society's prevailing attitudes are perceived as one of the structural forces influencing the formation of health policies which restrict refugee claimants from accessing health care. Substantiating this claim is a poll taken in 1989 where 36% of Canadians believe immigrants are a drain on our health care system (Employment & Immigration, 1989). Furthermore, Siler-Wells (1988) argues that as consumers, Canadians want access to all interventions of modern medicine, but as taxpayers are not willing to pay additional tax dollars to ensure these benefits are available to everyone in society; hence, the paradox, "access for me but not for we" (p. 11). Thus, in addition to participants experiencing negative social attitudes on a personal level (discriminatory experiences), they also are marginalized by social attitudes at large which shape health policy.

Siler-Wells' (1988) comment indicates that negative attitudes of the social domain arise from economic concerns. There is evidence to suggest that economic concerns also trouble those who rule within the political domain and formulate health policy. According to Deppe (1989), political institutions exert their influence on health policy for economic purposes by expanding restrictions on health care expenditures during times of economic crises. Economic constraint is an underlying issue behind the provincial government's restricting refugee claimants' access to provincial medical coverage. This assumption is substantiated by the province's Royal Commission on Health Care and Costs. While the report by the Commission does not explicitly address the issue of refugee claimants' health care expenditures, the recommendation that the federal government and not the province be responsible for all immigrants' and refugees' health and social costs for a five year period (The British Columbia Royal Commission on Health Care and Costs, 1991), depicts how economic concerns shape health care policy and how economic concerns take precedence over the health care needs of individuals. While some participants in this study were able to obtain adequate health care, others experienced human suffering and decline in health status. These negative experiences were outcomes arising from policy disputes over refugee claimants' health care expenditures. While Anderson (1990) argues that the ruling corporate elite who implement health care policies are unaware of the impact their policies have on individuals' illness experiences and illness management, Smith (1990) recognizes that refugees (and refugee claimants) are pawns of domestic policies.

Health care policy contributed to participants' marginality by enforcing medical coverage restrictions and by making it difficult for participants to get medical authorization and consequently, health care services. Furthermore, their health care seeking experiences were marginalizing in and of themselves. Participants' marginal experiences at
CEIC involving line-ups, long waits and repeated visits were described by participants as 'dehumanizing'. What made these experiences particularly difficult was their awareness of their powerlessness and inability to alter the system. Participants were also marginalized when their suffering and legitimate need for medical coverage were minimized by CEIC employees' insensitivity and when they were refused coverage because their health problems were considered non-emergencies. These circumstances reflect CEIC employees' adherence to policy. It also indicates that the treatment participants received was determined by policy rather than compassion. Rahnema (1991), in his expose' on poverty, describes loss of compassion in relation to the evolution of bureaucracy.

The impact of health policy at the health care institutional level also contributed to participants' marginality. Although at the city level, the public health department has responded to the needs of refugee claimants by allowing them access to free clinics, barriers in accessing the larger health care system exist, such as, when free clinic physicians' were unable to make referrals for uninsured participants. Waitzkin (1989) acknowledges the frustration physicians encounter when they are unable to arrange needed hospitalization, diagnostic procedures and or treatment for uninsured/underinsured individuals.

A more dramatic example of policy influence at the health care institutional level was health care professionals' refusal to care for uninsured participants. Such actions can be analyzed from a political, economic and social perspective. Waitzkin (1979) believes that health care professionals serve as a 'social control' agent by maintaining peoples' adherence to norms of appropriate behaviour. Applying the phenomenon of 'social control', health care professionals refusing to care for participants who lacked CEIC authorization, conveys their adherence to policy; that is, their actions help to reinforce participants' social/political status by maintaining their unequal access to health care. In addition, their actions may also have economic underpinnings; for without medical coverage, non-salaried health care professionals are unable to collect payment.

Toulmin (1986) and Murray (1986) label health care professionals' adherence to the 'state' and to the patient as 'divided loyalties.' Concern arises over health policies forcing health care professionals into an ethical dilemma. Health care professionals' economic/moral dilemma illustrates how the control of the political domain filters down to the health care institutional level and influences what transpires between health care providers and refugee claimants. A growing concern among health care professionals is precisely their lack of power within the health care system (Anderson, 1990). Navarro (1976) asserts that it is not health care professionals, but rather, the corporate ruling elite who dominate the structure and delivery of the health care system. The hierarchical flow
of influence and control depicted in the conceptual framework, illustrates that participants' (refugee claimants) difficulties in accessing health care begins at the macro political/social and economic domains which bears influence at the health care institutional level. While some participants perceived being denied medical care as discrimination on the part of health care providers, the root cause lies in policies that restrict refugee claimants from obtaining health care.

Being denied medical care marginalized participants. Feelings of rejection and abandonment left one participant with thoughts of suicide. Such an impact indicates that while health care policy influenced participants' health care seeking experiences, its influence at the health care institutional level perpetuated marginality, vulnerability, decline in health status and suffering. The importance and need for health care institutions to be available to all individuals is addressed by Daniels (1982).

"Normal functioning is an important component of the opportunity range open to individuals in society; health care institutions are among a variety of basic institutions which are important because they ensure that an individual's range of opportunity is maintained, restored or compensated for loss of normal functioning" (p. 130).

Daniels' (1982) view that health care institutions promote/maximize an individual's potential and opportunity is significant because it underscores the benefits of individuals having access to health care. In contrast, participants' experiences of being denied medical care fostered marginality as opposed to opportunity. Rejection not only had immediate impact on participants' health status, it also had long term consequences which influenced participants' every day psychosocial/economic realities. Such influence is depicted in this study's conceptual framework.

In discussing inequity in health care access, Daniels (1982) and Whitehead (1992) make the following claims:

"...situations are considered unfair and unjust when they are unnecessary and avoidable; the label of inequity is applied when the cause is judged to be unfair in the context of what is going on in the rest of society....Equal access to available care implies equal entitlement to available services for everyone...and removal of access barriers" (Whitehead, 1992, pp. 433, 436).

"Inequity in health care service distribution occurs when individuals receive services according to their place in the social structure, instead of according to need..." (Daniels, 1982, p. 58).

The claims put forth by Whitehead (1992) and Daniels (1982) concerning what constitutes inequity, suggest that policies restricting claimants' access to medical
coverage/health care services are unfair and unjust, since these policies are based on an individual's political status and the fact that no other group in Canada experiences the same restrictions. Although some may argue that refugee claimants are non-Canadian citizens and therefore do not have the right to equal access, the claim of unfairness and injustice bears significance in view of human rights and current Canadian health policy which advocates preventive health care.

Summary
This discussion has focused on how social and health policies and social/economic forces, as depicted in this study's conceptual framework, perpetuated participants' decline in health status and ultimately their marginality. This discussion also addressed the impact of these forces at the health care institutional level. Study findings support Aday and Andersen's (1974) claim that health care policy is the most important variable influencing an individual's access to health care.
Summary and Conclusions

This phenomenological study investigated the perceptions of 9 Central American refugee claimants' experiences of obtaining health care either for themselves or for their family members. Although there is a body of knowledge addressing barriers to health care, no studies were found examining refugee claimants' experiences of accessing health care. While only a small group of individuals were recruited for this study, and it is recognized that each individual interprets his or her own unique experience accordingly, government policies dictating restrictions to all refugee claimants' access to health services suggests that this study's findings may be applicable to the general refugee claimant population in Vancouver.

Researching participants' health care seeking experiences has provided insight into the difficulties refugee claimants encounter when trying to access health services. By rooting their experiences within the context of their past and present realities, an overall sense of their vulnerability is conveyed.

Analysis of the research findings was guided by a model developed by this researcher depicting 3 macro interdependent domains. The political domain's policies, the social domain's attitudes/values and the allocation of resources of the economic domain were hypothesized as having an impact on refugee claimants' psychosocial and economic realities, their access to health care and on their health status. As well, the influence of the political domain at the health care institutional level is also depicted, which subsequently shapes refugee claimants' health status.

Participants were recruited through multicultural, Hispanic and grassroots agencies. Using interpreters, 7 participants were interviewed twice, while 2 participants were interviewed a third time for a total of 20 indepth interviews. Interviews lasted from 50 to 135 minutes, with trigger questions (Appendix C) initiating the interview process. Translated interviews were transcribed verbatim by the researcher and analyzed according to Giorgi's (1975) method of analysis where interview data were coded according to emerging categories and later clarified or validated by participants. This study's summary and conclusions are as follows:

1) Difficulties participants experienced in their every day lives and while seeking health care had social, political and economic underpinnings and were embedded within the context of past suffering and loss of familial support. In terms of central concepts, many
participants felt marginalized, vulnerable and powerless. While past experiences and undetermined legal status were initial forces behind participants' vulnerability, government policies restricting their access to work, as well as discriminatory experiences, perpetuated marginality and powerlessness. Participants' inability to obtain work fostered low self esteem and loneliness. Situations perceived by participants as discriminatory, which occurred in a number of different settings, left participants feeling inferior and marginalized.

2) Provincial/federal policies restricting refugee claimants' access to the province's medical insurance program and the federal government's (Canada Employment and Immigration Commission-CEIC) policy of covering only 'emergency' situations, as well as bureaucratic processes associated with the issuing of medical authorization (medical coverage) at CEIC, profoundly influenced participants' health care seeking experiences. Restrictions to the province's medical plan (MSP) resulted in participants requesting medical authorization from CEIC. The hardship associated with this process deterred or delayed participants' requesting medical coverage and ultimately health care services, since the process involved finding interpreters, long waits, possible insensitive treatment by CEIC employees or being denied coverage.

3) Reasons for some participants being denied or delayed medical authorization when they did go to CEIC were associated with CEIC's policy of covering only 'emergency' situations and bureaucratic protocol. The impetus behind participants' persevering with repeated attempts at trying to secure coverage at CEIC was primarily from witnessing the suffering of family members. With CEIC controlling the issuing of medical authorization, along with participants perceiving they had no access to comprehensive medical care without coverage, initiated fear, uncertainty and a sense of powerlessness because participants felt they lacked control over the outcomes of their medical crises. Those participants who experienced chronic health problems did not attempt to secure because they were aware that CEIC covered only medical 'emergencies'.

4) As a result of policies restricting refugee claimants from obtaining medical coverage, participants primarily utilized free clinics since major barriers to health care were eliminated. That is, free clinics diminished participants' need to find interpreters and to obtain medical coverage from CEIC since services were free and clinics had either rotating staff that could speak Spanish or had interpreters. While appreciating such services, participants' accounts indicate that these facilities offered limited services and could not adequately address their more complex, chronic health conditions.
5) Health care policies restricting refugee claimants from having continuous medical coverage had implications at the health care institutional level. Without MSP or medical coverage from CEIC, free clinic physicians were unable to make referrals for participants for diagnostic assessment and comprehensive treatment. Furthermore, while some participants who lacked medical coverage received treatment from specialists and family/emergency physicians, other uninsured participants were refused treatment at hospital emergency departments.

6) Progression of illnesses or injuries, the development of alarming symptoms, prolonged suffering and general functional decline which hampered participants’ employment/social opportunities and interactions with family members, were outcomes arising from participants’ not being issued medical coverage, being denied medical care or receiving inadequate treatment. For 2 individuals, being denied medical care when they were uninsured potentiated the development of a life threatening illness and thoughts of suicide. These outcomes reveal the devastating impact health policy had on participants’ health status and well-being. Participants’ decline in health status compounded their marginality and vulnerability. This study’s findings substantiate Aday and Andersen’s (1974) claim that health policy has the greatest impact on individuals’ ability to access health care services.

**Implications for Nursing**

This study provides insight into the difficulties refugee claimants encounter in their daily lives and while trying to access health care services. Difficulties in each context impacts on refugee claimants’ health status and is thus a concern to public health nurses, particularly since the definition of public health nursing includes the mandate of assessing and responding to the needs of given populations (Canadian Public Health Association, 1990). Some health care professionals argue that equitable access to health care is a matter of social responsibility and nursing’s accountability to society (Asoskar, 1992). The following recommendations address nursing professional associations, practice, education, research and administration.

**Nursing Professional Associations**

Access to health care is a political issue and therefore requires political action. Outcomes arising from participants’ restricted access to medical coverage substantiates the need for both federal/provincial governments to change their policies allowing refugee claimants access to medical coverage and to preventive, acute, chronic and emergency
health care services. In order to facilitate change in government policies, provincial and federal nursing associations need to lobby provincial and federal governments and amalgamate with concerned professionals, such as, physicians, lawyers, social workers, human rights activists, together with community organizations and refugee claimants themselves. A collective stance on this issue is warranted in order to increase pressure on governments to change current policies.

**Nursing Practice**

With the contemporary climate of change in the province's health care system, nurses will increasingly become the point of entry into the system (Canadian Nurses Association, 1993) and will have a greater opportunity to fulfill a primary health care provider role for the refugee claimant population. Rather than waiting for refugee claimants to overcome barriers to health care, nurses need to initiate contact with this population by expanding traditional boundaries and becoming more visible in claimants' informal settings. Discussing with community grassroots persons ways of developing and establishing visibility, acceptability, approachability with the refugee claimant population, is a viable means of initiating this process. While informal community satellite settings are places for public health nurses to establish initial contact, provide health teaching and support, the developing of a clinic with integrated services is also suggested in order to facilitate continuity of care.

In addressing such issues as unemployment, loss and isolation and vulnerability to substance abuse, nurses need to examine the root cause behind such circumstances and devise actions aimed at facilitating change, with the awareness of the need for long term commitment since no 'overnight' solutions exist. While there is need for addressing root causes underlying these issues, more immediate strategies are also of benefit. Advocating for the funding of projects aimed at assisting refugee claimants, working with allied professionals, as well as empowering communities to create support networks for claimants and to develop work programs where claimants could use their skills and acquire new ones, are strategies addressing the issues of unemployment and isolation. Such programs have a preventive focus aimed at improving claimants' mental health status and promoting their general sense of well-being.

In this study, participants were found to lack knowledge of the health care system and what services different health care facilities offered. An important role for nurses is to provide information that will demystify the system. Knowledge of available services and method of access could empower refugee claimants whereby they would be able to choose the services they wish to utilize. In addition, working with refugee claimants requires
nurses to be non-judgmental, non-threatening and caring. These attributes promote not only rapport and trust, but also encourage claimants to seek services. Lastly, while nursing associations can engage in lobbying for policy change, at the individual level, nurses can negotiate with CEIC on behalf of refugee claimants who require or have been denied medical coverage. Such action potentiates the possibility of refugee claimants' receiving comprehensive assessment and treatment for their illnesses and injuries. Negotiative action reflects the role of advocacy.

**Nursing Education**

Many difficulties participants encountered in obtaining health care were embedded in the political domain. Knowledge of the political process, public policy, lobbying, lines of power in municipal, provincial and federal governments is mandatory in order for nurses to effectively advocate for refugee claimants and other groups who require political support. Hence, adequate teaching on political processes in undergraduate and graduate nursing programs is required. As well, major concepts and themes such as marginality, powerlessness, vulnerability, loss and isolation need to be included in nursing curricula to provide theoretical direction for nursing practice.

**Nursing Research**

Research addressing issues concerning the accessibility of health care services is needed in order to advocate change and to promote ethical principles of equal access. By not researching further the issue of access and refugee claimants, nurses lose power to effect change. Silence, ultimately, condones the discriminatory policies that restrict refugee claimants from accessing health care.

This study was with a small sample representing one minority group. Research with other minority groups is needed in order to discern whether this study's findings are transferable. Furthermore, there were unclear aspects concerning influences on participants' health care seeking patterns. Additional research exploring how societal discrimination, alienation and emotional trauma shape refugee claimants' access experiences is needed. As well, research exploring the moral dilemmas faced by health care professionals in relation to health policies that restrict refugee claimants' access to health care would also be of merit.

The Latin American Community Council (1990) addresses the economic benefits of eliminating refugee claimants' restrictions to medical coverage and medical services. The cost benefits include: a cut in manpower costs at MSSH, CEIC, Medical Services Plan and Social Service agencies; early access to services would allow claimants' health problems
to be assessed and treated before conditions require extensive medical care and hospitalization. Such early access has the potential to reduce health care spending and would eliminate unpaid hospital bills which often involve collection agencies (Latin American Community Council, 1990). To support this rationale, an audit examining refugee claimants’ expensive treatment/hospitalization in relation to what the cost benefits would have been if early intervention had occurred would substantiate the claim that access to health care without restrictions is a cost saving measure.

Nursing Administration

Participants indicated they felt discriminated against in various health care settings. Where possible, quality control and appropriate follow up needs to be carried out in order to ensure the dignity and proper care refugee claimants deserve.

Development of a formalized protocol for keeping government institutions and agencies dealing with refugee claimants up to date on services available to refugee claimants is needed in order to facilitate dissemination of information and to promote the health of refugee claimants. Nurses could take on the task of informing government/agency staff about the intricacies of the health care system; how it operates and what services are available in various settings. The fact that some non-profit grassroots agency staff are themselves newcomers to the country and may not have had the opportunity to enhance their knowledge of the health care system and the specific services offered in various health care settings, substantiates the need for nurses to fulfill this role.

In summary, findings from this phenomenological study reveal the kinds of difficulties Central American refugee claimants experience while trying to access health care services in Vancouver. The greatest barrier to their obtaining health care was government policies. Policies restricting their access to health care had repercussions at the health care institutional level and subsequently on participants' health status. In view of human rights and the current thrust of health prevention, restricting refugee claimants' access to medical coverage/health care services warrants policy change.
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APPENDIX A 1

PARTICIPANT INFORMATION LETTER

My name is Denise Beaupre. I am a Registered Nurse and a student in the graduate program in Nursing at the University of British Columbia. Over the years I have come to care about new people who come into my country. Because I am a nurse I am aware of the difficulty refugee claimants have in trying to get medical care here in Vancouver. Hence, I am conducting a study looking at the problems refugee claimants have in getting medical care. Nurses need to know more about these experiences in order to help make accessing medical care easier for refugee claimants. I would, therefore, like to invite you to participate in my study. I have asked staff of different agencies who work with refugee claimants, to help me find individuals who would be interested in participating. Your participation would involve about 2 or 3 meetings, approximately one hour long, with myself and a translator (I unfortunately do not speak Spanish), at a place and time that is good for you. I will ask you questions about your experiences in trying to get medical care as a refugee claimant, or for a family member refugee claimant who was needing medical care. Meetings will be tape-recorded with your permission and only the translator, myself, 2 professors overseeing my study, and possibly a typist, will have access to the tapes. Your name will never be mentioned on tape or on written material--your identity will be protected.

YOU ARE UNDER NO OBLIGATION TO PARTICIPATE IN MY STUDY. REFUSAL TO PARTICIPATE WILL IN NO WAY JEOPARDIZE THE HELP YOU RECEIVE FROM THIS AGENCY, OR CREATE FURTHER DIFFICULTY WHEN TRYING TO GET MEDICAL CARE. FURTHERMORE, SHOULD YOU WISH TO PARTICIPATE IN THIS STUDY, YOU HAVE THE RIGHT TO LEAVE THE STUDY AT ANY TIME. YOU ALSO HAVE THE RIGHT TO REFUSE TO ANSWER QUESTIONS AND MAY REQUEST TO HAVE TAPES ERASED SHOULD YOU FEEL UNCOMFORTABLE WITH THE INFORMATION YOU HAVE PROVIDED.

If you wish more information about this study, I will be more than happy to meet with you (with a translator present, if necessary), to answer any of your questions. Please feel free to call me at_______. Should you agree to participate in my study, your signature on a form will be needed, allowing me permission to interview you. Should you wish to participate, I hope you will not mind accepting a gift of $30. (thirty dollars) at the last of our series of meetings, as a means of expressing my appreciation for your valuable contribution to this study. Thank you for considering participating in my study.

Sincerely,

Thesis Supervisor: Denise Beaupre R.N. B.S.N.
Dr. Joan Anderson Master Student in Nursing
Telephone:_______ Telephone:_______
Mi nombre es Denise Beaupre, Enfermera Registrada y estudiante en el programa de Graduados en Enfermería de la Universidad de British Columbia. Por muchos años he cuidado de personas recién llegadas a nuestro país quiero ayudarlos de cualquier forma que yo pueda. Debido que soy una enfermera y se de las dificultades que los solicitantes de refugio tienen para obtener asistencia médica aquí en Vancouver. Por lo tanto, estoy dirigiendo un estudio sobre los problemas que los solicitantes de refugio tienen al tratar de conseguir asistencia médica. Las enfermeras necesitamos saber más sobre estas experiencias para ayudar a que sea más fácil el conseguir asistencia médica para los solicitantes de refugio. Me gustaría además invitarte a participar en mi estudio. Yo he preguntado al personal de diferentes agencias, quienes trabajan con solicitantes de refugio, para que me ayuden a encontrar individuos que podrían estar interesados en participar. Tu participación podría ser dos a tres sesiones, aproximadamente de una hora conmigo y el traductor, si tu hablas Español (desafortunadamente yo no hablo Español), sea a la hora y el lugar adecuado para el participante. Yo hare preguntas acerca de tu experiencia para conseguir asistencia médica. Las reuniones serán grabadas con tu permiso y solamente el interprete, yo, y dos profesores observaran el estudio; y posiblemente la mecanografa tendrán acceso a las grabaciones. Tu nombre nunca será mencionado o grabado, o escrito; tu identidad será protegida.

TU NO ESTAS BAJO NINGUNA OBLIGACION DE PARTICIPAR EN MI ESTUDIO. RECHAZAR LA PARTICIPACION NO PONDRA EN PELIGRO LA AYUDA QUE TU RECIEDES DE ESTA SI DESIAS PARTICIPAR EN EL ESTUDIO, TU TIENES EL DERECHO DE DEJAR EL ESTUDIO EN CUAQUIER MOMENTO, TU TAMBIEN TIENES EL DERECHO DE RECHAZAR LAS PREGUNTAS Y PUEDES PEDIR QUE SE BORRE LO COPIADO, SI NO TE SIENTES BIEN CON LA INFORMACION QUE HAS PROPORCIONADO.

Si deseas mas información acerca del estudio, yo me sentiría contenta de hacerlo (con un interprete presente, si es necesario), para contestar alguna de tus preguntas. Por favor sientete libre llamarme al ________. Si tu estas de acuerdo en participar en mi estudio, tu firm en la solicitud sera necesaria, autorizándome para entrevistarte. Si estas dispuesto a participar, espero que tu aceptes, en la última de nuestras sesiones, un pequeño regalo de $30. (treinta dolares), como una expresión de mi aprecio a tu valiosa contribución a mi estudio. Gracias por el tiempo que tomaste en considerar ser participante de mi estudio.

Sinceramente,

Supervisor de la tesis
Dr. Joan Anderson
Fono:_________

Denise Beaupre R.N. B.S.N.
Estudiante de Enfermería
Fono:_________
I understand that this study, Central American Refugee Claimants’ Experiences Accessing Health Care, is looking at either refugee claimants who have not been able to get medical care, or claimants who have had difficulty getting medical care here in Vancouver. I understand that should I agree to be in this study, that I will be asked questions concerning trying to get medical care when I was a refugee claimant, if I am no longer a claimant, or when trying to access medical care for a family member who was, or is a refugee claimant. I am aware that I will be asked questions regarding: (a) what sickness I or my family member had that required medical services; b) what I had to do in order to try and get the medical care I or my family member needed; (c) what difficulties I experienced when trying to get medical help, or, why I was not able to get medical care either for myself or for my family member; and, (d) what problems I and/or my family have had as a result of this difficulty. I understand that there will be 2, possibly 3 meetings, each approximately one hour long, at a place and time that is good for me to talk to the researcher, Denise Beaupre, about my experiences. I agree to have a Spanish speaking translator present should a translator be needed and to have the meetings audio taped.

I AM AWARE THAT I DO NOT HAVE TO BE IN THIS STUDY. SHOULD I DECIDE TO BE IN THE STUDY, I HAVE THE RIGHT TO LEAVE THE STUDY AT ANY TIME. I ALSO HAVE THE RIGHT NOT TO ANSWER QUESTIONS AND TO HAVE TAPES ERASED AT ANY TIME. I AM AWARE THAT LEAVING THE STUDY WILL IN NO WAY JEOPARDIZE THE HELP I AM CURRENTLY RECEIVING FROM THIS AGENCY, OR CAUSE FURTHER PROBLEMS IN GETTING MEDICAL CARE.

I am aware that I can ask the researcher any questions that I have regarding the study. I am aware that my name will not be on any tapes or written material; my identity will be protected. I understand that only the researcher, 2 professors overseeing the study, the translator, and possibly a typist will have access to what I have said at the meetings. I understand, however, that this study will be published as the researcher’s thesis and that papers may be written or presented regarding the study’s findings. I am aware that it is the researcher’s hope that I will accept a gift of $30. (thirty dollars) at the last of our meetings, as a means of expressing her thanks for my participation in the study. My signature below shows that I have agreed to be in the study and that I have received a copy of this consent and the study’s information letter.

_________________________Signature of Participant __________Date

_________________________Signature of Witness __________Date

Thesis Supervisor: Denise Beaupre R.N. B.S.N.
Dr. Joan Anderson Master Student in Nursing
Telephone:__________ Telephone:__________
APPENDIX B 2

SOLICITUD DE CONSENTIMIENTO

Yo entiendo que este estudio sobre las experiencias de acceso a los Cuidados de Salud de los Solicitantes de Refugio de Centro América está buscando tanto solicitantes a refugio que no han tenido asistencia médica, o solicitantes que han tenido dificultad en conseguir esa asistencia médica en Vancouver. Yo entiendo que estoy de acuerdo en participar en este estudio, que se me preguntará acerca de cómo consegui asistencia médica cuando yo fui solicitante de refugio, si ya no soy un solicitante, o cuando se trata de conseguir asistencia médica para un familiar quien fue o es un solicitante de refugio. Se que se me preguntara acerca de: 1) Para que enfermedad, yo o un miembro de la familia ha requerido asistencia médica. 2) Que hice para conseguir asistencia médica cuando yo o un miembro de la familia lo necesito. 3) Que dificultades pase cuando trate de conseguir asistencia médica, o porque yo no fui competente de conseguir asistencia médica para mi o para un miembro de mi familia. 4) Que problemas, yo y un miembro de la familia hemos tenido como resultado de esta dificultad. Entiendo además que habran al menos dos o posiblemente tres reuniones aproximadamente de una hora cada una en el lugar y hora que sean adecuadas para mi con el fin de conversar con el investigador, Denise Beaupre', acerca de mi experiencia. Yo estoy de acuerdo en tener presente un interprete que hable Espanol y en grabar las sesiones.

ESTOY EN CONOCIMIENTO QUE NO TENGO QUE ESTAR EN ESTE ESTUDIO SI NO LO DESEO. SI YO DECIDO ESTAR EN ESTE ESTUDIO, TENGO EL DERECHO DE RETIRARME EN CUALQUIER MOMENTO. YO ENTENDO QUE DEJAR EL ESTUDIO NO PONDRA EN PELIGRO LA AYUDA QUE ACTUALMENTE RECIBO DE ESTA AGENCIA O QUE CAUSE MAS PROBLEMAS PARA CONSEGUIR ASISTENCIA MEDICA.

Estoy en conocimiento que yo puedo preguntar al investigador cualquier incognita que yo tenga sobre el estudio. Se que mi nombre no aparecera en ninguna grabacion o escrito. Mi identidad sera protegida. Entiendo que solamente el investigador, dos profesores que observaran el estudio, el interprete, y posiblemente la mecanografa tendran acceso a lo que yo he dicho en las sesiones. Yo se sin embargo que este estudio sera publicado en la tesis del investigador y que los documentos pueden ser escritos o presentados de acuerdo a los estudios encontrados. Yo se que el deseo del investigador es que yo reciba un regalo de $30. (treinta dolares), al final de nuestras sesiones como una forma de expresar su agradecimiento por mi participacion en el estudio. Mi firma abajo muestra que yo estoy de acuerdo en este estudio y que yo he recibido una copia de este permiso y la carta de informacion.

__________________________  ________________________
  firma del participante       fecha

__________________________  ________________________
  firma del testigo          fecha

Supervisor de la Tesis
Dr. Joan Anderson
Fono:____________

Denise Beaupre R.N. B.S.N.
Estudiante de Enfermeria
Fono:_______
APPENDIX C

INTERVIEW TRIGGER QUESTIONS

1. What made you want to get medical care?

2. What did you do in order to try and get the medical care you wanted at that particular time? Where and to whom did you go?

3. What difficulties did you have in trying to get the medical care you wanted or what stopped you from getting the care you needed?

4. What feelings did you have when you were trying to get medical help?

5. What problems have you and your family experienced as a result of the difficulties you have had in getting medical care, or in not being able to get the care you wanted?
APPENDIX D

LETTER TO THE AGENCY

My name is Denise Beaupre and I am a graduate student in the Master of Science in Nursing program at the University of British Columbia. I will be conducting a study pending approval from the University of British Columbia’s Behavioural Research Ethics Committee, titled Central American Refugee Claimants' Experiences Accessing Health Care. The purpose of this study is to investigate from the perspective of port-of-entry refugee claimants, their experiences in obtaining health care. Research is needed in this area in order to promote change in federal/provincial policies concerning refugee claimants’ access to health care, as current policies and processes make it difficult for these individuals to secure medical care.

It is estimated that 8 participants will be needed for this in-depth study. Recruitment is being sought at more than 1 agency. Participant criteria is that they be: Central American, male or female between the ages of 19 and 65, who are or have been port-of-entry refugee claimants in British Columbia and who have needed to access health services out of psychological or physical need. Non-refugee claimants, meeting all of the other above criteria, will be considered potential candidates if they have sought health care services on the behalf of a family member who was a port-of-entry claimant. Participants will be asked questions regarding: what health concern/medical problem they had that necessitated health care services; at what point did they seek care; what they did in order to try and access the services they needed, as well as the difficulties they encountered, and lastly; what problems they or their families have endured as a result of the difficulty/inability to access health care services.

Refugee claimants’ participation in the study will involve 2 or 3 interviews, each approximately 1 hour long. Interviews will be audio taped with the permission of the participant. A Spanish translator(s) will be recruited for interviewing purposes, should participants not understand or feel uncomfortable with speaking English—unfortunately, I do not speak Spanish.

Participants’ rights in the study include the following: 1) the right to leave the study at any time 2) the right to refuse to answer questions 3) the right to have tapes erased at any time. As well, the identity of the participant will be protected. Their names will not appear on tapes or written material. Data from the interviews will be kept confidential. The only people who will have access to the interview data will be my thesis committee advisors, the translator(s), myself and possibly a typist. In appreciation of their valuable contribution to this study, I am offering participants an honorarium of $30. (thirty dollars) which will be given to the participant at the last interview.

The University of British Columbia Behavioural Sciences Committee requires that I obtain written permission from the agencies who are willing to offer participant recruitment assistance. Space is provided on the following page for agency approval, should you wish to grant me permission to access potential candidates for this study. Thank you for taking the time to consider your agency’s involvement in my study.

Sincerely,

Thesis Supervisor: Denise Beaupre
Dr. Joan Anderson R.N. B.S.N.
Telephone: _____ Telephone: _____
THE AGENCY, GRANTS RESEARCHER, DENISE BEAUPRE, PERMISSION TO ACCESS PARTICIPANTS FOR THE STUDY, CENTRAL AMERICAN REFUGEE CLAIMANTS' EXPERIENCES ACCESSING HEALTH CARE.

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Signature

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Date