

**José Manuel Calheiros**

**CHRONIC DISEASE AND FAMILY COPING:  
A STUDY IN URBAN PORTUGAL**

The University of Connecticut

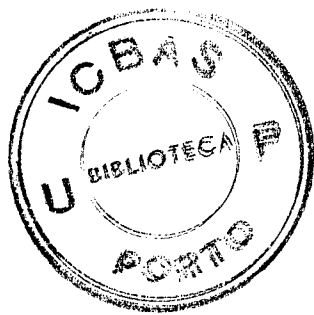
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## CHRONIC DISEASE AND FAMILY COPING:

### A STUDY IN URBAN PORTUGAL

Jose Manuel Calheiros, M.D., M.P.H., Ph.D.

The University of Connecticut, 1986

Cerebrovascular Disease (CVD) is extremely frequent in Portugal, where it has been the leading cause of death for several decades. In 1979, CVD accounted for 23.4 percent of all deaths. Nevertheless, information describing sociocultural and epidemiological aspects of CVD is very limited in the Portuguese health and/or social sciences literatures. These disorders, which present themselves under a wide severity range, often require multidisciplinary, organized, and integrated forms of care, aiming at minimizing its impact on the individual, the family and the community.

In Portugal, despite the importance of these disorders, an explicit national policy has never been formulated. Currently there are no organized programs for the support of CVD patients and their families.

This research was conducted in Porto - a large urban area in Northern Portugal - on patients with several forms of CVD. Quantitative and qualitative methods are used to describe the current patterns of disease in Porto, and the approaches of



Jose Manuel Calheiros -- The University of Connecticut, 1986

the contemporary Portuguese social and health care systems that attempt to meet the broad needs of these patients and their families. Family coping abilities and strategies are studied here under the process of adaptation, using the ecological model of illness. Family variations are accounted for in terms of a set of sociocultural and economic variables.

The data show that: (1) the frequency of CVD in Porto is high when compared with equivalent studies in other communities. Particularly high frequencies were found for hemorrhagic stroke, especially in males aged 64 or less; (2) the contemporary Portuguese health care system heavily relies on families as a major source of care during both acute and non-acute phases; (3) although most families were identified as coping satisfactorily, a small number of families is particularly vulnerable to the social consequences of stroke and have major difficulties in providing the family component of care implicit in the present health system. Education (patient and maximum family level) was identified as the major determinant of successful adaptation; (4) current rehabilitative approaches have major limitations both in terms of the type of services available and in patient selection.

CHRONIC DISEASE AND FAMILY COPING:  
A STUDY IN URBAN PORTUGAL

Jose Manuel Lage Campelo Calheiros

M.D., University of Porto, 1972

M.P.H., University of Connecticut, 1985

A Dissertation

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at

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1986

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APPROVAL PAGE

Doctor of Philosophy Dissertation

CHRONIC DISEASE AND FAMILY COPING:

A STUDY IN URBAN PORTUGAL

Presented by

Jose Manuel Lage Campelo Calheiros, M.D., M.P.H.

Major Adviser:

*Pertti J. Pelto*  
\_\_\_\_\_  
Pertti J. Pelto

Associate Adviser:

*Stephen D. Schensul*  
\_\_\_\_\_  
Stephen D. Schensul

Associate Adviser:

*David L. Gregorio*  
\_\_\_\_\_  
David L. Gregorio

The University of Connecticut

1986

## PREFACE AND ACKNOWLEDGMENTS

Cerebrovascular Disease (CVD) is extremely frequent in Portugal, where it has been the leading cause of death for several decades. In 1979, CVD accounted for 23.4 percent of all deaths. Nevertheless, information describing socio-cultural and epidemiological aspects of CVD is very limited in the Portuguese health and/or social sciences literatures. These disorders, which present themselves under a wide severity range, often require multidisciplinary, organized, and integrated forms of care, aiming at minimizing its impact on the individual, the family, and the community.

In Portugal, despite the importance of these disorders, an explicit national policy has never been formulated. Currently there are no organized programs for the support of CVD patients and their families.

This research conducted in Porto -- a large urban area in Northern Portugal -- focus on patients with several forms of CVD. It also describes the current disease patterns in Porto, and examines the approaches of the contemporary

Portuguese social and health care systems that attempt to meet the broad needs of these patients and their families. This research views the sum of the current individual management strategies as the implicit policy and/or programs and, accordingly, analyses the implications in a family perspective. Family coping abilities and strategies are studied here under the process of adaptation, using the ecological model of illness. Family variations are accounted for in terms of a set of sociocultural and economic variables.

Although this project is based in a major health institution, it should be emphasized that the research herein presented and the problems identified are not limited to the research institutional base. My previous experience in other areas and settings in Portugal, and the reported experiences of colleagues working in other health institutions throughout the country, clearly suggest that the problems associated with the care of CVD patients are of national character and constitute reason for a national concern.

I am therefore grateful to all institutions and individuals that made this research possible. My deepest gratitude is due to the members of the Clinical and Administrative Boards of the Hospital Geral de Santo Antonio, Porto, for their understanding of the need to develop this research from inside the hospital into the

community. I am particularly indebted to Dr. Castro Lopes (Director of Clinical Services) and Dr. Mario Pereira (Hospital Director) for their support and confidence, which was also crucial in obtaining the required permissions from the Portuguese authorities in order for me to attend the present academic program at the University of Connecticut. I believe this research will help develop further activities and programs involving the community, the Hospital Geral de Santo Antonio, and the Instituto de Ciencias Biomedicas, "Abel Salazar".

I also wish to convey my deepest gratitude to the Calouste Gulbenkian Foundation for the generous fellowship support which made possible this academic program, and to the University of Connecticut for the scholarship that covered tuition during this period. This research was also supported in part by a grant from the University of Connecticut Research Foundation.

To my major supervisor, Pertti J. Pelto, I owe special thanks. His vision of the relationships between Anthropology and Health Sciences deeply contributed to improve my understanding of the complexities of this multidisciplinary area. I am particularly grateful for his understanding of my identity as a health professional to which social sciences have added new roles and responsibilities.

Stephen Schensul and David Gregorio, associate advisors in this project, have been colleagues and friends as well.

Together with Holger Hansen, who was associated advisor till is sabbatical leave, they immensely contributed to the stimulating academic environment I encountered at the University of Connecticut.

My deepest gratitude also goes to Professors Corino de Andrade (Instituto de Ciencias Biomedicas "Abel Salazar", University of Porto), Aloisio Coelho (Director, National Institute of Health, Lisbon, and Chairman, Department of Community Health, Instituto de Ciencias Biomedicas "Abel Salazar", University of Porto) and James E. C. Walker (former Chairman, Department of Community Medicine and Health Care, University of Connecticut Health Center). Professors Corino de Andrade and Aloisio Coelho have honored me with their support and confidence since the very beginning of my career in Community Health, while Professor's James Walker vision of international community health created the opportunity for this program. This research is dedicated to them.

I also wish to thank my colleagues and friends Antonio Leite Carneiro, M.D. (Department of Neurology, Hospital Geral de Santo Antonio), and Benjamin Crabtree (Doctoral Candidate, Department of Anthropology, University of Connecticut) for their professional help and support, especially for caring to take time from their busy schedules to provide answers to my requests. Antonio Carneiro reviewed neurologic information, particularly CT scans, and Benjamin



Crabtree provided statistical and computer expertise.

My gratitude also goes to three groups of people without whom this research was not possible. I thank Belarmino Gomes and his colleagues of the "Servico de Doentes" (Hospital Geral de Santo Antonio) for their patience and support, and the group of students from the Department of Community Health lead by Teresa Oliva, with whom I shared the joys and hardships of field research.

Last and above all, I wish to convey my deepest gratitude to the patients and their families for accepting to participate in one more research that did not offer immediate solutions to their often dramatic problems. The main intention of this research was to identify these problems and special vulnerable groups. I hope that, in the near future, the information gather this way will make possible the development of appropriate mechanisms which, through the involvement of patients and their families, local community authorities, health care providers, and other relevant agencies, result in shared responsibilities and the implementation of appropriate policies.

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NATO - North Atlantic Treaty Organization  
NHS - National Health Service  
NSS - National Survey of Stroke  
OBS - Intermediary ED Unit  
SAH - Subarachnoid Hemorrhage  
SAS - Statistical Analysis System  
SMS - Servicos Medico-Sociais  
UConn - University of Connecticut  
TIA - Transient Ischemic Attack  
TIB - Thrombotic Infarction of the Brain  
WHO - World Health Organization

## CHAPTER 1

### INTRODUCTION

In this research I examined socio-cultural and epidemiological aspects of Cerebrovascular Disease (CVD) in a population of the city of Porto, in northern Portugal. The main objectives of the study were: (1) to provide an accurate epidemiological description of CVD in a population selected from Porto's inner city, including the natural history of the disease; (2) to examine the current care practices available to CVD patients; (3) to build a composite picture of family coping mechanisms for home-based CVD cases; and (4) to account for the variation in family coping abilities in terms of a set of sociocultural and economic variables.

This study was carried out on an inner-city population that includes a large proportion of the poorest segments of the population of Porto. I have chosen to study this population and this topic for the following reasons: (1) there is a lack of clear-cut data on the impact of social and economic factors on the disease; (2) few epidemiologi-

cally oriented studies have examine the natural history of this disease in Portugal, and (3) there has been limited attention paid to the social consequences of CVD, its impact on the family and the community, and its relationships with the prevailing patterns of care.

The experiences of families in which a member has survived stroke [1] are the central focus of this dissertation. The study recognizes the importance of examining a chronic disabling disease in terms of its impact on the socio-cultural system. An examination of the disease and its context provides a holistic perspective on both its biomedical and socio-cultural consequences. Ultimately, this provides some explanations for the various responses or adaptative styles of the families of the affected persons.

A major interest of this study involves human behavioral adaptation to stroke. This includes an interest in health care systems and delivery, the affected persons and their families, and the existent social support systems. It provides data and analyses pertinent to a better understanding of successful adaptation to disability, taking into consideration the facilities, the resources and the structure of the various systems involved ( i.e., cultural, social, and health systems). It also aims to provide quantitative data relevant to further program planning,

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[1] For full definitions of CVD and stroke see pages 4-5.

design, and implementation, by providing basic information on salient variables which enable patients and their families to cope or adapt successfully to this potentially fatal chronic disease. Finally, the information generated by this study is expected to contribute to the establishment of appropriate national and local health policies, aimed at effectively serving the populations in need, which may lead to new health care delivery configurations in Portugal.

This theoretical framework - "the ecological model of illness" - is central to recent Medical Anthropology research. It identifies and links aspects of health and illness which are often dealt with separately in health research, integrating the primary orientations of the epidemiological and social sciences in the study of an area of common concern. The "social epidemiologic paradigm" and the "ecological model of illness" will be addressed in detail in the next chapter.

Foster outlined what he considered to be the research priorities of the 1980s for anthropologic research on health problems. The author placed major emphasis on applied research (Foster, 1984:851) [1], and suggested three major research topics: (1) specific diseases, (2) specific health problems, and (3) health care delivery systems. This research follows the above priorities by emphasizing applied

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[1] See also DeWalt and van Willigen (1984).

research in a major health problem, and addressing the three suggested topics using CVD as the specific disease. In addition, rehabilitation issues are also addressed which, as Olesen (1975:423) points out, have been dealt with in Medical Sociology but not in Medical Anthropology.

### 1.1 Cerebrovascular Disease

The term "cerebrovascular" denotes those disorders in which (1) an area of the brain is transiently or permanently affected by ischemia or bleeding, or in which (2) one or more blood vessels are primarily involved in a pathologic process, or (3) a combination of both. The term "cerebrovascular" is now well established as covering the range of disorders just mentioned (see World Health Organization, 1978). The more common term, "stroke", despite being frequently used rather loosely, is commonly used in English language literature to cover the same range of disorders. In this study, the definition formulated by the Advisory Committee of the National Survey of Stroke, sponsored by the National Institute of Neurological and Communicative Disorders, edited by Weinfeld (1981), will be adopted:



Stroke is a clinical syndrome consisting of a constellation of neurological findings, sudden or rapid in onset, which persists more than 24 hours, and whose vascular origins are limited to:

1. Thrombotic or embolic occlusion of a cerebral artery resulting in infarction, or
2. Spontaneous rupture of a vessel resulting in intracerebral or subarachnoid hemorrhage.

This definition excludes occlusion or rupture due to traumatic, neoplastic, or infectious processes which produce vascular pathology (Walker, et al. 1981:I-13).

Although sharing the same pathophysiology, cerebrovascular disorders of less than 24-hour duration are not the main focus of this research because these episodes, usually designated by Transient Ischemic Attacks (TIAs), do not leave sequelae. Nevertheless they equally require appropriate diagnosis and organized preventive actions.

Two main types of stroke - hemorrhagic and ischemic - traditionally described in medical literature are recognized in the above study definition. Hemorrhagic strokes may consist of bleeding into brain tissue (parenchymatous) or into the subarachnoid space (subarachnoid hemorrhage). Ischemic strokes, may be due to an intrinsic occlusion of a vessel (thrombotic infarction), or an extrinsic or foreign body plugging the lumen of a vessel (embolic infarction). In order to facilitate a clear distinction between the different categories of stroke, the above-mentioned Advisory Committee developed a clinical algorithm that will also be

extensively used in this study. Differentiating sets of criteria allow the vast majority of individual patients to be identified as suffering from subarachnoid hemorrhage (SAH), intraparenchymal hemorrhage (IPH), thrombotic (TIB) or embolic (EIB) types of stroke (see Addendum A in Walker et al., 1981:I-32-37).

## 1.2 RESEARCH BACKGROUND

My interest in cerebrovascular disease is the direct result of previous professional experience and of my present professional activities. In 1972, when I graduated from the University of Porto Medical School, I felt just like a professional with a degree but with a limited understanding of medical realities. Initially, my career options included public health and/or general practice. Since internship programs in general practice did not exist in Portugal until 1981, a career move into that direction would mean no opportunity for further scholastic training after completing the post-graduation compulsory hospital residency (2 years). Due to my perceived limitations of undergraduate preparation, I strongly rejected this alternative.

With regards to the available public health alternative -- the graduate program of The National School of Public Health, Lisbon -- I had a very limited understanding of its activities and career perspectives. Key personnel from

various health sectors recommended that I should try to complete a residency program in one of the "traditional" medical specialties as a way to protect my professional future and later consider public health. In Portugal, both general practice and public health have often been viewed as last-choice career alternatives by both the general public and the medical profession.

This advice, to which I am particularly grateful, was my first contact with a cultural and professional reality that I had not been previously aware of. Fortunately, unexpected events in Portugal, provided me with the opportunities to develop my career along lines that ultimately integrated both general practice and public health.

When the Portuguese Revolution put an end to 48 years of dictatorship (April 25, 1974), and important social changes began to occur, I was a second-year resident working at the same university hospital where I had received my undergraduate training. This was a nearly 1,000-bed facility staffed by as many physicians as its number of beds. In the meantime, I began working part-time for the domiciliary sector of the Portuguese Medical-Social Services. This provided my first contact with services other than hospital care.

The Portuguese Medical-Social Services may be described as a social security scheme, run by the Portuguese

government, which provides outpatient and ambulatory care to the vast majority of the population. The same social security plan also covers the expenses of hospital care and provides general benefits, such as for pregnancy, sickness, or retirement.

In June 1974 I was drafted and in January 1975 sent as a military doctor to the island of Santa Maria (Azores). There, together with the only local doctor, I provided care to a population of approximately 6,000 people. This was part of a Portuguese Armed Forces' program to provide medical care to underserved areas which, by 1975, was also extended to nonmilitary physicians. A year of "rural practice" became compulsory for all physicians who planned to pursue their careers in government posts.

Much has been written on the rationale and the broad consequences of programs such as the one mentioned, which will not be discussed here. From my point of view, I consider that I greatly benefited from it both in terms of personal and professional development. I had the opportunity to develop skills in making decisions without relying on any additional help from senior colleagues, as would have been the case if I were still working in continental Portugal. I am sure that I must have made mistakes, some of which might have been important, but I am also sure that this period of my professional life has made me more cautiously evaluate the impact of my decisions.

I also had a unique opportunity to understand the benefits of integrating preventive and curative care. Working at the government's Maternal and Child Health Clinics in Santa Maria, with the clinic's team of public health nurses, it soon became evident that with my arrival the population gained strong confidence in the services. My presence in the island meant easy access to a much-needed, reliable source of acute care which therefore resulted in a more cooperative and interested participation by the local population in preventive activities. For several years, the public health team had been working without the cooperation of a physician. This along with the local physician's opposition had severely limited its ability to provide preventive care.

My initial concern with cerebrovascular disease was the result of both my practice in ambulatory care in the Medical-Social Services and my work in Santa Maria. Both situations provided me the opportunity to experience the problems associated with "nonhospital" management of these patients, and to gain a broad understanding of its impact on the individual, family life, and community. I was struck by the lack of integration, which frequently meant the total non-existence, of the Portuguese Health and Social Services' responses to these problems.

In 1975 and 1976, still in the Azores, I also had the opportunity to participate in two major epidemiological

studies that opened new perspectives to me. The first was a study of hypertensive disease in the population of the island of Flores by a team from the Hospitais Cíveis de Lisboa, under the direction of Drs. Alfredo Franco and Castel-Branco Mota (Franco et al., 1977). This study introduced me to field research and to epidemiological concepts to which I had not been previously exposed at the undergraduate level.

The second project was the study of a major degenerative central nervous system disorder affecting Portuguese families in the Azores, conducted by Prof. Corino de Andrade and Dr. Paula Coutinho from the Institute of Neurology, Department of Neurologic Diseases, Hospital Geral de Santo Antonio, Porto (Coutinho et al. 1977; Coutinho and Andrade, 1978). I greatly benefited from my participation in this project not only improving my field research abilities, but also developing clinical skills in the subjects being studied.

In 1976, after returning from the Azores, I started a five-year residency program in internal medicine at the Hospital Geral de Santo Antonio (HGSA), Porto. At the same time, I was invited by Prof. Andrade to join the faculty of a new medical school in Porto -- the Instituto de Ciencias Biomedicas, "Abel Salazar" (ICBAS) -- which would have an innovative curriculum based on a community perspective,

integrating the areas of teaching, research and service. I was offered a position in the Department of Community Health, where I would work under the direction of Professor Aloisio Coelho, and was given the opportunity to develop my knowledge in the areas of Community Health and Epidemiology. Subsequently (1977-1978), benefiting from a scholarship of the British Council, I attended the "Combined Course on Epidemiology and Biostatistics" at the London School of Hygiene and Tropical Medicine (Professor Geoffrey Rose, Program Director), followed by a six-month training program in the teaching of community health and epidemiology at the Department of Community Medicine, University of Southampton School of Medicine (Professor E.W. Waters, Chairman).

These activities, and the present program at the University of Connecticut -- sponsored by the Calouste Gulbenkian Foundation (which includes the Masters Program in Public Health and the current Ph.D. program in Medical Anthropology) -- are part of the broad personnel development program of the ICBAS.

In 1978, ICBAS' Department of Community Health initiated its activities for undergraduate students. Since then, I have been teaching community health and epidemiology, as well as participating in associated research and educational activities.

My combined work at the two institutions has provided

the opportunity to develop my interests beyond the walls of health facilities, directly into what I consider to be relevant problems of the community. In 1978, I studied CVD mortality in Portugal and made the appropriate international comparisons (Calheiros, 1978). In 1980, as a development of my work at the Emergency Department (ED) of the HGSA in a team lead by Dr. Castro Lopes, I presented evidence from the HGSA files supporting the need for redefinition of current admission criteria for CVD patients, as well as the need to evaluate the current types of health care available to these patients after discharge (Calheiros, 1980). This study was the result of my increasing awareness of the magnitude of the stroke problem in Portugal, and more specifically in the city of Porto, and of the need to expand epidemiologic research beyond traditional etiological issues.

My work at the ED and at the Internal Medicine and Neurology wards led to frequent contact with the families of these patients, and to a better identification of their problems -- mainly those associated with admission and discharge. The majority of CVD cases have an initial contact with the health services at the ED due to some combination of the following: (1) the frequent life-threatening presentation of these disorders, (2) the practical impossibility of obtaining an emergency home visit by a physician, and (3) the increasing inability of the families to cope with this



extreme situation. When a visit occurs, the physician's need for diagnostic reassurance frequently requires the use of additional procedures, namely computerized axial tomography (CT), leading to a visit to the ED where these services are currently easily accessible. Nevertheless, the feeling that little or nothing can be done for a CVD patient is common among both hospital- and nonhospital-based physicians, including its younger members. Therefore, low interest and low priorities are frequently given to these patients, as compared to individuals with less frequent and/or less severe disorders.

I have already mentioned that CVD is a major public health problem in Portugal. Its relative importance must be kept in perspective by considering the role of other potentially competing disorders, especially other cardiovascular disease. I will address the social epidemiology of cardiovascular disease and the present Portuguese health situation in chapters to follow.

While CVD is linked with most risk factors known to affect atherosclerosis, its close association with hypertensive disease has been established beyond doubt (Kannel et al., 1971 and 1976; Shekelle et al., 1974; Nicholls and Johansen, 1983). It is also well known that considerable risk reduction results from antihypertensive treatment (Veterans Administration Cooperative Study Group on Antihypertensive Agents, 1970 and 1972; Hypertension

Detection and Follow-Up Programme Cooperative Group, 1979). The epidemiology of CVD and the strategies for its prevention have been extensively studied in developed countries such as the U.S.A., Great Britain, and Japan. They have not been as well studied in less developed countries of Europe and the Third World [1].

Regarding the prevention of CVD, an editorial in the British Medical Journal (Anonymous, 1981) and an extensive report by the Arterial Disease Working Party, appointed by the Royal College of General Practitioners of London (1981), estimate that 50% of all strokes in people under the age of 70 are preventable. However, multiple barriers must be removed in order to attain this objective, including those associated with current practice patterns, which often ignore that chronic diseases frequently share a number of common causes. As a result of this approach preventive programs have been usually oriented towards a specific factor or disease (heart disease, diabetes, salt consumption), taking one condition at a time in isolation from other diseases. A "multiple-disease strategy" was proposed by Epstein and Holland (1983) as a way to organize more effective and efficient preventive programs for a community. This integrated approach, was recently launched by the World Health Organization (WHO) in selected

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[1] See, for example, Siekert (1980), Rose (1981), Takahashi (1981), Weinfeld (1981), Tanaka et al. (1982a), Kimura (1983).

participating countries, aiming "to improve the health of total communities through a broadly structured program that can be integrated into the normal health services and will improve preventive activities on a broad front" (Epstein and Holland, 1983:136; see also Glasunov, 1983).

In recent years the concept of "primordial prevention" -- that is, "preventing the emergence of predisposing conditions in countries in which they have not yet appear," has emerged in the literature (World Health Organization, 1982:9; Watkins, 1984). This concept, which elaborates on early notions such as "mass prevention" (see Rose, 1981) and "anticipatory care" (see Anonymous, 1981; Arterial Disease Working Party 1981:5), adds a new dimension to prevention. These efforts, particularly designed for areas of low prevalence of selected disorders, have the objective of averting the development of health problems similar to those currently experienced by developed societies (see Dodu, 1984). I will return to the issue of prevention in later chapters.

When prevention is either not possible or unsuccessful, CVD expresses itself under a wide variety of clinical presentations. Severity may range from a minor disturbance, sometimes lasting just a few minutes, to a life-threatening situation that can result in death or severe permanent disability. Frequently diagnosed and responded to on an acute-care basis, the curative care resources of health care

systems are relatively powerless to deal with those situations that result in significant physical and social sequelae. Beyond the acute phase, health care responses require a high level of integration and coordination of its various components. This does not seem to be present in countries where health care resources are limited and health systems are traditionally based on the "acute-curative care" and "medical" models. I will return to these issues later when discussing the present patterns of care for CVD cases in Portugal, and especially in Porto.

## CHAPTER 2

### THE RELATIONSHIPS BETWEEN EPIDEMIOLOGY AND ANTHROPOLOGY (SOCIAL SCIENCES)

#### 2.1 GENERAL BACKGROUND

Human communities have long been the concern of the historian, the anthropologist, and the sociologist. In more recent years, they have also engaged the interest of the epidemiologist, frequently considered the basic scientist of preventive medicine. Historically, however, it is possible to note the practice of epidemiology, centuries before it began to be recognized as a special branch of medical science. This recognition happened only a little more than a hundred years ago, with the establishment of the Epidemiological Society of London in 1850 and the publication in 1873 of John Parkin's book Epidemiology; or the Remote Cause of Epidemic Disease in the Animal and Vegetable Creation (see Doll, 1982:xi-xii).

The formal relationship between anthropology and medicine is believed to have begun one hundred years ago when Rudolf Virchow, pioneer of studies on the social etiology of disease and currently better known for his

pathology studies, helped found the first anthropological society of Berlin (von Mering, 1970:272).

Social variations in the distribution of health and disease have been observed for centuries. However, the reasons for these differences in physical health status are yet not well understood. For many years it was assumed that these differences could be explained by variations in ethnicity or genetic stock, exposures to noxious stimuli in the physical environment, or access to medical care resources. While these factors undoubtedly account for some of the differences in disease rates among members of different social groups, accumulating evidence suggests that certain conditions and circumstances within the social environment or social cultural milieu per se have disease consequences. It is these factors which are usually within the purview of the social epidemiologist.

Another perspective is that of historical materialist epidemiology. The field's antecedents include the classical research of Engels, Virchow, and of the nineteenth-century school of social medicine in Europe. Simply defined, historical materialist epidemiology relates patterns of death and disease to political, economic, and social structures of the society. This field emphasizes changing historical patterns of disease and the specific material circumstances under which people live and work (Waitzkin, 1983:62), an approach that has been largely forgotten and rediscovered with each

succeeding generation. Since the mid-1970s, historical materialist epidemiology has concerned itself with the social etiology of disease. Social contradictions, especially the contradiction between profit and safety, are thought to foster illness and impede change. These issues, however, did not emerge for the first time during the last decade; there is a long history of research and analysis that has been neglected, despite its relevance to current situations. Engels' The Condition of the Working Class in England (1845), Chadwick's Inquiry into the Sanitary Condition of the Labouring Population of Great Britain (1843), Shattuck's Report (1850), and several of Virchow's works are excellent examples of early research relating health to the social environment. The patterns and problems of life in the urban environment have since then engaged the attention of many social scientists and Robert E. Park was the first author to use the concept of "the city as social laboratory" (Smith and White, 1929).

For epidemiologists, despite the fact that a large number work in departments of "community health" or "community medicine," communities are not usually of primary interest in and of themselves. Epidemiologists' concerns are mainly to elucidate pathogenic mechanisms: identify risk factors in disease and, to the extent possible, etiologic agents. Nevertheless, it is clear that epidemiological investigations are best conducted on subjects who are

selected from clearly defined populations in order to insure the validity of inferences drawn from the study findings. In general we might say that "epidemiology is the study of the distribution of a disease or physiological condition in human populations and of the factors that influence this distribution" (A. Lilienfeld, 1976:3). McMahon and Pugh (1970:1) define it as "the study of the distribution and determinants of disease frequency in man." However, limited consensus exists as to what exactly is the scope of the discipline. David Lilienfeld, after reviewing 23 definitions of epidemiology elaborated between 1927 and 1976 (no one refers to "social epidemiology") proposes his own:

Epidemiology is a method of reasoning about disease that deals with biological inferences derived from observations of disease phenomena in population groups (D. Lilienfeld, 1978:89).

Implicitly or explicitly, this definition is currently the operational one in most biomedical sectors. According to David Lilienfeld (1978:89),

The biological inferences made by an epidemiologist "must" concern a disease phenomenon, e.g., a disease's etiology and/or natural history. Therefore, the evaluation of health care and its administration can "not" inherently be within the scope of epidemiology, unless such an evaluation directly results in an inference being made about a disease phenomenon; such evaluations should, therefore, be considered examples of medical sociology.

Social epidemiologists focus further on social conditions and disease processes. Syme (1974) has suggested that



social epidemiology may be seen as that part of epidemiology that is concerned with psychosocial determinants. Even though the boundaries of social epidemiology are somewhat vague and overlap with those of other social-behavioral sciences (medical anthropology, medical sociology, psychology, psychosomatic medicine, etc.), within this segment of collaboration between the social sciences and medicine there is a primary concern with psychosocial determinants of the following (Kasl, 1977:161):

- (a) illness or disease onset (incidence of new events)
- (b) course of illness or disease (exacerbations, repeat events)
- (c) outcome of disease process and/or degree of recovery

However, because of the ecological orientation of epidemiology and the centrality of such concepts as agent-host-environment, or person-place-time, epidemiology is considered to have always been, to a certain extent, "social." In addition, to some investigators the term "social epidemiology" also means a broadening of "states of health" or "disease" to include health-relevant behaviors. Thus, these days one may also be studying the epidemiology of drug abuse or the epidemiology of smoking (Kasl, 1977:162).

Another perspective is the one held by Stallones

(1980:70-73), who embraces "as a matter of faith" that only one epidemiology exists, and that three significant classes of applications of epidemiology can be identified:

- (a) epidemiology of specific diseases
- (b) evaluation of medical care
- (c) ecologically based epidemiology

For Stallones, epidemiology is very properly a subset of the field of human ecology, and we may not have gained much by subdividing this field.

As the claims of potential contributions of social epidemiology to other disciplines and fields of endeavor grow (e.g., Cassel 1974a and 1976), so does, of course, the blurring of disciplinary boundaries. Overall, one is forced to conclude that one can neither set precise boundaries on "epidemiological methods" or discipline territories and constituencies, nor identify methodological approaches unique to epidemiology and not shared by other disciplines, such as social psychology, sociology, anthropology, or demography (Kasl, 1977:162).

Medical Anthropology, as a branch of social and cultural anthropology, is also concerned with a wide range of biological phenomena, especially in connection with health and disease. As a subject, it therefore also overlaps the social and natural sciences in a similar way to that

described for social epidemiology.

The field of health is a field in crisis and transition. Serious questions regarding the validity of traditional health theory are forcing a critical reexamination of the assumptions on which the theory is based and on the conceptual approach to which it has given rise (Ratcliffe, 1980:41). Indeed, it is probably not too much to say that the health field is experiencing a paradigm shift (Kuhn, 1970:77-91) a process that may ultimately give rise to a radical restructuring of health theory and a fundamental reorientation of the way health problems are defined and policies conceptualized. To a great extent, this shift comes from the convergence of the works and interests of social science and public health, and of increasing (although still limited) interdisciplinary work. These issues will be addressed next.

## 2.2 THE RECENT PARADIGM SHIFTS IN THE HEALTH FIELD

Rudolf Virchow said that medicine is social science, and politics is nothing but medicine on a large scale. The same belief is shared by many other social sciences and health professionals. John Knowles (1979:viii) states:

I believe that medicine is a social science as well as a physical and biological science and that it needs the social sciences and the effects of their study as never before in history.

This influence of social sciences in health care has not been confined to the work of persons trained and identified with social sciences themselves. The public health fields of epidemiology and health services research have also contributed to this by integrating and using theories and methods developed by the social sciences. Examples of these theories include those about complex organizations, networks, and social support. Examples of methods include survey techniques and scaling of variables. In addition, some or all of the independent variables used in public health are also derived from social science research, such as social class, personality type, family/household types, and gross national product.

The above-mentioned social research has identified three broad effects of sociocultural conditions on health. In the first instance the matter of how health is defined in any society is itself an aspect of the culture, as are the behaviors usually associated with roles wholly or partially determined by an individual's health status. A second aspect is the already referred area of particular interest to social epidemiology, documenting the impact of socioeconomic and cultural variables on changing health levels. A third domain of social science concern is in matters of policy - efforts intended to influence health levels by means of altering the availability of medical care and changes in social, economic and political conditions.

Since the 1970s significant changes in anthropological methodology have been growing. According to DeWalt and van Willigen (1984:845), these changes have contributed to decrease the differences between anthropology and other social sciences at the level of data gathering techniques. In addition, these authors propose the adoption of more efficient and responsive ways of defining research foci. As a consequence, they recommend that in a Third World context, anthropologists should change their research focus from questions of acceptability of Western medicine to traditional consumers to questions of accessibility and allocation, and more research on providers.

To a large extent, these changes are already evident in selected groups and schools of thought, mainly the ones that support the action-research model. The maintenance of the above-mentioned trend and the extension of the suggested research strategy to include developed countries, will certainly contribute to further approximating anthropology and epidemiology, and to cross-disciplinary research, as it is increasingly recognized that no one discipline is equipped to adequately deal with the complex issues related to health.

Relationships between social sciences, in particular anthropology and epidemiology, have been slowly developed throughout the twentieth century, especially around public health issues (both inside and outside public health

arenas). Areas of mutual concern have been recognized. The concept of specialized training for public health, with its focus on health conditions and social problems in the context of the community, can be traced to the eighteenth century. Although the first school of public health was founded in Munich in the middle of the nineteenth century, it was not until the next century that schools of public health were established in the United States. Until the 1940s, public health schools were primarily concerned with the detection and control of specific communicable diseases, applying new biomedical and sanitary engineering technologies to disease control. Given these predominantly bacteriologic perspectives, it is not surprising that anthropology and other behavioral sciences had little influence on public health in the early part of this century (Schreiber, 1975).

As the definitions of health and the ethical concerns of societies have changed, so too the content and goals of public health education have changed. Programs were originally concerned with sanitation, immunization, biostatistics, and epidemiology. They were directed first only at physicians, and then at medical professionals and engineers. Although most schools of public health developed relatively independent of medical schools in both the United States and many other countries, in many cases public health

schools were responsible for teaching subjects such as epidemiology in affiliated medical schools. Only in the 1960s did schools of public health began to accept nurses for additional training, and then people without any previous medical or health-oriented degrees.

Most current public health curricula concentrate on health problems and disease prevention in communities, which may also be regarded as the constituency of anthropologists. The style of individual institutions varies, but generally public health schools concentrate on both the basic public health sciences of biostatistics, disease control, environmental sciences, epidemiology, and the applied fields of health care organization and resource administration. Both areas have broadened to encompass the social factors that affect health and disease, ranging from the ecology of human interactions with the environment to cultural factors in the use of health services. As the research and teaching emphasis changed, more non-M.D.s were hired in a wide variety of fields, including the social sciences. As behavioral scientists began to work in public health, it became generally accepted that other disciplines had an earlier and more pervasive influence on this field than anthropology, including sociology, psychology, economics, and political science (Schreiber and Scrimshaw, 1979).

The social ferment of the 1960s, largely responsible

for some of the above-described changes, precipitated an enormous interest in the health of disadvantaged individuals and social groups. Awareness of the importance of social and economic factors as determinants of health became acute. Furthermore, the discrepancies of access to health care associated with social, economic, and cultural factors became clear. Medical students were outraged that these injustices had not been previously recognized and corrected. Curriculum "reform" became the by-word of the day. An important part of this reform was to be the enhancement of the social, especially behavioral, sciences in medical teaching and practice. New faculty members were recruited, new courses were developed, and whole new departments sprang into being. Students and faculty alike were urged to view the patient as a "whole" person and terms such as holistic medicine, comprehensiveness of care, continuity of services, began to appear frequently in the literature.

Simultaneous with this increased awareness of social factors as determinants of health in disadvantageous groups came an awareness of many unsatisfactory aspects of the health care system for all segments of society. Increased specialization and fragmentation of medical care as it was delivered by many specialists and subspecialists to a single individual led to the conviction that no one was keeping an overall eye on the health problems of any one person. The concept of a new health care provider, the



family physician [1], grew rapidly. If health and disease are seen as entities on a continuum ranging from excellent health at one end to severe disease at the other end it is clear that most physicians function at the disease end of the spectrum. The one notable exception is the family physician who is likely to function anywhere along this continuum (Bergner and Gilson, 1980:135). This is also true of a large proportion of the epidemiologists (clinical epidemiologists, genetic epidemiologists, etc.) who follow David Lilienfeld's concept and work almost exclusively at the disease end of the above mentioned spectrum. The majority of these researchers have sought little or no collaboration at all with the social sciences.

Over the last few years, developments at international and global levels (the United Nations' "New International Economic Order," the World Health Organization's "Alma-Ata Declaration," and "Health for All by the Year 2000 Strategy"), have also helped foster a major paradigm shift in the health field. John Ratcliffe (1980:41-42) describes it as follows:

"The Traditional Health Paradigm" is based on the assumption that health and mortality levels are primarily a function of the interaction between the individual and the physical environment, including physical contact with other diseased individuals. Another fundamental assumption is that the delivery of modern (i.e., western) medical technology and associated services has been primarily responsible for

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[1] "General practitioner" is the equivalent denomination in the United Kingdom and most European countries.

observed declines in mortality and broad improvements in national and international health trends and levels. These basic assumptions have given rise to particular definitions of health problems and issues; they have also generated two fundamental strategies for improving health levels among human populations. The first is the curative, or clinical, approach, which relies on medical technology and services to relieve disease symptoms and/or cure diseases after they have been contracted... The second strategy is the traditional public health, or preventive, approach, which utilizes medical technology to mediate between the individual and the physical environment in ways that will lessen the probability of contracting disease.

It is noteworthy that none of these conventional strategies attempts to influence health levels by modifying the "social", human-created environment in which the individual lives and must act. That is, attempts to influence health levels have taken place within the confines of the "system", which is taken as given. The result is that strategies of change that are of first order nature (incremental), in that they do not affect the established system itself. The social environment is not considered to be variable or instrumental, or even problematic, and perhaps in need of a second-order change as a condition necessary to effect widespread improvements in health trends and levels.

Given these basic assumptions and strategies, it is not surprising that the adoption and diffusion of innovations have been the conceptual approach that has dictated health research foci and priorities, conclusions drawn from

research findings, and policy recommendations for some four decades. Despite the recognition that "early adopters" of modern medical technology and services are consistently characterized by higher income and education levels, and by greater physical and material security, such features rarely are viewed as structural in nature. In fact, the key factors limiting the diffusion of modern health principles are assumed to be the conservative values and fatalistic attitudes of the poor and uneducated segments of the society.

Such approach also assumes that "modern" health behavior spreads from more to less innovative individuals through a "multiplier effect". The practical effect of this approach is to justify the concentration of available resources and services among the more advantageous groups and urban enclaves, while relying on an indirect, or "trickle down", effect to reach the poor and the disadvantaged.

"The Emergent Paradigm" is based on research relevant to the field of health that has illuminated the relationship between structural factors and health processes. Such research has shown that the available evidence does not support the proposition that observed mortality declines are attributable to the diffusion of medical technology and services. The implication is not that modern medicine has been without impact; rather, the impact of modern medicine

on mortality trends and levels has been vastly overrated. In fact, particular curative and preventive measures served only to slightly accelerate the substantial declines in mortality already well underway before either germ theory or specific causes of disease received wide acceptance.

Historical epidemiological and social sciences evidence indicates that improvements in such socioeconomic conditions as education, nutrition, housing, sanitation, and working conditions (rather than medical advances per se) combined to bring about mortality reductions and increased life-expectancies [1]. Evidence indicates that the effect of improved nutritional status in the control of communicable disease seems to be of particular importance and that education is a major factor influencing mortality and life expectancy, both in developed and developing countries. The study of Kitagawa and Hauser (1973), focusing on socioeconomic differentials in mortality in the United States, demonstrated that education is the single most powerful explanatory variable, even more important than income.

Although improved levels of nutrition and education may rank first among the socioeconomic factors responsible for declining mortality, others are not far behind in importance. Improved levels of personal income and employment also contribute to host improvement, and, thus, to reduced

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[1] See, for example, Dubos (1965), Powles (1973), Illich (1975), McKeown (1979).

mortality and increased life expectancies.

However, a major point to be noted is that observed levels of income, education, socioeconomic class, and therefore nutritional and mortality levels, are themselves not determined by the physical environment but by the political and economic system in which they are embedded (Ratcliffe, 1980:44). Infant mortality rates, even in advanced industrial societies, are still largely dependent on fluctuations in the national economy, this being true not only for the United States, but also for countries such as England and Sweden (Brenner, 1983 and 1980).

Recent literature offers impressive evidence of the role that sociopolitical, socioeconomic, and sociocultural barriers have in the implementation of public health and health care. In this context, and addressing the roles of anthropologists in international health planning, Kleinman (1978:74) points out that:

If medical anthropologists are to have a significant impact on the creation of international health plans that address the cardinal effects cultural and social structural forces exert on health, sickness and health care, one reason will be because they have legitimated the ethnomedical framework in the process of international health planning and further have translated its key concepts and findings into the problem framework and program objectives held by their colleagues in international medicine and public health.

Kleinman (1978:74-76) also emphasizes that the ethnomedical approach should not replace the biomedical approach,

but rather complement it.

The ethnomedical model states that "health" and "sickness" are semantic subjects which are inseparable from the differing ways they are conceptualized by patients, families, communities, and practitioners. Whereas the biomedical model reduces health and sickness to mechanical states divorced from person and social context, the ethnomedical model interprets them as labels of social statuses inextricably bound within networks of meaning that tie them to general cultural norms and concrete interpersonal transactions.

Further works by Kleinman explored this relationship in what the author called "the borderland between anthropology, medicine, and psychiatry" [1].

Overall, social science research in health has given us invaluable information in many spheres that have extensively contributed to the formulation of this new theory. A brief listing of such studies would include the dynamics of illness generating socioeconomic conditions; the analysis of community health and needs; the influence of prepaid insurance programs on the use of health services; the dynamics of solo versus group practice; role expectations among the various categories of health workers, including doctors, nurses, physician assistants, social workers, dietitians, and medical researchers; the influence of social and economic class in the receipt and use of services; the evaluation of types of organizations designed to give

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[1] See also Kleinman et al. (1978), Kleinman (1980), Eisenberg and Kleinman (1981).

comprehensive, continuing health care in ambulatory clinics; the internal organization of the hospital and its paradoxical arrangements of authority and responsibility; public attitudes toward the general hospital, the mental health institution, the public health unit, and so on; the assessment of medical (health) care programs for special population groups such as ethnic minorities, the medical indigent, dependents of military personnel, and the chronic and mentally ill; the effect of cultural determinants on the use of health services; the cultural construction of clinical reality; the fundamental distinctions between illness and disease; and the recruitment, development, organization, and retention of health personnel.

Clearly the results of such studies have tremendous implications for all of us interested in the health of our communities, whether we are professional purveyors or non expert recipients of health care.

Some of this work has been the result of cooperation between social and medical sciences. The bases for this interdisciplinary approach have been multiple and varied. In many cases, their origins were shared institutional bases and/or constituencies, and shared social interventions. The action research and advocacy model in community health, and community development issues [1], and that of disease

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[1] See, for example, S. Schensul (1973 and 1979), S. Schensul, and Borrero (1982b), J. Schensul et al., (1982).

prevention through health education and/or nutrition programs [1] constitute excellent examples of these developments.

Epidemiologists and other public health professionals and, to a certain extent, some physicians involved in clinical work, are increasingly aware of the impact of human behavioral variables on the transmission of infectious and parasitic disease, on the etiology of malnutrition and chronic degenerative disease, as well as on the acceptance of disease control programs. However, issues such as community development, although equally relevant, are usually given little or no attention by the medical establishment. Its traditional approaches have been either to ignore them, to deny them, or to consider that the problems lay out of the professional field of activities.

Yet the potential benefits of this collaboration seem evident. Social sciences and in particular anthropology, can communicate the value of the holistic approach to health-related problems to a group of professionals that frequently uses models that explore one disease factor at a time. They can also provide the precision and depth of understanding that can be obtained through the variety of methods used in ethnographic work. In addition, disease control programs (as "natural" experiments) and the epidemiological data that

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[1] See, for example, Jerome (1979), Ault (1983), J. Brown (1983), P. Brown (1983), Foster and Deria (1983), Gruenbaum (1983).



they generate can contribute to a better understanding of cultural systems, sociocultural change, and biocultural evolution - important research topics for both the applied and theoretical fields of anthropology and of other social sciences.

### 2.3 SOCIAL EPIDEMIOLOGY - A MULTIDISCIPLINARY MARRIAGE

The need for interdisciplinary work in studying health issues has translated into a wide variety of implicit and explicit "marriage proposals", present in the biomedical and social science literatures. Among the more recent and significant ones, one may refer the following:

1. THE MARRIAGE OF PRIMARY CARE AND EPIDEMIOLOGY (Hart, 1974; Morrell and Holland, 1981)
2. THE COMMUNITY MEDICINE-PRIMARY CARE CONNECTION (Deuschle and Bosch, 1981)
3. EPIDEMIOLOGY IN HEALTH POLICY (Terris, 1980; Modan and Barell, 1981)
4. APPLIED MEDICAL ANTHROPOLOGY AND COMPARATIVE HEALTH POLICY (Hill, 1984)
5. THE CASE FOR COMMUNITY-ORIENTED PRIMARY CARE (Kark, 1981; Madison, 1983)

Two other relevant, although less explicit, "proposals" refer to the responsibilities of medical education in meeting the health needs of the society (Fullop, 1977) and to the adoption of a new code of ethics that would lead to a

socially oriented medical behavior (Roemer, 1982:362-363).

Common to these "proposals" that reflect the opinions of a wide variety of constituencies is the growing discontentment among selected health and social science professionals with the current state of health care provision and with the research associated with it. In the case of the first "marriage" it addresses the separate and frequently antagonistic lives of university departments of epidemiology and primary care, and the lack of interest of practicing physicians for the health of the communities they serve. Often, communities are merely viewed as a group of individual cases.

The second proposal focuses on the academic nature of most departments of community medicine. Although emphasizing the teaching of epidemiology, biostatistics, behavioral and management sciences, they are frequently isolated from "real life" community issues by the nature of their lack of involvement in health care provision and/or planning.

The third and fourth proposals reflect the need to base health policy not only on sound epidemiological data but also on a thorough knowledge of the sociocultural system. According to Terris (1980:323), several major constraints frequently restrict the influence of epidemiology in this area, including: (a) the failure of the health professions to understand the primacy of prevention, (b) their unwillingness to accept the validity of epidemiological discove-

ries, and (c) the power of private interests. The author also points out that these factors may act singularly, or together.

The last marriage refers to the fact that, primary care is frequently confined to the treatment of individual patients, particularly in developed countries. Community-oriented primary care means the enlarging of the traditional horizons of the primary care practitioner from the strictly clinical to the epidemiologic and community aspects of care. To a large extent this is a 1980s variation of 1974s Tudor Hart proposal. However, it is important to note that its proponents insist on limiting primary care to the provision of health services, a position frequently held by the medical personnel of developed countries, which is in total discordance with the generally accepted concept of WHO.

Overall, the work of the above authors reflects the need to overcome a wide variety of gaps, both intra- and interdisciplinary, that frequently are "the expression of societally imposed socio-political divisions". According to these authors, "these divisions can be characterized as the academy vs. the community, action vs. research, Anglo vs. Puerto Rican (or other ethnic or nonethnic subdivisions), scientific objectivity vs. subjective commitment" (S. Schensul, and Borrero, 1982a:7). In order to overcome these and other difficulties that concern the whole field of social science-medicine, Kasl (1977:161-162) proposes that

it should be divided not along disciplinary lines but rather in terms of major problem areas, primary orientations or emphases, and levels of analysis. He suggests the following classification:

1. Concern with psychosocial determinants of:

- (a) illness or disease onset
- (b) course and outcome of illness or disease (in the context of medical care or without treatment)
- (c) medical care utilization
- (d) behaviors and practices with health implications (e.g., smoking, use of seat belts, adherence to a medical regime)

2. Concern with the impact of health/illness on the behavior and well-being of the individual (e.g., impairment-disability, role performance) and of significant others (e.g., marital happiness, spouse's role performance).

The above concerns can be expressed at different levels of analysis:

- (a) the individual (e.g., perception and interpretation of symptoms)
- (b) a dyad (e.g., barriers to doctor-patient communication)
- (c) the social network of significant others (e.g., legitimization of seeking treatment)
- (d) organizational (e.g., preventive health behavior in a prepaid health maintenance organization vs. fee-for-service systems)
- (e) community (e.g., effects of catchmenting)
- (f) societal (e.g., medicine as an institution of social control).

According to Kasl, this classification cannot adequately express the richness and complexity of some of the current work in the field: multiple concerns, several levels of analysis, longitudinal perspective with multiple feedback loops. Nevertheless, this listing, to which many other examples could be added, is adequate for the purpose of showing how difficult (and arbitrary) it would be to "assign" a particular topic exclusively to social epidemiology, epidemiology, or any one of the social sciences.

Stallones (1980), for whom only one epidemiology exists, helps clarify these points. According to him, one scientific discipline is distinguished from another by three components: (a) the body of knowledge accumulated by the discipline, (b) the methods of study whereby this knowledge was collected, and (c) the theory guiding its collection. Neither the body of knowledge nor the methods are necessarily unique to a discipline, for knowledge referrable to one field may be assembled from a variety of disciplines, and methods may have broad applicability.

This seems to be particularly the case of epidemiology. Its body of knowledge has benefited greatly from social sciences research, which may ultimately help epidemiology adjust its focus in order to adequately and systematically integrate social factors in the etiological chain (Graham and Reeder, 1979:73). We may claim that, to a large extent, this may become the major achievement of the advocates of

social epidemiology, for if we accept Stallones' perspective, most of this interaction would fall into one of the applications of epidemiology proposed by him - "ecologically based epidemiology." However, as previously described regarding the health/disease spectrum, there will always be researchers (epidemiologists or social scientists) who place themselves anywhere along this continuum, differing markedly in their interpretation of what the primary orientations, the emphases, and levels of analysis are, although they may share areas of interest.

Regarding methodology, we have seen how anthropology and other social sciences have reduced the differences between themselves and biological sciences at the level of data collection, by more frequently adopting quantitative techniques. Major changes are also evident in research designs through the development and use of selected types of quasi-experimental designs (Cook and Campbell, 1979). Frequently, notable resemblances with classic epidemiological study designs (i.e., case-control, cohort studies, etc.) are evident. In addition, these changes also imply the adoption of appropriate sampling procedures and of a level of data analysis that until recently was not common in social science research.

Theory, however, is more likely to remain unique to a field and therefore may be the most distinctive feature of a discipline. Theory usually changes less rapidly than know-

ledge or even methods. Indeed, the stability of a theory is a measure of its success. The volume of the components of a discipline is also sharply ordered; few theories control many methods, the application of which may generate enormous numbers of bits of information. For Stallones (1980:80), epidemiology is based on a central axiom, not subject to proof, and without which, no epidemiology is possible:

AXIOM: Disease does not distribute randomly in human populations.

COROLLARY 1: Nonrandom aggregations of human disease are manifested along axes of measurement of time, of space, of individual personal characteristics, and of certain community characteristics.

COROLLARY 2: Variations in the frequency of human disease occur in response to variations in the intensity of exposure to etiologic agents or other more remote causes, or to variations in the susceptibility of individuals to the operation of those causes.

Unlike content, these statements appear to be substantially invariant. Unlike methods, they are peculiarly and uniquely referrable to epidemiology, although they are not limited to any specific type of epidemiology. If one tries to understand the differences and the potential advantages of social epidemiology vs. traditional epidemiology, those are not to be found predominantly in knowledge, methods, or theory, but rather, on how problem areas, the primary orientations or emphases and, eventually, the levels of analysis are selected. It is in this respect that social

epidemiology has had, and is expected to continue to have, a major contributory role to community health by helping focus on relevant issues that will later be translated into culturally appropriate interventions, along the lines of the action-research model (see for example, S. Schensul, and Bymel, 1975).

This relationship may be particularly relevant because epidemiology does not currently have a strong advocacy component, and even less so a full action-research commitment. Frequently, significant progress is made at research levels that are only belatedly translated into practice (e.g., malaria vaccine, schistosomiasis drug therapy, etc). The same applies for the recent involvement of epidemiology in the policy-making and intervention processes.

Epidemiologists have shown a very limited concern with cultural aspects that are extremely relevant to these processes that may be the key to the failure or success of a program. The best examples of this programs are the malaria and the smallpox eradication programs, the former very successful, the latter, not (Gruenbaum, 1983; P. Brown, 1983; Ault, 1983; Foster and Deria, 1983). Program implementation is another area where the development of appropriate interactions may result in significant progress.

Traditionally, epidemiology has been mainly concerned with the etiology of disease and less so with its population



content. Frequently populations have been used for methodological reasons only, in order to contrast "abnormal" with "normal" components of the community. Research on illness and, to a large extent on health, has been mainly the responsibility of the social sciences. In addition, epidemiology has been risk-factor oriented, frequently based on the old "one-cause, one-disease" explanation. The use of simplified techniques and/or variables has been advocated, as a means of being able of gathering large volumes of data. As a result, variables such as ethnicity, have often been treated as a homogeneous rather than multifaceted variable (e.g., religion, diet, education, etc). The use of intraethnic variation, therefore, has had, at best, limited use in such research.

It is now evident that we will never solve the noncommunicable disease problems (cardiovascular disease, cancer, mental health, etc.), if we do not also take into consideration a wide array of social and cultural factors. The field of mental health provides a clear example of how shared concerns (problem areas) are addressed by completely different orientations and emphases. While anthropology focuses on cultural explanations of behavior and allows for the cultural construction of normality, epidemiological research focuses on the different outcomes of various behaviors as eventually a means for intervention. Addressing this problem area through these two independent approaches

has obvious problems that can only be fully overcome by its complete integration.

A new strategy of epidemiological investigations has to take these factors in consideration. We may also call the "Emergent Paradigm" described above (see pages 30-31) the "Social Epidemiological Paradigm". It provides a model of causation -- based on the concept of the "etiological chain of events" -- whose efficiency varies according to the disease being studied. In order to achieve a complete, coherent theory of causation of a given disease, data of various sorts (biosocial, biochemical, biophysical) must generally be obtained and each kind determined to be consistent with the others in relation to the disease (Graham and Reeder, 1979:73). An early example of the role of social factors in the development of a disease can be seen in the chain of events leading to the contraction of scrotal cancer. In 1775, Sir Percival Pott, studying the disease in England, found the following:

1. an environmental need for heated dwellings
2. met with a sociocultural response in the form of installation of home space heaters,
3. and the preferred fuel for them produced so much smoke and soot that
4. exhaust passages required frequent cleaning,
5. resulting in the creation of the chimney sweep, which brought the worker into close and frequent contact with soot, which, in susceptible individuals caused scrotal cancer.

Not surprisingly, this chain of events is quite similar to that of many present-day occupational disorders (asbestos disease, lead disease, etc.). Interrupting the chain of events at almost any stage can control the disease. Thus, Pott vastly reduced the incidence of scrotal cancer by prescribing a simple measure - bathing, that in modern times may be translated into proper engineering control devices, such as air exhausts. Similar chains can be described for other chronic disorders, eventually presenting less evident occupational links, such as ischemic heart disease, gastric cancer, and many others. However, even for almost wholly genetic diseases, it is currently agreed that they are also affected by social and environmental factors, that may become of particular relevance in its management, such as for the case of sickle-cell anemia or thalassemia (Book, 1980).

The extension of the "social epidemiological paradigm" beyond its exclusive role in causation into health policy, including health planning and implementation, has not been adequately used or emphasized. By doing so, we would take into consideration the intervening sociocultural, economic, and political factors that may eventually support the concept that the health system itself is also a "major risk factor" and so should be included in the above-mentioned etiological chain (see, for example, Hill, 1984:861).

This issue is of particular relevance for the present research, especially regarding the health system's failure to prevent what is preventable and/or to provide appropriate forms of care for all levels of the health problem.

The "ecological model of illness", to be discussed next, is central to most recent medical anthropology research. It integrates the above-discussed epidemiological concepts of causation with the concept of human adaptation, with particular emphasis on problem-solving, decision-making, and coping behavior in managing illness and promoting health.

From what I have pointed out, there is much to gain if we are able to overcome the dysfunctional definitions that prevent us from combining our knowledge, skills, and talents to create positive social change (S. Schensul, and Borrero, 1982a:7). A balanced combination of the two main approaches used in anthropology for the study of society and culture -- the ethnographic and the comparative approaches -- coupled with an increased use of quantitative research techniques, and appropriate epidemiological study designs, will certainly be the indispensable tool for our present times, whether we are assessing the health of rural or urban populations, or implementing and/or evaluating health policies. In this way, we may expect that social sciences and epidemiology can fully develop appropriate collaborative efforts and avoid further unnecessary

splitting of the field that would ultimately lead to the creation of a multitude of other epidemiologic subdisciplines, including "cultural epidemiology", as has been implicitly suggested by Helman (1984).

### 2.3.1 Applying the social epidemiological paradigm

In recent years, a growing number of research studies throughout the world have been based on the social epidemiologic paradigm described above. The relevance of these studies, not only in terms of the target populations and the potential benefits that could (or should) result from such endeavors, but also in terms of the demonstration that such an interdisciplinary approach is feasible and highly recommended, ought to be fully emphasized. One of the most important documents of our times is the Report of the Working Group on Inequalities in Health, also known as the "Black Report" (after chairman Sir Douglas Black, President of the Royal College of Physicians), published in August 1980 by the United Kingdom's Department of Health and Social Security. This working group was appointed in 1977 at the request of the then Secretary of State for Social Services, with the task of reviewing information about differences in health status between the social classes, considering possible causes and the implications for policy, and suggesting further research.

The working group was comprised of two medical and two

sociological members: Sir Douglas Black (Chairman), President of the Royal College of Physicians and then Chief Scientist at the Department of Health and Social Security (DHSS); Professor J.N. Morris, Professor of Community Health at the London School of Hygiene and Tropical Medicine; Dr. Cyril Smith, Secretary of the Social Science Research Council; and Professor Peter Townsend, Professor of Sociology at the University of Essex.

The report showed in great detail the extent to which ill/health and death are unequally distributed among the population of Britain. It suggested that these inequalities have been widening rather than diminishing since the establishment of the National Health Service (NHS) in 1948. The report concluded that these inequalities were not mainly attributable to failings in the NHS, but rather to many other social inequalities influencing health: income, education, housing, diet, employment, and conditions of work.

In consequence, the report recommended a wide range of strategies of social policy measures to combat inequalities in health. These findings and recommendations were virtually disowned by the then Secretary of State for Social Services. Very few copies of the Report were printed and few people had the opportunity to read it [1]. Gray (1982), publishing

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[1] A paper back edition of the report, edited by Townsend and Davidson (1982), is available in Great Britain and Canada.

in the International Journal of Health Services, provides a useful summary of and commentary on the report, and an extensive and selective bibliography on inequalities in health.

Almost simultaneously, two other relevant efforts, partially sharing the same framework, were conducted in London. The first one, "A Survey of Primary Care in London," the report of a working party led by Dr. Brian Jarman (1981), provides detailed documentation on both the illnesses of patients in London and the characteristics of their general practitioners, as well as other demographic, social, and medical information based on data predominantly dating from 1977.

The second document, "Primary Care in Inner London" (The Acheson Report), is the result of the work of the London Health Planning Consortium Study Group (1981). It diagnoses health care problems in inner-city London, especially regarding the provision of primary health care. The report documents difficulties new patients encounter when finding physicians who would accommodate them to their lists. It also provides an array of recommendations in the form of financial incentives and disincentives to improve the organization of general practice - recommendations that have disconcerted and threatened physicians and led to significant delays in the government's response (Anonymous 1983a).

The problems of providing satisfactory primary health care in large cities are becoming acknowledged as universal, as pointed out by John Fry (1982). Now inner London has been added to the list compiled by the World Hospitals (1977) in which various authors reported the problems of New York, Toronto, Sidney, Bogota, Mexico City, Hong Kong, and Manila.

The size of this list can be greatly increased if we add research from other areas of the world. Among them we may cite the research conducted in inner-city minority communities in Hartford, Connecticut (Urban Health, special issue, editors S. Schensul and Borrero, 1982b; Hogle et al., 1982), or the work of the Centro de Estudios y Asesoría en Salud, C.E.A.S. (Breilh et al., 1983), in Quito, Ecuador. This group has recently published an extremely important study entitled "Ciudad y muerte infantil - investigación sobre el deterioro de la salud en el capitalismo atrasado: un método" focusing on societal contradictions that have resulted in the deterioration of the health status of Quito's children during the rapid expansion of Ecuador's oil industry. Major emphasis was placed on the determinants of child health and the enormous differences in infant mortality rates experienced by different social classes. The authors reminded us that the use of national figures, frequently showing notable improvements, may be, deliberately or not, hiding tremendous inequalities. Furthermore, such inequalities are more likely to occur in what they



classified as countries of undeveloped capitalist systems, as is the case in much of Latin America or other developing countries.

Another relevant work refers to present pattern of health care in the United States. Davis and Rowland (1983), from the Department of Health Policy and Management of the Johns Hopkins University, studied the uninsured and underserved in the United States (estimated to be over 25 million). They provided a timely review of what we know about the consequences of inadequate health insurance coverage, the characteristics of the uninsured, their patterns of health care utilization, and assess the policy implications of these facts. They also offered recommendations for future public policy to ensure access to health care for all.

Common to these studies is the fact that social epidemiological research has provided important new knowledge. However, that knowledge, and the clear directions it offers for the formulation of public policy, have not always been used -- partly because of a lack of political will (a basic requirement of the Alma-Ata/Health for All strategies). This suggests, as Knowles (1979:ix-x) points out, the need for further research on the relationships between health and politics.

A final note refers to epidemiological studies of specific diseases that, although disease oriented, take into

consideration its multifactorial origin along the lines of the social epidemiological paradigm. The works of John Cassel, often in collaboration with other researchers [1], clearly demonstrate the relevance of the interaction between social sciences and epidemiology in this area.

The above-cited examples have been drawn from a wide variety of geographic areas, concerns, orientations, and/or constituencies. The possibilities of replication or adaptation are endless. These studies represent some of the most illustrative and rewarding examples of the "multidisciplinary marriage" required for a broader understanding of ill/health in people of different cultures and social conditions.

#### 2.4 CHRONIC DISEASE, ADAPTATION, AND THE ECOLOGICAL MODEL OF ILLNESS: THE CONCEPT OF FAMILY COPING

Chronic severe illness, especially that which produces serious disability, places heavy psychological and social strains on the individuals and on their families, particularly if they are under home care. Although the stresses imposed by the chronically disabled in the family are not a new phenomenon, the new cultural features and

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[1] See "The legacy of John C. Cassel," Ibrahim et al. (1980). See also Kasl (1977), Jenkins (1977); Marmot et al. (1975); Marmot and Syme (1976); Marmot (1980) and (1981) Guarnaccia, (1984), and Bernal, (1984).

lifestyles brought about in urbanizing, industrializing societies impose new conditions. Some of these aspects make the care and maintenance of a severely disabled person at home very difficult, particularly if all adult members are expected to be out of the house, involved in wage-earning activities.

Society's attitude toward the family role in health care is rooted in the centuries old pattern of village life in which extended family members lived in close proximity and were so interdependent that there was no question that they care for one another, especially because resources for care outside the family were scant. With larger families, more individuals were available to share the load.

In the 20th century, there has been a dramatic shrinkage in family size with the falling birth rates. In addition, a dramatic increase in the longevity of the population has occurred. At the same time, mechanization, faster transportation, and the growth of the cities -- with changing patterns of employment -- have all contributed to split up the extended family. Consequently, today the burden of care is often inordinately heavy for just one or two relatives. In close-knit communities, such as rural ones, expectations seem to have change little over the years. In the urban setting there is evidence that significant ambivalence and heavy burdens of expectation are frequently still placed on the single daughter (Raymond, 1983:215-216).

Furthermore, ambivalence is expressed in social policies, and allocation of financial resources to health and social services for these individuals, which have always had a low priority relative to acute services. Nevertheless, over the last decades and as a result of the above changes, we have been observing the development of complex health/social security schemes aimed at complementing, or eventually substituting, the family in care of these members. Most of these programs reflect the growing concern in industrialized countries with the current demographic transformations and its consequences [1], especially those associated with the increasing proportion of persons aged 80 or over (Jefferys, 1983).

The last decade has seen several lines of inquiry in the literature of chronic disease. These works demonstrate the importance of psychological, social, and cultural factors in promoting patient and family well-being, in addition to illness-related factors. Today, research efforts increasingly include the broad array of factors hypothesized to influence the etiology and onset of disease which (debated in previous sections), as well as those that influence the experience, course, and outcome of illness. Responses to treatment and the modes of health care utilization have also received increased attention. These

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[1] See, for example, Davies (1985), Heikkinen et al., (1983), Jackson (1985), Lopez and Cliquet (1984), Macfadyen (1982), Smith (1983), Svanborg et al. (1982).

represent efforts to understand social and cultural factors affecting patient behavior and family well-being [1]. The scope of these factors has been continuously broadened, moving away from focusing on the individual or even the individual's interaction with the health system. It has become increasingly clear that the entire family is affected by a disease problem of one of its members, and that it will have different impact whether it is an acute or chronic disabling condition. This means that the family should be included in any assessment of coping behavior, and that general coping patterns are affected by social, cultural, and psychological factors.

This type of research constitutes the bulk of most recent medical anthropology research [2], which is based on a systems approach -- a holistic view of health and disease in the context of cultural systems -- frequently called "medical ecology" (see McElroy and Townsend, 1979:xviii) using "the ecological model of illness" [3]. Since anthropology is a biological science as well as a social science, it is not surprising that medical anthropology has embraced

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[1] See, among others, Ben-Sira (1981, 1983 and 1984), Choi et al. (1983), Christensen et al. (1983), Coelho et al. (1974), Grave and Pless (1976), Miller (1983), Moos and Tsu (1977), Pless and Pinkerton (1975), Sultz et al. (1972).

[2] See, for example Bernal (1984), Book (1980), Brilliant and Brilliant (1985), Dressler (1978 and 1985), Guarnaccia (1984), Hogle (1982), Hogle et al. (1982), Ready (1985), S. Schensul and J. Schensul (1982).

[3] For an extensive review, see Guarnaccia (1984:39-96).

biological phenomena (Foster, 1975:427). Of particular importance in this context is the problem of adaptation in cultural and biological evolution.

The ecological approach, now widely current in medical anthropology and related fields, identifies and links aspects of health and illness which have frequently been dealt with separately in health research: (1) the biological and psycho-social factors that focus on disease causation, and (2) the behaviors of the affected individuals in coping with health problems, such as the use of home remedies and management behaviors, (Guarnaccia, 1984:41). Despite some overlap, particularly regarding the role of cultural factors which through behavior may be relevant to causation, we may consider that the previously debated "social epidemiological paradigm" focus predominantly on the etiological component of this ecological approach.

Medical ecology emphasizes the health implications of the interaction between human groups and their physical and biological environments (Fabrega, 1974:46 and 59-76). In its concern with the ways human populations adapt to environmental problems, maintain health, and persist through time, medical ecology provides a useful balance to the clinical preoccupation with the disease and the anthropological focus on ethnomedicine. In addition, the holistic concept of the health care system proposed by Kleinman (1980:35-60) allows us to investigate, under the same theoretical framework, the

interactions of households/families with the issues of chronic disease and available patterns of care. For Foster (1984:853), and in accordance with Kleinman's concept, "medical anthropology research requires knowledge of two socio-cultural systems: the client community and the health care system." Foster (1984:853), also states that "it is as participant observers, working within a health care system, that anthropologists learn its structure, mode of operation, professional roles, and the goals of the organization and its members." Similarly, health policy, one component of the global policy system, should also be viewed as a part of the total sociocultural system (Hill, 1984:861).

The concept of environmental adaptation [1] through evolutionary mechanisms is a key concept in medical ecology. The unit of analysis is the total ecosystem rather than individuals or a society. Thus, health and disease become indicators of a group's effectiveness in dealing with the environment (Dubos, 1965:xvii); or, as Lieban (1973:1031) says, "health and disease are measures of the effectiveness with which human groups, combining biological and cultural resources, adapt to their environments".

Particularly important in this context is the concept of coping, which White (1976:19) refers to as "adaptation under relatively difficult conditions." Coping also refers

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[1] See Alland (1970), Bennett (1969 and 1976), Dubos (1965).

to "ongoing life adjustment" (Moos and Tsu, 1976a:1) associated with clusters of life events which are, in this case, related to illness and disease. Crisis theory asserts that life transitions or crises, present both an opportunity for personality growth and a danger of increased vulnerability. Crises are conceptualized as relatively short periods of disequilibrium in which people are more susceptible to being influenced by others than they are during periods of stable functioning.

Most of the research in this area has been done on individual coping behaviors. In this context, Lipowski (1970:93) defines coping as "all cognitive and motor activities a sick person uses to preserve bodily and psychic integrity, to recover reversible impaired function, and to compensate to the limit for any irreversible lost." For Lazarus (1966:151), a psychologist, coping is defined "as strategies used to deal with threat." From a sociological perspective, Mechanic (1978:294-295) refers to coping as "the instrumental behavior and problem-solving capacities of persons in meeting life demands and goals. It involves the application of skills, techniques, and knowledge that a person has acquired" (see also Miller, 1983:16-18).

Thus, coping is viewed as problem solving, that is, confronting the realities of a problem while still maintaining functionality, while coping strategies can therefore be described as the specific techniques a sick



person selects to deal with illness and its consequences. Dressler (1985:499) integrates these concepts by stating that:

Coping can be defined as cognitive and behavioral attempts to change, tolerate or avoid problematic situations (stressors), including attempts to change, tolerate or avoid emotional responses to stressors. Conceptually and operationally coping as been viewed alternatively as a personality disposition or trait; a "style" or set of beliefs about how to approach problematic situations; or, as a set of specific strategies adopted in response to specific events or circumstances.

According to Moos and Tsu (1976b:11-12), two areas have provided empirical data for the development of this field. The first includes detailed naturalistic and interview studies of coping behavior under extreme stress (i.e., studies of coping and adaptative behavior in the Nazi concentration camps, of severely burned patients, sudden death of spouse or close relatives). The second empirical trend developed out of an emphasis on life changes in relation to health and disease (especially in the area of mental health), including migration, school entrance, job changes and failures, important births and deaths.

These and other associated studies influenced the development of "crisis theory" which is concerned with how individuals can cope with life transitions and crisis. Crisis theory asserts that people generally operate in consistent patterns, in equilibrium with the environment, solving problems with minimal delay by habitual mechanisms

and reactions. When the usual problem-solving mechanisms do not work, a crisis may occur; that is, a relatively short period of disequilibrium in which an individual tries to work out new ways of handling a problem through sources of strength in himself and in his environment (Moos and Tsu, 1976b:13). A crisis is by definition self-limited. When a crisis of illness extends over many months or years, it presents to patients and families new issues and circumstances that may leave them in a constant state of provisional equilibrium. Even though it may be temporary, some resolution must be found, some equilibrium reestablished, within a few days or weeks (Moos and Schaefer, 1984:8).

A similar approach may be applied to the study of "a unit of individuals associated by a linking process," which is the concept of family proposed by Mauksch (1974:522). We may then conceptualize family coping "as what the family does and what it fails to do to recover from an illness or to maintain physical, emotional, or intellectual health" (Christensen et al., 1983:1).

In recent years, major interest has developed in family health studies. Social epidemiological research and health care activities have frequently adopted the family approach [1], based on the fact that the family is not only the basic unit for human social organization and the principal

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[1] See for example, Christianson (1983), Litman (1974), Mauksch (1974), McEwan (1974), Miller (1974).

mediating agent between the individual and his society (McEwan, 1974:489), but also the one that is most accessible for preventive and therapeutic intervention. Litman (1974:495) summarizes the family role in health:

In addition to performing such basic functions as biological reproduction, emotional development, socialization, the organization of statuses and roles and relationships with the community, the family constitutes perhaps the most important social context within which illness occurs and its resolved. It consequently serves as a primary unit in health and medical care. Familial involvement, in such processes as defining whether a member is sick or not, as well as providing preliminary validation for the sick role and precipitating the initial steps in seeking out and utilizing the necessary available care (including participation on its ministration) for instance, all constitute important family transations.

Drawing examples from the area of mental health, the author concludes that:

There seems to be fairly good evidence that the attitudes and actions families take may affect not only such diverse elements of the therapeutic process as the timing of the initial identification and hospitalization, the choice of a patient's placement in the community as well as the chances for and time of hospitalization and/or rehospitalization, to say nothing of the role family members may play in the etiology, treatment and recovery of the patient (Litman, 1974:495).

Concluding, it is evident that the health of a family goes beyond the physical and mental conditions of its members, to the extent that it provides a social environment for the natural development and fulfillment of all who live within its ambience.

The family situation is changing, dynamic, and varies in forms from one culture to another. As a consequence, family definitions may vary, depending on the purpose to which they are placed. Traditional approaches in sociological literature define the family as a network of interacting personalities and roles, as structural arrangements of positions, as status networks, or as institutions representing the performance of cultural tasks (Mauksch, 1974:522). In health studies, the definition of the family has been left to the patient, by including significant family members -- those persons whom the patient perceives as meeting the roles and functions of the family (see, for example, Christensen, 1983). This concept is in accordance with the definition used by Christianson (1983:208):

The "family" consists of those individuals who have an impact on health processes. The traditional nuclear family typically has this kind of impact, but there are other important intimate relationship groups in the society which rival the nuclear family in intensity and impact. Any such group is of concern to the family systems thinker. Thus, this model (the author refers to the family systems model) leads to the definition of "family" as a group of intimates with a history and a future. There is no normative concept of what a family ought to be.

As previously described, the coping strategies and behavioral responses of families and individuals comprise the other half of the ecological model. Coping both at the individual and familial, levels has been described as problem solving. Coping behavior is effective when the

behavior utilized resolves the uncomfortable feeling associated with threat and/or loss, preserves the integrity of the individual and the family, preserves the ability of the family members to function effectively in relationships and life roles, maintaining positive self-concepts.

In regards to variables affecting individual coping, Miller (1983:17-18) [1] lists the following:

1. intrapersonal factors (i.e., age, personality, intelligence, specific self-care skills, values, beliefs, emotional state, cognitive capacity)
2. environmental factors (i.e., presence of support network of significant others and friends, access to health services, physical resources for living, and financial resources)
3. illness-related factors (i.e., type of illness, its location, degree of impairment, meaning of the illness to the individual, rate of onset and stage of progression).

These variables constitute the "general determinants" in the "integrative conceptual model" developed by Moos and Tsu (1977:8-17), a model that also includes individual "adaptive tasks" and "coping skills" as the major factors affecting outcome on individual basis.

Regarding family coping, an early use of the concept is present in the work of Freeman and Lowe (1964). Based on previous research on family public health nursing needs (see Freeman and Lowe, 1963) the authors developed the family

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[1] See also Lipowski (1970); Moos and Schaefer (1984).

coping index "as an approach to identifying the family's need for nursing care and assessing the potential for behavioral changes, and as a method of determining in a more systematic way how the nurse can help the family to manage" (Freeman and Lowe, 1981:564). In 1983, based on these concepts, Choi et al. attempted to improve the above index by revising its operational guidelines. Choi and his associates define "health-specific family coping index for noninstitutional care" as an instrument that assesses how well a patient's family is coping or functioning thus affecting the decision of whether the patient should stay at home or be institutionalized (Choi et al., 1983:1275). The index evaluates the following coping domains: (1) physical independence, (2) therapeutic competence, (3) knowledge of health condition, (4) application of general principles of hygiene, (5) health care attitude, (6) emotional competence, (7) family living patterns, (8) physical environment, and (9) use of community resources.

Guarnaccia (1984:65-96) proposes a model of factors affecting family coping behavior that extends beyond the above concept. The integrated model proposed by the author, drawn from a multidisciplinary area of theory and research, includes the following categories and their components:

1. FAMILY FEATURES - ethnicity, family structure, economic resources, languages skills, social support.
2. FAMILY HEALTH CULTURE - health beliefs, home treatments, previous experiences with health services, health preparedness.
3. INSTITUTIONAL FEATURES - types of services, payments accepted, types of providers, language skills, location.
4. INSTITUTIONAL CULTURE - models of disease, treatment approaches, attitudes towards clients.
5. INDIVIDUAL FEATURES - including those features mentioned in the above model for individual coping.
6. OTHER ENVIRONMENTAL FEATURES.

Families' abilities to cope with stroke are conditioned by social structural factors, such as family economic resources and social supports, location of residence, etc. In the above-mentioned model, Guarnaccia (1984:67) deals extensively with these factors. Here I will refer to two key concepts which are central to this model and the present research: (1) the concept of family health culture, and (2) the concept of institutional culture. Guarnaccia (1984:67) refers to the first as "the family's composite cognitive map of health and illness and what to do about health problems." In the context of the present research, it includes health beliefs about stroke and associated notions of severity of the "attack" which lead to different types of interventions (i.e., the decision to use acute care facilities). It also includes attitudes about rehabilitative

actions which are shaped by a wide diversity of factors, such as the already mentioned severity concept. This interacts with the age of the patient and the perceived potential benefits and dangers of rehabilitation.

Of extreme importance is also the notion of intra-cultural diversity. Families select their coping strategies and change them over time as the result of perceived needs and previous experiences in the use of health care resources. Care-seeking strategies are shaped by a variety of factors which include (1) the availability of preventive examinations and services, (2) the length of waiting times, (3) the average costs of care, and (4) the degrees of both provider and client satisfaction with their interactions (see Guarnaccia, 1984:72; and Dutton, 1978:361-362). Frequently a strategy of "trial and error" is adopted by the families to solve specific health problems and regain the lost equilibrium, as a result of learning new strategies from care providers, kin and neighbors. This may lead to the simultaneous use of various sources of care in order to maximize potential benefits, because clients and providers often have differing views of what is appropriate use of care resources (Guarnaccia, 1984:75).

Coping strategies are shaped by health care institutions' characteristics, including types of providers and available services, models of disease and treatment adopted, and the control these providers have over specific



treatments and services. Institutional culture is of particular importance in the case of CVD in general, because frequently there are significant differences in the models used by providers and receivers of care, namely concerning issues such as home vs. hospital care. Extensive negotiation may be present.

Families coping with stroke may need access to both the acute care services and the preventive, continuity, and rehabilitative components of the care services. Appropriate care of these patients frequently requires a continuous flow of health and social interventions. Thus, integration and continuity of care may be viewed as relevant indicators of the type and quality of the interactions between the above family and institutional features.

## CHAPTER 3

### CARDIOVASCULAR DISEASE: A SOCIAL EPIDEMIOLOGIC PERSPECTIVE

For many decades diseases of the circulatory system (traditionally called cardiovascular diseases) have been not only the leading cause of death in most developed countries, accounting for one half of all fatalities, but also responsible for the largest epidemics yet encountered in industrialized societies. Frequently they have been called "modern epidemics" in opposition to communicable diseases epidemics. Because of their dramatic social and economic impact, it is not surprising that cardiovascular diseases have been the object of intense, independent or combined, biomedical and social sciences research and intervention. Changes in the mortality rates attributed to these conditions have been followed with avid interest, and over the last few decades a growing evidence suggests that, to a variable extent, a major turn around is occurring in several countries, in what concerns selected cardiovascular diseases.

Cardiovascular disease comprises a wide variety of

disorders of the circulatory system. The relative importance of the disorders included in this major category has also been changing over time. Major distinctions have to be made. In this chapter I will refer exclusively to the group usually connoted with modern socio-cultural systems, of which the more relevant are Hypertensive Disease, Cerebrovascular Disease and Ischemic Heart Disease (IHD) [1].

A brief reference is made here to Rheumatic Heart Disease, a disorder of equally dramatic social and economic consequences, but in which a clear interaction with an infectious agent has been well established. Due to this fact, the social epidemiologic features and the strategies for prevention of rheumatic heart disease are usually dealt within the context of communicable disease rather than within the one of the above mentioned group of cardiovascular disorders. Marked declines in morbidity and mortality due to rheumatic heart disease have been reported for developed countries since the early 1940's. This decline preceded the widespread use of chemoprophylaxis and is clearly associated with general improvements in living standards, ranging from housing to nutrition, improvements that are equally responsible for similar decreases of other communicable diseases. In recent literature it is evident a

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[1] The term Ischemic Heart Disease has been proposed in the International Classification of Diseases instead of Coronary Heart Disease, and will be used here accordingly.

growing concern for the consequences of rheumatic fever, especially its cardiovascular damages, in the developing countries. Urban slums have an explosive mixture of the requirements for major outbreaks, and so prevention should be considered with particular attention by the health authorities. Pilot community programs, developed under a WHO international cooperative project, were shown to be practicable and effective in reducing the burden of these disorders in the developing countries studied (World Health Organization, 1980a and 1980b; Strasser et al., 1981). Since 1982, and following the results of the mentioned pilot projects, the World Health Organization and the International Society and Federation of Cardiology initiated a worldwide action program, which concentrates on countries where the disease has a higher prevalence. Strasser (1985) elaborates on the reasons why given economic restrictions priority has been given to organized and systematic secondary prevention.

Rheumatic fever and rheumatic heart disease will not be discussed further.

In what concerns the diseases of the cardiovascular system in general, it is frequently argued that their mortality rate trends have been on the increase since the beginning of the century. To a variable extent, both developed and developing countries present this trend. In

addition, the sustained mortality declines observed in industrialized countries over the last few decades have been attributed to the use of selected therapeutic agents (e.g., antihypertensive), despite the fact that some of these downward trends had been evident prior to widespread use of such products (see for example, Nicholls and Johansen, 1983:153). I will return to this point later.

According to the above mentioned authors, hypertension and cerebrovascular disease mortality began a steady decline at least in the early fifties. For Canada, it first became apparent in the 55 to 64 age group. Subsequently, older and particularly younger age groups have also benefited having the rate of decline become progressively steeper for all of them. The decline in cerebrovascular mortality was preceded by a reduction in hypertensive disease mortality and both trends show some similarities, of which the absence of marked sex predominance, and the observed parallel declines in different racial groups, are of particular importance. Since 1964, similar trends have been described for England and Wales (Haberman, et al. 1978 and 1982). For Japan, this downward trend began in 1965 and accelerated in 1971 (Tanaka et al., 1982a).

The first suggestion that a turn around had also taken place in ischemic heart disease mortality rates was reported in the U.S.A. in the middle seventies (Walker, 1974). Since then, similar declines have been confirmed in Australia,

Belgium, Canada, Finland and Japan, while in other industrialized societies these trends remained unchanged or continued to rise. As Rose (1981) points out little change has been observed in England and Wales, which has the dramatical implication that, eventually, "we are failing to prevent a preventable disease." Despite frequent claims of the contrary, he clearly states that "we do not know why the Australians and the Americans have done well in their control of coronary heart disease, or whether (if we did know) we could have shared their good fortune. Yet surely, as a profession, we should at least feel deeply disturbed by the problem and involved in it."

The controversies surrounding these issues are far from being over. Nevertheless, marked progress has been achieved in last two or three decades. Traditional epidemiological research, in particular, has clarified the role of major risk factors, and social scientists have demonstrated the significance of associated socio-cultural factors. Graham and Reeder (1979:80) consider that "the growing interest in the etiological relationship between socio-cultural factors and specific diseases is one of the remarkable features of modern medicine." Some of the most relevant examples of this interaction between biological and social sciences research come from the field of cardiovascular disease.

### 3.1 THE LINKS BETWEEN "CARDIOVASCULAR DISEASE" AND "SOCIO-CULTURAL MODERNIZATION"

Numerous papers have been published in the past years describing from a traditional epidemiological point of view the relationship between selected risk factors, including hypertension, and ischemic heart disease and/or stroke. Several individual and institutional proponents for one or more risk factors as "the most important etiologic factor" have appeared and vanished over recent years. Various studies have resulted in the elucidation of, among others, the following "known" basic descriptive facts:

1. Incidence and mortality due to ischemic heart disease and stroke increase with age.
2. Incidence and mortality from ischemic heart disease are much higher in men than women, and for stroke only slightly higher in men than women, at least in the younger age groups (under 65).
3. There are marked geographic, variations among countries and within countries for both stroke and ischemic heart disease (and hypertension frequency).
4. There are marked racial and socioeconomic variations in the frequency of these diseases.
5. In selected countries, there have been declines in the death rate and incidence of stroke over the last three decades. Mortality rates for ischemic heart disease have also begun to decline. In some countries, diverging trends in cerebrovascular disease and ischemic heart disease mortality have been observed.

6. Cardiovascular diseases are not derived from the same basic etiology. Factors that are associated with an increased likelihood of ischemic heart disease (e.g. elevations of serum cholesterol, increased levels of blood pressure, history of smoking behavior, "type A" behavior) do not have the same role in stroke, where hypertension is undoubtedly the cardinal risk factor.
7. There are genetic/metabolic diseases associated with a marked increase in the frequency of heart attack (e.g. familial hypercholesterolemia). However these predominantly genetic abnormalities account for only a small proportion of the total cases of ischemic heart disease, and there is no evidence that they are related to stroke.

Recent research has also revealed that one must be extremely cautious in considering these disease entities as homogeneous. The term "cerebrovascular diseases" should replace cerebrovascular disease in as much as they constitute a group of disorders that have major epidemiologic and physiopathologic differences. Regarding ischemic heart disease, recent evidence suggests that there is also an absolute need to keep separate track of myocardial infarction and angina pectoris, since the two are likely to involve a different set of risk factors (e.g., psychosocial) (Jenkins, 1976:1037).

A brief review of the major social epidemiologic studies on the links between these disorders and socio-cultural modernization is presented next, and will focus on (1) hypertension, (2) cerebrovascular disease and



(3) ischemic heart disease. Most cardiovascular research, using the social epidemiologic approach, was initiated around issues concerning hypertension. However, due to its extreme importance in the vast majority of industrialized countries, the great bulk of research has been mainly concerned with ischemic heart disease. Nevertheless, findings from studies in a particular area have frequently proven to have significant repercussions on other interconnected areas of cardiovascular disease.

#### 3.1.1 Hypertension

In the past three decades, most of the work on psychosocial epidemiology of high blood pressure has focused on a single hypothesis, sometimes vaguely, sometimes precisely formulated. According to Ostfeld and D'Atri (1977:20):

In the simplest terms, this hypothesis is that rapid social cultural changes leads to psychological stress and subsequently to high blood pressure. Stable, traditional societies will exhibit little or no high blood pressure and little or no rise in blood pressure with age. In societies undergoing rapid transition, the opposite will be noted.

The methodology used has been a mixture of the techniques of medical anthropology and descriptive epidemiology. Kasl, reviewing the above mentioned work of

Ostfeld and D'Atri, summarizes "established concepts":

Essentially, it had been part of accepted medical wisdom that (a) rise in blood pressure is part of "normal" aging and that (b) blood pressure levels may be a sensitive indicator of "stress" in many individuals. The observation that there were many societies in the world in which blood pressure levels do not rise with age seemed to have a dual impact: (a) it held promise for a more objective study of cross-cultural differences in stress in relation to societal structure, and (b) it suggested that increased blood pressure with age was not a universal biological norm but could perhaps be interpreted as the accumulated impact of living in more stressful societies and settings (Kasl, 1977:181).

Since his early works, John Cassel was perhaps the foremost proponent of the "sociocultural change/high blood pressure" hypothesis (see Henry and Cassel, 1969). Evidence supporting this hypothesis came from a wide variety of studies in different settings. In the poor rural community of Holmes County in Central Mississippi, 41% of all black adults of ages 18 through 79 were found to have definite hypertension. In addition, 21% had borderline hypertension, and others showed normal blood pressures only because they were already taking prescribed medication (Eckenfelds et al., 1977:505-507). This is of particular interest since it is among some african communities that low average levels of blood pressure and lack of rise with age have been reported. To show the contrast, Vaughan and Miall (1978) compared the data from two studies in Africa with a study of people in

Jamaica of African ancestry. In order to reduce variability in the methods of measurement, one of these investigators (W. Miall), supervised the measurements in the three locals of the study (Gambia, Jamaica, and Tanzania). The three populations were racially similar though not identical, all derived from Negroid peoples in Africa. Tanzanians are Bantu and ethnically similar to West African Negroes, but a minority have features suggesting Hamitic ancestry. Gambians are West African Negroes and have a common ancestry with many of those taken to the Americas as slaves from the 16th century to the end of the 18th centuries. Jamaicans are descendants of both West African Negroes and Bantu, with different degrees of miscegenation.

Each of the communities studied was chosen nonrandomly as being reasonably typical of rural agricultural populations in the three countries. However, the Jamaican study took place in a farming area close to the capital city of Kingston, with which there was regular communication. The study showed that blood pressure distributions were shifted towards higher values in both sexes and all age groups in Jamaicans compared with Tanzanians, who in turn had higher values than Gambians (Vaughan and Miall 1978:286-7). Jamaicans also presented a clear rise of blood pressure with age for both sexes, not present in the two other study populations. These results are of particular interest since

blacks in the U.S.A., have very high average blood pressure levels, which rise steeply with age a pattern that it is not present in rural African communities (see also Marmot, 1980:132-133).

Other traditional, isolated societies show the same pattern of the above African communities. The Yanomamo Indians of Venezuela typically have blood pressures of 100/65 at all ages from the teens until age 50 and older (Oliver, et al. 1975). The Bushmen of the Kalahari Desert also maintain low blood pressures during aging (Truswell et al., 1976:182-183).

When the blood pressures of rural, unacculturated groups have been compared with more urbanized groups in developing countries in Asia and Pacific, there have been similar findings: higher blood pressures are present in the more urbanized. When making these comparisons one must ask if the groups are comparable in respects other than their degree of urbanization, e.g., might the groups being compared be genetically different? One approach to this question is provided by the study of migrants. This may be illustrated by the Tokelau Island Migrant Study conducted by Prior and his colleagues (Prior et al., 1974). The Tokelau islanders live on Pacific atolls just south of the equator. Since 1966, the New Zealand Government established the Tokelau Island Resettlement Programme as a means of dealing

with the expanding population and very limited resources and scope for development on the atolls. Baseline data on the population of the atolls was collected in 1968. In 1973, the study population was assigned either to pre-immigrant and non-immigrant status according to the residence changes that occurred during this five year period, and the base line data analyzed.

The findings are suggestive of the presence of a selective process whereby the younger and more athletic males are the active initiators of migration, while the females and older males who migrate tend to do so in response to the decision made by younger males and for this reason show no differences from non-migrants (Prior et al., 1974:231). Further unpublished data from the Tokelau Island Study by Prior and associates is presented by Marmot (1980:134-135). Surveys of the Tokelauans carried out both on the islands and in New Zealand where they live mainly in the cities, show a rise of blood pressure with age for both the migrants in New Zealand and the Tokelauans on the islands. The blood pressures of the migrants are significantly higher, 10mmHg or more, than the blood pressures of the islanders. Marmot (1980:134) points out that:

these results are certainly consistent with an urban-rural difference in cardiovascular disease in developing countries. They are, however, subject to the criticism leveled at all migrant studies: that migrants may be different from non-migrants in ways other than having chosen to migrate. It must be asked if the migrants are a special population, liable to hypertension.

A prospective study of the Tokelauans conducted by Prior and associates provides a unique answer to this question. The unpublished results are presented and discussed by Marmot. Blood pressure measurements were taken of the potential migrants while still resident on the islands and latter in New Zeland. These were compared with Tokelauans who remained residents in the islands, i.e. non-migrants. Both groups had blood pressure readings taken between 1968 and 1971 on the islands. The follow-up readings were taken an average of 6 years later, on the islands for the non-migrants, and in New Zeland for the migrants. The unpublished data by Prior and collaborators discussed by Marmot, reveals that:

while on the islands, the non-migrants and the pre-migrants had similar levels of blood pressure. Six years later, the blood pressures of the migrants had risen, to a greater extent than the blood pressures of the non-migrants. Similar changes were founded with plasma lipids (Marmot, 1980:135).

A careful reading of Cassel's more recent work (1974b:205), reveals that even as he reaffirmed his belief

in the fruitfulness of the "socio-cultural/high blood pressure" hypothesis, he also saw the limitations of previous evidence, and specifically recommended the study of various intervening variables, including dietary ones. Pursuing this research hypothesis, Burkitt (1982) presents evidence linking the emergence of Western diseases with diet (see also Trowell and Burkitt, 1981). He considers that these disorders -- also denominated "diseases of civilization" -- represent a failure of adaptation to the dramatic changes in diet that have been associated with the emergence of modern western culture. Burkitt reviews the physiopathology of inadequate fiber intake and recommends that as a general guideline, the proportion of energy provided by starch foods as well as the intake of fiber should be doubled.

Ostfeld and D'Atri (1977:31), after extensively reviewing the available evidence, offer the conclusion that the association between rapid sociocultural change and greater prevalence of high blood pressure involves the intermediary mechanism of diet changes and weight gain, and so it is unnecessary to postulate stressful social processes. According to Kasl (1977:182), a reference to dietary changes in salt intake as well would make the postulated intermediary mechanism even more comprehensive and defensible.

This area of research has been frequently criticized

and major methodological failures and oversights have been described. Ostfeld and D'Atri, consider that all but a handful of the numerous studies they did review are guilty of several of the following problems:

1. The variables of cultural change, social change, and psychosocial stresses are still not defined precisely, not assessed in a standard way or not described in enough detail to permit replication.
2. The blood pressures are not recorded in a standard manner.
3. The social and cultural assessments are not made in ignorance of what the blood pressure readings are, and vice versa.
4. Social scientists are still relatively uninvolved. The data of moment are usually brief general quantitative descriptions by physicians, without discipline or standard methods.
5. The samples are usually "chunk" or "convenience" samples, which means anybody around who lets his blood pressure be taken.
6. Only one new longitudinal study of blood pressure and sociocultural change has been undertaken to test the hypothesis tested here.
7. Age is less accurately known in some societies than in others, and its correlation with blood pressure in some settings is uncertain. In some areas there where no vital statistics, no birth certificates, no calendars and no recorded time (Ostfeld and D'Atri, 1977:29).

Water hardness, or more precisely, calcium content in drinking water is one of the elements complicating the issue of geographical differences in blood pressure. Together with other biogeochemical factors, Takahashi (1981) discussed



extensively their potential role. Regional variations in stroke mortality (an indirect measure of hypertension frequency) in Japan, U.S.A., England and Wales and West Germany, present a negative correlation with the calcium and magnesium contents of drinking water and soil characteristics. Recently these and other nutritional factors (vitamins A and C, potassium) regained new prominence with the controversial study of McCarron et al. (1984:1397). The authors claim that regardless of the definition of hypertension applied to the study population, and in part, independent of the effects of age, race, sex, body mass index, or alcohol consumption, lower consumption of four nutrients - calcium, potassium, vitamin A, and vitamin C, was statistically associated with hypertension. The implications of these findings are of particular importance at several levels, including providing support for the mentioned diet hypothesis. They suggest that it is possible to promote primary prevention of hypertension through appropriate nutritional measures; that the links between hypertension and modern socio-cultural systems have an important nutritional component; and that it may be possible to revise current, expensive, anti-hypertensive drug treatments, which frequently have important side effects, in order to take into consideration nutritional components previously believed to be not relevant.

### 3.1.2 Cerebrovascular Disease

From a social epidemiologic point of view, cerebrovascular disease has been the least studied of the three cardiovascular disorders here presented. The fact, now well documented, that hypertension is the strongest risk factor for both thrombotic and hemorrhagic stroke, may well have resulted in that a large proportion of studies focused on hypertension, being stroke only secondarily considered, often as an indirect measure of the magnitude of the hypertension problem.

From Japan, where stroke has been the leading cause of death for many decades, comes a large number of stroke studies. Together with the other cardiovascular diseases it accounted for about 40 percent of all deaths, emerging as the most important Japan's disease problem. However, since 1965 a decrease in the age-adjusted death rates, for both sexes has been observed. This downward trend accelerated in 1971 and it is expected that cancer will occupy the first place during the 1980's. As Tanaka et al. (1982a:574) refer:

this is not due to artifacts such as changes in diagnostic methods of stroke and in rules for coding cause of death on death certificates. The progress and spread of detection, treatment and control of hypertension appears to have been the greatest contributing factor. Furthermore, improvement in the dietary habits, that is, a decrease in salt intake and an appropriate increase in the amount of animal fat and protein taken are also considered to have contributed to the observed decline.

However, evidence from other countries presenting similar declines, reveal that this downward trend began well before the widespread use of hypotensive drugs, and it has include the older age groups among whom hypotensive therapy has not been so widely used. In addition, findings of community surveys in various settings indicate that even among middle-age and younger people only a disappointing small proportion of hypertensives are being detected and effectively treated. Barker and Rose (1979:92) and Haberman, et al. (1978) present convincing evidence of this problem for England and Wales, while Kurtzke (1980:160-163) presents data for the U.S.A. revealing similar declines that date back to the beginning of the century, for both sexes and for whites and non-whites. Furthermore, in the U.S.A., the rate of decline has increased after 1972 (Soltero et al., 1978:549), being the decline for non-whites, in both sexes, relatively and absolutely the greatest observed. This last observation is believed to provide additional evidence to support continued emphasis in public health efforts to control hypertension.

The interpretation of these trends is compounded by the diversity of clinical outcomes to be considered (thrombosis, embolism, intracerebral and subarachnoid hemorrhage, transient ischemic attacks), by the difficulty involved in detecting and ascertain cases and also by the impact of

other cardiovascular risks affecting similar population groups at earlier ages. Haberman, et al. (1978 and 1982) observed, for England and Wales, a fall in cerebral thrombosis mortality and increased ischemic heart disease mortality. Given the likelihood that atherosclerosis is a major etiological factor for both disorders, this finding is unexpected. According to the authors, the failure to demonstrate similarity between recent changes in mortality due to these conditions could be due to a wide variety of factors, including the possibility that "stroke-prone" persons are being eliminated by ischemic heart disease before they reach the age at which they would have suffered a stroke.

Type specific diagnosis is often difficult because there are no pathognomonic laboratory tests corresponding to the role of the electrocardiogram and specific enzyme tests in myocardial infarction, and there are no uniformly accepted indications for the performance of special diagnostic tests, some of which are not available in many communities (e.g. computerized axial tomography - CT). Moreover, in fatal cases, even at autopsy it may be difficult to distinguish among some of these entities (Kagan, et al. 1980). These authors, studying men of Japanese ancestry in Hawaii, found that mortality has fallen sharply from the experience in Japan to approximately the

experience of whites in Hawaii, which in turn, is close to that of whites in the United States. The authors refer to previous studies (see Worth et al., 1975; Syme et al., 1975) conducted in three different sites which revealed that stroke prevalence and stroke mortality in Japan was three times that of the Japanese-American cohorts in Hawaii and in California. In accordance with early works by Gordon (1957 and 1967), a gradient of increasing IHD mortality among Japanese men in Japan as compared to Hawaii, and, in turn, to California, was noted, along with a trend in the opposite direction for CVD. The same authors also found the distribution of the different types of stroke to be similar in Caucasians and Japanese. This study contributed to confirm the role of the various risk factors in the different types of stroke. The principal risk factors for thromboembolic stroke were elevated blood pressure, glucose intolerance, age, and electrocardiographic evidence of left ventricular hypertrophy or strain. Attributes associated with increased risk of intracranial hemorrhage were elevated blood pressure and its related electrocardiographic signs of longstanding activity (left ventricular hypertrophy and strain), and alcohol intake. Serum cholesterol level was found to be negatively associated with the risk of intracranial hemorrhage, a finding not reported for Caucasians, that confirms other studies of Japanese (Konishi

et al., 1976; Tanaka et al., 1982b).

Takahashi (1981) did an extensive study of the geographic distribution of cerebrovascular disease and environmental factors in Japan. He found that the age-adjusted death rate for stroke is highest in the northeastern prefectures of the main island (Tohoku Region), and lower in the southwestern areas. In order to understand such pattern, he studied some suspected factors, including ambient temperature, local agricultural products, dietary habits, and the biogeochemical environment. Tohoku is a less developed region of Japan, and the rural inhabitants still follow the traditional way of life, particularly in what regards their diet and dwellings. Familial aggregation of hypertension and stroke is observed in this area. He formulated the hypothesis that the observed pattern is related to the social, economic and traditional inheritance from parents and ancestors, such as subsistence on a rice field with a small vegetable field, a taste for salty pickles and miso soup (soy bean soup), dwellings without heating arrangements and less protective structures against winter, lower content of minerals in well water as well as in food, rather than to genetic factors.

Support for the effect of ambient temperature comes from the fact that the adjusted death rate is higher in the colder northern region, and that the number of deaths from stroke, as well as from ischemic heart disease, is higher in

winter months. In addition, he measured blood pressure both in summer and winter, and the probability product of differences was statistically significant. Similar results had been previously obtained comparing blood pressures of surface and underground (hot) coalmine workers.

The Tohoku Region is considered the rice granary of Japan. Farmers retain some surplus production for their own consumption. Correlation coefficients between the death rates for cerebrovascular disease and rice production per person by 46 prefectures were shown to be statistically significant. People in this area are more robust than the national average what may relate to the known link between obesity and hypertension. In addition, the correlation coefficients between purchased quantity of salt per person and age-adjusted death rates for cerebrovascular disease by prefecture were also statistically significant. The salt contents of miso-soup and pickles were higher in farm regions, especially in Tohoku, what is confirmed by the work of Tamashiro et al. (1981).

Within the region there are also variations in the age-adjusted death rates for stroke, being lower in the Pacific coast areas and higher in the inland rice crop areas and the Japan Sea sandy coast. The author describes the different geological origins and mineral contents of each area and concludes that the contents of calcium, as well as magnesium, correlate with the observed differences in stroke

mortality. Similarly, he describes for several western countries (U.S.A., Great-Britain and West Germany), geological patterns that support this hypothesis.

Further evidence of the role of hypertension as the major risk factor for stroke in Japan, comes from the study of Ueda et al. (1981). In addition to the demonstration of similar declining trends of incidence and mortality from stroke during the period 1961 to 1976 in the Hisayama community, the authors present evidence of an associated marked reduction of the prevalence of hypertension in the community, between 1961 and 1973-4. Again, the possibility that the observed incidence and mortality declines may be linked to the successful control of hypertension is suggested, supporting previous observations of Garraway et al. (1979) in the population of Rochester, Minnesota.

As we have pointed out most of the social epidemiologic research on stroke have been primarily oriented to hypertension. The present declines in stroke mortality and incidence may be related partially to either effective and efficient treatment of hypertension, to reductions in the risk of stroke among persons with hypertension and/or a decline in hypertensive disease in the population, secondary to changes in the risk factors for elevated blood pressure (Haberman et al., 1982). It is important to emphasize that several countries do not follow this decreasing pattern. Such is the case of Portugal, where hypertension is still



highly prevalent (Miguel and Padua, 1980) and significant increases in stroke mortality have been observed over the last decades (Calheiros, 1985). There is evidence that salt consumption is extremely high and that consumption of vegetables is low. However, a systematic study would be required to assess regional differences in stroke mortality and the presence of known risk factors, including potential major differences in mineral content of drinking water. Important regional differences in health care practices should also be evaluated, including the frequency of treated and controlled hypertension and the variations in death certification criteria due to regional or local diagnostic fashions.

A final note refers to studies of the social and economic implications of stroke to the individual, the family, and the community. Jefferys (1983) recommends that these studies should timely take into consideration the importance to society of the growth of its elderly component. These studies will not be debated in this chapter as they only indirectly address etiological issues and will be extensively dealt within the next chapters. In these studies the social epidemiologic approach may contribute for a thorough understanding of the adaptative processes involved, what eventually may lead to adequate health planning (see for example, Weddell, 1974; Brocklehurst, 1981).

### 3.1.3 Ischemic Heart Disease

In 1977, Jenkins offered an extensive review of published epidemiological studies of the psychosomatic aspects of coronary heart disease. According to this author:

Traditional epidemiological studies of coronary heart disease have usually omitted consideration of dynamic variables of interest to social sciences workers, primarily due to the difficulties in measuring these variables reliably. On the other hand psychosomatic studies have tended to be too small to be considered truly epidemiological because of the depth of investigation required for a comprehensive examination of the variety of mechanisms that might be operating in patients and controls. Despite these obstacles to the combination of the best features of social sciences and epidemiological breadth, an impressive array of studies has been published recently, making IHD better investigated from the social epidemiologic point of view than perhaps other chronic or infectious disease, excluding psychiatric disorders (Jenkins, 1977:1-2).

Despite these efforts, the value of "established risk factors" is still questioned. (e.g., elevated blood pressure, high serum cholesterol, cigarette smoking, and overweight). Recent epidemiological studies using traditional risk factors reinforce the validity of the above variables, but also reveal that in combination they can explain only about half of the variability in IHD rates among population groups. For instance, the "Framingham Risk Factor Equation", when applied in other settings may predict results that do not correspond to the observed (see Garcia-Palmieri et al., 1972; Jenkins, 1977). A similar finding is

reported by Keys et al., (1972) in applying multiple logistic risk factor equations from the USA to European data and vice versa. It should also be kept in mind that any one standard risk factor is not associated with IHD incidence or prevalence in all populations (Keys, 1970; Jenkins 1977). Jenkins (1977:2) summarizes the present situation in the following statement:

Thus it would appear that although much is known about the precursors of IHD, at least an equal amount remains unknown. It is into this obscure area of IHD etiology that we must throw the searchlight of psychosomatic and epidemiologic study.

These efforts have much benefited from an extended cooperation between social and behavioral scientists and epidemiologists. The combined efforts have included not only etiologic issues but also the broad domain of adaptation considered at individual, family and community levels.

For IHD, problems of classification-diagnosis are not severe, as for example they may be for the different stroke types, thus giving us a reasonable assurance that the same condition is being assessed in different studies. However, as we have already mentioned, it is becoming increasingly obvious (Jenkins, 1976) the need to study separately myocardial infarction and angina pectoris. Moreover, the classification of the latter is based on "softer" data and we are beginning to understand some of the biases which might be involved in perceiving and/or reporting clinical

symptoms of IHD (see for example, Croog and Levine, 1969; Reeder et al., 1973). The methodological significance of these studies would presumably apply to the classification of "silent" myocardial infarction as well.

#### 3.1.3.1 The role of psycho-social factors

It has been generally recognized that IHD is a disease of industrialized, urbanized societies. Evidence also indicates that, mortality for this condition has an urban-rural gradient within these societies. A variety of studies have tended to support the notion that cardiovascular diseases may increase as people adopt an urban way of life (see for example, Scotch, 1960; Labarthe et al., 1973; Prior et al., 1966; Henry and Cassel, 1969). All findings indicate increased IHD rates with modernization. Although data on social and social-psychological factors vary in quality, the best of them provide strong "inference" for their relevance and significance in the etiology of IHD. A partial list of such findings follows.

##### I - Social Status

Data suggest that certain characteristics and/or locations in the social status hierarchy may be more stressful than others, and individuals occupying these locations are at greater risk.

a) Social Class - should be conceived as multi-dimensional (Berkman, 1980). Social class gradients on mortality, morbidity, and disability have been described. In general, upper and middle classes have lower rates for most disorders. IHD has been described as deviating from this general pattern. However, recent changes in its class distribution have been reported for England and Wales by Marmot et al. (1978b). These results will be discussed later (see section 3.1.3.2).

b) Marital Status - is related to IHD mortality; however, so is mortality for every other major cause (National Center for Health Statistics 1970). Studies on marital status and health consistently reveal that those who are married have lower mortality rates than those who are single, widowed, or divorced.

b) Religious Affiliation and Religious Attendance - continue to be studied in relation to IHD, but failure to replicate previously observed differences seems to be common faith of initially promising results. At this point, the best guess would seem to be that unless one is studying religious groups with known and striking differences in life styles and habits (e.g., Mormons and Seventh Day Adventists), differences due to religion are likely to remain inscrutable and vulnerable to nonreplication.

c) Occupation - remains a promising area of investigation. Differences in IHD rates across specific occupations have been described, but at the same time it was observed that certain occupational groups have rates lower than expected, when compared with other groups of similar social status, level of physical activity or physical hazards in the work environment (Kasl, 1977). In addition, most data show that men between the highest and lowest occupational ranks within organizational structures tend to be at greater risk. The occupational-status model suggests that a status rank is an indirect indicator of other variables more immediately related to health and illness.

## II - Culture change, social mobility and status incongruity

a) Migration - Several studies indicate that migrants tend to experience rates intermediate between those in their country of origin and those prevailing in the host country (Medalie, et al. 1973; Marmot, 1975). Thus, a critical risk factor appears to be the actual process of culture change. Greater rates found among the first-generation are consistent with other studies of so-called marginal men, where the children of immigrants or migrants must learn a new language and cultural patterns and are caught in conflicts between the old ways of their parents and the new social milieu (Graham and Reeder, 1979).

b) Social Mobility - Many studies, stimulated by the work of Syme and his colleagues (1964, 1965, 1966), have been made of social mobility, another component in the process of social and cultural change. It was found that in both a rural and urban community, men of American-born fathers had higher rates of ischemic heart disease than men of European-born fathers. Moreover, men who had experienced occupational or geographical mobility had higher rates than men who were stable.

c) Status incongruity (inconsistency) - continues being explored as a possible risk factor for IHD (Jenkins, 1976) and one again has the impression that the results are quite fragile. Moreover, there is a good deal of methodologic controversy regarding the adequacy of data analysis in the status of incongruity studies, particularly to the extent to which main effects (due to individual status dimensions such as education or occupation level) have been removed before one searches for interaction (incongruity) (Kasl, 1977). The particular incongruity which may be most promising as a risk factor is the combination of relatively low education with relatively high occupational level in men (Bruhn et al., 1968; Christenson and Hinkle, 1961; Hinkle et al., 1966 and 1968; Wan, 1971). Conceptually, this might represent a work situation in which the job demands exceed the skills and training of the man, leading to work pressures and overload.

d) "Coronary-prone behavior pattern" (type A) - is another area of intensive research. It is characterized by some or all of the following: intensive striving for achievement; competitiveness; easily provoked impatience; time urgency; abruptness of gesture and speech; overcommitment to vocation or profession; and excesses of drive and hostility (Friedman et al., 1958; Rosenman et al., 1964 and 1970; Jenkins et al., 1974; Jenkins, 1976). The concept has been used both prospectively and retrospectively in scores of studies. Jenkins (1976) points out "that this behavior pattern is not the same as 'stress'. It represents neither a stressful situation, nor a distress response, but rather a style of behavior with which some persons habitually respond to circumstances that arouse them." Overall, and among others, the following conclusions seem justified: (1) type A behavior is a prospectively established risk factor for IHD among men, and the increased risk is independent of other firmly established risk factors (Rosenman et al., 1975; Brand et al., 1976); (2) among men with a single previous IHD event, type-A behavior increases the risk for reoccurrence, independently of other risk factors (Jenkins et al., 1976); (3) factor analysis of a self-report test (the Jenkins Activity Scale) has yielded three major factors - job involvement, hard-driving, and speed and impatience.

Initial work in these areas was described as promising by Jenkins (1971), but the results of more recent studies of the same author (1976) have produced a confusing array of nonreplication and methodological controversy. According to Kasl:

A pessimistic conclusion from these inconsistent findings would be that they have failed to coalesce into any kind of interpretable picture and thus cannot help us understand the possible role of social mobility and status incongruity (or inconsistency) in the psychosocial etiology of ischemic heart disease. An optimistic conclusion would be that these results point to a good deal of specificity of effects and that the effect of mobility and incongruity will eventually form a coherent and consistent picture once the relevant variables, with which they apparently interact, are considered at the same time (Kasl, 1977:174).

### 3.1.3.2 Current beliefs about the nature of ischemic heart disease: a review

In two recent works, Marmot (1980, 1981) reviews the current literature on affluence, urbanization and IHD, and questions the three common statements and beliefs ("conclusions") about the nature of IHD: (1) that it is a disease of affluence; (2) that it is associated with modern, urban way of life; and (3) that it is associated with a diet rich in saturated fat, with smoking and with a sedentary life-style. According to the author this concept of the causes of IHD, it is too simple a picture. Each of the above "conclusions" bears further examination, in both developed and developing countries.

Marmot proceeds to demonstrate that the above "conclusions" hold only under certain circumstances, offering the following modified versions.

#### I - Ischemic Heart Disease as a disease of affluence

Data for England and Wales, from the 1971 Decennial Supplement of Occupational Mortality (Office of Population Census and Surveys, 1978) shows the lowest standardized mortality ratios for classes I and II, the most affluent. Further support for this inverse association between social class and IHD mortality comes from a longitudinal study of civil servants working in Whitehall, in London (Marmot et al., 1978b). The death rate for IHD among men in the lowest



grade of employment was nearly four times that of men in administrative positions (highest grade).

In another study, Marmot (1978a) examined for England and Wales, the association between IHD mortality and social class. The study showed that:

Allowing for changes in diagnostic fashion, it appears that deaths from IHD were more common in upper-class men until 1951. By 1961 the rate for upper-class men had begun to level off, but the rates for working class men had continued to rise and had overtaken the rates of classes I and II.

The author concludes that

what we are seeing in England and Wales is a changing pattern. IHD may have been predominantly a disease of affluence during the period when its mortality was rapidly increasing. It is no longer either rapidly increasing or a disease of the most affluent (Marmot, 1980:129).

Additional evidence comes from the U.S.A.. Stamler (1967) presents 1962 IHD mortality data for blacks and whites aged 50 to 54. Men have very similar death rates. In women, blacks have twice the mortality of whites. Once again, these data appear to be in conflict with traditional clinical teaching and current beliefs. Marmot (1980:130) considers that

it is possible that this is analogous to IHD distribution among the social classes in Britain. At an earlier stage of America's development, before there was a large migration of blacks from the rural south into the cities of the north, the disease may have been relatively more common among whites.

This is consistent with the results from the Evans County Study (Cassel, 1971) which was carried out in a largely rural population, where blacks were still working as farm laborers and sharecroppers under poor conditions. The study of IHD incidence over 7 years follow-up showed for whites higher rates for both sexes.

Socio-economic factors may well explain the described differences between blacks and whites what is consistent with the picture in Britain. Marmot (1980:130) concludes that:

when the whole population has gone beyond a certain level of economic development, IHD is no longer a disease limited to the more affluent members of the society.

If this is true, one might expect that in poorer countries IHD would be still a disease of the more affluent. Despite the shortage of data on cardiovascular disease from developing countries, Marmot presents evidence from India (Sarvotham and Berry, 1968) and South Africa (Shaper, 1973) supporting this hypothesis, to which we may add the recent study by Chen (1980) who documents that Singapore has now health indicators similar to those observed in developed countries. In addition, Dodu (1984) refers to similar trends being observed in other developing countries such as Malaysia, Mauritius, Sri-Lanka and several Latin-America countries, to which we may add Taiwan, and Philippines (see Reed and Feinlieb, 1983).

Marmot revised the first conclusion and proposed a new formulation:

In general, IHD is more common in affluent countries than in poor countries, although there are some exceptions. Within less affluent countries it is the wealthier members of society who appear to be at highest risk; within wealthy countries IHD is more common among the poorer members of the society (Marmot, 1980:131).

## II - Ischemic Heart Disease as a disease of modern life

Unpublished data from the England and Wales Office of Population Census and Surveys for the years 1969-1973 is presented by Marmot. For both sexes, IHD mortality is only slightly lower in rural areas than in towns and cities. In urban areas there is no association between size of the city and IHD mortality. Thus, British data scarcely contributes to provide evidence for the hazards of urban life.

In countries less urbanized and less developed, the picture is somewhat different. In countries considered to be at an intermediate stage of development such as Yugoslavia and Puerto Rico IHD incidence is nearly twice as high among urban residents than among rural residents (see Kozarevic et al., 1976; Garcia-Palmieri et al., 1978).

In the developing world limited information of urban-rural differences in IHD rates is available, but nevertheless the already mentioned studies on the

distribution of hypertension suggest the presence of such gradient. However, caution must be paid to the fact that blood pressure does not carry the same risk for IHD in low risk countries as it does in high risk ones, but it may be one step further towards its development. Recent studies reveal a growing concern with the observed trends in countries where the life-style patterns associated with high rates of IHD are not yet widespread and average level of critical risk factors in the community at large are still favorable. It is with these countries in mind that WHO developed the concept of primordial prevention already debated (see pages 14-15 and 102; see also Dodu, 1984; Watkins, 1984; WHO, 1982).

The above data on social class and urban-rural differences in IHD and hypertension, allow us to develop a better understanding of the problem.

In developing countries it is the more wealthy urbanized groups who are at the highest risk of IHD. In the industrialized wealthy countries, if this pattern used to exist, it does no longer. The urban-rural differences for IHD are small and it is the poorer members of the society who have the most vascular disease. It appears that the most recent groups to become urbanized and achieve a threshold level of economic development have the highest risk of IHD. Those exposed to the urban way of life are perhaps less able to adapt to the biological and social challenge (Marmot, 1980:136).

Additional evidence comes from studies in countries with different stages of development, such as studies of

urban migrating Zulus and the study of residents of the predominantly rural North Carolina State, as its counties were becoming progressively more urbanized (Scotch, 1960 and 1963; Tyroler and Cassel, 1964).

In what concerns the second conclusion Marmot considers the results of these studies to be consistent with two observations:

- rural residents living in areas that have become largely urbanized have higher IHD rates than rural residents less affected by urbanization
- as urbanization has increased, rural residents have lost their apparent protection from IHD when compared with urban residents. It is those newly exposed to urbanization who appear to be at highest risk (Marmot, 1980:138).

### III - Ischemic Heart Disease, Fatty Diet, Smoking and Sedentary "Life-Style"

There is a large body of evidence linking fatty diet, smoking and lack of physical activity to an increased risk of IHD. Most of the current preventive efforts are based on this evidence although these factors do not explain the total occurrence of the disease. In the already mentioned Whitehall study (Marmot et al., 1978b), less than half of the IHD differences between the classes could be attributed

to differences in smoking, blood pressure, plasma cholesterol or obesity.

The rule that countries with high rates of IHD have a national diet that is rich in saturated fat does not have well documented exceptions. Although these countries share other characteristics, it is difficult to avoid the possibility that the high rates observed for IHD may be related to the high level of consumption of saturated fat. However, the reverse is not necessarily true, as populations with a high level of consumption of saturated fat may not have high rates of IHD as Prior et al. (1966), studying Polynesians living in the Cook Islands demonstrated. Other authors have argued that studying this failure of adaptation we are looking at the wrong component of diet. The reasons for the increasing rate of IHD and other diseases "western diseases" is not too much fat consumed, but too little dietary fiber (see Burkitt, 1982; Trowell and Burkitt, 1981).

Japan constitutes an extraordinary example of the complexities in studying populations undergoing change. Despite being highly urbanized and highly industrialized, Japan continues to have low rates of IHD. When Japanese migrate to the United States their risk of IHD is intermediate between the high level of the USA and the low level of Japanese in Japan. One obvious reason is the change in dietary fat consumption. However, this change did not

provide a complete explanation for the change in IHD occurrence (Marmot et al., 1975). Further studies on the Japanese in California, using an index of "culture of upbringing" show that Japanese brought up in a more traditional Japanese way had lower IHD prevalence than those men brought up in less traditional patterns. The observed differences could not be explained by differences in dietary pattern, smoking, blood pressure or plasma cholesterol levels (Marmot, 1980:141; see also Marmot and Syme, 1976).

- In what concerns the relationships between diet and other life-style components it is clear that the third conclusion, on which most of the current strategies for prevention are based, is only partially true, and that social networks and associated psychosocial factors may have an equally important role.

Marmot (1980) concludes with the new notion of a "threshold of economic development" below which IHD is not frequent. Groups that recently reached that threshold are at higher risk, while it appears that a process of adaptation may be present in more affluent countries, which is potentially responsible for the observed declines in IHD mortality (Marmot, 1980:141-142).

A final note refers to narrow etiologic formulations involving a single psychosocial factor or a single

constellation of factors which are now past history. A more pragmatic, richer exploration of many possible interrelated epidemiological and psychosocial factors is the major characteristic of current studies. The works of Jenkins (1977) and of Marmot (1980 and 1981) help us understand the major classes of variables being studied, and conclude which areas are yielding cumulative, convergent evidence, as opposed to evidence which is increasingly more confusing, inconsistent and divergent (Kasl, 1977).

### 3.2 SOCIO-CULTURAL FACTORS AND CARDIOVASCULAR DISEASE

We may now look at cardiovascular disease from another perspective. The culture in which people live affects their beliefs, their attitudes, their behaviors, and their social groupings. This may influence their disease patterns in a wide variety of ways.

Socio-cultural factors can be either causal, contributory or protective in their relation to ill-health. Helman (1984:185-188) presents a list (not meant to be exhaustive) of 23 such factors, which are the ones more commonly examined by social scientists and epidemiologists. These factors range from family structure, gender roles and



marriage patterns to funerary customs, culturogenic stress and/or lay therapies. These factors may be of particular importance in many etiologic chains affecting people in a wide variety of settings.

To a large extent, the role of socio-cultural factors in cardiovascular disease etiology was presented above. Here we will focus on how those factors may become important components of the currently accepted multicausal model of cardiovascular disease etiology, and on the various potential roles that they play. In addition, we will discuss the increasing evidence that psychosocial factors may change the risk of disease, and how a particular feature of the environment may or not become a stressful factor depending on the "meaning" of that feature to the individual who is experiencing it.

Overall, the influences from social sciences have contributed to our understanding that not all mediating processes between the environment and some illness outcome needed be via altered biological processes, but can be also via altered behavior and functioning with their own consequent health status changes. However, increasing evidence suggests that behavior itself, is at least in part, biologically mediated. The area in which these interrelationships are probably best exemplified, is the area of "social stress and disease", of which cardiovascular disease is a major component (Kasl, 1977:164).

### 3.2.1 The Role of Cultural Factors

#### 3.2.1.1 Behavior affects exposure

Cultural and social influences clearly affect a wide variety of behaviors relevant to disease. Dietary habits, physical activity patterns, religious practices, smoking, alcohol and other drug-taking are all intimately bound up with cultural traditions, and may all influence the risk of disease. Traditional epidemiological studies examine the risks associated with these facts. In addition, behavioral sciences provide invaluable aid from their studies of these influences, in particular how people from different cultures have different patterns of exposure, are differentially affected, and to what extent observed inter and intra-cultural differences, can be explained by cultural factors influencing exposure.

#### 3.2.1.2 Culture affects illness behavior

Cultural traditions affect what people recognize as disease and what they do about it once they define themselves as sick. This area of growing convergence between social sciences, social epidemiology and psychosomatic medicine, has produced an important body of data, perspectives, and theoretical formulations, including those involving (a) the sick role, (b) illness behavior, perception of symptoms, and health care seeking, (c) the

role of the family and social network support. "The Health Belief Model" (Becker, 1974) has become a useful framework within which to understand the whole spectrum of health-related behaviors and various health-maintaining or risk reducing activities, including adherence to medical regime, staying in treatment, and altering one's habits and activities (Kasl 1975).

### 3.2.1.3 Patterns of illness relate to specific cultures

It has now been a common observation that there are societies round the world where the average blood pressure is low and shows little rise with age (Henry and Cassel, 1969). These societies are characterized as being small-scale, rural, with the members of the society living a traditional or unacculturated way of life. By contrast urban societies show a much greater average blood pressure, which rises steeply with age, and the prevalence of clinically defined hypertension is high, with important repercussions on IHD and stroke rates.

IHD also shows wide variations in occurrence around the world, and in a similar way to hypertension it is more common in countries that are modernized, industrialized, and urbanized. One approach to the study of these differences has been the various studies of migrants already mentioned. Evidence from the study of Marmot et al. (1975), concerning the observed differences in IHD rates between Japanese men

in California, Hawaii, and Japan, strongly suggests that it is unlikely that they may be due only to changes in smoking, serum cholesterol, or blood pressure.

It had been proposed that the Japanese are protected from heart disease because their culture contains devices that act as buffers against stress (Matsumoto, 1970). Matsumoto suggested that the strong, tightly knit, social group in Japan acts as a means of social support. Competitiveness in Japan tends to be between groups rather than individuals, so the individual person is less vulnerable to social stress. The study of Marmot and Syme (1976), tested this hypothesis in Japanese men living in California, and it showed that more traditional men had a lower IHD prevalence than the non-traditional men. Thus this study did not directly measure stress, but it did show an association between IHD and particular cultural traits that was independent of the known biological risk factors for heart disease. Alternatively, it is logically possible that western culture may have harmful features, in particular the coronary-prone behavior (type A) described in America (Friedman and Rosenman, 1959). In a large prospective study, with 8 1/2 years of follow up, the men who displayed behavior pattern A had twice the IHD incidence of those classified as type B. This increase in risk was independent of other known coronary risk factors (Rosenman et al., 1975). However, it is not completely clear what one should

understand by "type A behavior pattern" - how much is a deeply rooted psychological trait, and how much is a reaction to a particular social or cultural environment.

#### 3.2.1.4 Illness is associated with cultural change and other stressful "life-events"

We have seen how members of a particular culture will be expected to manifest disease patterns characteristic of that culture. In addition, the process of social or cultural change in itself may be stressful and that such stress may increase an individual's predisposition to disease. According to Cassel et al. (1960), "stress arises when an individual is confronted with a situation for which his background and previous experience have left him unprepared". The initial study of rural mountaineers in Appalachia who had come to work in a factory (Cassel and Tyroler, 1961), and the studies of Syme et al. (1964, 1965, 1966) seem to confirm that this process of social and cultural change may be endemic in the modern western way of life. These studies showed that men who had experienced occupational or geographical mobility had higher rates of IHD than men who were stable. The implication is that a discontinuity or incongruity between past and present circumstances may provide a potentially stressful situation (Marmot, 1981:332).

The blood pressure findings of the already presented

study of Zulu in South Africa (Scotch, 1963), have been similarly interpreted, being the new urban arrivals the individuals that experience the most stress, and so have greater rates of disease. Marmot (1981) emphasizes that this hypothesis is in direct conflict with the one based on migrant studies observations that predict that the longer a migrant had lived under a new culture, more likely would be to experience the disease pattern of that culture. The author concludes that

there may be elements of truth in both arguments; i.e., there may be a risk of disease associated with cultural change and certain cultures may have distinctive disease patterns associated with them. We need (i) a clearer formulation of the hypothesis relating psychosocial factors to disease, and (ii) more precise measurement of what is actually happening in the individual; i.e. whether or not the individual experiences a situation as stressful (Marmot, 1981:332).

Conflicting evidence also comes from the study of cerebrovascular disease, which in Japan is found to be more frequent in traditional, less developed communities. The powerful roles of hypertension (which has an important genetic component) and nutrition in its etiology may account for this pattern. However, further studies are required to understand the role of socio-cultural factors other than the ones associated with hypertension in the etiology of this group of diseases.

### 3.3 PATHWAYS LEADING FROM THE SOCIAL ENVIRONMENT TO PHYSICAL ILLNESS

A final note refers to the pathways linking the social environment and physical illness. In a 1980 work, Berkman presents the current knowledge on this subject. The author considers that

the mechanisms by which conditions in the social environment might influence health status in human populations is still a relatively unexplored area. In search for such mechanisms, it is important to keep in mind that social conditions seem to be associated with a wide range of outcomes rather than any single disease entity. This would suggest that there are several pathways leading from social circumstances to illness and/or that such circumstances lead to a compromised resistance to disease in general (Berkman, 1980:63).

John Cassel (1976), was a major proponent of the latter hypothesis. He formulated the hypothesis that

psychosomatic processes acting as "conditional" stressors will, by altering the endocrine balance of the body, increase the susceptibility of the organism to the direct noxious stimuli, i.e., disease agents. The psychosocial processes thus can be envisaged as enhancing susceptibility to disease (Cassel, 1976:109).

Initially Cassel believed in a complete absence of etiologic specificity, thus the psychosocial processes would enhance susceptibility to all disease in general. Later, referring to recent developments in animal studies he admitted that there may be several clusters of diseases

associated with different psychosocial situations. An elucidation of these issues is critical since by understanding the process by which social factors lead to poor health we can learn where to intervene most effectively and prevent unnecessary illness and death.

Berkman (1980:63) taking the approach that it is likely to be multiple biological pathways, outlined several potential processes: (1) behavioral processes whereby people living in certain social and cultural circumstances maintain health practices which are either beneficial (e.g. physical activity) or harmful (cigarette smoking) to their health; (2) psychological processes whereby people respond to circumstances by becoming depressed or changing their coping and appraisal processes; (3) direct physiological changes in both known biological risk factors (e.g. blood pressure, serum cholesterol) and undefined processes which are directly altered by exposure to certain environmental circumstances. The author concludes that

in the exploration of this chain leading from environmental conditions to health outcomes, we must also recognize that the factors which in this chain are considered mediators may also directly influence socio-environmental factors, reversing the causal chain. Thus, it is possible, for instance, that psychological states such as depression could influence social conditions (Berkman; 1980:64).

Behavioral factors including health practices, preventive utilization of health services, and compliance



with treatment regimens are obvious and likely candidates for linking socio-environmental conditions to disease consequences; however as we have pointed out, several studies demonstrate that health practices are capable of explaining only a part of the environment/disease association, suggesting that other pathways must also be involved, and in most cases a cross-sectional association between the social condition and health behavior was noted.

Psychological factors such as depression or coping processes also seem likely candidates as mediators between environmental conditions and illness responses. It has been hypothesized that when individuals are habitually confronted with situations in which their responses either are or appear to be ineffective, they ultimately come to conclude that events in general are uncontrollable and that they are powerless to effect a particular outcome. Stahl et al. (1975:34-36) propose the use of a conceptual model that takes into account the influence of perception upon the relationship between structural variables (including sociological and psychological) and disease as a behavior (adaptation). This model helps us understand, for instance, how "self-esteem" plays a major role in the incidence of peptic ulcers, issues such as "compliance", and the inconsistencies of the studies of "status incongruence". The model proposes:

that only persons who view their incongruity as problematic to their definition of self or goal attainment inhibiting, are likely to adapt to the incongruity by a physiological behavior such as hypertension. That individual who is either unaware of, or not bothered by this incongruity, has not reason to so adapt (Stahl, 1975:35).

The status incongruent individual who perceives of his incongruity as problematic can either (1) develop an "inappropriate" behavior (e.g. hypertension), (2) change his perception of the problematic nature of the structure or (3) attempt to change the structure itself. The latter two behaviors would be considered "appropriate" from the perspective of human behavior as rational.

While the previous hypothetical pathway suggests that the critical role social factors play in disease causation is not due to objective circumstances themselves, but to the way in which such circumstances are more subjectively perceived and mediated, it is also possible that there may be a pathway leading directly from social circumstances to physiological changes in the body which increase either general or specific susceptibility. Neural, hormonal, and immunologic control systems have frequently been invoked as potential pathways by which stressful social circumstances might cause disease. Numerous animal experiences suggest the presence of a hypothalamic defense reaction as well as of a sympatho-adrenomedullary activity as potential human pathways. In this discussion it is important to keep in

perspective that socio-environmental conditions may serve as predisposing factors (Cassel, 1976; Berkman and Syme, 1979) which affect a person's general resistance to disease and that other factors (e.g. genetic susceptibility, exposure to noxious stimuli) may determine specific disease vulnerabilities.

## CHAPTER 4

### PORTUGAL AND ITS CONTEMPORARY SOCIAL SYSTEM

Portugal is a small country, a very simple fact but one which must never be overlooked in any consideration of its history, its politics and its society (Robinson, 1979:1).

Portugal is one of the oldest countries in Europe and has had established frontiers since 1297. Its geographical position on the extreme west rim of the European Continent (The Iberian Peninsula), often called the "Western Rim of Christendom", partially explains the series of maritime and geographical discoveries on which the Portuguese and Castilian were engaged. These fifteenth and sixteenth century endeavors changed the course of world history (Boxer, 1969:2). As a consequence Portugal developed a large seaborne colonial empire of which a major component lasted till 1974.

On April 25th, 1974, a new era began for Portugal. The military coup that took place led to major social, political and economic changes in Portugal, of which the most

significant is the independence of all but one of its former colonies. This exception is Timor which was invaded by Indonesia and where a complex situation remains. Selected international circles still consider Portugal to be the administrative power, although actually no Portuguese administration remains in the island. Under an agreement with the People's Republic of China, Portugal still administers Macau. In what concerns the formerly inhabited Atlantic islands of Madeira (308 square miles) and Azores (905 square miles), settled in 1402 and 1430 respectively, although remaining part of Portugal, these archipelagos achieved special political-administrative autonomy as a consequence of the above changes.

Despite its former colonial empire, Portugal is currently the poorest country of western Europe. Its development level is similar to that achieved ten to twenty years ago by Spain and other mediterranean countries. According to the World Bank (1984), Portugal should be included in the middle-income developing countries, a position that in Europe is shared only by Greece, Yugoslavia, and Turkey. The 1985 report of the World Bank adopts a modified classification. Portugal is included among upper middle-income countries, which include the above European countries with the exception of Turkey (a middle-income oil exporter economy), and countries such as Algeria, Jordan, Malaysia, Chile, Brazil, Argentina, Venezuela,

Mexico, and Israel.

As a member of the European Free Trade Association (EFTA) and of the North Atlantic Treaty Organization (NATO), and by virtue of its former overseas possessions, Portugal in recent past has played a much greater role in both European and world affairs than its small size would suggest. After a lengthy negotiating process initiated in 1977, Portugal became a member of the European Economic Community (EEC) in January 1986. During the transitional period now initiated major economic changes will be introduced which will hopefully help the country narrow its development gap with the rest of Europe.

By nature of Portugal's position as a NATO member and of its socio-cultural and economic linkages with its former colonies, major expectations are placed in Portugal's broker role linking the new nations with the so called western world. However, over the last decade, cooperation has been scanty and markedly influenced by the fast changing Portuguese political environment, which has frequently interfered with the development of specific programs.

The development Portugal's earlier seaborne empire is masterfully depicted in the work of Wolf (1982). Further readings on Portugal's history and on the decline and collapse of the empire and its authoritarian order may be reviewed, for example, in the works of Livermore (1976),

Graham (1975), Figueiredo (1976), Mailer (1977), Robinson (1979), and Gallagher (1982).

#### 4.1 THE LAND AND THE PEOPLE

Continental Portugal is a narrow rectangular country, occupying slightly more than 15 percent of the Iberian Peninsula (34,170 square miles / 88,500 square kilometers). Portugal has only two neighbors, the Atlantic Ocean (South and West) with which it shares a coast line of 527 miles, and Spain (North and East). Its 755-mile frontier with Spain is rather the product of historical development since, as Robinson (1979:4) demonstrates, "Portuguese individuality has precious little to do with linguistic, ethnic, or geographical factors".

Geographically, Portugal is neither homogeneous nor a peculiar distinct unit. North-west Portugal has physical features, climate and forms of cultivation similar to those of Galicia. North-eastern Portugal is merely a prolongation of the Castilian plateau, The Meseta Iberica, while the more southerly regions of Beira-Baixa and Alentejo are geographically one with, and indeed socially and economically akin to, the Spanish region of Extremadura.

Despite its small area the country displays a great diversity of geographical features. Most of it consists of lowlands, with only 11.6 percent of its area lying above 2,300 feet - and most of that north of the Tagus River (Rio

Tejo), which cuts the country in two distinct parts. Over 90 percent of Northern Portugal lies above 1,300 feet, with high mountains rearing up only 30 miles from the sea, and huge plateaus cut by deep valleys. The Southern part of the country is a region of plains and low tablelands, of broad river basins.

Specific regional features will not be addressed here. I refer the reader to an excellent review by Robinson (1979:4-21).

The present population of Portugal is descended from a historical mixture of ethnic groups, some of which are lost in the mist of prehistory. According to Robinson (1979:3-4),

if one restricts oneself to going back no further than the first millennium BC, which would seem far enough, successive waves of settlement, conquest or partial colonization may be noted: Celtic, Phoenician, Greek, Carthaginian, Roman, Germanic (especially Suevic), Arab and Berber. To this list may be added Jews, Gypsies, and Black Africans imported as slaves before the final abolition of that institution on the Portuguese mainland in 1761. Twenty-century ethnographic studies confirm the assimilation of all these elements, with the exception of some 92,000 gypsies who, as in other countries, remain nomadic social outcasts to be founded chiefly in the Alentejo... Leaving aside the Gypsies, there are no distinct "nations" or sub-national groups in Portugal to correspond to the Basques or the Catalans in Spain, and so in this sense the Portuguese population may be termed homogeneous. There are no physical differences between the populations living on either side of the Luso-Spanish border...(The) inhabitants of Portugal are more likely than not to be of medium stature and dark in complexion and therefore comparable to other European residents of comparable latitudes such as Spaniards, Italians and Greeks.

Having established that there is nothing peculiarly



different geographically or ethnically about the Portuguese, there remains the question of language. Portuguese, which has been described as less harsh than Castilian and less musical than Tuscan, is spoken by over 120 million people in Brazil, and has been adopted as the national language by most of the former Portuguese colonies. According to Robinson (1979:4),

The Portuguese language arose as a synthesis in the twelfth century of the Galego-Portuguese of the Christian north and the Mozarabic-Lusitanian of the Muslim south; residual differences in dialect reflect these distant origins. Within the modern Portuguese language four principal dialects are said to exist: the northern or interamnense in the Minho and Tras-os-Montes; the central or beirao, in the Beiras; the southern, on the rest of mainland (including Lisbon), and the insular, spoken in the Adjacent Islands and which could be said to include Brazilian... Nevertheless, despite such differences in dialect, Portuguese is a distinct Romance language which also contains over five hundred words of Arabic origin, many of them describing clothing, furniture and utensils, agricultural tools and scientific devices.

#### 4.1.1 Demography

The population of Portugal probably totaled about a million at its maximum in the Middle Ages. At the beginning of the 20th century the population of metropolitan Portugal, a designation that also included the adjacent islands, had reached 5,000,000. In 1983, the total population was estimated to be 10.1 millions, representing an average density of 285.4 persons per square mile (110.2 per sq km). It is expected that by the year 2010 Portugal will reach

reproduction rate 1, and the hypothetical size of stationary population will be 13 million.

In Portugal census are taken every ten years. Table-1 gives the relevant figures for recent decades, which clearly demonstrate the importance of emigration, especially during the 1960-1970s. Emigration will be discussed in the next section.

YEAR	POPULATION	% INCREASE
1930	6,826,000	-
1940	7,722,000	13.1
1950	8,510,000	10.2
1960	8,889,000	4.4
1970	8,668,000	-2.5
1980	9,884,000	14.0

TABLE-1: Population of Portugal, 1930-1980.  
Source: INE, various years.

The crude birth rate decreased from 30 per thousand population in 1930 to 23 in 1965. In 1983 its value was 15, what represents a 34.8 % decrease for the period between 1965 and 1983. The north and the Islands are still the areas where larger families can be found. The diminishing family size, initially observed in the south, is now also observed in the northern regions. The total fertility rate for 1983 was 2.0 (World Bank, 1985).

The crude death rate declined 13.5 % between 1965 and 1983, a decline that was mainly due to significant reductions in infant mortality. The infant mortality rate

dropped from 144 per thousand in 1930 to 65 in 1965. In 1983 the infant mortality rate was 25, which represents a 61.5% decline for the 1965-1983 period.

Despite these marked decreases Portugal still has a high infant mortality rate by European standards. Marked regional and local variations are present; rates in less developed, underserved areas of the country may be twice the national average. It should be pointed out that Portugal's 1983 rate is still higher than that observed in France in 1965, and equal to that observed in Ireland in the same year. Spain had values similar to Portugal's 1983 rate a decade before.

Table-2 summarizes the evolution of infant mortality and life expectancy at birth for males and females in Portugal and comparable European countries (see pages 121 and 122). Data for France, Ireland, Italy, and Spain is also presented.

Country	<u>Life Expectancy at Birth</u>		<u>Infant Mortality</u>	
	<u>Male</u>	<u>Female</u>	<u>Rate</u>	
	1965	1983	1965	1983
PORTUGAL	61	68	65	25
GREECE	69	73	34	15
YUGOSLAVIA	64	66	72	32
FRANCE	68	72	22	9
IRELAND	68	70	25	11
ITALY	68	73	36	12
SPAIN	68	73	38	10

TABLE-2: Life expectancy at birth (years) and infant mortality rate (per thousand live births). Source: World Bank, 1985

The net result of the above demographic trends is that the Portuguese population is getting older (Table-3), progressively approaching the pattern of industrialized nations, such as France, The Federal Republic of Germany, the United Kingdom or Sweden. Table-4 presents the most recent available population distributions for selected countries.

Age-Group	Year				
	1952	1965	1975	1979	1983
0 - 14	29.2	29.0	27.3	27.9	25.9
65 +	7.1	8.4	10.2	9.9	10.5

TABLE-3: PORTUGAL - Population distribution by age (%).  
(Estimates for 1952, 1965, 1975, 1979 and 1983).  
Source: INE, various years.

Country	Year	% Distribution by age	
		0-14	65+
PORTUGAL	1980	25.9	10.5
GREECE	1981	22.4	13.2
YUGOSLAVIA	1980	24.4	9.4
FRANCE	1983	21.8	13.2
IRELAND	1979	30.6	10.7
ITALY	1981	21.4	13.6
SPAIN	1978	26.6	10.7
GERMANY (Fed. Rep.)	1981	17.5	15.3
UNITED KINGDOM	1981	20.3	15.3
SWEDEN	1981	19.2	16.5

TABLE-4: Population distribution by age.  
Source: World Health Statistics Annual (1984).

Marked regional variations, associated with migration and marked decreases in natality, are evident (Table-5). In the interior regions (e.g., Castelo Branco, Guarda, Portalegre) and the Algarve the population 65 and more years currently represents approximately 15% of the total population.

District	Both Sexes	Males	Females
AVEIRO	8.5	6.6	10.1
BEJA	12.7	12.1	13.4
BRAGA	7.3	6.0	8.6
BRAGANCA	11.2	6.1	12.1
C.BRANCO	14.7	13.6	15.7
COIMBRA	12.9	10.8	14.6
EVORA	12.3	11.7	12.8
FARO	15.3	13.5	17.0
GUARDA	14.6	13.0	16.0
LEIRIA	10.1	8.7	11.4
LISBOA	9.6	7.3	11.6
PORTALEGRE	14.7	13.9	15.4
PORTO	7.3	5.5	8.8
SANTAREM	12.8	11.5	14.0
SETUBAL	7.4	6.3	8.9
VIANA	11.5	9.6	13.0
VILA REAL	9.3	8.4	10.2
VISEU	11.7	9.8	13.4
ACORES	9.2	7.7	10.6
MADEIRA	8.2	7.1	9.0
PORTUGAL	9.9	8.2	11.3

TABLE-5: PORTUGAL (1979) - Population aged 65+ years, by District (%). Source: INE.

#### 4.1.2 Migration

Portugal has one of the highest emigration rates in Europe. Between 1860 and 1930 some 30,000 Portuguese a year went abroad to seek their living. During the 1890-1940 period, 92 percent of legal emigrants came from northern parts of the country Brazil being the destination of 83 percent. After 1930, restrictions were placed on immigration by Brazil and other countries prompted by worldwide depression. The emphasis in Portugal turned to internal migration. From the late 1950s Portugal, like other Mediterranean countries, became a supplier of labour to the more advanced countries of Western Europe. It is estimated that in 1965 about 100,000 persons of eligible working age left the country, while the natural population increase was 115,112. By 1970 official emigration to foreign countries stood at 66,300, 33 percent of whom went to France, 30 percent to the Federal Republic of Germany, 15 percent to the United States, and 17 percent to other North and South American countries (Brazil, Canada and Venezuela).

Illegal emigration, especially to France, was extremely heavy. Robinson (1979:155) presents evidence suggesting that the 1970 total above should be 209,632, and that 64.7% of these emigrants (135,667) are the totals for France, which include illegal emigration. Emigration to the United States was a phenomena much associated with the Azores and, to a lesser extent Madeira; the centers of settlement were New

England and, to a lesser extent, California. Canada was also a major destination for Azoreans particularly in the 1960s, while Madeirans favored Venezuela and South Africa. As for the mainland, emigration was principally a phenomenon associated with the north-west until the 1950s when it became general to the whole country. It became more attractive for rural workers to go in search of the higher wages of France and Germany than to migrate to Greater Lisbon or Porto; better wages were also a lure for urban workers, skilled and unskilled, while for those of military age illegal immigration had the added attraction of avoiding conscription and colonial war.

It is expected that within the next decade 0.5 million Portuguese emigrants in Europe will return to the country, since their services are no longer welcome by the host countries. As Dacosta (1984a) says:

The most important phenomena for Portugal in the 1980s is going to be the return of the Portuguese emigrants, in a similar way to the 1970's return of 1 million "retornados" [1] from Portuguese colonies... Having closed the "Empire Cycle", Portugal now sees the "Emigration Cycle" also come to an end... Without having recovered yet from the loss of the empire, Portugal has to face the future loss of the emigrants' remittances.

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[1] National refugees were initially labelled "retornados", what means someone who returns home or to the homeland. Unfavorable connotations led to the rejection of the denomination by the refugees. The word "desalojados", which means a guest to whom lodge is no longer granted, was then adopted. Frequently, the refugees would prefer to call themselves "ex-residents" of the Portuguese colonies.

The exact number of "retornados" is unknown, but it was officially estimated at 650,000 in May 1976. Since then the numbers certainly increased significantly with further arrivals from Mozambique, Cape Verde and Timor. Dacosta points out that

Some returned to us without having left from us. They are migrants from other areas and other "misfits". They are Indus, Pakistanis, Shiites, Sunnites, Ismailians, coming from Mozambique where, by virtue of their economic power, they had become strong ethnic, religious and cultural communities; to these communities we must add the people from Timor who came under the most precarious conditions (Dacosta, 1984b:52).

The socio-cultural and economic impact of decolonisation was dramatic. As Robinson (1979:261) says,

The "retornados" have presented an enormous social problem, particularly at a time of economic recession. They swelled the ranks of the unemployed... While it would seem that up to 90 percent found accommodation with or through relatives, the remaining 10 percent had to be temporarily put into hotels and or lived in wretched conditions in refugee camps or overcrowded housing.

Ten years later we observe what Dacosta (1984b:54) described as the "africanization of Portugal", referring to major changes in the Portuguese socio-cultural environment brought about by the integration of the national refugees (i.e., modes of association, art manifestations - especially music, major culinary changes which led to the proliferation



of restaurants promoting what can be called "colonial cuisine" integrating ethnic food and food practices).

Despite wide variations, we may consider that most refugees are fully integrated, actively participating in the Portuguese social life, contributing to the country's development. For most of the refugees, those who, in the words of Dacosta, left from us and return to us,

to build a house and start a "business" was the big project away and back home. The first (only?) thing the Portuguese did in Africa and in Brazil was to build a shelter, open a "shop", find a wife and have children; retail activities were, and still are, his best tool... Therefore he is only able to get organized on economic basis and his ideology is "the absence of ideology". The peoples from whom he descends (i.e., Jews, Romans, Phoenicians, Carthaginians) all came through the same corridor, the Mediterranean, and all had commercial characteristics. They were non-agrarian peoples (Dacosta, 1984b:55).

In what concerns those peoples who did not originate from mainland Portugal, those from the Indian subcontinent developed well structured communities based on commercial activities. The opposite is observed in large proportions of the Cape Verde and the Timor communities where adaptation is far from being achieved. Most still live under extremely deprived conditions in segregated slums around Lisbon caught in the unemployment/poverty cycle characteristic of a major metropolis. (Melo, 1983; Mailer, 1977:11).

According to a study by Silva et al. (1984), by 1990

50 % of the emigrants in EEC countries are expected to have returned to Portugal. 68% of the Portuguese emigrants have stays shorter than 15 years. Germany is the country where the shortest average stay is observed, while in France we observe the longest.

While abroad, the great majority (85%) did not attend any professional or nonprofessional courses. The authors concluded that "to a nonqualified emigration among whom low schooling prevails, corresponds an equally nonqualified/low schooling returning population." It is among those who received any form of professional training that one finds those less interested in returning to Portugal.

The dramatic consequences of these major demographic movements have to be followed attentively. In the short period of two decades Portugal, will have absorbed a returning population of 1.5 to 2 million individuals, who will certainly foster major changes in the Portuguese socio-cultural and economic life.

#### 4.1.3 Population Distribution

Population and settlement reveal striking contrast between the denser north and the more sparse southern parts of the country. A number of rural areas have suffered considerable population losses resulting in economic and

social depression, particularly in parts of the north, the central east, and the southern costal areas. The coastal zones between Braga in Minho and Setubal just south of Lisbon, with their low-lying plains and urban development, have encouraged a large proportion of the population to settle there. Lisbon and Porto urban agglomerations became major industrial areas.

In 1965, the urban population was 24 percent of the total. Data from 1981 showed for the cities of Lisbon and Porto populations of 812,400 and 329,100, respectively (United Nations, 1984). If we now consider their urban agglomerations Lisbon had a total 1,611,887 and Porto a total of 1,314,794.

The definition of "urban" is quite variable and therefore most international comparisons are inappropriate (see for example United Nations, 1984:173-175). According to the Portuguese definition (agglomerations of 10,000 or more inhabitants) 1983 data show that 30% of the total population is urban (World Bank, 1985), while 51% lives in agglomerations of less than 1,000 inhabitants (INE, 1984a).

#### 4.2 SOCIETY

If we concede that there is a Portuguese culture, then its salient elements must be examined. In 1959, Professor Jorge Dias (quoted by Robinson, 1979:24) said:

To describe the national character in a phrase, we can say that the Portuguese is a mixture of dreamer and man of action, or better still, an active dreamer, who has a certain practical and realistic basis. Portuguese activity does not have its roots in cold-blooded will, but is nurtured on imagination and dreams, since the Portuguese are idealistic, emotional and imaginative, rather than deeply reflective.

Descamps (1935), also quoted in the work of Robison (1979:25), detected a tendency towards anarchic individualism, concluding that the Portuguese were "unstable communitarians rather than true individualists": the main bonds of social solidarity were based on family, clan and patronage.

As in other southern European countries, what one may term the national culture (one should be extremely cautious not to be tempted to overgeneralize) is for historical reasons an urban culture, with contrastive regional cultures of varying degree.

In Portugal, as elsewhere, the general tendency is for regional differences and customs to become less deeply felt as the progress of modernization advances. Although, as stated by Robinson (1979:22), it is impossible to be very precise in this area, it would still seem to be true that the principal divisions are the rural-urban disjuncture and

the perceived and felt differentiation between north and south as well as between the mainland and the islands.

#### 4.2.1 Family Structure and Values

An excellent review of the Portuguese family organization is presented in the context of family therapy among Portuguese immigrants in the United States in the work of Moitoza (1982). I find this overview, to be equally applicable to describe Portuguese families in general, since the author stresses general family structures and values shared for most Portuguese, irrespectively of its place of residence.

As in every ethnic group, values, beliefs, and behavior among the Portuguese vary according to socioeconomic status, education, age, and geography. Yet, the illiterate peasant farmer from norther Portugal's Trás-os-Montes, the hard-working fisherman from the Azorean Islands, the cosmopolitan business executive from Lisbon, and the Portuguese immigrant factory worker in the United States, do all appear to share common characteristics, particularly those referring to family. Indeed the importance accorded to family appears universal among the Portuguese, with differences tending to occur more at the level of structure. The Portuguese immigrant families followed by the Egas Moniz Clinic [1] have been found to have both significant nuclear and extended contents, organized for the most part in a "closed" typology... The nuclear unit is ostensibly patriarchal, yet... much internal and external familial facilitation and negotiation is handled by the female/wife/mother. Authority tends to be organized vertically, flowing from the parental dyad to the oldest son or daughter. (Moitoza, 1982:415-416).

[1] The Egas Moniz Clinic, is neighborhood mental health center of the Cambridge Hospital in Cambridge, Massachusetts.

Both children and adults are expected to gratify most of their personal, social, and emotional needs within the nuclear or the extended family, though family activities may be supplemented with occasional church-based social and religious ones. Parents, in what is seemingly an attempt to insure family unity, stability, tradition (and in the case of immigrants, ultimate survival), demand loyalty from other family members, with familial needs and goals generally superceding individual ones. A good example is the case of the families of immigrants whose members, without exception, are expected to make financial contributions so as to make possible the rapid purchase of a house, the repository of family life.

Moitoza (1982:416) elaborates further in what he considers to be an important characteristic of most Portuguese families:

Boundaries between extended and nuclear family membership frequently blur. Variables such as illness of a relative, death of a parent or a relative, migration of a family member, need for child care, financial demands, and work schedules, can alter the make-up of the family unit as the nuclear family looks beyond its immediate members to meet its special needs. As a result, both the quantitative size and qualitative functions of the Portuguese family change frequently.

This is consistent with Dias' (1950:19) remarks, also quoted by Moitoza (1982:416):

Relationships among the members of the [Portuguese] family are almost always very intimate and frequently exclusive. Parents and children, brothers and sisters, aunts and uncles and nieces and nephews, cousins and cousins, are paired for tight and often confusing nets which a stranger penetrated only with difficulty.

In order to insure economic, familial and social security, Portuguese families sometimes "extend" their membership through such means as cross-cousin marriages, god parentage, and multiple sibling cross-family marriages.

Discussing Portuguese family life, Rogers (1980:817) refers to what he regards as a positive aspect of family solidarity -- "the tendency of the Portuguese to care for their ill at home insofar as they can." The same author also stresses aspects of family life that actually contribute to the dissolution of the group namely "the near tyranny that can be exercised by fathers and brothers over daughters, sisters, and even widows", which often prompts rebellion. In the case of the Portuguese immigrants in the United States, this rebellion has been expressed by women marrying outside the group, and sometimes even outside the church (Rogers, 1980:818).

Godparents are extremely close and powerful members of a Portuguese family. There is perhaps no stronger aspect of the Portuguese life than that of godparentage. For the Portuguese, godparents truly are sponsors in and for life. Robinson (1979:420) suggests that it is perhaps

because of the Portuguese underlying sense of fatalism that godparentage becomes such an important aspect of the culture. The belief that survival is perhaps insured with a second set of parents is strongly suggested.

Godparents are usually selected within the immediate or extended family or are chosen because of their superior wealth or power in the community. In some cases children are given to their godparents for rearing.

The traditional responsibility of the godparents is to see that the godchild is brought up as a good Catholic. However the mores go beyond such a spiritual relationship and impose economic responsibilities in the case of premature death of either or both biological parents.

Family bonds are generally described as looser in the Alentejo than elsewhere. The "alentejanos" have a reputation for a notorious religious indifference. There is a tendency to be less concern than elsewhere with the formalities of marriage, and high illegitimacy rates prevail. The association of these characteristics with regional economic features, largely dependent on land tenure patterns, is stressed by Robinson (1979:14):

It has been argued that the communal life of migrant laborers in the crowded accomodation of the "montes"[1] encourages promiscuity, but it has also been argued

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[1] Complexes of buildings (master's house, barns, stables, bakery, lodgings for permanent workers and accomodation for seasonal laborers) that form the center of the large agricultural units characteristic of this region.



that the seasonal migration of males and females from the townships, often at different times of the year, militates against the institution of marriage. If the bonds of kinship are weaker than elsewhere, bonds of patronage and spiritual kinship (compadrado) in the Alentejo are possibly stronger.

The "typical" character and role of the various members in Portuguese families will not be addressed here. For those interested, I suggest a review of the work of Moitoza (1982:417-421).

#### 4.2.2 Kinship and Patronage Networks

A salient figure of the Portuguese society, one that does not differentiate it in kind from any other south European society, is the prevalence of networks of kinship and patronage. Lengthy and complicated laws and regulations may be constantly drawn up, promulgated and revised to settle the rules by which society is to operate, but in practice the Portuguese knows that such rules are there to be bent and circumvented as one's own needs dictate and in so far as means can be found to achieve this. Robinson (1979:22-23) elaborates further on this situation:

For historical reasons, including the political instability of the last two centuries, it can be said that no concept of the objective legitimacy of law or government has ever taken root in Portugal. It is assumed that those who make law or govern do so to further their own interests rather than those of the society as a whole, and therefore the taking of countermeasures in self-defence is a natural and legitimate activity. From time to time there is a

breakdown of the governmental system, a change of political regime and new laws result, but these changes do not usually make much impact on the substructure of social relationships... Thus whatever the regime, the individuals and families need to be well connected to survive, to prosper and, if possible, to advance their standing and interests. Since Portugal is a small country and therefore has a small "elite" - facts which perhaps differentiate it to a certain extent from larger south European countries - who is related to whom, who knows whom, who owes whom a favour, are the essential elements in social relationships. Whether it be in one of the government ministries or in some rural area, those in positions of authority and influence constitute the centres of patronage. The protection of one's interests or the advance of one's career is to a considerable extent dependent on whose system or network of patronage one belongs to.

Robinson concludes:

Portuguese society is in one sense little more than a large number of competing "families" organised for survival and advancement... As it is to be expected, those who lose in the competition are wont to denounce corruption and injustice, while those who are doing well either keep quiet or defend themselves on the grounds that careers are open to talent and they had proved themselves more able. There are rules of the game which must be observed and seen to be observed but after that point patronage is an important, if of necessity sometimes obscure, social fact, be it in politics or in simple economic transactions.

#### 4.2.3 Religion

Portugal is a Catholic country in as much as there is no rival to Catholicism [1]. It is much stronger as a social force and as a religion in the northern and central parts of the mainland and in the islands than it is in Lisbon and the

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[1] Small Protestant communities are organized in Lisbon, Porto, Coimbra and costal areas. There is also a small Jewish community with synagogues in Lisbon and Porto.

south. Although a large proportion of the population would declare themselves Catholic (over 90%), surveys have found a low attendance at mass and as much as 70% of the population who never went to social or cultural activities organized by the church (Robinson, 1979:29). In addition, Portugal has one of the highest illegitimacy rates in Europe and, despite the lack of official statistics, hospital practice suggests that illegal abortion rates are extremely high [1].

The Portuguese have long marked change points in both the individual's and the family's developmental life cycle with religious and secular ceremonies and celebrations. Also an important feature of Portuguese life (particularly in the north and in the Azores) is the celebration of saints' days ("festas and romarias"), often accompanied by communal eating, fairs and fireworks as well as the decoration of churches.

The immigrant communities have maintained these traditions which seem important in revitalizing spiritual zeal. They are also designed to deepen an individual's allegiance to his or her ethnic group, and to provide a joyous respite from the drudgery of daily working life. An excellent example are the activities of Portuguese

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[1] The last available contraception rates show that 66% of married women of childbearing age use contraceptives. Data on nonmarried women are not available (World Bank, 1985:213).

communities in the United States, where the "Blessing of the Fleet", "St. John's Day" and the "Shrine of the Holy Ghost", are celebrated. These festivities are, to a large extent, replicas of similar traditions in the mainland and the Azores, and constitute excellent demonstrations of the powerful interrelationship of home, cuisine, and religion in Portuguese culture.

A strong belief in miracles and miraculous solutions is common among the Portuguese. Moitoza (1982:422) describes it:

Tangled in the Portuguese's religious beliefs and attitudes about day-to-day life, is their reliance on assistance and intercession by numerous saints, Christ, and the Virgin Mary. These "agents" are called upon for luck (destiny) by acting as mediators between the person and God (God is never to be approached directly as He is too powerful and awesome). Much religious metaphor is used in this rather secret and supernatural evocation for assistance. Examples might include asking for assistance with a health problem or seeking better luck for a married daughter. This is usually done by women whose role in the family includes the religious and spiritual realm. Vows are also made to saints. These are special promises of deeds to be done by the person as payment for a fulfilled request. The promise might be to make a donation of some money to the church or to perform a particularly charitable act.

Promises may also take the form of penitential acts such as walking to a particularly distant shrine (e.g., Fatima, Bom Jesus) where often a certain distance is performed kneeling. These penitential activities are frequently fulfilled in association with some of the promises of deeds mentioned above.

Since the 1960s the Portuguese Church has been under a severe crisis. This is best measured by marked reductions in the membership of "Catholic Action", and by the rapid decline of the number of seminarists. Robinson (1979:163), suggests the importance of the Second Vatican Council in accentuating the Catholics' tendencies to divide on political (e.g., colonial war), social (e.g., contraception) and even theological issues, a growing phenomenon during the final years of Portugal's old regime.

#### 4.3 ECONOMY

When Salazar took over the Ministry of Finance in 1928, Portugal could be classified as a underdeveloped country. Most of the population earned their living from agriculture. The country possessed no heavy industry and its manufacturing industries, mainly textiles, were of modest proportions. Its exports consisted for the most part of primary products.

Salazar's perspectives on the country's economic reconstruction are commented by Robinson (1979:128-129):

Salazar's aim was the regeneration of Portugal by means of a well-ordered economy. For the economist Salazar, as for Marxists, political forms were subordinate to socio-economic priorities; the corporative system was the product of ideological preconceptions, but mere changes in political superstructure and institutions were not the all-embracing aim of the New State. The New State was rather to reflect and represent the

national society after the preceding period of disorder and indiscipline. The aim said Salazar in 1938, was "a progressive revolution, which, having once brought within its scope all industrial, commercial and agricultural activities, will change the aspect of our economic and social structure, thereby conferring on the state its own specific characteristics."

The corporative system that followed, was outlined in the National Labor Statute of 1933 [1]. Although intended to be eventually independent of the state and a middle way between capitalism and socialism, this system was crowned by a state institution, the National Institute of Labor and Social Insurance, whose function was to "see to the execution of the laws protecting labor and others of a social character, and to integrate the workers and other productive elements in the corporative organization". However, as Robinson (1979:133) points out,

the legislation on working conditions, together with the ban on strikes and lock-outs (including "revolutionary lock-outs"), gave few advantages to the worker. Despite the panopoly of labour courts, collective contracts and agreements, corporative commissions, etc., the achievements of the system in furthering social justice were meager; improvements in the workers' lot usually stemmed from conjunctural factors in the labour market.

The corporative system was seen by Salazar as ideologically the best solution for the "social question" since it was the one advocated by the teachings of the church. It also had the advantage in practice of preserving

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[1] For details on its structure and organization see Robinson (1979:131-134).

a private enterprise economy while at the same time legitimising moderate government intervention permitting overall control of the economy.

The consequences of Salazar's administration, including the short period of what was denominated "Salazarism without Salazar" under Prime Minister Caetano, are known. Portugal moved in the years 1930-1970 from underdevelopment to semidevelopment but showed few signs of being able to narrow the gap between itself and the developed countries, which had been a long term policy aim. The development model selected made industry the motor of progress. This led to the rise of the industrial-financial bourgeoisie within the Portuguese economy and society, tending to replace the predominantly agrarian and trading forces in political power.

In the words of Pereira de Moura (1969), quoted by Robinson (1979:157), industrialization had its price:

Portuguese industrialization was based on the sacrifice of the labouring classes (low wages, high price levels for consumer goods, weak state intervention with regard to redistribution [of wealth], be it direct or indirect through public investments and expenditure of a "social" type, such as education, housing, health, social security and rural advancement). It was a capitalist process, albeit with the State intervening to an important extent, but in the sense of helping the private sector, and not compensating for or correcting the latter's abuses and shortcomings in a human perspective.

In the 1960s, the outbreak of colonial wars not only brought high human costs, but also introduced a major drain

to national resources, both in terms of money and manpower. The inability of the regime and of the dictator to negotiate a political solution led to increased international isolation (Fields, 1976:226). Facing increasing internal opposition, the autocratic regime disregarded all basic civil rights and pursued a violent domestic political repression campaign which affected a large proportion of Portuguese families. Thus, the period of celebration and high expectations that followed the 1974 revolution has to be understood as a reaction to this dark period of Portuguese history.

Post-revolutionary Portugal came into being as contemporary of a major worldwide recession. The severe economic crisis that soon developed was directly brought on by a drop in the number of tourists from abroad, in the amount of foreign investments and of money being sent by emigrants back to homeland. This crisis was heightened by the sudden swelling of the population due to the influx of Portuguese from the newly independent African colonies. Behind these directly observable effects, there is broad evidence suggesting the intervention of various international regulatory agencies which, through predominantly economic mechanisms, control contemporary world politics [1], therefore limiting change in dependent nations.

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[1] See, for example, Fields (1976:235), and Graham and Wheeler (1983:287-366).



Since 1974 each of the several governments involved systematically disclaimed any responsibility in the development of the "crisis", while promoting often unidentifiable "recovery achievements". As a result of this long-lasting economic crisis, large sectors of the Portuguese population are currently under its severe effects. In addition, the above mentioned economic gap (see page 147) has increased, leaving limited hope for rapid improvement (Table-6, page 153).

COUNTRY	GNP per capita	
	1961	1983
PORTUGAL	270	2,230
GREECE	364	3,920
YUGOSLAVIA	246	2,570
SPAIN	274 *	4,780
* 1960		

TABLE-6: Gross National Product (GNP) per capita (U.S. Dollars). Sources: Robinson (1979) and World Bank (1985).

By the end of 1984 Portugal's foreign debt was estimated to be 14,000 million dollars and the World Bank (1985:201) estimated the 1983 current account balance deficit of 983 millions of dollars. During 1984, investment dropped 20.5%, and extremely high interest rates (30% on average) prevailed.

Amaral (1984) discusses OCDE data for Portugal,

relative to the 1983-1985 period [1]. A significant reduction of the gross national product and record inflation rates (1984 annual average was 31.0) are the two major characteristics of this period. In 1984 a 12% reduction in the value of "real salaries" was observed. Morgado (1983) had previously documented that during the 1974-1982 period, "real wage" increases were only observed in the first two years of the period. 1976 marked the beginning of a continuous major decline in the economic power of most of the Portuguese population.

1984 also presented a marked increase in the number of workers with unpaid wages (see Amaral, 1985) [2], which were estimated to be 150,000 during most of the 1983-1984 period. The unemployment rate grew from 9.5 in 1983 to 12.0 in 1984.

This dramatic economic crisis had to translate into a wide variety of social consequences. Various sources, including church representatives, documented the existence of "hunger pockets", of which the most notorious was located in the heavy industrialized Setubal region; housing shortages became acute and rapidly deteriorating social conditions persist in particularly in the underserved and

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[1] See also Costa (1985).

[2] Despite not being paid, these workers maintain regular work activities thus not being entitled to unemployment benefits. The rationale for this unique situation, associated with the wide spread unemployment, is the fear of hindering economic recovery, thus further jeopardizing future stable employment.

neglected communities such as those of the Lisbon shanty towns, and of the Se neighborhood in Porto [1].

Under these circumstances, it is not surprising to observe the development of new strategies of adaptation. A recent study by Lobo (1985) estimated that a million Portuguese are involved in parallel (not officially declared) economic activities of whom 116,000 are schoolage children. The author stresses that this last figure is in accordance with Ministry of Education recent estimates of children not attending school.

Other mechanisms have also been described. In certain areas of the country, nearly 40% of workers were found not to be enrolled in the compulsory national social security scheme, therefore avoiding the collection of the required fees (Anonymous, 1984b). The same source also documents major frauds concerning social benefits involving sickness pay, major disability subsidies, while similar problems have been found in what concerns prescription benefits (Castanheira, 1985).

The current model of development also favours industry as the motor of progress, making Portugal heavily dependent in terms of food supplies, energy, manufacturing goods and associated technology. In 1983, the agriculture sector contributed only 8% of the overall gross domestic product

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[1] See, for example, Melo (1983), Melicias (1984), Silva, Germano (1984) and Anonymous (1984a and 1985).

(GDP). Table-7 shows for Portugal the changes in GDP proportions by sector, 1953-1983, which are parallel to observed changes in labor forces distribution (see Table-8).

Year	Agriculture	Industry	Services
1953	32	27	21
1960	25	30	21
1969	18	36	24
1983	8	40	51

TABLE-7: Changes in GNP proportions by sector, 1953-1983.  
Sources: Robinson (1979) and World Bank (1985).

Sector	1930	1940	1950	1960	1970	1981
Agriculture	56	49	48	43	30	28
Industry	21	21	25	29	37	35
Services	23	30	27	28	33	37

TABLE-8: Labor Force (1930-1981) - Proportion employed by Sectors. Source: Robinson (1979) and World Bank (1985).

These tables document for Portugal a trend towards labor force distributions similar to those found in industrial market economies. 1983 data show that the contribution of agriculture to the GDP may be as low as 2% (e.g., Belgium, United Kingdom, United States), countries in which the proportion of the labor force in the agriculture (1981) was reduced to 2-3% of the whole working population.

In the 1980s, the economic crisis, the model of development for Portugal, and the associated type of state intervention have created conditions which closely resemble those described in 1969 by Pereira de Moura, quoted in page 147. In addition, major cuts in public expenditures are incompatible with the much needed development of basic infrastructures (e.g., water and sewage disposal systems, appropriate housing) an efficient health system, and a welfare system based on social justice.

Data from the 1981 census reveal that 1,100,000 families do not have basic shower facilities, less than one third of all families live in housing connected to public sewage disposals, and only 58.2% had piped water at home. If we compare these data with 1970 figures presented by Faria (1974:256), the situation is slowly improving but the fact that 51% of the Portuguese population still lives in agglomerations of less than 1,000 inhabitants makes a global solution extremely difficult.

Despite this crisis situation, important incongruencies persist of which those of the military and the health sectors constitute excellent examples. Table-9 presents the last available distribution of central government expenditures.

## PUBLIC EXPENDITURES

GNP million US \$	<u>Military</u>		<u>Education</u>		<u>Health</u>	
	million US \$	% GNP	million US \$	% GNP	million US \$	% GNP
23,657	864	3.7	900	3.8	760	3.2

TABLE-9: PORTUGAL (1980) - Central Government Public Expenditures. Source: World Bank (1985).

The relative importance of the military sector compared to the educational and health sectors points out to the fact that Portugal has not yet been able to fully adjust to noncolonial and peacetime. In addition, the health sector persists in adopting a model (to be discussed later) that places heavy emphasis on tertiary and curative care, and which favours the satisfaction of immediate needs, resulting in heavy consumption of medical goods.

The proportion of the health budget allocated to primary prevention was 0.8% in 1970 (Campos, 1983a:12-13). Since then this proportion has been steadily decreasing, to reach a record low in 1980 - 0.2% of all health expenditures. Thus, the potential long-term benefits of prevention are largely disregarded. Similar decreases were also described for the administration, teaching and investigation sections.

#### 4.4 THE SOCIAL SECTOR

In this section I will concentrate exclusively on the welfare and health sectors. A brief note is presented here concerning education.

In 1980, the adult literacy rate was 80% (Sivard, 1983:36). The numbers for schoolage children not attending school (see page 151), which is compulsory between the ages of six and 14, should be a reason for major concern. This is in accordance with the figure on the proportion of schoolage population in school which, according to Sivard (1983:36), is 72%. Primary school enrollment is 118% (World Bank, 1984:12), a figure that reflects the current high failure rates.

The situation on the educational sector is one that closely reflects past and present social policies. The above figures clearly demonstrate the need for major improvements in basic schooling, a major factor that has been unequivocally related to health (see pages 32-33).

##### 4.4.1 Welfare

The system of social insurance developed by the corporative system was based on the principle that the state was not a welfare organization. Somewhat as in France, workers and employers would jointly finance a social security system through their respective contributions, thus leaving the state free of the burden. The system that

evolved was a corporative version of self-help, which was designed to be of slow growth. Robinson (1979:133) shows how the system created major asymmetries.

Rural workers and fishermen organizations had extremely small budgets when compared to those of industrial workers. Family allowances and sickness insurance took priority over the provision of old age pensions or payments to the victims of industrial accidents. Robinson (1979:133) summarizes the situation:

In short, the social insurance schemes of corporatism, while steadily increasing in terms of payments and numbers of people covered, increasingly lagged behind developments in other (admittedly richer) countries. Whereas the state was not a contributor it was a beneficiary since the funds of the savings banks were largely invested in state bonds.

Social welfare was a theme which Prime Minister Caetano's administration liked to stress. In May 1969, family allowances were extended, as was oldage, sickness benefits and accident insurance, to rural workers, tenants and smallholders. In 1970, social insurance provisions were extended to fishermen, and later also to newspaper vendors and domestic servants. Pension schemes for state employees covered only a few thousand people in 1968, but by 1973 all military and civil service personnel had full pension schemes; in addition, Caetano introduced the thirteen-month year for pay purposes for civil servants to give them rough parity with the private sector. More hospitals (though never



enough) were built, while attempts were made to deal with the housing shortage. During this period, according to Robinson (1979:173), "for a significantly large section of the population living standards and conditions noticeably improved."

The present system is still strongly based on its original development under the corporative system. The important progress made under the first constitutional government in post-revolutionary Portugal, has to be seen in the light of economic and social policies pursued by the six previous provisional governments. Retirement and disability pensions in the private sector were increased, as were the more generous provisions for state and local government employees. The social insurance system for farm workers, family bonus schemes and maternity provisions were improved and further tentative steps were taken toward the creation of a national health service [1]. Innovations included the introduction of a social pension, unemployment subsidies and a national minimum wage, which was progressively increased with the rise in the cost of living.

Since 1974 the welfare sector has become a major political instrument. Pre-election increases in benefits have become common and campaign promises often

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[1] In 1974, the "Secretaria de Estado da Saude" (Secretariat of State of Health), had published a technical report on the National Health Service, designed to stimulate debate on various alternatives being considered.

translated into limited deeds after election. Despite these frequent increases, the general level of benefits (particularly pensions) is far from being one that would allow its recipients a decent living would that be the only source of income.

Since its inception the Portuguese welfare system has been strongly intertwined with the health sector. For Barbosa (1974:172), it assumes the model of "social insurance" dotted with some marks of an assistance system. The same author argues strongly that a national health service is incompatible with a social welfare system, an issue to which I will return in the next section. This incompatibility largely explains important observed asymmetries (e.g., the urban-rural disjuncture, the low old age and disability pensions) which, despite major legislative efforts initiated in the 1970s, still persist.

Equally persistent are a wide variety of subsystems (e.g., for the military, post office, trains and banks personnel) which divide the Portuguese along employment lines in what concerns welfare status. This has led to frequent drawing from the resources of wealthier networks by kin and relatives not entitled to its benefits. The situation above mentioned, documented by Castanheira (1985) (see page 151), which affects the bank system, constitutes an excellent example not only of what has probably become a major fraud scheme, but also of the type of pressures of kin

on prescribing health personnel.

In general one can say that the net results of the recent legislative endeavors translate into increased coverage (currently estimated to be over 98%) associated with increased payments. Simultaneously the welfare system has been progressively transformed into a third party state controlled entity, which increasingly finances the private sector [1].

#### 4.4.2 Health

##### 4.4.2.1 The Current Health Situation

The current Portuguese health situation is progressively approaching the pattern observed in most developed industrialized nations. This pattern may be characterized by the simultaneous presence of the following trends:

1. A continuous decrease in the frequency of communicable diseases
2. A significant increase in the frequency of chronic degenerative disorders (e.g., cardiovascular diseases, tumors)
3. Marked increases in accident frequencies, particularly traffic accidents.

Table-10, bellow, documents these trends for Portugal during the 1965-1979 period.

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[1] See, for example, Campos and Mantas (1981:ii), Campos (1983a:13) and Anonymous (1983b).

CAUSE	1965	1970	1975	1979
Infective and Parasitic Diseases	4.3	2.6	2.2	1.7
Neoplasms	10.5	11.8	12.6	14.5
Diseases of the Circulatory System	31.5	35.5	40.1	43.2
Diseases of the Respiratory System	12.3	12.0	9.2	7.7
Motor Vehicle Accidents	1.3	2.1	3.4	3.2
Senility without mention of Psychosis	11.5	12.1	12.2	11.6
Symptoms and Ill-defined Conditions	3.6	3.2	3.3	3.5
Other	25.0	20.7	17.0	14.6

TABLE-10: PORTUGAL (1979) - Proportional Mortality for Selected Causes. Source: INE.

To the general pattern above described one must add characteristics which are specific of the Portuguese health situation (see Table-11, page 161), which include:

1. An inverse relationship between cerebrovascular disease and ischemic disease
2. A high frequency of gastric cancer
3. A large proportion of deaths ascribed to senility and ill-defined conditions
4. The presence of high frequencies of selected communicable diseases.

This health situation has been denominated a "transitional" one, since it includes characteristics of both developed and developing societies. Among the first, the high proportion of deaths associated with cardiovascular

ICD-8	CAUSE OF DEATH	A	B	C
A85	Cerebrovascular Disease	1	23.4	220.5
A136	Senility without mention of Psychosis	-	11.6	109.8
A83	Ischemic Heart Disease	2	8.7	81.5
A84	Other Forms of Heart Disease	3	4.9	46.4
AE138	Motor Vehicle Accidents	4	3.3	30.0
A82	Hypertensive Disease	5	3.1	29.2
A47	Malignant Neoplasm of the Stomach	6	3.0	28.5
A92	Other forms of Pneumonia	7	2.8	26.4
A102	Cirrhosis of the Liver	7	2.8	26.4
A58	Malignant Neoplasm of Other and Unspecified Sites	9	2.8	26.2
A137	Symptoms and other Ill-Defined Conditions	-	3.5	32.9
A93	Bronchitis, Emphisema and Asthma	10	2.5	23.9
<hr/> A - Rank    B - percent of each cause to all causes C - Death rates per 100,000 population.				

TABLE-11: PORTUGAL (1979) - The ten leading causes of death (both sexes). Source: INE.

disease, should be emphasized. However, the Portuguese pattern deviates from that of most industrialized countries. Cerebrovascular disease is nearly three times more frequent than ischemic heart disease, while in the Scandinavian countries, the United States of America or the United Kingdom, the situation is just the opposite. Portugal's pattern is shared by Japan where major declines in cerebrovascular disease mortality and morbidity are occurring (see

pages 86-87). There is no sound evidence that such a turn around has yet begun in Portugal.

The relative importance of mortality due to cerebrovascular disease and other cardiovascular diseases in Portugal was presented elsewhere (Calheiros, 1985) and will not be addressed further.

Gastric cancer is also an important concern. In most industrialized countries major declines have been observed in mortality due to this neoplasm. In Portugal, gastric cancer has been certified at an almost constant rate over the last decades, what is probably related both to the maintenance of relevant environmental factors and to the persistence of diagnostic fashions in certifying death.

The extremely high proportion of deaths ascribed to senility and ill-defined conditions (15%) is an indirect measure of the quality of health care available to the population. In most industrialized countries this proportion is less than 1%. Cardoso (1983:160-181) demonstrated the associations between cardiovascular mortality, the proportion of deaths classified as senility and ill-defined conditions, and regional development including the availability of health care. In addition, Calheiros (1985) demonstrated the need to take into account its importance when studying mortality or morbidity trends, and in evaluating health interventions.

Communicable diseases, despite major progresses,

particularly mortality, still represent an important problem. However, Portuguese health statistics these disorders have to be understood bearing in mind that they are notoriously affected by considerable underreporting.

In 1976, a major outbreak of diphtheria occurred in Lisbon, and in 1984 the same metropolis experienced a major measles outbreak. In addition, viral hepatitis, typhoid and paratyphoid fevers, tuberculosis, brucellosis, and several parasitic diseases, still have high rates in selected areas of Portugal (see World Health Statistics, 1983 and 1984).

Infant mortality was previously discussed (see pages 126-127). 1974 was the first year in which the national values for post-neonatal mortality were lower than those for neonatal mortality. This cutting point is usually considered an important index of national development, since it measures the level of control over the environmental causes which are predominant during the post-neonatal period. Compared to most European countries, Portugal reached this turning point 10-20 years later.

A short reference is also made here to maternal mortality which is still high by European standards. The last available value for Portugal is 30.6 per 100,000 live births (1979). For Greece the 1979 rate was 14.2, for Yugoslavia 21.8. The 1978 rate for Spain was 13.0 (World Health Organization, 1984).

Non-attended labor has been steadily declining from

43.5% in 1965 to 10.3 % in 1979, but wide regional variations still persist. These variations, also associated with regional development and the availability of health care, follow similar patterns observed for infant mortality.

#### 4.4.2.2 The Health System

The coexistence of a wide variety of sub-systems and services with antagonic philosophies may be considered the most salient characteristic of contemporary Portuguese Health System. Governmental and private nonprofit [1] and profit-making sectors have long traditions of providing care to the Portuguese. This situation, which persists after several decades and major "reforms", partially explains why the Portuguese health system has frequently been described as a sector in crisis [2].

The origins and subsequent evolution of the Portuguese welfare and health system are similar to those of most of the western world. The codification of "poor laws" in England in 1601, made permanent in 1623, established secular and legal obligations beyond the religious and moral, to help individuals in unfortunate circumstances. A tax was

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[1] In Portugal, nonprofit institutions are currently denominated as "Private Organizations of Social Solidarity."

[2] See, for example, Barbosa (1974), Campos (1983b), Coelho (1974), Ferreira (1972 and 1983) and Secretaria de Estado da Saude (1974).



levied on all households so that relief, or humane care, for young children, the aged and the sick or disabled persons could be provided at parish level.

Major controversies surrounded this "Old Poor Law". The burden of poor law expenditures and a growing moralistic philosophy, resulted in the "New Poor Law" of 1834. For example, relief for men and women disabled and incapacitated from work was attacked as "sentimentalism", and the administration of relief engendered stigma. However, from 1880 onward, there was a growth of humanitarian feeling and by 1918 the poor were accorded full rights as citizens rather than treated as inferior and incapable wards of the state (Greenwood, 1985:1241).

Other countries also progressed with public and voluntary social welfare programs. Even more acceptable to a growing business-oriented middle class, social insurance programs evolved that were based on the reforms of Prussia under Bismark in the 1880s. These welfare programs grew out of Bismark's view that the social insecurity of the worker was a real danger to the state. Compensation for industrial accidents, survivors' insurance following fatal accidents, sickness and invalidity, and old-age insurance plans marked a shift from general public assistance for those in economic need. Thus employers, trade associations and other corporate entities began bearing these costs and thereby expand the parameters of social welfare beyond governmental

responsibility alone. As the twentieth century progressed, state and national governments throughout most of the world accepted increasing responsibility for insuring the health and well-being of their populations, particularly those presumed less independent and more in need of assistance.

In recent years we have seen in various parts of the world the development of the movement of "justice in health" (Mahler, 1978), which regards health and medical care as a necessity and therefore a basic civil right. Opposition to the "right to health" takes various forms, including that which considers it neither a right nor a privilege but rather a service provided by doctors and others to people who want to purchase it (Sade, 1971). However, even in societies which have adopted the latter model we find that, along Bismark's lines, a wide variety of welfare and health services has been developed, which work as safety nets for those in economic and social need.

An intermediary type of situation is that in which we may include 1980s Portugal: the right to health is constitutionally sanctioned but its translation into practice is extremely precarious.

Barbosa (1974:170-172) made clear what is a basic characteristic of the right to health concept, that it is universal. This means that distinctions in attendance must proceed only from technical criteria.

Any distinction which is not derived from these criteria becomes an inequality completely unacceptable and, if it occurs, the right to health is either failing or is breaking its universal character (Barbosa, 1974:171).

A frequent argument associated with "the right to health" is that, since it is economically impossible to provide the "best available" care to everyone in the society, the most the right can imply is guaranteed access to some "decent minimum". In the case of Portugal we may consider that, in general and despite the persistence of marked inequalities, the provision of this minimum has been achieved. However, it should be pointed out that "decent minimum standards" are not static and so they tend to rise with society's progress.

Barbosa (1974:170-172) points out that the maintenance of social welfare services is a fact which is in itself incompatible with the notion of a Unified Health System. For this author, even when the risks are covered with an always growing enlargement, "the logic of the system itself is opposed to the generality of the right to health." Thus, it is not surprising to find that in Portugal, the designation "beneficiary" has persisted over that of "insured". According to Barbosa (1974:172) this depreciates the right to health as well as other rights that social security must ensure (Barbosa, 1974:172) therefore supporting its non-universality.

Within this historical context, nations have distinguished need in various categories (e.g., old-age, women with young children) for assistance programs (Greenwood, 1985:1242). Need has also been distinguished along economic lines: while the wealthiest population have traditionally continued to use private services, those who cannot afford these services use the traditional charity houses or what may be considered its modern equivalents - welfare.

In Portugal, the presence of a wide variety of subsystems has been already mentioned (see pages 155-159). Different types of benefits and coverage, divided along professional lines, are provided. The SMS subsystem, in which enrollment is compulsory, covers the vast majority of the population, and is the one that offers least benefits. It absorbs 28.5% of global salaries, of which the current proportion supported by employers is 20.5% while employees contribute with 8.0%. Table-12, bellow, presents 1980 type of enrollment.

It should be emphasized the existence of large duplicate enrollments not evident in table-12 due to the mode of calculation of SMS membership. The largest proportion of these cases are those who keep SMS enrollment while benefiting from any of the other subsystems.

Another type of discrimination - along place of residence - still subsists. This issue is addressed by

Subsystem	Beneficiaries	Relatives	Total	%
Social-Medical Services (SMS) [1]	-	-	7,428,293	77.8
Civil servants (ADSE) [2]	528,975	749,422	1,278,397	13.4
Military and Paramilitary Forces	131,343	290,083	421,476	4.4
Justice and other ministries	80,883	20,668	101,601	1.1
Bank personnel	51,598	140,515	190,913	2.0
Other *	40,782	80,938	121,720	1.3

\* Includes small subsystems (e. g., electricity, telephones and public transportation).

TABLE-12: PORTUGAL (1980). Covered Population by Public and Private Sub-systems and the general Social Medical Services subsystem. Source: Fonte (1981), quoted in Campos and Mantas (1981:4).

Robinson when describing the 1960-1970s urban-rural disjuncture between the northern and southern industrial areas and the rest of the Portugal:

The amenities of life, whether better wages, higher living standards, better medical facilities, greater educational opportunities, wider opportunities for social advancement, were increasingly and more obviously becoming concentrated in the two industrial areas. Change, in the rural areas, was principally associated with people living them - and the same could be said of the Adjacent Islands where the pull of emigration was also strong (Robinson, 1979:160).

[1] "Servicos Medico-Sociais" a medical component of the Portuguese Welfare System, which has a large number of clinics throughout the country. SMS enrollment was calculated by difference.

[2] "Assistencia na Doenca aos Servidores do Estado" - a "fee-for-service" subsystem based on private practice.

Marked regional variations persist, in the frequencies and types of health professionals, following closely differentials in regional development. National statistics show the concentration of health professionals in coastal urban areas, while several regions lack some of the basic elements of health care teams.

We may summarize the recent history of the Portuguese health system saying that, since the early 1970s, it has been subjected to deep and significant changes: the coverage of the population increased from 56% to 100%, the demand-utilization increased dramatically, health expenditures grew with similar or even higher growth rates. Legal support to this trend was provided by the above principle of the right to health, established in 1971 and reinforced in 1974.

Despite these efforts, the current situation is far from granting the universality of this right, suffering from the contradictions above described. In 1981, Campos and Mantas (1981:ii) characterized this recent evolution as follows:

Incapable of implementing quickly policy measures, health administration in Portugal suffers from reduced effectiveness and efficiency, due to structural inertia. As examples, the decision taken in 1971 to implement an health centers network aimed to merge the S.M.S. postes, was not yet performed; the transfer of S.M.S. dependency from the Social Security to the Health System, decided in 1974, was performed only by 1977. The inception of a National Health Service, established by a 1979 law, was revoked in 1980, allowing the coexistence, for the last two years of services structures obeying to opposed philosophies. The health system, designed to provide public goods

through public providers has been increasingly transferring funds to private providers. And getting more and more funds, even at diminishing rates by the end of the decade, the system suffers from common deficiencies on the public budget: insufficient funds in the initial budget, supplemented by additional funds later in the year, where it becomes impossible to implement programs; later budget approval; and lack of integration of budget and development plan funds. The new financing coordinative department - D.G.F.S. - is one positive sign of a new organizational era, but a global restructuration of the health system, allowing more autonomy to district and local level, is critically needed (Campos and Mantas 1981:ii).

Since this comment in 1981 the situation has not shown any signs of improvement, but rather of the contrary. In 1983, Professor Goncalves Ferreira, who was responsible for the policy changes associated with 1971 health services restructuration, expressed a particularly pessimistic point of view which has so far proven particularly accurate. In a long document (Ferreira, 1983) the author pointed out basic errors of recent administrations and suggested appropriate guidelines for change. The following is a free translation of part of Professor Ferreira's summary:

1. Through the continuing disruption of the health services structure, which was recently intensified by the destruction of the proposed national health policy, disease is being promoted and health improvements for the portuguese - starting at birth - are being delayed or rendered more difficult.

2. Disease promotion and the lack of interest in improving health will inevitably result in increased population insecurity, in obsessive concern with disease instead of health, in the withdrawal of already existent morbidity control measures, productivity decreases and increased absenteeism, as well as in

large increases in nonpriority expenses, which may result in limited benefits or eventually damage the health services.

3. The type of information need by future government representatives so that they may start to intervene constructively in the health sector, cannot depend only on the advice or opinions of political party representatives... but also requires that the advice of those with nonpolitical committed knowledge and expertise is heard.

Recent evidence, including that publicly expressed by major health authorities, suggests important deterioration of basic services such as hospital emergency departments [1]. This situation results not only from specific hospital practice conditions but also from the lack of improvements at primary health care level, which leads to much undesired ED over-utilization and population insecurity.

Over the years, SMS clinics have increasingly got involved in bureaucratic activities [2] while clinical care was reduced to a minimum. Thus, both physicians and nurses became mostly administrative personnel. Currently, daily appointments are filled with these types of situations and, in general, it is extremely difficult to obtain an appointment within two or three days. In most areas, home visits are even more difficult to arrange.

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[1] See, for example, Barao (1985), Barao and Malheiros (1986), Feio (1985), Fernandes (1985).

[2] These include the issue or renewal of sickness leave permits, prescription refills, copies of private practice prescriptions and/or diagnostic tests in SMS stationary in order to receive full benefits.



Civil servants, covered by a "fee-for-service" subsystem based on private practice (ADSE), often face another type of problem - the existence of two types of waiting list in private practice. For those covered by ADSE or similar third party payment systems, the waiting period, although quite variable, is usually longer than that for those who will pay full price.

Since over 90% of the population is covered by two systems that are not operating under minimum acceptable conditions, it is not surprising that major adaptative responses had to occur. Emergency department use, which also offers the conveniences of flexible scheduling and easy access to diagnostic tools and a wide variety of specialties, has become the last of the safety nets.

Evidence from the Hospital of Santo Antonio (1984a and 1984b) (Table-13, page 174) shows that, after a period of steady ED attendance increase, a decline has occurred during the 1980-1982 period. This decline was associated with the start of "walk-in clinics" for non-emergency situations. These clinics, affiliated with a state hospital ED, were designed to alleviate ED over-utilization and, to a large extent, contribute to solve the above described primary care problems. This decline was further accentuated in 1982 with the introduction of a utilization control fee. Since 1983 it is possible to detect a rebound in heavy ED utilization, a condition that persists in 1986. Over 800 patients per day

are observed at the Hospital of Santa Maria (Lisbon) (see Feio, 1985) while most EDs are daily flooded with non-emergency situations.

year	ED		Walk-in clinic		Total	
	1	2	1	2	1	2
1970	55,897	153	-	-	-	-
1975	152,127	416	-	-	-	-
1979	297,903	569	-	-	-	-
1980	202,434	553	47,326	129	249,760	682
1981	185,578	508	72,963	200	258,541	708
1982	134,068	367	48,847	134	182,915	501
1983	159,155	436	56,719	155	215,874	591
1984	171,566	469	49,732	136	221,298	605
<hr/>						
	1-Total		2-Daily average			

TABLE-13: Hospital Geral de Santo Antonio (Porto). Emergency Department movement. Source: HGSA (1984a and 1984b).

Following the steps of previous administrations, immediate solutions rather than long term ones are being adopted. Recent proposals, which face the opposition of selected sectors of the medical profession (Barao, 1985) include an increase in the number of EDs available in cities, particularly Lisbon, and in the number of ED subsidiary "walk-in clinics" for non-emergency situations.

This represents an implicit acceptance that primary care services are not operating in the best conditions and that no immediate solution is possible, thus rejecting the traditional belief that ED over-utilization is due to misinformation or client's convenience.

If the above proposals are adopted, access will be further increased and promoted, while the benefits of personalized, comprehensive and continuous care continue to be disregarded. This is in opposition to what has been clearly demonstrated: a prerequisite for efficient use of specialists is the existence of good primary generalists (Horder, 1977; Hart, 1981). In addition, further health services centralization, which causes patients from underserved areas to travel, sometimes long distances, to receive the care they need and are entitled to, is to be expected.

We may conclude that the situation closely resembles that described by Coelho (1974:194-195) regarding pre-1971 health care:

We may state that in Portugal the delivery of primary health care has been fragmentary, incoordinated and incomplete in nature up to 1971, both in what concerns the spectrum of services provided and the range of the covered population. But since 1971 there is legislation enabling the use of a service network adequate to this task, structured in accordance with the principles of modern health administration. As this work is not yet complete, it is absolutely necessary that the effort made for its organization proceeds, for in our times it is no more possible to admit, either on economic, political or social grounds, that populations may not have access to the whole range of health care they are entitled to receive - from health promotion to the prevention, treatment and recovery from disease.

Despite major geographical, institutional and professional asymmetries we may say that the current health crisis in Portugal is deeply rooted in societal features

- including institutional and professional characteristics - rather than on manpower, technical or financial constraints.

This statement is based on the following facts:

1. Tables-14 and 15 (page 177) clearly suggest that, with appropriate adjustments, it is possible to achieve an acceptable coverage for both urban and rural areas. Adjustments would include the return to full-time health care practice of SMS health professionals.

2. The current technical level of Portuguese health professionals and health institutions is one that allows performances well above the "decent minimum", provided that resources are used effectively and efficiently. Selected situations would require the development of appropriate refresher courses, while continuing education for all professionals should be promoted.

3. Current health expenditures, although not reaching the (undesireable) levels of most industrialized nations are enough to permit the full functioning of the health services. However, important resource allocation adjustments should be made, especially those favoring prevention and ambulatory care.

In order to find appropriate solutions for this long lasting situation, it is my opinion that two major and extremely controversial problems have to be faced in open public debate and negotiation. Both are associated, with the presence in the Portuguese society of two systems supported by antagonic philosophies - the private and the public sector - which are not allowed to compete freely.

This reality, rooted in different cultural and socioeconomic backgrounds and conceptions, is one with which the Portuguese have to learn how to live with. Similarly to what has happened over the last decade in most sectors of Portuguese economy and social organization, the efforts

Professional group	membership*	Health Institutions with beds	without beds
Physicians **	22,312	14,206	9,612
Stomatologists	605	-	-
Odontologists	441	-	-
Nurses	7,373 ***	17,101	6,308
Nurse Aids	-	669	256
Midwives	-	698	162
Social Workers	275	397	2
Administrative	-	15,030	14,090
Other	-	19,185	1,717

\* Medical Association or Union membership.

\*\* M.D.s with a specialty in stomatology are excluded.

\*\*\* Nurse aids and midwives also included.

TABLE-14: PORTUGAL (1983) - Health professionals distribution. Source: INE (1983).

Professional group	Estimated total	Rate professional /population
Physicians	22,917 *	1/453
Dentists	1,046 *	1/9656
Nurses	25,194 **	1/401
Social workers	399 **	1/25313
Administr. personel	29,120 **	1/347
Other	20,902 **	1/483

\* Based on membership.

\*\* Based on health institutions totals.

TABLE-15: PORTUGAL (1983) - Population/Health Professionals ratios. Source: INE (1983).

towards the development of a national health service failed to take into account these factors. As a consequence its implementation was strongly resisted and ultimately blocked despite its felt need being an issue on which most of the Portuguese would agree.

Professor Ferreira (1983) considers the following to be the most criticized points of 1979 law: (1) the complete gratuity of services irrespective of economic situation; (2) provisions that make medical practice almost exclusively dependent of the state; (3) the belief that state health services alone would be enough, thus minimizing the role of private competition; (4) the system of basing physicians salaries on general responsible activities rather than on specific medical acts.

1986 health policies and practices are still affected by these recent developments, which resulted in significant overreactions while opening the door to opportunism. In order to change the current chaotic situation I consider that it is the time for the health sector, especially the medical establishment, to fully accept and practice the rules of free competition for which it has lobbied so strongly. Currently, free competition in the sector is not possible due to the fact that a large number of medical professionals are active members of both sectors [1]. It is

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[1] A small number of other health professionals (e.g., nurses, rehabilitation professionals) should also be included.

impossible to deny that vested interests have to be present.

It seems inevitable that the incompatibility of public and private functions - extensive to other economic sectors of the portuguese society - has to be declared soon. This has already been the concern of government officials (Anonymous, 1983b).

A similar lack of free competition, due to compulsory enrollment in the SMS welfare subsystem, is present in what concerns health and retirement benefits in general.

In what concerns the much criticized, defrauded [1] and largely unsatisfactory welfare system, I believe that voluntary enrollment and direct central taxation would introduce major advantages.

The adoption of these measures would certainly be controversial and require extensive study and proper evaluation. It would also require the maintenance of acquired rights together with the development of appropriate measures to ensure that the needs of special groups were taken into account. In association with the above incompatibility status, the adoption of these measures would allow the government to restructure its welfare and health services, provide better care for those enrolled in the programs, while consumers would have to make participatory

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[1] Since welfare contributions are based on wages' value, employers and employees often agree in substituting wage increases by money allowances (e.g., gasoline or meals benefits), which are excluded from welfare taxation. See also page 151.

decisions regarding health, retirement or other welfare benefits instead of being passive recipients of state welfare. New health care alternatives such as health maintenance organizations or employees health services, would be left for the responsible creativity of the private health sector.

This public/private mix in funding and delivery of health services was recently studied by Navarro (1985). According to the author, countries with a "large for-profit" sector (e.g., West Germany, France, Canada, and U.S.A.) share the following characteristics:

1. Physicians have higher relative incomes
2. There is a larger expenditure on pharmaceuticals
3. There are larger administrative costs for health insurance and public agencies
4. Health coverage of the population is less extensive
5. There is a greater degree of direct payment by users of health services.

In summary, those countries in which central government plays a major role funding health services via general central taxation have been able to control the growth of health expenditures better than those where the central government has played a lesser role.

The model adopted for Portugal in the past has been one in which, despite frequent claims of the contrary, the interaction of the various socioeconomic forces involved has



resulted in limited effective state intervention. The "major reforms" of last decade have been mostly normative and largely disregarded. In addition, as already discussed (pages 159 and 169-170), the welfare system has been progressively transformed into a major third party financing institution, reflecting strong lobbying by the Portuguese Medical Association in favor of a "fee-for-service" system. All the characteristics of health services in countries with a "large for-profit" sector, described above in the work of Navarro, already present in Portugal, should be expected to become more evident if this model is further implemented.

A final note refers to the generalized belief, widely prevalent in Portugal, that health improvements are directly dependent of medical care. This belief is accurately measured by the rather small number of social workers in health care services, concentrated in the urban areas of Lisbon and Porto.

Almost one century of theory building has established clear relationships between illness and the socio-economic and political environment. If we take into account the population impact of the current economic crisis which has resulted in large sub-employment and unemployment areas, it becomes crucial to contribute for the development of this understanding in Portugal.

## CHAPTER 5

### METHODOLOGICAL APPROACHES IN A COMMUNITY CONTEXT

#### 5.1 DESCRIPTION OF THE COMMUNITY

This research was conducted in the population of the urban area of Porto, served by the Hospital Geral de Santo Antonio (HGSA), which is one of the two central (university) hospitals located in the city. Both have been assigned the care of a part of the city's population -- for whom they represent the local hospital -- as well as part of the country's northern region population, to whom they provide specialized coverage.

According to the last catchment area division, which became effective in January 16, 1984, the HGSA provides whole coverage to the districts of Braganca and Vila Real, and partial coverage to Aveiro, Viseu and Porto. Within the city of Porto it covers all administrative units called "freguesias" (see Figure-1, page 183 and Table-17, page 186) with the exception of Bonfim, Campanha, Paranhos and Ramalde (HGSA, 1984c). These four administrative divisions, assigned to the area of the Hospital de S. Joao (HSJ), are located in

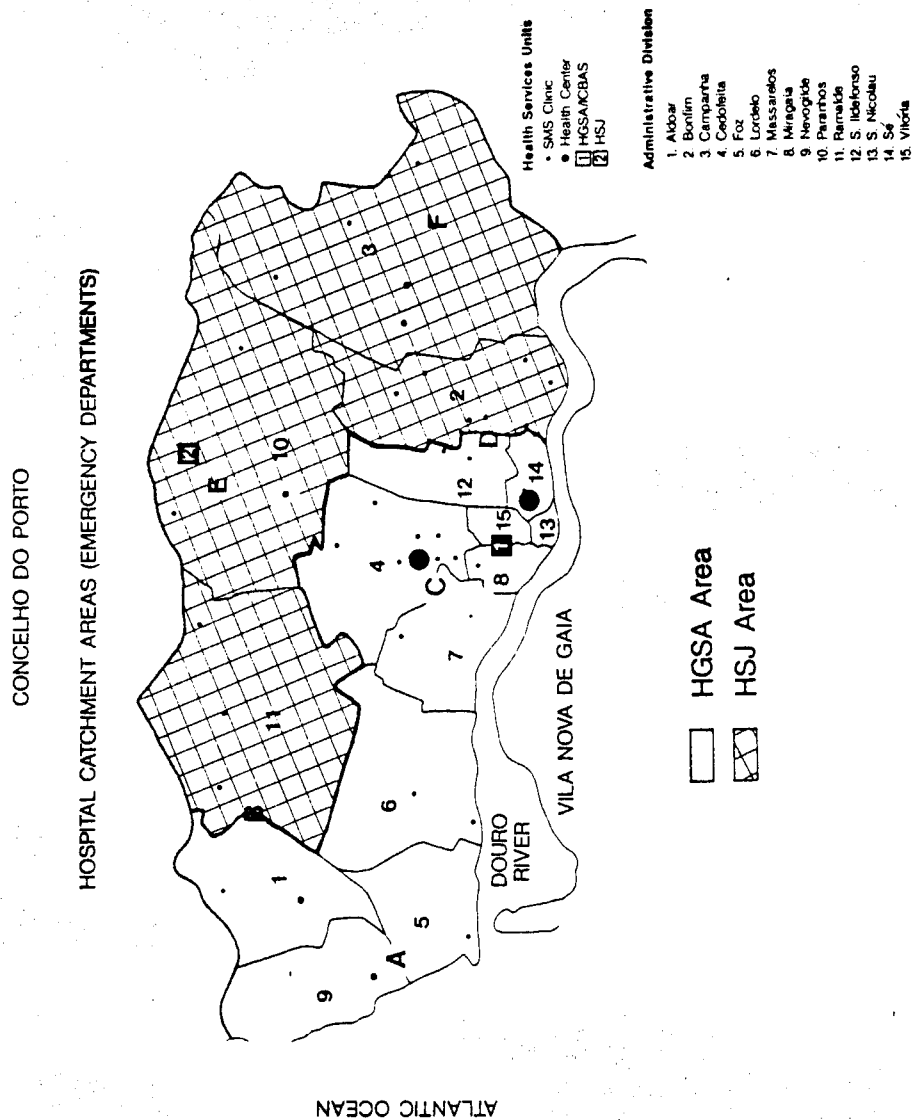


FIGURE-1

the periphery of the city and have the largest populations.

HSJ areas were not included in the present study. Aldoar, formerly from the HSJ area, was excluded since it changed from catchment area in the middle of the study period, therefore affecting health services utilization and its evaluation.

#### 5.1.1 General description of the community

Porto, also called Oporto (o porto, the port), has the distinction of having given its name to the whole country, Portugal being derived from the Roman Portus (now Porto) and Cale (Gaia) on the opposite bank of the river Douro.

Although the origins of the city remain unclear [1], it is known that the Romans had a flourishing settlement on the Douro's south bank and that the nomadic Alani tribe later founded the Castrum Novum settlement on the north bank. The Visigoths took possession circa 540 B.C. but yielded in to the Moors. In 997 the Christians recaptured Porto, which for a time became the capital of the counts of Portucalense during Moorish rule in southern Portugal. The Moors again held the city briefly, but in 1092 it was brought finally under Christian domination.

Porto, which lies chiefly on the Rio Douro's northern bank, is the nation's second city and the major commercial and industrial center of northern Portugal. Porto is also

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[1] see, for example, Machado (1968).

the capital of the district with the same name and of the "Douro Litoral" province.

According to the 1981 census, the district of Porto had a population of 1,562,287 grouped in 414,411 families of which 7.0% lived as multiple head family units. The district is constituted by 17 smaller units -- "concelhos", of which the ones of Porto and Vila Nova de Gaia are the largest with a population of 327,368 and 226,331 respectively. The city of Porto constitutes the "concelho" of the same name.

The population density of Porto is greater than that of any Portuguese city, and overcrowding is common. In the nineteenth century the city expanded outside its medieval walls mainly to north and west, along lines which radiate from its core around the cathedral, in the *Castrum Novum*.

Table-16 (page 186) presents the evolution of the population of Porto according to the available census. The impact of the late 1910s influenza epidemic and of the 1960-1970s migratory wave is evident. Since the late 1970s a new growth period has begun in association with the demographic changes already mentioned (see pages 130 to 134).

In a similar way to what has been observed in other cities, the tendency for the surrounding neighborhoods to become major residential areas is also observed in Porto. This phenomenon has become particularly intense in the last decades. Large population increases were also observed in surrounding areas such as Vila Nova de Gaia, and Matosinhos.

years	population	%	year	population	%
1864	89,349 *	-	1930	232,280	14.4
1878	110,707 *	23.9	1940	258,548	11.3
1890	146,739 *	32.5	1950	281,406	8.8
1900	167,955	14.5	1960	303,424	7.8
1911	194,009	15.5	1970	301,655	-0.6
1920	203,091	4.7	1981	327,368	8.5

\* adjusted for the present administrative area.

TABLE-16: PORTO - Census populations (1864-1981).  
Source: Oliveira (1973:340) and INE (1970 and 1984a).

Administrative Division	Census 1970	1981	% change
1.ALDOAR	11,780	12,708	+7.8
2.BONFIM	37,925	38,605	+1.8
3.CAMPANHA	45,215	49,289	+9.0
4.CEDOFEITA *	34,145	36,841	+7.9
5.FOZ *	10,095	13,266	+31.4
6.LORDELO *	17,525	22,316	+27.3
7.MASSARELOS *	10,400	10,100	-2.9
8.MIRAGAIA *	7,500	6,457	-13.9
9.NEVOGILDE *	4,120	5,674	+37.7
10.PARANHOS	47,635	52,206	+9.6
11.RAMALDE	29,805	38,257	+28.4
12.S.ILDEFONSO *	20,810	20,145	-3.2
13.S.NICOLAU *	7,175	4,840	-32.5
14.SE *	11,555	10,483	-9.3
15.VITORIA *	5,970	6,181	+3.5
TOTAL	301,655	327,368	+8.5
Study population	129,295	136,303	+5.4

\* study population

TABLE-17: PORTO - 1970 and 1981 census population and proportion change by administrative division. Source: INE.

Table-17 (page 186) presents 1970 and 1981 census data for the city of Porto and its smaller administrative divisions -- "freguesias". It is evident that the greatest increases occurred in the more peripheric areas (see figure-1) while in most of the old city areas the population has decreased, a phenomenon observed in five of the ten administrative divisions included in the present study.

The presence of large proportions of population aged 65 or more years is also a characteristic of the study area (table-18).

Administrative Division	Proportion aged			
	0-14 years (%)		65+ years (%)	
	M	F	M	F
1.ALDOAR	25.6	22.9	6.8	10.3
2.BONFIM	22.6	17.6	10.5	15.8
3.CAMPANHA	25.8	22.8	8.5	13.2
4.CEDOFEITA *	23.3	17.9	9.6	15.3
5.FOZ *	26.9	21.8	7.1	13.2
6.LORDELO *	26.1	22.0	7.7	12.5
7.MASSARELOS *	23.2	18.8	9.3	15.1
8.MIRAGAIA *	23.4	20.7	7.1	14.3
9.NEOGILDE *	25.9	20.4	8.7	12.7
10.PARANHOS	24.2	19.5	9.2	14.2
11.RAMALDE	25.3	21.0	7.8	13.0
12.S.ILDEFONSO *	21.8	15.7	11.7	18.1
13.S.NICOLAU *	24.9	22.5	8.1	15.8
14.SE *	24.5	20.9	10.1	17.9
15.VITORIA *	23.1	16.9	11.5	20.2
TOTAL	24.5	19.9	9.0	14.5
study population	24.2	19.3	9.2	15.4

\* study population

TABLE-18: PORTO (1981 census) - population distribution by age, sex and administrative division. Source: INE.

In addition, as table-19 depicts Miragaia, Vitoria, Se, and Cedofeita were found to have large nonresident populations in the 1981 census.

Administrative Division	resident	present	% difference
1.ALDOAR	12,708	12,650	-0.5
2.BONFIM	38,605	39,012	+1.1
3.CAMPANHA	49,289	48,851	-0.9
4.CEDOFEITA *	36,841	39,050	+6.0
5.FOZ *	13,266	13,118	-1.1
6.LORDELO *	22,316	22,098	-1.0
7.MASSARELOS *	10,100	10,622	+5.2
8.MIRAGAIA *	6,457	7,111	+10.1
9.NEVOGILDE *	5,674	5,577	-1.7
10.PARANHOS	52,206	55,203	+5.7
11.RAMALDE	38,257	38,728	+1.2
12.S.ILDEFONSO *	20,145	21,213	+5.3
13.S.NICOLAU *	4,840	4,854	+0.2
14.SE *	10,483	11,109	+6.0
15.VITORIA *	6,181	6,720	+8.7
TOTAL	327,368	335,916	+2.6
study population	136,303	141,472	+3.8

\*study population

TABLE-19: PORTO (1981 census) - resident and present populations. Source: INE (1981).

In the developing of the country's major industrial zones, there has been the tendency for Porto to be eclipsed by Lisbon. Both cities suffered the effects of accelerated urban growth - inadequate housing, pauperism, vagrancy, increased alcoholism, etc. The advance of Greater Lisbon is



usually considered to be reflected in the fact that since 1960 the service sector is the biggest employer of labor there, whereas in Porto, with its older industries, small enterprises and more conservatively minded business world, the industry sector has remain the biggest employer.

The city of Porto has been traditionally associated with port-wine trade with England and in the eighteenth century English merchants took over the trade from harvesting to bottling. Since then, however, several companies, while retaining their English trade names, have become locally owned. Port-wine caves are located in Vila Nova de Gaia, on the south bank of the river Douro. Other major industries include textiles, food canning, iron making, chemicals, leather, ceramics and filigree work.

Robinson (1979:17-18) describes basic Porto's characteristics and contrasts them with Lisbon:

Porto is a sad, dark town of granite and people of amusing accents. The "Portuenses" [1] have their pride and view Lisbon, 215 miles to the south and some four hours away by the fastest train, as a different world of which they do not all together approve... Despite Lisbon's current predominance the city still has the air of a major commercial center and a symbol of its past importance may be found in the extravagant pastiche of Alhambra to be found in the nineteenth-century stock exchange building. Porto gives the impression at times in its architecture and in its

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[1] "Portuenses" are also known by "tripeiros" (tripe eaters) a denomination historically associated with the conquest of Ceuta. The population of the city provided all the available meat for the enterprise and was left only with tripe which later became part of traditional dish.

social life and "mores" of still being in some ways a Victorian city... Lisbon certainly provides a contrast and seems more typical of the Mediterranean with its larger squares, broader avenues, greater spaciousness, light-coloured buildings, palm-trees and jacarandas, and livelier and noisier street life.

In the nineteenth century Porto was a liberal and even a radical city, but in the twentieth it has yielded these honors to Lisbon too, now having a reputation for conservatism and Catholicism. 1981 census data shows that 12.7% of the population of Porto aged 12 or more years did not answer the question regarding religion. 80.6% responded as Catholic, 3.6% had no religion, while all other religious groups combined accounted for 3.1% of the total population. Figures for the whole district show an even larger proportion of Catholics (87.9%).

In the present century the bishops of Porto have been among the most progressive in the country and their diocese is regarded as well organized. Nevertheless, ironically, the poorest and oldest part of this hilly conurbation lies in the area of the cathedral and episcopal palace - "o bairro da Se" (Se neighborhood).

The chronic problems of this neighborhood were well described in 1960 by two visitors, Peter Fryer and Patricia McGowan Pinheiro (1961), quoted by Robinson (1979:17-18):

... This quarter is a confusion of the narrowest alleys and steep stone steps you can discover anywhere in Portugal. These passages are filthy with the refuse of households without sewage; on either side are doors, the top halves opening inwards like stable doors, through which you glimpse tiny rooms filled with beds, stoves, cooking utensils... It is clear that whole families live in these cramped hovels. It is clear that in many there is no water supply, for now and then a woman or a child can be seen going in or out with a pitcher. Nor are there sinks. Dirty water, old cabbage leaves, potato peelings and fish bones are thrown in the gutters. Women sit on the doorsteps preparing food or sewing. Children cling about them, and skinny cats lurk against the walls or crouch apprehensively over pieces of rotting fish, ready to evade the inevitable kicks from passers-by... Children follow us about. Little, nimble, brown-skinned boys and girls in rags, dirty and thin-faced. Some of them have sores around their mouths and on their hands... This is still Europe - not a "backward", colonial country whose wretchedness the imperial-minded love to explain away. All these children, fair and dark, are children of a western nation. They creep up beside us begging for coppers, whispering and cajoling in the hoarse, sing-song voices of gutter children everywhere. Though it is the middle of the afternoon there are hordes of them, and we wonder why they are not at school.

Contrasting with wealthier areas of the city, where all modern urban life commodities can be found, the above description of the Se neighborhood remains, in the 1980s, particularly accurate. Community efforts have led to improvements in what is described by Oliveira (1985:51) as "the most visible problem" -- sewage and refuse disposal. However, the housing problem remains critical. Particularly severe winters have contributed to further deteriorate already damaged centuries old houses, which resulted in high population insecurity.

In 1984, 3,417 persons lived in a 1.66 acre ghetto area of this neighborhood (2058.4 persons/acre). Five or six persons living in a single room, inside buildings near collapse (Silva, G. 1984) is a common feature in this neighborhood. Oliveira (1985:49) criticises current approaches to the problems of the neighborhood pointing out that, following winter damages, it is not enough to restore habitability conditions:

The complex social environment of the neighborhood requires an integrated solution, fully based on appropriate social interventions.

Since 1974-1975, other parts of the historic center of the city have benefited from major general improvements. Meireles et al. (1985) analysed the integrated renovating process developed in the area of Ribeira-Barredo (S. Nicolau), which dramatically contrasts with the Se situation. In order to decrease population overcrowding and allow construction, nearly 750 families involving 3,000 persons were affected by temporary and in some cases permanent resettlement (Meireles et al., 1985:62).

Despite major financial, organizational and political constraints, this process has been able, to a large extent, to maintain the residential function of the neighborhoods within their socio-cultural context, while preserving its historical-architectural identity.

Extremely bad housing/environmental conditions are not

Administrative Division	1	2	3	4	5	6
1.ALDOAR	0.9	5.1	8.6	4.1	1.1	16.8
2.BONFIM	0.6	10.4	4.1	2.1	2.9	18.4
3.CAMPANHA	1.4	14.3	10.4	4.5	2.7	29.9
4.CEDOFEITA *	0.4	10.5	4.9	1.9	3.0	19.3
5.FOZ *	0.9	6.2	10.8	2.3	1.8	20.6
6.LORDELO *	0.8	7.0	5.6	2.5	1.2	14.0
7.MASSARELOS *	0.7	10.5	8.5	4.7	2.5	23.6
8.MIRAGAIA *	1.1	17.0	16.1	2.2	6.5	42.3
9.NEVOGILDE *	1.8	6.0	9.5	4.7	2.1	16.4
10.PARANHOS	0.4	6.0	5.7	2.2	1.1	14.2
11.RAMALDE	0.5	6.0	7.1	2.3	1.6	16.2
12.S.ILDEFONSO *	0.4	6.7	5.6	0.8	1.2	16.5
13.S.NICOLAU *	1.0	13.1	14.2	0.7	6.4	42.4
14.SE *	1.0	23.7	13.3	4.3	8.2	46.8
15.VITORIA *	0.3	9.1	9.3	0.5	5.3	32.6
City of Porto	0.7	9.5	7.3	2.6	2.5	21.1
DISTRICT TOTAL	4.0	9.8	27.8	22.7	2.5	41.0

\*study population

- 1 - No electricity
- 2 - No toilet
- 3 - Toilet without flushing system
- 4 - No home water supply
- 5 - Water in the building, but outside the home
- 6 - No bath

TABLE-20: PORTO (1981 census) - Proportion of families affected by selected housing and sanitary conditions (%). Source: INE (1981).

exclusive to the Se neighborhood. Table-20 documents the magnitude of the problem for each of the "freguesias" of Porto, and presents global data for the city and the district.

The above numbers, which refer to the proportion of affected families, become even more dramatic if the total

number of affected persons is presented. According to 1981 census data, 55,434 persons live in the district of Porto without electricity, 140,127 do not have toilet, 408,761 do not have home water supply, and 645,119 do not have bathing facilities. In the city of Porto, the lack of electricity is negligible but there are 27,271 persons without toilet, 14,270 without home water supply, and 62,255 persons do not have basic bath facilities.

We may conclude that this is a picture of a society in which poverty and severe inequalities prevail. The sanitary conditions of large proportions of the population of Porto and its district are far from reaching minimum acceptable standards, therefore requiring the urgent development of appropriate policies and interventions.

#### 5.1.2 The research institutional base

The present research was not possible without the support and understanding of the population being studied. No major difficulties were encountered during field work, which may be viewed as indicating wide interest in the research topic, as well as a direct measure of the identification of the research effort with its supporting institutions -- the Hospital Geral de Santo Antonio and the Instituto de Ciencias Biomedicas "Abel Salazar" (University of Porto).

#### 5.1.2.1 Hospital Geral de Santo Antonio

The Hospital Geral de Santo Antonio (HGSA) is a two centuries old health care institution, the construction of which was begun in 1770. Its construction reflected the increasing health care needs of the rapidly expanding eighteenth century population of Porto. The old "Hospital de D. Lopo" -- the successor of the "Albergaria-hospital Rocamor" -- was becoming rapidly insufficient (Oliveira, 1973:271-273).

Currently, the HGSA is a 904 bed facility, which include those beds located at the "Hospital Rodrigues Semide" (approximately 5 miles north). A "burn unit" and the orthopedic, plastic surgery, and rehabilitation departments are located in this institution (220 total beds, of which 30 are rehabilitation beds).

What is usually referred as the HGSA is a facility located in downtown Porto, opposite to the Instituto de Ciencias Biomedicas "Abel Salazar" (ICBAS), in the center of a vast commercial and residential area. The last available HGSA report (1984b) provides valuable information regarding the facility, its services and activities during 1984. All major medical specialties and subspecialties are available, and most have their own wards. Thus, departments such as medicine and surgery are fragmented (e.g., cardiology, endocrinology, plastic surgery).

In 1984 a total of 18,737 patients were admitted. The

average length of stay was 12.9 days, ranging from 4.0 in gynecology to 63.8 days in rehabilitation. For the two medicine departments (126 beds) this average was 24.5 days (Medicina-1) and 22.6 (Medicina-2), while for Neurology (24 beds) it was 21.4 days.

62.7% of the total admissions were processed through the ED, where 171,566 patients were observed during the same year. In addition, 49,732 patients were observed at the near by "walk-in clinic", thus making an average daily total of 604.5 patients (see also pages 172-175).

Most of the departments have outpatient clinics which are designed to provide follow-up to previously admitted patients, as well as outpatient specialized care, following referral procedures.

In 1984, a total of 239,636 observations were performed by these clinics, including 22,573 and 21,578 which were ward and ED referrals, respectively. 21.4% of all outpatient observations were performed by ophtalmology (51,227) what reflects not only the difficulties of obtaining specialized nonhospital ophtalmological care, but also the current prestige and technical development of the department.

Table-21, below, depicts the origins of the patients observed by the various HGSA sectors. It is evident that the above mentioned catchment areas are not fully respected. 7.7% of the total ED cases are patients who live in the city of Porto, and that belong to the HSJ area. In addition,



patients from other areas such as the district of Braga, and other "concelhos" of Porto (e.g., Povoia, Matosinhos), which belong exclusively to the HSJ, regularly use various HGSA departments.

The ED, where hospital area rules are usually more strictly enforced, seems to be least affected. If such a situation occurs, particularly when admission is required, the patient is likely to be transferred to the assigned hospital, as soon as that is technically possible. HSJ and other hospitals in the northern region act similarly, thus a patient may end up being observed at more than one health facility.

Nearly 70% of the HGSA ED patients come from its urban catchment area. Aldoar, which was excluded from the present

<u>Origin</u>	<u>Department</u>		
	Admitted to a ward	Outpatient clinic	ED
<b>I-DISTRICT OF PORTO</b>			
1.City Porto			
HGSA *	31.7	31.6	69.9
HSJ	8.3	11.8	7.7
2.Other	27.8	34.8	13.4
<b>II-OTHER DISTRICTS</b>			
1.Aveiro	14.0	9.2	4.2
2.Braga	2.3	2.3	0.5
3.Braganca	3.4	2.1	0.7
4.Vila Real	6.8	4.2	1.5
5.Viseu	4.3	3.1	1.2
6.All other	1.4	0.9	0.9

\* includes ALDOAR

TABLE-21: HGSA (1984) - patient distribution (%) per place of residence and department. Source: HGSA (1984b).

study, represents 2.5% of all 1984 ED observations, and 1.2% and 1.5% of those patients admitted to a ward or using the outpatient clinics, respectively.

Discharge planning is usually left to be arranged by the attending physicians and the family, the latter being responsible for organizing all details of discharge when it will occur to a private institution. Other health institutions may be contacted when transfer is required (e.g., to local area hospitals) and, in general, an agreement is previously obtained. A summary of the clinical records and copies of relevant diagnostic procedures is usually sent. In general, family physicians are only sent a summary which includes reference to the diagnostic procedures performed.

It should be emphasized that these arrangements are extremely variable, depending most of the times on individual initiatives and case characteristics.

In September 1984, the HGSA started operating its Social Service. The department includes six members (three more are planned) and is currently participating in the activities of the following departments: intensive care, neuro-surgery, medicine-2, and hemodialysis wards, and family planning. Current activities include the development of appropriate networks between the hospital, its social services, and community agencies, especially with those that will provided social support after discharge. In addition,

specific programs are being developed with the medical sectors with whom it has been possible to establish cooperation (e.g., alcoholism and family planning projects in cooperation with Medicina-2 and Gynecology, respectively).

Prior to 1984, only the department of hematology included social workers in its staff. All problems of "social nature" in other sectors of the HGSA (e.g., discharge of a patient without relatives) were solved on an individual basis by a nonprofessional social worker, who was frequently powerless to find appropriate solutions within the limited community resources available.

Official statistics for the total number of social workers in Portuguese health services, which were presented in tables 14 and 15 (page 177), show the present minimal importance of this sector and its concentration in the two major cities.

Since 1978 a group of voluntary personnel has developed a unique experience in what concerns health care in Portugal. This group founded the "Liga de Amigos do Hospital de Santo Antonio" (LAHSA) -- The Friends of the HGSA -- which has been extremely active in promoting community activities to draw public, central government and local representatives attention to what according to the LAHSA's president is "the most neglected Portuguese community -- the sick" (see Anonymous, 1984c). In addition to these activities designed to increase public awareness, the LAHSA

provides in hospital social support and organizes social activities. It also publishes the magazine "Comunidade e Saude".

Public participation in hospital decisions affecting the community has been in the law since 1977. However, this participation has not yet become effective, still waiting government regulation (Anonymous, 1984d).

#### 5.1.2.2 Instituto de Ciencias Biomedicas "Abel Salazar"

The Instituto de Ciencias Biomedicas "Abel Salazar" (ICBAS) was created in 1975 and together with the HGSA constitutes a new medical school. Its first class graduated in 1982. The school has an innovative curriculum for Portugal, placing major emphasis on community health and primary health care, and on integrated community teaching, research, and service activities. The two institutions have developed strong relationships at various levels, including joint programs.

Although the current Portuguese health and professional realities frequently make it difficult to teach along the above lines, it is generally accepted that most of the new graduates have developed an acceptable understanding of other than hospital health care problems. Traditional Portuguese medical schools curricula do not include such an emphasis.

The Department of Community Health has introduced in its curriculum the teaching of epidemiology and associated basic social sciences concepts to third year medical students. The development of a community project -- usually a relevant community health issue -- to be developed in association with local health services, is also a major curriculum component. Field research for this project, which will be discussed later, was organized along these lines.

In addition to these student group projects, the department has been involved, in cooperation with other ICBAS departments and local health services, in a wide variety of projects, mostly focusing on community health needs assessment.

Future department activities are expected to maintain the above format, and strengthen the relationships between academia, the local health services, and the community.

## 5.2 METHODOLOGY FOR APPROACHING THE COMMUNITY

This research has two major components. The first provides the epidemiological picture of stroke in Porto's study population, and analyzes associated patterns of acute care. This component is exclusively based on emergency department (ED) and other HGSA available records. It involved clinical identification, case ascertainment, and record linkage procedures.

The second part, is a community assessment based on

case identification provided by the first component. It includes follow-up and evaluation of stroke survivors, in-depth household interviews, and evaluation of family coping abilities.

No sampling procedures were performed. All study population cases identified by the processes described in the next sections, were included.

### 5.2.1 Hospital records and case identification

#### 5.2.1.1 Hospital records

In order to fully examine the HGSA clinical records written permission to the Hospital and Clinical Directors was requested. Although I have been a member of the HGSA medical staff since 1976, and as such entitled to request and study any clinical records, I consider that the scope of the problems being studied and the research objectives should be clearly presented and discussed with the appropriate authorities. The support and understanding granted are gratefully acknowledged.

Written consent was sent by the above HGSA authorities to the head of the "Servico de Doentes" -- patients service -- who instructed his personnel to provide all needed support. The first step was to further understand the current HGSA recording keeping processes beyond general knowledge acquired as a practicing hospital physician. I was instructed in this process by all the members of the sector,

who patiently answered my multiple questions.

It is striking that currently, despite the volume of patients and clinical acts performed, the HGSA does not have computerized patient data processing. All patient records rely on traditional filing and book keeping, and the available computerized system is predominantly used for personnel and accounting purposes.

When a patient enters the ED a simple clinical record process is initiated. An identification bulletin (known in the local medical jargon by the "BI") is issued. This document, to which I will also here refer as the BI, includes ED case number, date, time at entrance and at discharge, patient identification, physicians' observations and prescriptions, as well as discharge information.

Discharge from ED may have several alternatives, each one associated with different administrative procedures:

(1) the patient is not admitted to a ward (ED or hospital ward) -- No further records are initiated; physician notes on the BI may mention discharge either home or to personal physician. The BI is usually returned to the administrative personnel, located at the main entrance, by the patient or relatives when leaving the ED.

(2) the patient is admitted -- A new and more elaborated clinical record process is initiated what in local medical jargon is known as "abrir tabela" ("to issue a form"). Discharge notes on the BI refer to which of the ED

or hospital wards the patient has been admitted. Administrative personnel keep the BI and issue an individual clinical file which contains appropriate sectors for detailed clinical history, probable diagnosis, and further observations. All diagnostic tests and procedures will be later appended. Physicians may request previous HGSA clinical records. However, this is only possible if the patient had previously been admitted to a HGSA ward or used a out-patient clinic.

(3) the patient is not formally admitted, but remains under observation -- procedure-2 (above) is not initiated. The patient waits clinical decisions in a non-intensive care ED ward, to which I will refer as "OBS" (observation), which the local medical jargon calls the "sala das macas" -- the stretcher room. Clinical decisions will be followed by one of the above procedures.

ED observations are later assembled in daily books -- each page is the numbered individual BI issued at the entrance, which now has the written clinical records. The BIs of admitted patients, from which all relevant information was transferred in procedure-2, are also included. Occasionally referral letters and results of diagnostic tests are appended.

Clinical records initiated through admission -- similar for ED and non-ED ("normal") admissions -- have the traditional clinical format. The first page, is usually the



"tabela", and includes a section stating diagnosis and patient's situation at discharge, as well as a partial record of patient expenses. This part, which has a different color, is filed separately by day of discharge, and may later be used for billing and similar administrative purposes. All other components of the individual clinical record are filed in the main archives, and may be used or requested in future clinical observations. Several departments (e.g., Medicine, Neurology) keep their own admission and discharge records. A copy of these discharge bulletins is usually appended to the individual clinical file and may also be sent to the family physician, as the patient's record summary.

Two general card files are also available -- one for the outpatient clinic's patients and another for all patients who had been admitted. Each admission is one card, and the cards of patients currently in the wards are kept separately. These cards have only basic information -- identification and the individual clinical record numbers. The department of neurology has also similar files for different patient groups.

A major problem encountered results from the fact that, unless admission occurs, ED patients do not have an individual clinical file. The only record available for non-admission situations are the daily books, and so it is possible for a patient to have more than one observation in

the same day or consecutive days and be considered as different patients. Only through accurate date and hour recall is possible to track these observations on the ED daily books. Occasionally these patients may have been referred to an out-patient clinic or previously admitted to a ward, and so the card files may provide additional information.

A second problem results from the well known fact that medical records are usually incomplete. Individual clinical records were missing in 9 cases (4.5%) in this study, and a very small proportion had extremely incomplete notes. Frequently, this was the case of the BIs of admitted patients which had only probable diagnosis and instructions to open the individual clinical file.

#### 5.2.1.2 Case identification

Step-1 - In order to select all stroke cases (see definition, pages 4 and 5) observed at the HGSA's ED during the one year study period (October 1, 1983 - September 30, 1984) I reviewed carefully all ED records (174,215 BIs). For those patients who lived in the HGSA urban area (described in pages 182-184) the following situations were selected:

1. Cases in which the diagnosis of stroke was unequivocal
2. Those situations in which stroke was mentioned but there was not enough evidence that it had occurred during the study period
3. Those situations in which stroke was likely but BI information was incomplete.

These BIs were then photocopied and sorted by alphabetic order.

In order to maximize ED information and better understand individual patient care patterns, I requested additional photocopying of those situations that could in any way be constructed as CVD. In addition, severe hypertension, cardiac dysrhythmias, diabetes, and TIAs, as well as patients classified as "social cases or social situations" were also included in the initial register. These BIs were also sorted by alphabetical order and checked against the above.

I expected that these "basic linkage procedures" would provide additional information, otherwise impossible to obtain.

Step-2 - Consisted of tracking all other HGSA information on patients selected by step-1. Such information included other observations frequently mentioned in the BI, such as -- "The patient refers:" (1) "I was at the ED two days ago;" (2) "I was admitted to a medicine ward in July;" or eventually, "I am enrolled in the Neurology outpatient clinic."

Step-3 - All available clinical records were scrutinized for case ascertainment, using the stroke definition already mentioned and following the procedures of the clinical algorithm formulated by the advisory committee of The National Survey on Stroke (Weinfeld, 1981). All

situations in which clinical doubts subsisted were evaluated by a neurologist who studied clinical records and diagnostic tests, particularly CT scans, available from its department files.

Step-4 - The above information was transferred to pre-coded forms -- involving 106 variables -- adapted from the hospital abstract forms also used in the mentioned stroke survey (Weinfeld, 1981:I-38-I-44). A total of 127 males and 144 females was selected. Reasons for case exclusion and its implications will be discussed later in this dissertation.

#### 5.2.2 Household Interviews

The next step in the process was to develop a detailed household interview to assess the social consequences of stroke. This component was only administered to families of stroke survivors, or families of patients with incomplete information. Patients who died in hospital were excluded, as well as those for whom discharge was requested by the family and there was enough evidence suggesting that the patient was terminal ill [1].

A total of 208 possible contacts (104 males and 104 females) was selected this way (see table-22, page 209),

[1] Families often request the attending physician not to issue the death certificate so that the patient may be discharged as moribund. This practice is associated with traditional preference for death to occur at home within the family, but also represents a way of avoiding the complex and expensive bureaucratic arrangements required for transport and burial at distant places.

representing 76.8% of all cases selected in step-1 (24.7% hospital mortality).

Type of discharge	Males	Females	Total
Refused to be admitted	1	1	2
Home	96	92	188
Private hospital	3	1	4
General hospital	2	2	4
Nursing home	-	3	3
Family requested	2	5	7
Total	104	104	208

TABLE-22: Household contacts by type of discharge.

As I have pointed out, no sampling procedures were performed. All possible interviews were attempted, with the exception of the following situations, which represent 5.3% of total possible contacts:

	Males	Females	Total
Subarachnoid hemorrhage	2	3	5
Incomplete address	1	1	2
Transferred to HSJ	-	1	1
distant general hospital	1	1	2
still in hospital	-	1	1
Total	4	7	11

TABLE-23: Reasons for interview exclusion.

SAH cases were excluded because, although within the study stroke definition, management and associated problems are completely different. Incomplete addresses were those which were located in a long road or street and had a

missing door number, what would make virtually impossible any attempt to locate them. Another patient, although using a valid HGSA address, was latter sent to HSJ and the address corrected. The final number of contacts was 197.

Field research for this study was conducted by me and a group of eleven third year medical students. Under my direct supervision this study and its subsequent report (Oliva et al., 1985) fulfilled the requirements of the discipline of Community Health, and provided an excellent opportunity of putting into practice basic curriculum objectives.

Details of the organization of work between students and me, and of the general and specific study objectives were extensively discussed in several meetings. Previously outlined research methodology for this dissertation was presented and discussed with the group. Before approving the final version of the community research instruments, several tentative ones were elaborated and extensively debated by all members of the group.

Since the very beginning the students were fully aware that I would provide my best supervision to their own project while at the same time they would cooperate in the data collecting process of this dissertation. For the purposes of field work assignments, I considered myself the twelfth member of the group, and therefore I performed the same number of interviews as did the students.

The questionnaire [1] contained the following components:

Section-1 - provides a summary of the hospital abstract form, identifies the patient and presents relevant clinical characteristics.

Section-2 - includes data on the interviewer and the interview, as well as basic identification of the household interviewees.

Section-3 - contains several of Kleinman's explanatory model questions (Kleinman 1980:106), and ascertains date of onset, duration of symptoms, previous episodes, and patient situation at the time of the interview.

Section-4 - includes a simple disability assessment (global and specific disabilities), which evaluates reported disabilities prior to the study episode, at maximum level of impairment, and at the time of interview. Also included are questions regarding previous knowledge of risk factors, associated control measures, and current therapy.

Section-5 - focuses on type of health and social security coverage, on general family health services utilization and patterns associated with the CVD episode being studied.

Section-6 - includes questions regarding the presence or not of a chief carer, and family adaptation processes involved. Carer responsibilities and major problems encountered are also studied.

Section-7 - evaluates, when applicable, other than HGSA institutionalization.

Section-8 - includes information on the use of community resources such as personal physician, nursing, occupational, vocational and rehabilitative services, home help, and community agencies. Also the use of devices and aids is recorded.

Section-9 - refers to the use of various hospital resources for patients who had been admitted.

Section-10 - includes patient characteristics, such as marital status, housing conditions, occupational activities. Characteristics at the time of interview were compared with those existent prior to the study episode. In addition,

[1] A copy is available from the author.

detailed socio-demographic information was collected on household, other supportative kin, and chief carer(s).

Section-11 - this section evaluates family and case participation in community activities, and assesses support received from those community organizations.

Section-12 - assesses family coping abilities along the nine domains described in page 66.

Section-13 - provides additional space for interviewee(s) comments or suggestions and interviewer field notes.

In addition to extensive discussion of the research objectives and the interview schedule, training of the interviewers and quality control involved several other procedures. A 10% random sample of the 197 final possible contacts was selected. Each two students identified those located in parts of the city that they knew well. Relevant information I had previously gathered from the HGSA records was provided to the interviewers. Each group then visited with me those patients and their families, where they were exposed to contact and consent procedures, and participated, at least, in one complete interview. Once this was achieved no further pilot interviews were performed.

A letter on ICBAS stationery which explained, in a simple way, the stroke problem in Portugal, the objectives of the study, and assured confidentiality, had been previously sent. First contact was made directly to the patient's ED address, and telephone contacts were only used to set further appointments. Contacts were attempted on at least two different days and times.



The pilot study provided appropriate interviewer training as well as a general understanding of the major problems to be expected and adjustments to be made. These aspects were discussed in a meeting during which all pilot field work experiences were shared and analyzed.

A total of 14 contacts was attempted in the pilot phase. Seven complete interviews were performed, 2 persons were not located and were not known by local residents, 2 other had died, 2 patients did not recognize having had a stroke, and another patient who, according to a local resident, used a relative's address of a house under construction, lived in a rural area and it was not possible to contact her.

Complete interviews proved to be approximately two hours long. The potential inconveniences were balanced against eliminating certain sections and it was decided to leave it unchanged. In what concerns the interview schedule, only two minor adjustments were required. One refers to the unforeseen possibility that relatives would take turns in caring for a patient. Thus, the possibility of a rotating household structure of care was considered in the final version. The other adjustment referred to the scale used in various social support measurements. Often we encountered the non-quantifiable answer "when needed" which later was also included in the interview schedule.

The final version of the interview schedule was 15 page

long and was ultimately coded into 335 variables. It included a section with open ended questions, while all other sections were precoded. In what regards section-12, each student was provided with a Portuguese version of the operations manual (Christensen, 1983), clarifying and differentiating the various domains.

Since the protocol used in the pilot study did not required any major changes, and it provided an evaluation similar to that of the final version, pilot study cases are included in the final results.

Another important conclusion provided by the testing period was the inefficacy of sending the above mentioned letter. In most cases the letter had been received but not read; in a few cases it seemed to have made the persons less willing to participate; and in the numerous situations in which we had to contact neighbors it was of no use at all. It was decided that it was better to hand it out at the beginning of the contacts, and that interviewers would mention that the letter identified who we were and what we were doing, assured the confidentiality of information, and provided instructions on how to contact the research team should any further information be required. This strategy proved appropriate. Willingness to participate was systematically granted upon appropriate explanations. In a large proportion of complete interviews we were invited in the house. Consent practices in Portugal, usually do not

require written format. Consent is granted or not during the negotiation process between the involved parties, which requires appropriate skills and strategies. Of the 197 contacts made only 5 (2.5%) refused to participate.

The interviewers were free to decide if they would prefer to perform the interviews individually or maintain the initial pairs. Some of those assigned to supposedly less safe areas of the city preferred the latter.

A total of 98 complete interviews was obtained (49.7% of all total attempted contacts). It includes 7 interviews with relatives of patients who had already died. Interviewers had been previously instructed that if this situation did occur it was left to their decision whether or not to proceed, according to the willingness of the interviewee(s) in cooperating.

All interviews were reviewed by me and the interviewer(s) in the next few days (often on the same day).

### 5.3 DATA PROCESSING AND STATISTICAL PROCEDURES

The data were prepared for computer entry in the following ways:

1. Individual hospital based information was transferred to a precoded hospital abstract form, adapted from the one used by the National Survey of Stroke (Robins and Weinfeld, 1981:I-9 and Addendum B:I-38 to I-44).
2. Information regarding household interviews was transferred to appropriate coded forms. Previously, a code book, which reflected already established

categories from the interview schedule, had been developed.

Data prepared this way was initially entered using an "IBM-PC" system, and "Wordstar" software in non-document mode, both available at the University of Connecticut Health Center Library (Farmington). The complete data set was later transferred to the UCONN IBM VAX computer (Storrs), and analyzed using the Statistical Analysis System (SAS).

In addition to regression and multiple regression, the following statistical procedures were the ones predominantly used in the present study:

1. Analysis of Covariance - "The analysis of covariance is used most often by researchers to compare group means on a dependent variable, after these group means have been adjusted for differences between the groups on some relevant covariate (concomitant) variable... Thus, for example, a one-way analysis of covariance is similar to a one-way ANOVA, the main difference being that the former includes a covariate variable while the latter does not" (Huck et al., 1974:134 and 136). This technique is particularly relevant in this study because a large number of the variables are categorical.

2. Stepwise Multiple Regression - studies the relationship between several continuous independent variables and a single continuous variable. The backward elimination procedure, which starts with the complete regression model and attempts to eliminate one independent variable at a time, was selected.

Case data and other qualitative information are reviewed both in relation to developing the descriptive analysis and also as contextual information for the statistical data. These data are incorporated throughout the text.

#### 5.4 RESEARCH SCHEDULE

Table-24 depicts the time-line of the work of the cerebrovascular study, which included the following phases:

---

1984

March-April

Research proposal development.

May

Dissertation proposal approved by the graduate school.

October

HGSA based data collection initiated.

1985

January-February

Development of household interview;

Recruitment and training of interviewers (ICBAS 3d year medical students);

HGSA data collection completed and transferred to precoded hospital abstract forms.

March

Community survey (case follow-up and household interviews);

Review of all cases interviewed.

April

Preliminary analysis and student support regarding the Community Health students project.

May-July

Coded interviews.

August-September

Data entered into UCONN computer.

October

Statistical analysis and writing up research results, initiated.

1986

April

Conclusion of the dissertation.

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TABLE-24: Research time-line

## CHAPTER 6

### CEREBROVASCULAR DISEASE IN THE COMMUNITY: DISTRIBUTION AND PATTERNS OF ACUTE CARE

Clearly stroke disease presents the medical profession with a wide range of problems, arguably a wider range than any other disease. The challenges are not restricted to the individual physician managing the individual patient. Many other professions are closely involved in caring for and helping stroke patients. In addition, stroke is such a common disease and causes so much long-term disability that it must be the concern of society to ensure that the resources devoted to this disease are well used. A stroke may afflict anyone and it is in the interest of everyone in the community to ensure that the health system which copes with this illness does so satisfactorily. A good system would be one based upon scientific evidence as far as possible, and not solely upon personal experience. The second characteristic of a good service is that it should be based upon a system which ensures that standards of care are maintained, because any system relying upon the performance of particular individuals is likely to fail from time to time (Wade et al., 1985:ix).

Stroke is the most common serious neurologic problem in the world. In Portugal as in Japan, parts of China and many developing countries it kills more people than any other disease. In North America and most European countries, despite declining incidence, it remains the third commonest cause of death. The National Survey of Stroke (NSS) in the

United States estimated that every year there are 414,000 new victims. Similarly the survey estimated prevalence which is believed to be approximately 1.7 million (Baum and Robins, 1981:I-62-67). Direct and indirect costs for 1976 exceed 7 billion dollars, to which we must add immeasurable human costs (Adelman, 1981:I-71-72).

It is known that hypertension is the leading risk factor, and also the most treatable risk factor for all types of stroke. It predisposes to intracerebral hemorrhage and accelerates and complicates atherosclerosis. Ischemic heart disease, which may result from atherosclerosis and hypertension, is an index as well as a risk factor for stroke (Hachinski and Norris, 1985:1).

Although it remains a controversial issue, mortality declines over the last decades in some industrialized countries have been associated with better diagnosis and treatment of hypertensive disease. A significant decline in deaths due to rheumatic heart disease (associated with mitral stenosis and atrial fibrillation), has also been observed, and may be responsible for decreased cerebral embolism.

In Portugal, declines in CVD mortality and morbidity have not yet been observed. As reported elsewhere (Calheiros, 1985), in 1979 Portugal had the highest standardized mortality rates for men aged 40 or more years, when compared with 25 European countries, Japan, the United

MALES		FEMALES	
PORTUGAL	601	BULGARIA	447
BULGARIA	502	PORTUGAL	446
JAPAN	451	CZECHOSLOVAKIA *	342
CZECHOSLOVAKIA *	430	ROMANIA	328
HUNGARY	386	JAPAN	307
ROMANIA	350	HUNGARY	298
NORTHERN IRELAND	339	NORTHERN IRELAND	291
AUSTRIA	320	SCOTLAND	269
SCOTLAND	312	GREECE	259
SPAIN	296	SPAIN	246
GERMANY, Rep. Fed.	279	AUSTRIA	246
ITALY	271	ISRAEL	235
IRELAND	269	GERMANY, Fed. Rep.	216
FINLAND	263	YUGOSLAVIA	215
GREECE	256	ENGLAND and WALES	205
YUGOSLAVIA	245	ITALY	203
BELGIUM	243	FINLAND	202
ENGLAND and WALES	235	BELGIUM	200
ISRAEL	225	NORWAY	181
FRANCE	223	FRANCE	154
NORWAY	205	IRELAND	148
SWITZERLAND	191	NETHERLANDS	146
NETHERLANDS	176	SWITZERLAND	146
SWEDEN	166	ICELAND	144
POLAND	162	POLAND	137
DENMARK	161	SWEDEN	137
USA	159	DENMARK	128
ICELAND	148	USA	132

\* 1975

TABLE-25: Cerebrovascular Disease (1978). Age-Adjusted Mortality Rates per 100,000 population (40-85+ year age group). Source: WHO statistics.

States, and Israel. Only Bulgaria had higher rates for females (Table-25).

The Portuguese situation is further complicated by the presence of large proportions of deaths ascribed to senility (see Table-26, below). It is believed that CVD rates for Portugal are even higher than those presented, and that improvements in diagnostic accuracy will be translated into



MALES		FEMALES	
PORTUGAL	368	PORTUGAL	293
POLAND	134	POLAND	114
BULGARIA	92	BULGARIA	93
JAPAN	71	GREECE	78
GREECE	63	JAPAN	74
YUGOSLAVIA	62	YUGOSLAVIA	60
ITALY	44	SPAIN	46
SPAIN	42	ITALY	40
BELGIUM	39	BELGIUM	39
AUSTRIA	28	AUSTRIA	25
FRANCE	22	FRANCE	23
CZECHOSLOVAKIA *	21	CZECHOSLOVAKIA *	21
IRELAND	19	GERMANY, Fed. Rep.	18
GERMANY, Fed. Rep.	17	IRELAND	12
NORWAY	13	ISRAEL	12
NETHERLANDS	12	NETHERLANDS	11
SWITZERLAND	7	NORWAY	11
ISRAEL	7	SWITZERLAND	7
ENGLAND and WALES	3	ENGLAND and WALES	5
NORTHERN IRELAND	3	SWEDEN	3
SWEDEN	3	DENMARK	3
DENMARK	2	FINLAND	2
FINLAND	2	NORTHERN IRELAND	1
HUNGARY	1	SCOTLAND	1
SCOTLAND	1	HUNGARY	1
USA	1	USA	1
ICELAND	1	ICELAND	1
ROMANIA	0	ROMANIA	0

\* 1975

TABLE-26: Senility without mention of psychosis (1978). Age-Adjusted Mortality Rates per 100,000 population (40-85+ year age group). Source: WHO statistics.

increased CVD rates. Transfer from senility, a problem also reported for Ireland by Radic and associates (1977), has occurred extensively over the last decades (Calheiros, 1985).

In the early 1970s, WHO developed a series of actions aimed to prevent stroke by controlling the underlying

conditions, particularly hypertension and atherosclerosis, and to promote better care for its victims. In 1971, a number of pilot programs in countries differing in social and economic structure and health services were established. Hatano (1976), presents the major objectives of these stroke control programs:

- (1) to collect complete and accurate data on mortality and morbidity from stroke in the community;
- (2) to assess existing facilities for care and rehabilitation and their use;
- (3) to disseminate knowledge on the prevention of stroke and the rehabilitation of stroke patients; and,
- (4) to promote the use of preventive methods and make the most efficient use of existing facilities.

Stroke registers were instituted to serve as indicators of the effectiveness of the action taken. Uniform data collection techniques were followed by the 17 centers involved, both in developing and developed countries. Aho et al.(1980:113) describe the purposes of these community-based stroke registers which collected data on:

- (1) the magnitude of the problem of stroke in the community;
- (2) the social and clinic profile of stroke patients;
- (3) the preventive measures, diagnostic procedures, and rehabilitation applied to the patient; and
- (4) the natural history of stroke.

Portugal did not participate in this WHO collaborative

study. As a consequence, most of the program questions remain unanswered in the Portuguese population.

The present study carried out in a large urban area meets some of the original WHO program requirements and objectives (i.e., a population of 100,000 or more and at least 100 new stroke patients per year) to assess existing facilities. However, it should be emphasized that the desired completeness of the stroke picture is affected by several constraints.

First, it was out of the scope of the present research to ensure the much needed cooperation of local physicians whose cooperation in activities that involve reporting to a coordinating body has traditionally been very limited (i.e., communicable disease notifications). In addition, the number of physicians needed to be involved would probably be the major constraint. In 1983, 2,997 physicians were practicing in the city of Porto, with a total for the whole district of 4,964. As previously noted, these professionals interact with different subsystems of the complex Portuguese health system, relying on the use of emergency services when diagnostic procedures or specialty observations are required.

In 1982, the HGSA acquired computerized tomography (CT) facilities, a technique that currently has a major role in the study of these patients. In November 1983, the service became routinely available to ED patients. Since then, the

hospital plays a special role in meeting the diagnostic needs of stroke patients in Porto. Patients observed at other hospitals (e.g., HSJ, Military Hospital), or by private physicians are frequently sent to the emergency department of the HGSA to have a CT performed (7.4% of the cases in this study were referred by another physician).

Prior to 1982, in the city of Porto, only a small private hospital had these facilities. CT was not performed routinely for stroke patients and was not available on an emergency basis. A new private CT facility has started operating in 1985, and the HSJ is soon expected to have its own.

Several neurologists and internists involved in private practice in Porto, with whom I discussed this issue, referred to the extensive use of HGSA's CT facilities during the study period, noting its availability and easy access. It is likely that during this period the HGSA's emergency department was also used by patients that would have otherwise been taken care of exclusively in the community. More comprehensive case identification may have resulted.

Due to time and resource constraints it was not possible to study two other potential sources of additional cases. The first one was the study of death certificates which, according to WHO stroke register criteria, should only have been included, even if confirmed by autopsy, if death was preceded by a clinical stroke within the study

definition (Aho et al., 1980:115).

The second component was the study of stroke occurring in the hospital. In order to include these cases, an additional study of nearly 19,000 individual hospital files should also have been performed.

The results presented next, although representing the great majority of the stroke cases in the study population, should be viewed with these constraints in mind.

## 6.1 THE EPIDEMIOLOGY OF CEREBROVASCULAR DISEASE IN PORTO

### 6.1.1 Subjects studied

Case selection followed the procedures described in pages 201 to 208. After reviewing all the available information, a total of 271 cases was selected. Table-27 presents the numbers of stroke patients by sex and age group. 53.1% of the cases were females and 46.9% males. There

Age Group	<u>Males</u>		<u>Females</u>		<u>Total</u>	
	n	%	n	%	n	%
-44	4	3.2	7	4.9	11	4.1
45-54	18	14.2	8	5.6	26	9.6
55-64	30	23.6	29	20.1	59	21.8
65-74	49	38.6	45	31.3	94	34.7
75-84	22	17.3	51	35.4	73	26.9
85+	4	3.2	4	2.8	8	3.0
all ages	127	46.9	144	53.1	271	100.0

TABLE-27: Number and percentage of study cases by sex and age group.

were more men in the younger and more women in the older age groups -- 41.0% of the men were less than 65 years, while only 30.6% of the women were in the equivalent age group. 73.2% of the men and 35.4% of the women were married. In addition, 48.6% of the females were widowed, while only 15.7% of the men were in this status. Table-28 summarizes marital status for both sexes.

Marital Status	<u>Males</u>		<u>Females</u>	
	n	%	n	%
single	11	8.6	20	13.9
married	93	73.2	51	35.4
widowed	20	15.7	70	48.6
divorced	3	2.4	2	1.4
unknown	-	-	1	0.7
total	127	100.0	144	100.0

TABLE-28: Marital status in the study population.

In what regards occupational status, 39.7% of the males and 7.1% of the females were active. The great majority of the patients were retired -- 60.3% of men and 73.8% of women. In addition, 19.1% of the women were described as housewives.

311 cases initially abstracted were excluded. Table-29, below, presents the reasons for exclusion. The vast majority of the cases included stroke in the initial diagnostic hypothesis.

	<u>Sex</u>		<u>Total</u>	
	M	F	n	%
Transient ischemic accident				
- Definite	43	38	81	26.0
- Probable	15	38	53	17.0
"Old" stroke	9	15	24	7.7
Dementia	4	9	13	4.2
Post-stroke epilepsy	1	1	2	0.6
Psychosomatic disorder	0	4	4	1.3
Ophtalmologic disorder	2	6	8	2.6
Brain tumor	4	2	6	1.9
Brain metastasis	1	4	5	1.6
Head trauma	2	3	5	1.6
Chronic subdural hematoma	2	2	4	1.3
Other neurologic disease	8	10	18	5.9
Other non-neurologic disease	16	9	25	8.0
Dead on arrival	24	15	39	12.5
Incomplete information	7	17	24	7.7
Total	138	173	311	99.9

TABLE-29: Number and percentage of excluded abstracted cases by reason for exclusion.

Following review procedures, 26.0% and 17.0% of these cases were diagnosed as definite and probable TIAs, respectively. 24 cases had incomplete information of which date of onset was the most common. 39 patients were pronounced dead on arrival and it was not possible to obtain further diagnostic information that would satisfy WHO requirements. In Portugal, for the vast majority of cases in which crime is ruled out, families request the legal authorities not to perform an autopsy. Under these circumstances diagnosis reliability is very low.

### 6.1.2 Diagnostic characterization of stroke

After careful review each study patient was classified into one of five diagnostic categories, according to the clinical algorithms used by the National Survey of Stroke (NSS). These categories are (1) subarachnoid hemorrhage (SAH), (2) intraparenchymal hemorrhage (IPH), (3) thrombotic infarction of the brain (TIB), (4) embolic infarction of the brain (EIB), and (5) stroke of unspecified type.

Only 7.4% of the cases were classified as an unspecified type of stroke. This very low proportion is largely due to the fact that the majority of the patients was observed by a neurologist and that a CT scan was performed in 63.5% of the cases.

This is also evident in table 30, below, in which the level of diagnostic confirmation by diagnostic category is presented. According to NSS' clinical algorithm, four diagnostic levels were used -- definite, highly probable, probable, and undocumented. The majority of the cases was included in the definite category, what is a direct consequence of the availability of CT facilities. No cases were included in the highly probable diagnostic level. This level involved the performance of a spinal tap, a practice that has become less frequent since CT is available (1.5% of patients in the present study).

Prior to the wide use of CT scans, it was generally accepted that the error of misclassifying some of the unspe-



		Stroke Type					
		SAH	IPH	TIB	EIB	Unsp.	Total
Definite	n	5	45	91	31	0	172
	%	100.0	88.2	60.3	70.5	0.0	63.5
Probable	n	0	6	60	13	19	98
	%	0.0	11.8	39.7	29.5	95.0	36.2
Undocu- mented	n	0	0	0	0	1	1
	%	0.0	0.0	0.0	0.0	5.0	0.4
Total	n	5	51	151	44	20	271
	%	1.9	18.8	55.7	16.2	7.4	100.0

SAH: subarachnoid hemorrhage; IPH: intraparenchymal hemorrhage; TIB: thrombotic infarction of the brain; EIB: embolic infarction of the brain; Unsp.: stroke of unspecified type.

TABLE-30: (BOTH SEXES) Level of diagnostic confirmation by diagnostic category.

cified strokes as TIB was much less than that introduced by not including them as TIB (Alter et al., 1970). When presenting data on ischemic cerebrovascular disease, and along the lines of the NSS (Robins and Baum, 1981:I-48 to I-49) this criterion will also be adopted.

The pathological diagnosis was intracranial hemorrhage (includes SAH and IPH) in 56 cases (20.7%), and cerebral infarction (including TIB, EIB and unspecified type) in 215 cases (79.3%) for both sexes combined.

Tables 31 and 32, below, present for each sex the numbers and percentage of acute strokes by age. Only initial

		Stroke Type					
Age Group		SAH	IPH	TIB	EIB	Unsp.	Total
-44	n	2	2	0	0	0	4
	%	50.0	50.0	0.0	0.0	0.0	3.2
45-54	n	0	5	11	2	0	18
	%	0.0	27.8	61.1	11.1	0.0	14.2
55-64	n	0	7	20	3	0	30
	%	0.0	23.3	66.7	10.0	0.0	23.6
65-74	n	0	9	31	4	5	49
	%	0.0	18.4	63.3	8.2	10.2	38.6
75-84	n	0	2	17	2	1	22
	%	0.0	9.1	77.3	9.1	4.6	17.3
85+	n	0	1	2	1	0	4
	%	0.0	25.0	50.0	25.0	0.0	3.2
all ages	n	2	26	81	12	6	127
	%	1.6	20.5	63.8	9.5	4.7	100.0

SAH: subarachnoid hemorrhage; IPH: intraparenchymal hemorrhage; TIB: thrombotic infarction of the brain; EIB: embolic infarction of the brain; Unsp.: stroke of unspecified type.

TABLE-31: (MALES) Percentage of acute strokes by age and diagnostic category.

attacks are included.

Intraparenchymal hemorrhage represented 20.5% of strokes in males and 17.4% of those in females. Of all hemorrhagic types of strokes 57.1% occurred in men aged less than 65 years, while the proportion in women was 32.1%. Mean age for hemorrhagic stroke was 59.2 years in males and 66.2 in females, while for ischemic stroke it was 67.4 and

Age Group		Stroke Type					Total
		SAH	IPH	TIB	EIB	Unsp.	
-44	n	1	1	1	4	0	7
	%	14.3	14.3	14.3	57.1	0.0	4.9
45-54	n	0	2	4	1	1	8
	%	0.0	25.0	50.0	12.5	12.5	5.6
55-64	n	1	4	19	5	0	29
	%	3.5	13.8	65.5	17.2	0.0	20.1
65-74	n	1	10	23	8	3	45
	%	2.2	22.2	51.1	17.8	6.7	31.3
75-84	n	0	7	23	12	9	51
	%	0.0	13.7	45.1	23.5	17.7	35.4
85+	n	0	1	0	2	1	4
	%	0.0	25.0	00.0	50.0	25.0	2.8
all ages	n	3	25	70	32	14	144
	%	2.1	17.4	48.6	22.2	9.7	100.0

SAH: subarachnoid hemorrhage; IPH: intraparenchymal hemorrhage; TIB: thrombotic infarction of the brain; EIB: embolic infarction of the brain; Unsp.: stroke of unspecified type.

TABLE-32: (FEMALES) Percentage of acute strokes by age and diagnostic category.

69.6 years, respectively.

Embolic infarction of the brain was more frequent in females (22.2%) than in males (9.5%). Mean age for this type of stroke was 66.8 years for males and 68.3 for females, respectively.

The "unspecified" category of stroke was more common in women (9.7%) than in men (4.7%), and was predominant in

the older age groups, reflecting the current practice of limiting diagnostic procedures in these groups.

### 6.1.3 Incidence rates

There were 271 cases identified as strokes in the population of the defined area of Porto. The study population was constituted by 136,303 individuals and its age distribution is presented in table-33.

Age group	<u>Study population</u>		<u>All Porto</u>	
	n	%	n	%
0-14	29,197	21.4	71,984	22.0
15-24	23,053	16.9	55,994	17.1
25-34	21,066	15.5	48,954	15.0
35-44	15,959	11.7	38,399	11.7
45-54	16,048	11.8	39,724	12.1
55-64	13,818	10.1	33,168	10.1
65-74	11,045	8.1	25,400	7.8
75-84	5,111	3.7	11,520	3.5
85+	1,006	0.7	2,225	0.7
All ages	136,303	100.0	327,368	100.0

TABLE-33: Age distribution of Porto and study populations.

The incidence rates presented here should be understood in the light of the already mentioned constraints. They are emergency department based utilization rates for stroke, in a population that extensively uses an ED which has special characteristics. These rates provide a general estimate that may be useful for present and future comparisons.

The overall incidence rate was 199 per 100,000

population. Age and sex specific rates for the two major stroke categories are presented in table-34. Incidence rates are consistently higher for men than for women, with the exception of hemorrhagic strokes in the 75-84 age group. A dramatic increase with age is observed in Porto, which confirms the results of many other studies such as those of Alter et al. (1985), Aho et al. (1980), and Robins and Baum (1981). Two exceptions are evident: females aged 85 or more years and males aged 75-84 years have lower than expected rates when compared to other studies. These facts will be addressed later in this work.

Stroke type	Sex	Age group						all ages
		-44	45-54	55-64	65-74	75-84	85+	
Ischemic*	M	0.0	187	415	1002	1429	1304	162
	F	13.3	66	290	482	1186	387	154
	Both	6.8	118	340	670	1252	596	158
Hemorrhagic**	M	11.2	72	126	225	143	435	46
	F	5.3	22	60	156	189	129	37
	Both	8.2	44	87	181	176	199	41
All strokes	M	11.2	258	542	1227	1571	1739	208
	F	18.6	88	350	638	1374	515	192
	Both	15.0	162	427	851	1428	795	199

\* Includes TIB, EIB and Unspecified types

\*\* Includes SAH and IPH

TABLE-34: Age-specific stroke incidence rates (per 100,000) by sex in Porto's study population (October 1983 to September 1984).

#### 6.1.4 Comparison with other studies

Table-35, compares the incidence rates of all categories of stroke combined for Porto, with equivalent NSS results.

It is evident that incidence rates in younger age groups, especially males, are higher in Porto. Men aged 75-84 and both males and females aged 85 or more years have lower age- sex-specific rates in Porto.

Stroke type		Age group						all ages
		-44	45-54	55-64	65-74	75-84	85+	
ALL STROKES								
males	Porto	11.2	258	542	1227	1571	1739	208
	NSS	11.1	123	341	658	1714	2504	148
females	Porto	18.6	88	350	638	1374	515	192
	NSS	9.6	90	191	542	1180	1501	133
Both	Porto	15.0	162	427	851	1428	795	199
	NSS	10.3	106	262	583	1383	1825	141

TABLE-35: Age-specific stroke incidence rates (per 100,000) by sex in Porto (October 1983 to September 1984) and in the study population of the National Survey of Stroke (NSS) (1975-1976).

Table-36 below, presents similar data comparing the results of Porto with those of Lehigh Valley, a region of Pennsylvania and New Jersey, U.S.A., where a survey took place between July 1982 and June 1983.

Stroke type		Age group					all ages
		-44	45-64	65-74	75-84	85+	
1.ISCHEMIC							
males	Porto	0.0	288	1002	1429	1304	162
	L.V.	4.4	149	755	1478	2044	145
females	Porto	13.3	173	482	1186	387	154
	L.V.	1.3	94	476	1235	2063	153
both	Porto	6.8	221	670	1252	596	158
	L.V.	2.8	120	597	1322	2057	149
2.HEMORRHAGIC							
males	Porto	11.2	96	225	143	435	46
	L.V.	3.7	31	64	30	128	16
females	Porto	5.3	40	156	189	129	37
	L.V.	3.2	18	49	117	209	19
both	Porto	8.2	64	181	176	199	41
	L.V.	3.5	24	55	86	185	18
3.ALL STROKES							
males	Porto	11.2	384	1227	1571	1739	208
	L.V.	8.1	180	819	1509	2173	161
females	Porto	18.6	213	638	1374	515	192
	L.V.	4.4	112	525	1352	2272	172
both	Porto	15.0	285	851	1428	795	199
	L.V.	6.3	144	652	1408	2243	167

TABLE-36: Age-specific stroke incidence rates (per 100,000) by sex in Porto (October 1983 to September 1984) and in Lehigh Valley (L.V.) (July 1982 to June 1983).

Similarly to what was observed when comparisons were made with the results of the NSS, higher incidence rates are observed in Porto for all age groups up to 74 years, while lower rates are observed in the older population, to a

larger extent in females.

When compared with Lehigh Valley, rates for hemorrhagic stroke in Porto are on average three times higher in males and twice those observed for females.

#### 6.1.5 Medical history

Table-37 (page 237) summarizes the reported medical histories by age group, and by sex. Previous stroke had been experienced in 16.6% of the patients (20.5% for males and 13.2% for females), and TIAs in 12.2% of cases.

History of myocardial infarction was present only in patients aged 65 or more years ( $p < 0.001$ ) (3.7% of all cases), and other heart disease (excluding atrial fibrillation) was reported predominantly in young females ( $p < 0.01$ ). 15.5% of all patients were known diabetics.

In what regards hypertension, 37.8% of males and 47.2% of females were known hypertensives. The disorder was predominantly reported in males aged 64 years or less ( $p < 0.05$ ). However, if we also include those who had abnormal blood pressure values measured at the ED, than the frequency of hypertension rises to 53.5% in males and 66.7% in females. This finding should be viewed with extreme caution since dysautoregulation has been demonstrated both in hypertensive and stroke patients (Standgaard et al., 1973, Fieschi et al., 1968, and Buonanno and Toole, 1981:9).



			Age Group		
			0-64	65+	All Ages
<u>Stroke</u>					
males	n	9		17	26
	%	17.3		22.7	20.5
females	n	5		14	19
	%	11.4		14.0	13.2
<u>TIA</u>					
males	n	6		8	14
	%	11.5		10.6	11.0
females	n	8		11	19
	%	18.2		11.0	13.2
<u>Diabetes</u>					
males	n	7		7	14
	%	13.5		9.3	11.0
females	n	11		17	28
	%	25.0		17.0	19.4
<u>Hypertension</u>					
males	n	25		23	48
	%	48.1		30.7	37.8
females	n	20		48	68
	%	45.5		48.0	47.2
<u>Myocardial infarction</u>					
males	n	0		5	5
	%	0.0		6.7	3.9
females	n	0		5	5
	%	0.0		5.0	3.5
<u>Atrial fibrillation</u>					
males	n	3		4	7
	%	5.8		5.3	5.5
females	n	3		5	8
	%	6.8		5.0	5.6
<u>Other heart disease</u>					
males	n	4		2	6
	%	7.7		2.7	4.7
females	n	12		8	20
	%	27.3		8.0	13.9
<u>None of the above</u>					
males	n	17		31	48
	%	32.7		41.3	37.8
females	n	10		32	42
	%	22.7		32.0	29.2

TABLE-37: Frequency (%) of past medical history of stroke patients, by sex and age group.

Atrial fibrillation was reported in 5.5% of men and 5.6% of women. Higher frequencies were observed if we also included those first diagnosed at the ED (8.7% for males and 13.9% for females).

## 6.2 THE CARE OF ACUTE STROKE

The decision whether to treat the patient at home or in the hospital is affected by such considerations as local custom, socioeconomic conditions, the availability of a hospital bed, the desires of the patient and his family, and the gravity of the illness (Toole, 1984:251).

Admission of stroke patients to hospital is a extremely controversial issue. The WHO collaborative project (Aho et al. 1980:122), clearly showed that the use of hospital resources in association with the acute phase depends upon local circumstances, including social, financial, and cultural aspects.

Strokes are estimated to consume 4.6% of all the United Kingdom's National Health Service resources and most of this expenditure occurs within hospitals. A study conducted by Carstairs (1976:516-528) in Scotland showed that stroke patients account for 6% of all hospital running costs and occupy 13% of all general medical bed-days and 25% of

geriatric bed-days. Stroke is the third commonest single cause of hospital admission (Garraway, 1976), and is responsible for about 8-11% of admissions to acute medical wards (Acheson et al., 1968).

Wade and Hewer (1983), divide the reasons for admission in two major categories: (1) admission for diagnosis, and (2) admission for treatment. In this controversial article, the authors extensively discuss current positions concerning admission. On one side there is WHO's recommendation that all strokes should be admitted (WHO, 1971), a position shared by neurologists in the United States and Canada, who consider hospital admission essential (Toole, 1984; Hachinski and Norris, 1985). An alternative perspective is that of Wade and Hewer themselves (1983), who consider that with appropriate community support it would be possible to reduce the number of those admitted to hospital.

The first position is defended by Toole (1984:251) who considers that

patients with recent onset of TIAs, changing neurologic deficit, coma, or status epilepticus and those suffering intracranial hemorrhages must be hospitalized immediately; the occasional patient who is first seen a week or so after the onset of what has become a well-established, non-progressive cerebral infarction need not be admitted to the hospital if arrangements for proper neurovascular evaluation can be made on an ambulatory basis. As a general rule, TIAs within 2 weeks of onset, incomplete evaluation of signs, or risk factors, which could result in immediate disaster (uncontrolled hypertension, atrial fibrillation, symptomatic carotid bifurcation atherosclerosis) are situations which necessitate emergency hospitalization for their evaluation and control.

Hachinski and Norris (1985:13), who share Toole's position, consider that stroke patients are managed inconsistently and often poorly.

Stroke is a medical emergency needing hospitalization, since correct treatment depends on accurate diagnosis, which requires expertise and technology only available in hospital. Many patients are still treated at home, even in developed countries. For instance, 42 percent of 84 acute stroke patients in a single general practice in northeastern England were managed without hospital admission [1] and, as recently as 1983, Wade and Hewer [2] argued against admitting acute stroke patients to the hospital. Scarcity of beds, finances, cultural factors, and the belief that hospital treatment does not change prognosis may influence admission. In the hospital, patients may be looked after by a family physician, internists, geriatrician, neurologist, or other type of physician, and their quality of care is often a matter of chance. Only recently has the need for a consistent approach and a minimal level of expertise been urged [3]... Many physicians are therapeutic nihilists concerning stroke, creating a vicious circle in which lack of knowledge retards the search for effective therapy, generating even more negative attitudes.

For Wade and Hewer (1983:807) evidence from various studies suggests that the major reason for admission relates to nursing needs during the acute illness. The authors consider that this could be done at home in more cases than at present, and that rehabilitation services should be more readily available to patients at home, so that fewer need to be admitted and those admitted can return home sooner. The

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[1] See Waters and Perkin (1982).

[2] See Wade and Hewer (1983).

[3] See Caplan (1984).

authors conclude that this might lead to a more appropriate rehabilitation, less anxiety and depression in the patient and his family, and more efficient use of limited resources.

Previously, in 1978, Brocklehurst and associates had raised Wade and Hewer's question -- "Why admit stroke patients to hospital?" The authors also had concluded that

since the overall reasons for admission were principally the need for nursing care in association with social problems at home, increased domiciliary support and early day-hospital care might well diminish further the number of stroke patients admitted to hospital (Brocklehurst et al., 1978:100).

WHO's collaborative study reported by Aho et al. (1980:122) shows that in the European centers and in Israel about three quarters of the patients were admitted to hospital, whereas in Japan more than half the patients were treated at home. Admission rates in Japan were influenced by factors such as age and sex of the patient; they were much lower for elderly stroke patients than for younger ones and much lower for females than for males. In Europe such trends were negligible. Hospital admission was apparently independent of whether the patients were living alone or with relatives, but less than half the patients who were living in nursing institutions were transferred to hospital -- even in centers with high overall admission rates.

As regards the influence of the clinical state, most non-hospitalized patients either had mild strokes that were

treated at home or had particularly severe strokes that became fatal before admission could be arranged. However, in the Japanese centers hospital admission seemed to be independent of the severity of the stroke.

For all centers combined, 80% of the patients who were referred to hospital were admitted on the day of onset, and only 11% were admitted later than the third day after onset. In this respect, differences between the centers were small.

#### 6.2.1 The role of the Emergency Department

Some emergency rooms, no matter how their functions are defined by their staff and by the hospital administration, are viewed by the surrounding community as primarily a social agency (Soskis, 1985:3).

Emergency departments have become extremely complex organizations in which decisions regarding individual patients are shaped by the wide variety of factors mentioned above, to which we must add local health professions' culture. Soskis (1985:1-3) describes recent changes in emergency room usage and points out major contributors to the current heavy use:

- (1) great improvements in trauma care, so that more people now reach the emergency room alive;
- (2) other medical advances in coronary care and other areas of ambulatory care;

- (3) more complex technology that makes office treatment less appropriate than hospital treatment for certain conditions;
- (4) the concentration of resources in hospitals and their availability 24 hours a day, especially when physicians have restricted their hours and outside visiting;
- (5) growing specialization in medical care so that a patient without a primary care physician does not know whom to call;
- (6) lack of physicians in the inner city, where many large hospitals are located;
- (7) increasing mobility among the population which leaves many people without a regular family doctor;
- (8) insurance programs which cover visits to the emergency rooms but not to doctor's offices;
- (9) the increasing prevalence of chronic disease needing regular or medical attention (particularly among the growing ranks of the elderly, who may be trapped in the inner city);
- (10) cutbacks in social service programs providing free health clinics, psychiatric assistance, and other help;
- (11) the de-institutionalization of psychiatric patients many of whom are unable to maintain themselves;
- (12) the rising expectations of medical care, fueled by the media, which lead people to seek emergency room services for all kinds of problems.

Based on these twelve reasons, which are valid for most settings, Soskis offers the following four conclusions:

- (1) More people with severe trauma and serious illness survive until they reach the emergency departments and have a better chance of staying alive once they get there;

- (2) In spite of the advances in care of the seriously ill and injured, most people coming into emergency rooms suffer from problems and conditions that are important to them but not urgent in medical terms;
- (3) A small but substantial number of people coming to emergency rooms use it as their regular source of primary care, even when efforts are made to provide alternatives;
- (4) A sizable proportion of people visiting emergency rooms have no major medical complaint or sometimes no complaint at all, and often few or no resources -- social, economical, or otherwise -- to help them cope with the problems that brought them in.

It is in this often crowded and chaotic environment that a large component of the socialization of recently graduated MDs takes part.

Interns and residents (known as house staff) are continually faced with the "nuts and bolts" of everyday patient management as well as theories and diagnosis of rare and poorly understood diseases (Mizrahi, 1985: 216).

Decision making in these environments is a complex process. Mizrahi (1985) provides an excellent sociological description and analysis of everyday problems that affect doctor-patient relationships in a large proportion of settings serving deprived communities.

Admission of stroke poses special problems, which are commonly found associated with other conditions. Warren et al. (1967:149), presented evidence from London hospitals, supporting the observation that:



older people in general and patients suffering from abortions, cerebrovascular accident, cardiac failure, and terminal cancer experience difficulty in obtaining emergency admission. The difficulties are aggravated in the months of January, February and March.

Since internal medicine and its subspecialties have traditionally given priority to the acquisition of diagnostic skills, these patients are often considered uninteresting and frustrating. In addition, admission of a stroke patient usually represents blocking a bed for a long and often unpredictable period, which depends of outcome and the family's ability to care for the patient. Mannon (1976:1004), in his study of "problem patients" in a hospital emergency room points out that

emergency ward doctors and nurses define patients whose illness require prolonged and comprehensive care as threats to the mission of the ward.

To a large extent this represents, from a professional point of view, the rejection of the role of the hospital as a social agency accepted by most communities. These conflicting perspectives are well documented in selected Porto's case-histories to be presented in the next chapter.

#### 6.2.2 Admission patterns for acute stroke in Porto (HGSA)

As described above (see pages 195 to 200), most Portuguese emergency departments suffer from extensive overcrowding both in terms of patients but also of health

professionals. Everyday, large numbers of patients are observed by an increasing number of professionals, most of whom are recent graduates.

Interns are responsible for the initial contact with patients, being supervised by residents or fellows in three major clinical areas -- internal medicine, surgery or pediatrics. When an actual emergency occurs, residents usually take charge, being responsible for transmitting appropriate information to the specialists in charge of the sector. Admission to a ED or hospital ward is usually proposed by residents and, usually requires the consent of both the head of the ED team and of the specialist responsible for the clinical sector, who take into consideration a wide variety of factors which include severity, current or future availability of a bed, etc.

When a patient is admitted (see pages 202-205), a "tabela" is issued, what formally means that the hospital is responsible for the care.

During the study period 271 stroke patients living in the study area of Porto were observed at the emergency department of the HGSA.

In what regards the interval between onset of symptoms and arrival at the ED, data were missing in 18.8% of the cases. For those on whom information was available, 61.5% (same proportion in both sexes) enter ED within less than 12 hours from onset. 13.5% of the males and 9.2% of the

females did so after more than three days. Six cases had more than one ED visit associated with the same phase of the stroke episode, and 13.3% of all patients had multiple ED visits during the study period.

152 patients (56.1%) were admitted either to a ED ward or a hospital ward, or both. A "tabela" was not issued for 119 patients (43.9%), who were discharged from ED according to the following alternatives: home, private hospital, refused admission or abandoned ED, or were discharged at the request of the family. Tables 38 and 39, below, depict, for each sex, the various possible pathways leading from admission to discharge.

A higher proportion of females was admitted (62.5%), compared to males (48.8%), and both sexes had a similar proportion admitted to an ED ward only -- 11.0% (males) and 10.4% (females).

When admission did occur, the "tabela" was issued on the same day for 68.8% of males and 87.6% of females. Formal hospital acceptance took longer than a day in 31.2% of males (range 2-6 days) and 12.4% of females (range 2-3 days).

Although having actually been admitted, a small number of cases (3 males and 6 females), identified in tables 38 and 39 as IC=0, never went further than the intermediate unit where patients usually wait clinical decisions, which is here designated as "OBS" (see page 204).

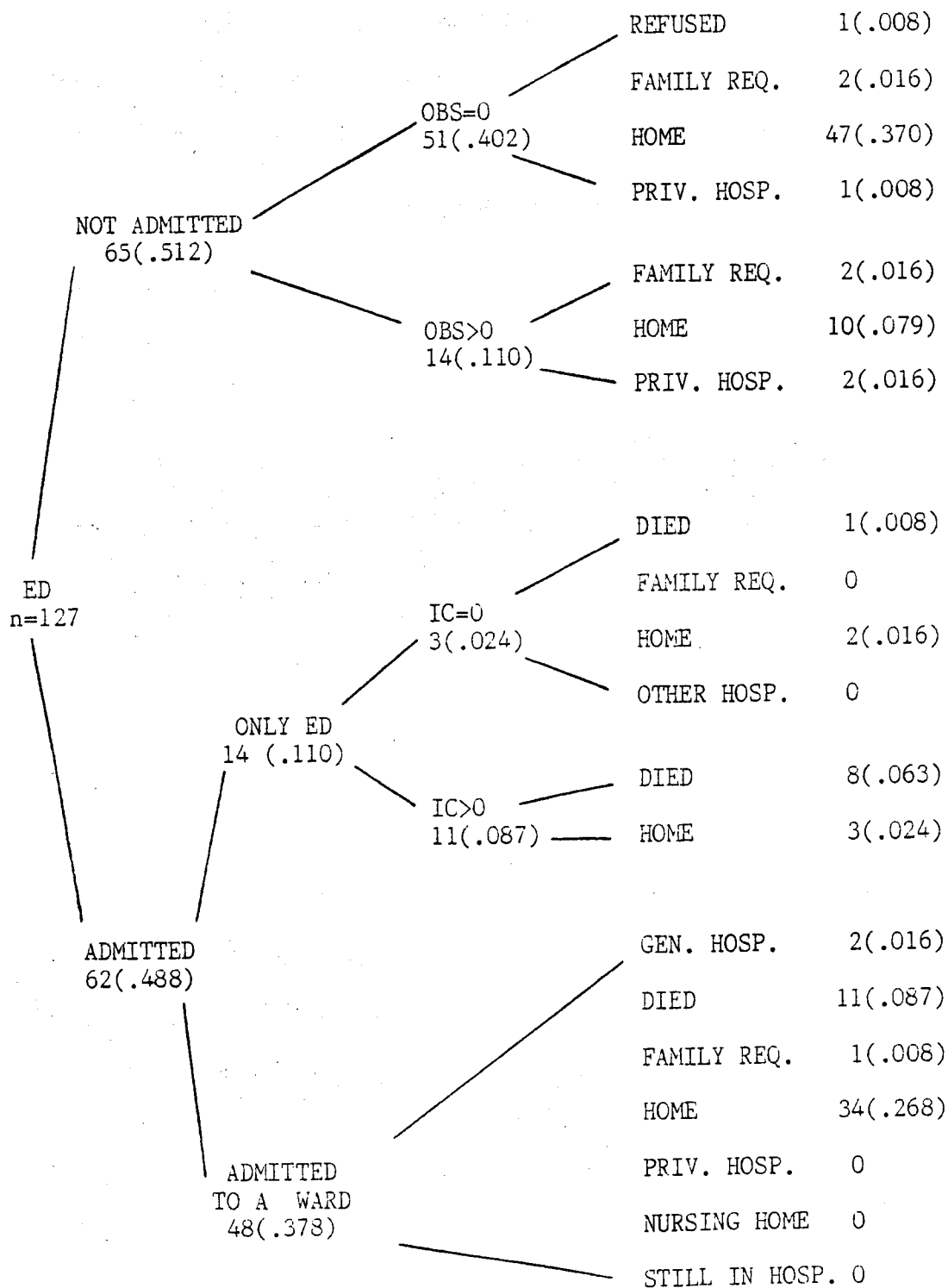


TABLE-38: (MALES) Admission and discharge patterns.

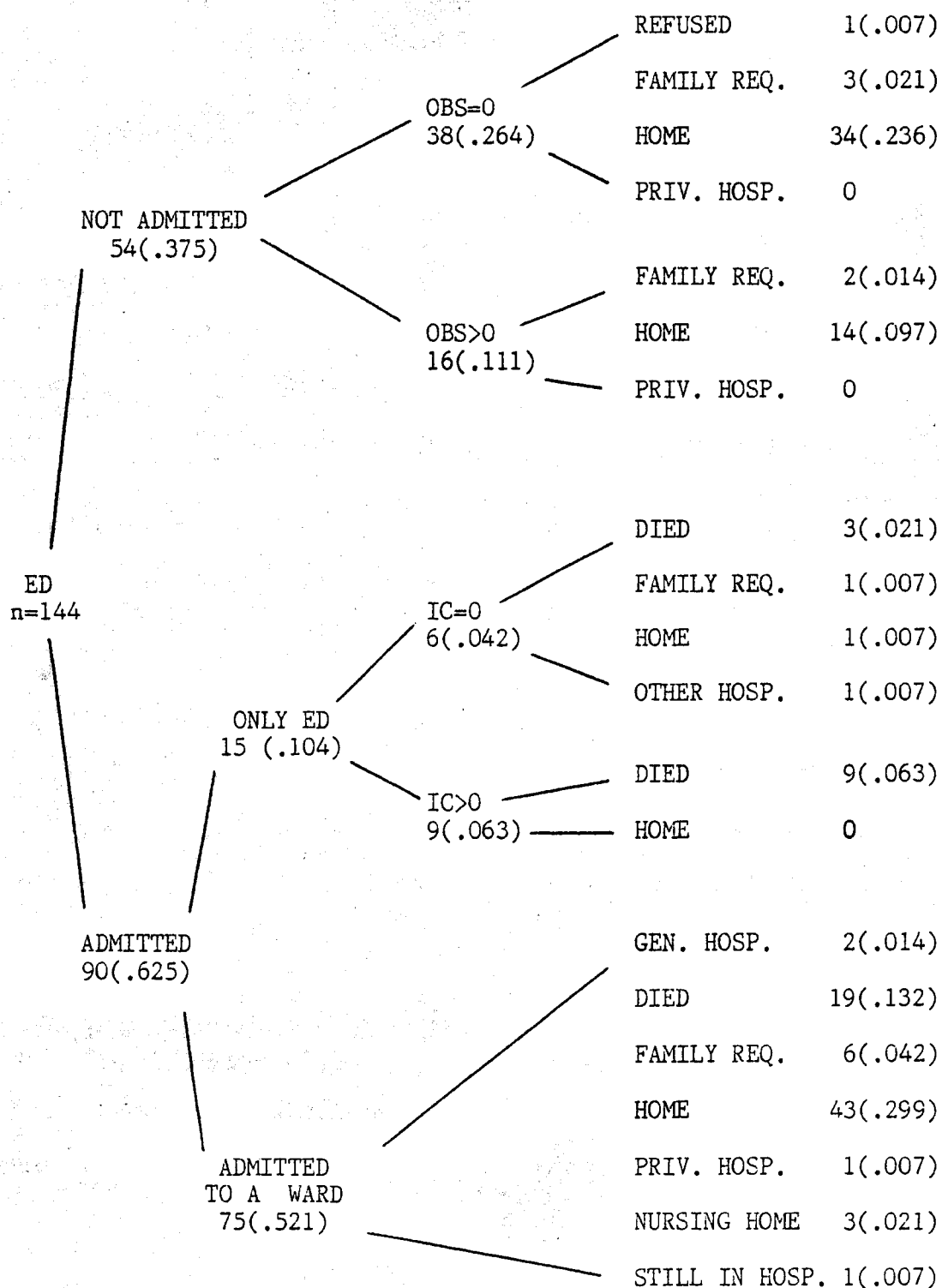


TABLE-39: (FEMALES) Admission and discharge patterns.

8.7% of males and 6.3% of females were admitted only to the ED's intensive care unit -- "IC". These were severe cases, requiring constant supervision and monitoring. A very high mortality was observed.

51 males (40.2%) were discharged from ED within the same day, and another 14 (11.0%) were discharged after a variable period in the OBS ward (OBS>0). In what regards females, a smaller proportion was discharged within the same day -- 26.4% (38 cases), and 11.1% of the total (16 cases) were temporarily in OBS.

Although it is not evident in tables 38 and 39, patients who were admitted to a non-ED ward also spent a variable time in the OBS and IC units. Overall 20.6% of the males spent more than one day in OBS (range 2-10 days), while for females this proportion was 17.0% (range 2-5 days). In what regards length of IC stay, 29.5% of the males and 19.8% of the females stayed over one day (range 2-9 days, for both sexes).

Tables 38 and 39 also show that transfer for a private hospital was more common for men, while discharge to a nursing home only occurred for females.

When we consider admission to any unit -- ED or hospital ward -- a larger proportion of women was admitted. Admission to a non-ED ward (e.g., medicine, neurology) is also more frequent for females (52.1% when compared with 37.8% observed for males). In addition, the above mentioned

lengths of stay in IC and OBS also suggest that it is usually easier for females than males to be admitted. This is also confirmed by the registered time interval between entering ED and the issue of the "tabela", which occurred on the same day or overnight in 68.8% of males and in 87.6% of females. This period, which reflects the length of stay in OBS, has also a wider range in males (2-6 days), when compared with females (2-3 days).

As table-40 depicts (both sexes combined), age was not a determinant of admission. On the other hand, two conditions which are frequently associated -- hemorrhagic stroke and the presence of alterations of the conscience -- were significantly associated with admission ( $p < 0.001$ ). As

		Admitted	Not Admitted	Chi-square	Prob.
<u>Sex</u>					
	male	62	65	5.128	0.003
	female	90	54		
<u>Age</u>					
	-64	57	39	0.652	0.419
	65+	95	80		
<u>Stroke</u>	<u>Type</u>				
	hemorrhagic	50	6	31.584	0.001
	ischemic	102	113		
<u>Level of consciousness</u>					
	disturbed*	54	9	29.250	0.001
	normal	98	110		

\* includes coma, stupor or unconsciousness

TABLE-40: Factors associated with admission.

we would expect sex was also significantly associated with admission ( $p < 0.01$ ). Similar probabilities were observed when the above factors were considered separately for each sex.

Admission to a hospital ward, which is deeply affected by ED outcome (e.g., death, admission refusal, transfer), was associated with the same factors (table-41). No association was found for level of consciousness. For stroke type a significant association ( $p < 0.01$ ) was found when both sexes were combined. This association was no longer significant for each sex considered separately ( $p > 0.05$ ). P-values for all other factors, by sex, were similar to those for both sexes combined.

		Admitted	Not Admitted	Chi-square	Prob.
<u>Sex</u>					
	male	48	79		
	female	75	69	5.558	0.018
<u>Age</u>					
	-64	47	49		
	65+	76	99	0.765	0.382
<u>Stroke Type</u>					
	hemorrhagic	34	22		
	ischemic	89	126	6.690	0.010
<u>Level of consciousness</u>					
	disturbed*	34	29		
	normal	89	119	2.438	0.118

\* includes coma, stupor or unconsciousness

TABLE-41: Factors associated with admission to a non-ED ward



It should be emphasized that this table presents the overall probability of being admitted to hospital ward. The results contrast with those present for admission in general (table-40, above), and reflect the selective role of ED in the admission process.

### 6.2.3 The use of hospital resources

In most western countries, stroke is a major consumer of health care. In the acute phase an important amount of hospital resources is consumed, which various surveys have estimated to be about 5-6% of all hospital costs. However, as Wade and Hewer (1983:289) point out, there is considerable variation among the different surveys, which suggests that savings might be possible. In this study, no attempt was made to measure these direct costs.

Another way to evaluate hospital use is to measure how long patients stay in hospital. Wade et al. (1985:290) refer that this approach has two major problems:

First, the large number of early deaths coupled with the few long-stay patients leads to a skewed distribution which makes the average length of stay unrepresentative. This problem may be overcome by dividing patients into three groups -- those who die soon after admission, those who are discharged alive back to their community, and those needing long-term care (e.g., those transferred to another hospital for custodial care, those going into nursing homes, those moving to supervised accommodation) -- and then defining the length of stay for each group. An alternative is to use the median length of stay rather than the average. The second problem is that most routine statistics

collected by hospitals do not distinguish between admissions for acute stroke and subsequent admissions resulting from sequelae of a previous stroke.

In what regards the latter problem, only first strokes were included in the present study. As table-29 (page 227) documents, 24 cases of "old stroke" were excluded.

Length of stay, divided according to the above suggestions, is depicted in table-42. The results from Porto are compared with those from Monroe County's (New York) study by Gibson (1974), presented by Wade et al. (1985:291).

Patient category	N	%	Median stay	Hospital-beds
Died in hospital				
Porto*	61	39.9	4 days	652 bed-days
M.C.	129	37.3	7 days	1696 bed-days
Discharged home				
Porto	83	54.2	29 days	2864 bed-days
M.C.	121	35.0	14 days	2076 bed-days
Transferred				
Porto	9	5.9	58 days	1230 bed-days
M.C.	96	27.7	20 days	2332 bed-days

\* includes two patients not formally admitted

TABLE-42: Use of hospital resources: Porto (October 1, 1984 - September 30, 1985), Monroe County (M.C.) (March 1 to June 30, 1971).

The most striking point is the proportion of patients transferred to non-acute care units, which is minimal in Porto, and occurs in over one quarter of Monroe County's patients. Extremely long hospital stays are observed for this group of patients in Porto. The median length of stay

is nearly three times that observed in the Monroe County study. In addition a small number of Porto's patients (n=9) is responsible for the occupancy of what would be over 50% of the total hospital beds used by 96 Monroe County patients.

For those discharged home the median length of stay in Porto is twice that observed in Monroe County.

WHO's collaborative project (Aho et al, 1980) also provides information of this measure of hospital resource utilization and of communities' ability to integrate these patients. In the European centers and Israel the median length of stay for those discharged alive was four weeks, contrasting with Japan, where 86% of the survivors stayed in hospital over that period, and with India where only 15% stayed in hospital longer than four weeks. Further comparisons are not possible because the study does not discriminate by discharge type.

In-hospital rehabilitation is another resource of extreme importance for these patients. During the initial phases of stroke, passive physical therapy is provided in most wards by nursing personnel which, in some cases, may have rehabilitative training. In 26.0% of all patients admitted to a ward it was possible to find evidence that the patient had been evaluated by a physical therapy specialist or resident, and that rehabilitative care was initiated. Different proportions were observed for the two sexes --

41.7% in males and 16.0% in females. Speech therapy, as well as occupational and vocational therapy were not available.

Hospital rehabilitation policies will be addressed later in this work in conjunction with those non-hospital based.

#### 6.2.4 Summary

The results above presented clearly demonstrate the importance of the stroke problem in the study area. Particularly relevant is the demographic and clinical information collected, which reveals major differences between the two sexes. 62.5% of females are widowed or single, while 73.2% of males are married. Stroke is more common among older women, while over 40% of strokes in males occurred in those aged 64 or less. Age-specific rates for hemorrhagic stroke, especially among young males, are particularly high when compared with results from other community studies.

It is also evident that the emergency department plays a major role in determining who is admitted or not. The above data show that females have a higher probability of being admitted, and that severity (measured by level of consciousness) and type of stroke are major determinants of admission. Admission to a ward, from where rehabilitative measures may be initiated, is dependent on the ED selection process in which, the high mortality observed in the first days plays a major role.

When compared with results from equivalent studies, longer hospital stays were observed in Porto for patients discharged home or to another health care facility. In addition, despite the fact that the latter patients only comprise 5.9% of the cases, they are responsible for 25.9% of all stroke bed-days. This observation strongly suggests that a small but particularly important group of patients may have special needs.

Another relevant point is the fact that HGSA's rehabilitation programs are limited to physical therapy. In addition, only one quarter of all patients admitted to a ward receive any form of specialized physical therapy while in hospital, and of those the majority is males.

## CHAPTER 7

### STROKE CARE AND FAMILY ADAPTATION

Stroke is a frightening experience not only for patients, but also for their families. Unfortunately, attention is focused almost exclusively upon the patient after a CVA [1] (stroke), and the family is ignored or expected to cope as best they can... To understand how stroke affects people other than the patient, it may be helpful to compare a CVA to a stone dropped into a calm pool. The ripples are largest and strongest nearer the point where the stone entered the water, but the rings expand outward beyond the point of impact. Similarly, the strongest effects of a stroke are experienced by the patient and those closest to him, usually the family. The ultimate effects of stroke, however, expand outward to touch friends, less involved relatives, and even job associates. (Bray, 1984:121).

In the previous sections the epidemiological profile of CVD in Porto was presented. In addition, the interaction between these patients and hospital care was studied from a health services utilization perspective. This chapter will address two major questions:

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[1] Cerebrovascular Accident.

1. From a community perspective, what is the global outcome of stroke?
2. What are the mechanisms involved in the various phases of the adaptation process to a stroke in the family?

Acute individualized care usually ignores these issues, and hospital based studies cannot provide the required answers.

I will begin by presenting data on post-hospital survival following CVD, which is one of the measures of the burden of stroke on families and communities, and a major determinant of the adaptative process. Next, based on qualitative data from selected case-histories obtained through above mentioned hospital record linkage procedures, I will illustrate the various mechanisms involved in the process of family adaptation. I will conclude by addressing the determinants of family adaptation from a quantitative perspective.

### 7.1 COMMUNITY FOLLOW-UP

Follow-up results are based on hospital data and on the previously mentioned 197 contacts. Table-43, below, depicts the relationships between stroke patients and interviewees. A large proportion of the contacts resulted in interviews which involved more than one participant. With few excep-

relationship	males n=99		females n=98		total n=197	
	n	%	n	%	n	%
patient	26	26.3	34	34.7	60	30.5
caretaker	30	30.3	27	27.6	57	28.9
spouse	21	21.2	9	9.2	30	15.2
1st degree relative	11	11.1	14	14.3	25	12.7
2d degree relative	6	6.1	12	12.2	18	9.1
other household	18	18.2	13	13.1	31	15.7
local resid. (not kin)	31	31.3	32	32.7	63	31.9

TABLE-43: Patient/interviewees relationships

tions, caretakers were either spouses or close relatives.

When compared with males, a larger proportion of female patients were interviewed. Spouse's participation was uncommon among females. Local residents provided 31.9% of all information of which the vast majority concerns patients unknown in the neighborhood.

As figure-2 depicts, length of follow-up was variable, depending on the date of entry into the register and survival.

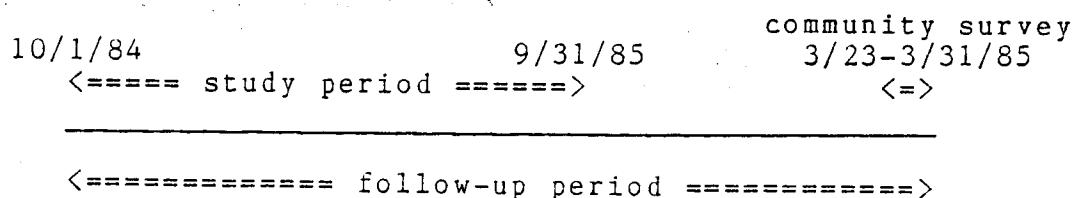


FIGURE-2: Study and follow-up periods



Situation	males		females		total	
	n	%	n	%	n	%
1.ALIVE	53	41.7	63	43.8	116	42.8
2.DEAD						
died in hospital	20*	15.7	31**	21.5	51	18.8
family requested	4	3.1	9	6.3	13	4.8
died at home	20	15.7	15	10.4	35	12.9
total	44	34.5	55	38.2	99	36.5
3.UNKNOWN	30	23.7	26	18.1	56	20.7
TOTAL	127	100.0	144	100.0	271	100.0

\* includes 3 cases not formally admitted to hospital

\*\* includes 1 cases not formally admitted to hospital

TABLE-44: Community follow-up: Situation of all cases, as of March 23, 1985.

Table-44, presents global follow-up results, for all stroke patients who used the HGSA's ED during the one year study period. It was not possible to establish contact with 20.7% of the cases, of which the largest proportion was males. Over one third of the patients (36.5%) were dead at the time of the interview. When compared with males, a larger proportion of female deaths occurred in hospital, but higher admission rates were reported for females (see pages 247-251).

In what regards patients for whom family requested discharge, the individual files of 10 cases clearly suggested that the patient was terminal ill and so no further contacts were pursued. For those whose situation was

situation	males	females	total
presumed dead	3	7	10
dead	1	3	4
situation unknown	1	1	2
private hospital	-	1	1
total	5	12	17

TABLE-45: Situation of patients for whom family requested discharge

not clear (n=7), an interview was attempted. Four of those additional patients were dead, two were not located, and one had been transferred to a private hospital. Table-45 summarizes these findings.

Table-46 (next page) depicts the current situation of 217 cases (80.1% of the total) for whom complete six month follow-up information was available. Included as alive are 7 cases (5 males and 2 females) classified in table-42 as unknown situation, for whom outpatient clinic records show that the patient attended an appointment over six month after initial stroke. Similarly, 9 cases (5 males and 4 females) previously classified as dead, had survival periods longer than 180 days and therefore were also included in the alive group. Excluded were 5 patients (3 males and 2 females) known to be dead, but on whom there was no information regarding date of death.

situation	<u>males</u>		<u>females</u>		<u>total</u>	
	n	%	n	%	n	%
1.ALIVE	63	63.6	69	58.5	132	60.8
2.DEAD						
1-7 days	20	20.2	31	26.3	51	23.5
8-21 days	7	7.1	4	3.4	11	5.1
21-90 days	6	6.1	9	7.6	15	6.9
91-180 days	3	3.0	5	4.2	8	3.7
Total dead	36	36.4	49	41.5	85	39.2
TOTAL	99	100.0	118	100.0	217	100.0

TABLE-46: Situation after complete follow-up (180 days).

Any interpretation of these results should bear in mind the implications of missing information. Nevertheless, the importance of stroke as a major cause of death in Porto's study population is evident. Over one third of the patients are dead within three months, and nearly 40% within six months. High mortality levels are observed during the first week, especially during the first 24 hours -- 7.1 % of the males and 10.2% of females. Six month mortality is particularly high for hemorrhagic stroke (57.1%), when compared with all ischemic strokes combined (24.5%).

These findings are similar to those of the WHO multicenter stroke register reported by Aho et al. (1980:127). Of the total series of patients, 23% died within one week, 31% within three weeks, and 48% within one year. WHO's study also showed that differences between fatality

rates in various centers were only moderate.

As in other studies such as the above mentioned WHO multicenter register, unfavorable prognostic factors for Porto's patients were old age, impairment of consciousness, and high blood pressure.

## 7.2 THE FAMILY ADAPTATION SYSTEM

Successful adaptation to a stroke in the family is a complex process that varies with the severity of the disorder, the coping strengths and styles of the family, and the health care resources available.

Initially, the major adaptative task has to deal with the often life threatening presentation of stroke and the need to seek acute care. This process is similar to that of any severe acute condition, in which the characteristics of the health care system and its availability are major determinants. Following this initial phase, adaptative mechanisms are predominantly directed at reestablishing family balance. This phase is also similar to that of other chronic diseases from which stroke differs by nature of its sudden onset.

Frequently, as a consequence of a stroke, the patient is no longer able to fulfill family roles. Someone else must step in and take over those functions. This often results in loss of status, thoughts of "being a burden to the family"

and finding "no meaning in life." In order to minimize these effects, new defined roles may eventually make the patient feel that he/she is still contributing to the family through meaningful activity.

Bray (1984) developed a theoretical model of family adaptation to CVD. The model identifies six stages experienced in many families as they attempt to reestablish homeostasis after stroke. Each level prepares the family for the demands which they will experience in the succeeding level. The early stages of the process may be directly observable during the interaction of patients and their families with the health system, while the last stages often occur when families are long removed from health care settings.

It is unusual for a family to skip stages in their initial movement through the process, but families progressing once again through after a regression (a common pattern) often move more rapidly through or accelerate beyond stages they have previously encountered (Bray 1984:123).

The time required for a family to complete the entire process is extremely variable. Many families require from six to twelve months, while others may require more than two years.

Bray (1984:135) also points out that many health professionals are not familiar with these adaptative

mechanisms, and often families' behavior only succeeds in alienating them from the staff. Several case-histories presented below document this process of adaptation and the major problems encountered by families in their relationships with the health sector.

(1) fear - The initial response of most families to a major assault of their homeostasis is fear. Confusion, emotional numbness and inability to make decisions are often reported. The family responds through fight or a flight. The fight response may translate into criticism of health care or of the professionals involved, or refusal to provide information to the staff. The family may also choose to fight the prevailing health system and challenge its bureaucratic rules. This is the case of patients who use false addresses so that they can obtain the care they believe they are entitled to and that they are not able to obtain for a variety of reasons. Place of residence and choice of care provider are particularly relevant.

Mr. C.L., 61 years old, married, worked in the national electricity company offices. He lived in HSJ area so when he suffered a non-life threatening stroke he used that ED accordingly. After evaluation he was discharged home. Hoping to be admitted the patient decided to try again and so, a few hours later, reported to HGSA's ED using his son's address. After evaluation and dissatisfied with delays in the admission procedures he left the ED.

Mr. A.A., 69 years old, married, retired, lived in a large urban area which is part of the great Porto conurbation. This area has its own hospital to which HSJ provides back up support for those situations which cannot be managed locally. After suffering a probable TIA, the patient used HGSA services. He referred having had a stroke five months ago. After evaluation, and having had his address corrected in the BI, the patient was discharged home. Twenty four hours later, under a new ED team, the patient tried again. His address was corrected again and this time the patient was discharged to the HSJ.

The study files provide clear evidence that HGSA patients are also being observed at the HSJ. When occasionally these "irregular" situations become evident the patient is likely to be transferred to the area hospital.

Occasionally, the flight response translates into physical abandonment of the involved family member, but in most circumstances, the family is extremely suspicious of hospital and health care providers and have difficulties in interacting. A flight response may be the most appropriate alternative when families have specific problems providing time and opportunity to make necessary arrangements. According to Bray (1984:128) the flight response is

an emotional pulling away from the intensity of the accident or illness. This pulling away causes increased levels of guilt and anxiety, but also results in significant increase in the energy available for use in coping with a major disruption ... Most families will experience this flight response and proceed to the next phase (denial).

Mrs. S, 48 years old, married, suffered a severe stroke while working in the office. Severe hypertension had been diagnosed several years ago. The patient was taken to the ED where she was comatose and diagnosed as having suffered a massive IPH. Six hours later, without having been admitted yet, the family requested discharge. Next day the patient was brought back to ED, being admitted to IC and later to Neurology. The patient survived 4 days and was discharged moribund.

(2) denial - the family rejects the full significance of what has occurred. This approach gives a temporary sense of control and distance from the overwhelming nature of what has occurred. This time is often constructively used to reassign short-term functions for family members, but occasionally may lead to disastrous events.

Mrs. A.B., 42 years of age, widow, worked as a servant in a boarding house. She had hypertension and a severe heart disorder (mitral stenosis) and therefore was regularly observed at Cardiology's out-patient clinic. One morning she woke up with a minor motor deficit in her face and her right arm and reported to the ED. Invoking family reasons the patient asked to leave ED where she was supposed to return a few hours later, which she never did. Three months later the patient was admitted due to a myocardial infarction and from then on a succession of events ended with a pulmonar emboli from which she died, 9 months after the initial stroke.

(3) bargaining - is a stage in which the family develops an agreement or contract concerning what the family will do in order for the patient to recover. As Bray points out, frequently these contracts are unspoken and subtle, but mutually agreed upon by the family members. Members may



quit a job temporarily or permanently, move into the patient home or, eventually, develop mechanisms through which the patient rotates through various households within the family.

This is a period when families tend to be very cooperative and encourage the family member in all aspects of care and recovery. The major benefit of bargaining is the family's acknowledgment that a problem of major significance has occurred. With the passage of time bargains made by the family begin to fail, and the family is confronted once again with the reality of their situation.

Mrs. E.P., a widow of 76 years of age, was taken to the ED by her grandson who reported that the patient had been permanently in bed over the last few months. She was observed by her physician every week. The grandson also referred that he decided to take the patient to the ED because his parents went on vacation and, due to his work commitments, he could not take care of the patient. After evaluation the patient was discharged home with a letter to her physician.

(4) depression - is a period in which the family feels overwhelmed. It may be expressed in two distinct ways: (a) internalized anger which is most easily recognized as depression and, (b) anger that is externalized and directed toward someone else (e.g., health professionals) rather than toward the family member, because that would result in feelings of guilt and escalating conflicts inside the family system. The family options at this level are to progress to the next stage or regress and reinforce depression.

The best example from the study files is a situation in which this anger was expressed directly by the patient after a family visit to the hospital ward.

Mrs. A.S., 53 years old, married, retired, suffered a probable embolic stroke. Initially the patient was confused, aphasic and presented light motor disability (right arm and face). She initiated anticoagulation therapy and was admitted to a ward. Ten days after admission the hospital files reveal that she had recovered from all deficits with the exception of speech. A request for observation was sent then to the Department of Physical Therapy. Below the acknowledgment that this request was made a note refers that the "hospital does not have speech therapy." Next day, after being visited by relatives, the patient became agitated and aggressive and tried to leave the ward. Two days later the patient swallowed a piece of metal foil and therefore was observed next day by ORL, after what she was discharged. Follow-up data reveals that nine months after stroke the patient maintains a severe speech disability, attends regularly the monthly SMS physician's appointment and that she never received any form of speech, occupational or vocational therapy, or used social services.

(5) mourning - it is a period of identification of specific loss. This period is often misinterpreted as depression. Old family myths are substituted by new beliefs. It is a period when family can work together to identify problems they can agree upon as significantly affecting all the family. Overprotectiveness may arise within the family since new expectations and roles have not yet crystalized.

(6) rapprochement - is a time when the family and patient search for new structure, roles, and goals. They begin to define new expectations and functions for each

family member, as well as revising remaining roles. It is the first stage in which the patient is reintegrated into the family system as someone who may significantly contribute to the operation of the family.

An example is that of patients in the present study who, after having suffered stroke, move to rural areas to live with relatives. Such movement probably reflects the difficulties in coping in urban environments, and the acknowledgment that the patient will be better integrated in rural areas. This situation is of particular interest since it is well known that the Portuguese health system has major assymetries which leave the rural areas deprived of basic health care services. The current inequalities are clearly depicted in the following case-history.

Mrs. A.J., 57 years old, married, is a rural worker in the northern part of Portugal to which HGSA provides back-up specialized care. The patient suffered a stroke and was admitted to the local hospital where she stayed one week. Two weeks later, having recovered from dysphasia and beginning to move her right leg, the patient reported to HGSA's ED where she was classified by the attending neurologist as "a non-urgent case, to be observed when possible." Later the same physician assessed the patient and his notes read as follows: "The only thing that it is possible to be done for this patient aged only 57 is to try to recover her walking abilities, by using what is left of her right leg motor strength. Thus, I think that she should be admitted somewhere where she can receive proper physiotherapy." The patient was discharged home the same day.

Current central hospital admission policies, ignore this urban/rural disjuncture and the inability of most rural

patients in obtaining the care they need.

Another note refers to the fact that the problems and adaptative mechanisms above described are not specific of stroke. A dramatic example is that of dementia. During the study period 13 patients with dementia were observed at the ED reporting symptoms that could be constructed as stroke, including multi-infarct dementia. Clinical evaluation led to their exclusion from the study (see table-29, page 227). In most circumstances the family described the situation as acute or referred that severe deterioration had recently occurred. The majority of these patients was not admitted, and when admission did occur a potentially reversible disorder was present.

Dementia is a chronic disorder that pushes family coping abilities to their limits. Families of demented patients have been particularly neglected in Portugal as in other western societies. This is an example of a chronic situation requiring further evaluation and the development of appropriate programs.

#### 7.2.1 Patients without family

In urban settings like Porto, patients without family constitute a group that poses special problems. In the rural areas of Portugal local hospitals maintain some of the social functions associated with their origin as charity houses, but these functions have been rejected by urban,

"more professional" settings. The case histories presented below clearly demonstrate that these institutions are not well equipped to handle situations in which an important social component is present. In addition, community health and social services are often non-existent or unaware of such problems.

Mrs. M.C., 79 years old, widow, lived alone in a poor Porto's neighborhood. She was taken to the ED by neighbors who described that "she was found lying on the ground, her face assymetric and her speech slurred." The patient was diagnosed as having suffered a TIB (right-hemisphere) and the CT scan also revealed an old TIB (left-hemisphere). Mrs. M.C. was described as not being able to do her domestic work only taking care of her personal hygiene which was markedly deficient. Neighbors also reported that the patient had severe alcoholic habits and that the only family member they were aware of was a nephew. He used to collect the patient's pension and give it to a neighbor who was in charge of feeding the patient. The patient stayed 258 days in a medicine ward and had little improvement of severe motor deficits. Later, she was transferred to a religious nursing home thirty miles from Porto.

Mr. A.L., 64 years old, single, described as retired as well as "without known occupation", lived in a boarding house in the Se neighborhood. Early in the study period, Mr. A.L. was admitted to a Medicine ward with the diagnosis of TIB. The patient remained bed-ridden during the entire hospital stay (474 days). He had no family and the only solution found was to discharge the patient to the hospital of the village where he was born where, eventually, he would still find relatives or friends.

Ms. M.A.B., 62 years old, single, retired, described by neighbors as a manicurist, suffered a IPH (right thalamus). In addition to hemiplegia and hemianesthesia, the patient had central blindness. After 82 days in a Medicine ward, neighbors were able to arrange for the patient to go living with relatives in a small village located approximately 40 miles from Porto.

More dramatic situations have been observed. By nature of their fragmented approaches and lack of integration, the social and health systems occasionally fail to, or rather belatedly, recognize the magnitude of extreme situations such as the one documented below.

Mrs. M.I.S., a widow of 76 years of age, lived in the Se neighborhood. She was taken to the ED by neighbors and diagnosed as having suffered a minor TIB. The patient was discharged home and prescribed antiplatelet agents. A week later the patient was brought back to the ED where she was described by her neighbors as "having stopped eating and become speechless." The attending physician classified the situation as "stabilized CVD" and recommended home care. Approximately six months after the initial observation, a social worker took the patient to the ED where she reported that Mrs. M.I.S. was living in an attic under complete deprivation. A friend of Mrs. M.I.S. was regularly paying a neighbor to feed the patient, but that was not occurring lately. The patient was formally admitted to a ward with the diagnoses of severe malnutrition, heart failure, and multiple decubitus ulcers. Attempts were made to transfer the patient to a nursing home what did not actually happen and the patient died 23 days after admission.

#### 7.2.2 Families and the unavailability of home and/or long term care

The home care component of the Portuguese health system has been dramatically reduced in recent years, and today it is practically non-existent. The unavailability of home care is a major challenge to families' coping abilities. As a result, the ED is the place where families seek care which otherwise could have been provided by the domiciliary sector. Such is the case of patients in need of a urinary

catheter, a feeding tube or, eventually, minor surgical procedures for decubiti, situations that add to the already heavy ED patient load.

In other instances, families that eventually can afford to use private services, may find that a bed for a stroke patient also may be difficult to obtain outside the public sector. This situation is documented in the two case-histories below.

Mrs. A.G.M., a widow of 77 years of age, was admitted to a Medicine ward with the diagnosis of TIB. Two days later, the patient was described as "waiting to be transferred to a private clinic." Three weeks after onset the patient was still in the ward and in another note the attending physician reported that Mrs. A.G.M. "is waiting to be taken home by the family." Two weeks later the patient died in the ward.

Mrs. V.S.M., 67 years old, married, retired, was admitted to a Medicine ward with the diagnosis of IPH. 33 days later she was discharged and physician's notes referred that the patient was transferred to a special nursing home, exclusive of members of an association of commercial workers. Follow-up notes show that the patient never used the service, and that she died at home approximately two months after discharge.

All the above case-histories clearly emphasize the complexities and insufficiencies of stroke care in Porto and the options available to families. Occasionally the system seems to work satisfactorily. These cases occurred in situations such as that of three patients transferred to the rehabilitative unit in the Hospital Rodrigues Semide, and of two patients who used the private sector extensively. One of

the latter had bought a "room-for-life" in a private/religious clinic. The other patient was covered by the fee-for-service post office workers health insurance.

As it was pointed out at the beginning of this section, family coping strategies depend on the available health care resources, as well as family characteristics. The above section has provided qualitative information on family adaptative styles, and identified what are the current choices available and the major problems encountered by families living in Porto. The next section will focus on the determinants of successful family adaptation, and on the interactions between the different factors involved.

### 7.3 THE DETERMINANTS OF FAMILY ADAPTATION

In the previous sections I discussed the general adaptative process following stroke and the importance of observed high mortality rates. This section focuses on survivors and long-term family adaptation. In-depth household interviews were conducted after a variable period since stroke onset (minimum six months).

The descriptive data already presented suggest that certain variables are of greater importance than others in determining families' adaptative mechanisms. Given the complexity of these mechanisms, it would be simplistic to



expect that any one variable could predict or account for the complete observed variation. The model proposed on figure-3 assumes this type of complexity and, therefore, proposes that combined effects of several variables are the best predictors of family adaptation. It is hypothesized that individual/family characteristics and community resources indicators are associated with each other, and that these in turn are associated with the dependent variable.

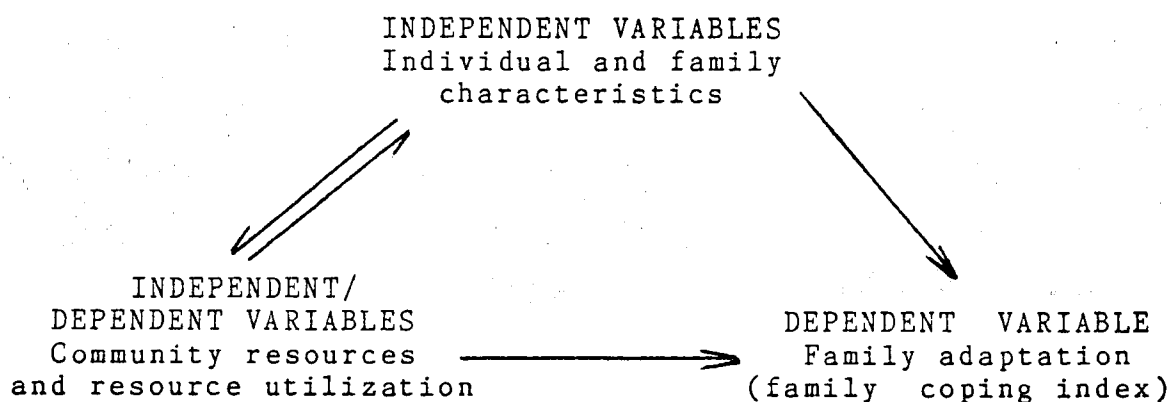


FIGURE-3: Predictive model of family adaptation.

Family adaptation was measured using the "health-specific family coping index for non-institutional care" which is "an instrument that assesses how well a patient's family is coping or functioning" (Choi et al., 1983:1275). The usefulness of the index has been extensively discussed by Freeman and Heinrich (1981), as well as by Choi and associates.

A five point scale (1=very rarely coping to 5=completely coping) was used to rate family coping along nine domains: (1) physical independence; (2) therapeutic competence; (3) knowledge of health condition; (4) application of principles of general hygiene; (5) health care attitude; (6) emotional competence; (7) family living patterns; (8) physical environment; and (9) the use of community resources. The mean of these nine scores is the family coping index.

General individual characteristics (e.g., age, sex, education, number of years in Porto, etc.) and personal characteristics directly associated with stroke (e.g., maximum and current global disability levels, history of CVD and type of stroke) were also included. Global disability was measured by the following five point scale (Royal College of Physicians of London, 1974:4):

DISABILITY	CAPACITY
I None	- able to carry out all usual activities.
II Slight	- able to walk; independent self care; some previous activities lost.
III Moderate	- walk unaided; some help with self-care.
IV Moderately severe	- unable to walk alone; no self-care unaided.
V Severe	- bedfast or chairfast; incontinent; constant care.

Family characteristics refer to both household relatives and non-household significant ones. The role of attributes such as family structure, family support, family participation in care and in community activities, and general socioeconomic indicators was also studied.

Community resources were evaluated measuring the actual use of available services such as those provided by local agencies (e.g., community groups, religious organizations) and/or health care services (e.g., medical, rehabilitative).

The relationships between these variables are presented below, based on data from 80 complete interviews. At the time of the community survey, 116 patients were alive (see table-44, page 261). However, as table-47 depicts, 31.1% of all contacts (36 cases) were excluded from further analysis,

	males	females	<u>total</u>	
			n	%
refused	2	3	5	4.3
incomplete interview	-	1	1	0.9
less than 24 hours duration	3	3	6	5.2
false address	9	4	13	11.2
changed residence	1	5	6	5.2
institutionalized	0	4	4	3.4
denies having had a stroke	-	1	1	0.9
Total	15	21	36	31.1

TABLE-47: Patients alive at the time of interview and reasons for exclusion from subsequent analysis.

due to a wide variety of reasons, including denial and the inability of recalling the time profile of the disorder. Among these cases were 11 complete interviews which were excluded because the patient did not actually live in Porto (5 cases), and six cases that reported that stroke symptoms lasted less than 24 hours.

### 7.3.1 Family Adaptation and Individual Characteristics

Age is a factor of major importance in both the etiology and behavior patterns associated with stroke. Age is also a major determinant of outcome. It is a generalized belief that, with few exceptions, CVD is a disorder of the elderly. Table-27 (page 225) shows that this is not entirely the case in this study population, among whom 35.5% of all strokes occurred in persons aged 64 years or less. Table-48 depicts the age structure of patients in the community survey. No patients aged 85 or more years were interviewed

Age Group	<u>Males</u>		<u>Females</u>		<u>Total</u>	
	n	%	n	%	n	%
-44	1	2.8	4	9.1	5	6.3
45-54	9	25.0	3	6.8	12	15.0
55-64	8	22.2	11	25.0	19	23.8
65-74	12	33.3	15	34.1	27	33.8
75-84	6	16.7	11	25.0	17	21.3
all ages	36	45.0	44	55.0	80	100.0

TABLE-48: Number and percentage of community survey patients by sex and age group.

and 45.1% of those contacted were aged 64 or less.

Age is also related to other independent variables such as education, socioeconomic data, and others. Table-49 presents the regression correlation matrix for family coping index and selected quantitative individual variables (age, years living in Porto, years at present residence, current global disability and maximum global disability).

family coping	age	years in Porto	years in residence	educat. level	current disabil.	maximum disabil.
family coping -	0.07	0.04	0.07	*** 0.39	-0.09	-0.06
age	--	*** 0.51	0.21	-0.18	0.18	-0.01
years in Porto		--	*** 0.37	-0.05	0.04	-0.09
years in residence			--	-0.01	-0.01	-0.02
education level				--	-0.17	0.01
current disability					--	*** 0.66
maximum disability						--

\*\*\*  $p < 0.001$

TABLE-49: Correlation matrix for independent individual factors and dependent variable family coping index.

Education was the only independent variable to show a statistically significant relationship with the dependent variable (family coping index).

Regression analysis on family coping index and the variables age and patient education (tables 50 and 51)

---

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	0.20174930	0.20174930
ERROR	78	42.02294206	0.53875567
CORRECTED TOTAL	79	42.22469136	

F VALUE = 0.37

PR >F = 0.5424

R-SQUARE = 0.004778

---

TABLE-50: Regression analysis for family coping index and age.

---

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	5.62647892	5.62647892
ERROR	78	36.59821244	0.46920785
CORRECTED TOTAL	79	42.22469136	

F VALUE = 11.99

PR >F = 0.0009

R-SQUARE = 0.133251

---

TABLE-51: Regression analysis for family coping index and patient education.

confirmed the lack of association between the first two variables, and the significant association between the family coping index and patient education.

An analysis of variance for the adaptation score and sex differences (table-52) did not show significant group differences. Similar results were observed for variables directly associated with stroke -- stroke type (hemorrhagic and ischemic), history of previous CVD, and disability level (tables-53 to 56).

---

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	0.07005861	0.07005861
ERROR	78	42.15463275	0.54044401
CORRECTED TOTAL	79	42.22469136	

F VALUE = 0.13

PR >F = 0.7198

---

TABLE-52: Analysis of variance for family coping index and sex.

---

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	0.00237154	0.00237154
ERROR	78	42.22231982	0.54131179
CORRECTED TOTAL	79	42.22469136	

F VALUE = 0.00

PR >F = 0.9474

---

TABLE-53: Analysis of variance for family coping index and stroke type.

---

 DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	0.01797975	0.01797975
ERROR	78	42.20671160	0.54111169
CORRECTED TOTAL	79	42.22469136	

F VALUE = 0.03

PR &gt;F = 0.8558

---

 TABLE-54: Analysis of variance for family coping index and history of stroke.

---

 DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	4	1.02441211	0.25610303
ERROR	75	41.20027925	0.54933706
CORRECTED TOTAL	79	42.22469136	

F VALUE = 0.47

PR &gt;F = 0.7603

---

		MEANS	
CURRENT DISABILITY		N	FAMILY COPING
level 1	1	28	3.7262
	2	20	3.8167
	3	18	3.5185
	4	8	3.6806
	5	6	3.5370

---

TABLE-55: Analysis of variance for family coping index and current disability.



## DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	4	0.99061020	0.24765255
ERROR	75	41.23408116	0.54978775
CORRECTED TOTAL	79	42.22469136	

F VALUE = 0.45

PR &gt;F = 0.7717

## MEANS

MAXIMUM DISABILITY	N	FAMILY COPING
level 1	11	3.6768
2	11	3.9495
3	19	3.5848
4	14	3.6667
5	25	3.6533

TABLE-56: Analysis of variance for family coping index and maximum disability.

7.3.2 Family Adaptation and Family Characteristics

Family characteristics studied included the number of individuals living with the patient in the same household and the significant ones described by the interviewee -- those considered part of the patient's support network, particularly those who performed special roles in association with the disease episode being studied. In order to characterize these individuals along demographic and occupational attributes, as well as family functions (participation in patient care and general family activities), a household and a non-household matrix was developed.

	family coping	house hold	non-hhold	empld	un-empld	max. educ.	soc. sup.	participation
family coping	-0.01	0.16	-0.12	-0.07	0.38	0.03	-0.03	
household	--	**	***	***	*	***	***	***
non-hhold		--	**	-0.31	-0.20	0.33	0.28	0.14
empld				--	**	0.16	0.50	0.52
unempl					--	0.02	0.29	0.30
maximum education						--	**	0.42
social support							--	***
participation in care								--

\*  $p < 0.05$     \*\*  $p < 0.01$     \*\*\*  $p < 0.001$

TABLE-57: Correlation matrix for independent family factors and dependent variable family coping index.

Table-57 presents the correlation coefficients for quantitative family variables.

Similarly to what was described for the relationship between family coping index and individual characteristics, the only significant association observed was with the maximum education level of household or non-household members, (see also table 58, below).

A significant negative correlation was found between the reported number of household and non-household members, which appears to reflect the fact that large families are more likely to use the coping resources available within their own household, at the same time reporting a smaller number of significant non-household relationships. Significant correlations were also found for the relationships between the patient's age and the number of household members ( $r=-0.27$ ,  $p=0.017$ ), as well as non-household members ( $r=0.31$ ,  $p=0.005$ ).

The variables "employed" and "unemployed" refer to the occupational status of household members. The positive correlation between employment and number of household members, and the negative correlation with number of non-household members are also expression of the inverse relationship between household and non-household membership.

The variables "social support" and "participation in care" measure the reported number of patient's daily contacts with household and non-household members, and those individuals daily participation in care. As expected, significant correlations were found between these variables and the number of household members. A low order correlation was observed for the relationship between non-household members and number of daily contacts. No association was found between daily participation in care and the number of non-household support persons. Similar results were observed

when weekly contacts and participation in care activities were considered.

These findings provide further support to the notion that family care resources were predominantly within household.

As already pointed out, with the exception of maximum education level, no associations were found between other family characteristics and family adaptation as measured by the family coping index. Tables 58 and 59 below, depict the relationships between family coping index and maximum family education level, and the interaction with patient education.

---

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	6.22206086	6.22206086
ERROR	78	36.00263094	0.46157219
CORRECTED TOTAL	79	42.22469136	

F VALUE = 13.48

PR >F = 0.0004

R-SQUARE = 0.147356

---

TABLE-58: Regression analysis for family coping index and maximum family education level.

It is important to notice that although the variables measuring education show a significant association with family coping, this association is not improved by the combined effect of both variables. A low correlation

## DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	3	10.69912766	3.56637589
ERROR	76	31.52556370	0.41481005
CORRECTED TOTAL	79	42.22469136	

F VALUE = 8.60                      PR >F = 0.0001  
R-SQUARE = 0.253386

SOURCE	DF	TYPE III SS	F VALUE	PR > F
CASE EDUCATION	1	1.08903412	2.63	0.1093
MAX. FAMILY EDUC.	1	1.29020193	3.11	0.0818
CASE EDUC.*FAM.EDUC.	1	0.05394698	0.13	0.7194

TABLE-59: Multiple regression between family coping index, patient education, and maximum education.

coefficient was found for the two education variables ( $r=0.11$ ,  $p=0.317$ ).

With regard to economic status, the great majority of the interviewees refused to report household income. In most cases the only information volunteered was that associated with the amounts of the pensions collected, which was the subject of complaints about its small amounts. Nevertheless it was possible to collect information regarding house ownership. However, this information should not be regarded as a good indicator of economic resources in the study area. An analysis of variance showed that there was no association between house ownership and family coping index (Table-60, below).

An indirect measure of economic power is the type of health insurance coverage available to the patient. While

## DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	0.94231091	0.94231091
ERROR	78	41.28238045	0.52926129
CORRECTED TOTAL	79	42.22469136	

F VALUE = 1.78

PR &gt; F = 0.1860

TABLE-60: Analysis of variance for family coping index and house ownership.

some of the wealthier classes may be covered by the general SMS system and use private services when in need, other Portuguese sub-systems (banks, civil servants, post office, electricity company, and others) provide either special schemes or fee-for-service coverage, which may be considered an indicator of higher socioeconomic status. The analysis of variance between the family coping index and type of

## DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	1.81528327	1.81528327
ERROR	78	40.40940809	0.51806933
CORRECTED TOTAL	79	42.22469136	

F VALUE = 3.50

PR &gt; F = 0.0650

HEALTH INSURANCE	MEANS	
	N	FAMILY COPING
SMS	69	3.6232
other	11	4.0606

TABLE-61: Analysis of variance between family coping index and type of health insurance.

health insurance (table-61, above) revealed a F value=3.5 ( $p=0.065$ ), which does not reach statistical significance at the point 0.05 level but, nevertheless, is a value that requires further analysis.

Multiple regression analysis involving type of health insurance coverage and the already discussed significant education variables (both individual and highest family level), showed a r-square of 0.27 ( $p=0.0001$ ) for the three variables combined (table-62).

---

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	3	11.51651862	3.83883954
ERROR	76	30.70817274	0.40405490
CORRECTED TOTAL	79	42.22469136	

F VALUE = 9.50      PR > F = 0.0001  
 R-SQUARE = 0.272744

SOURCE	DF	TYPE III SS	F VALUE	PR > F
HEALTH INSURANCE	1	0.87133794	2.16	0.1461
CASE EDUCATION	1	3.75153780	9.28	0.0032
MAX. FAMILY EDUC.	1	4.90952376	12.15	0.0008

---

TABLE-62: Multiple regression between family coping index, type of health insurance, patient education, and maximum family education level.

Controlling for type of health insurance (tables 63 and 64, below) education variables were found to be only statistically significant for the group covered by the general SMS scheme. This suggests that education may be particularly important when economic resources are limited,

---

TSMS=1 (General health insurance, SMS coverage)

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	2	10.40652386	5.20326193
ERROR	66	25.89514012	0.39235061
CORRECTED TOTAL	68	36.30166398	

F VALUE = 13.26

PR >F = 0.0001

R-SQUARE = 0.286668

SOURCE	DF	TYPE III SS	F VALUE	PR > F
CASE EDUCATION	1	4.31068128	10.99	0.0015
MAX. FAMILY EDUC.	1	3.32924066	8.49	0.0049

---

TABLE-63: Multiple regression between family coping index, patient education, and maximum family education, controlling for type of health insurance (general health insurance group).

---

TSMS=2 (Special health insurance)

DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	2	0.27100617	0.13550308
ERROR	8	3.83673794	0.47959224
CORRECTED TOTAL	10	4.10774411	

F VALUE = 0.28

PR >F = 0.7611

R-SQUARE = 0.065974

SOURCE	DF	TYPE III SS	F VALUE	PR > F
CASE EDUCATION	1	0.00910855	0.02	0.8938
MAX. FAMILY EDUC.	1	0.15866527	0.33	0.5810

---

TABLE-64: Multiple regression between family coping index, patient education, and maximum family education, controlling for type of health insurance (non-SMS coverage group).



and less so when a satisfactory economic status (measured by type of health insurance) has been achieved.

### 7.3.3 Family Adaptation and Community Resources

An important characteristic of Porto's current situation is the limited use and availability of resources associated with contemporary stroke care and rehabilitation. Physician's services are the exceptions, frequently being the only component of care. Table-65 depicts selected service utilization among the follow-up group, based on the question "ever used in association with the disease episode being studied."

Six individuals reported that they do not have a regular source of medical care, and 28 patients were

Service	n	%
Physician	74	92.5
Out-patient clinic	28	35.0
Nurse	13	16.3
Physical therapy	25	31.3
Home physical therapy	3	3.8
Speech therapy	2	2.5
Day center	4	5.0
Social services	2	2.5

TABLE-65: Service utilization in the follow-up group.

currently enrolled in one or more HGSA outpatient clinics: physical therapy - 2 patients (2.5%), neurology - 12 (15%), and internal medicine - 18 (22.5%). With regard to physical therapy, 25 patients reported some use of these services, of whom only 16 reported having more than 20 sessions. Very limited use of home physical therapy, speech therapy, day care centers, and social services was observed. Vocational and/or occupational therapy were non-existent. Eleven families (13.9%) reported the regular use of domestic services but no one reported the use of home visiting services, which have recently become available in selected areas of Porto.

Limited participation in organized community activities was also observed (table-66). This is an area that most families declined to elaborate. Their responses were in general terms such as: "We do not participate in anything. Life is going to work and back home." The observed frequencies for reported community activities by household members should be viewed with caution.

Activity	n	%
Cultural group	3	3.8
Sports group	4	5.0
Professional group	2	2.5
Religious activities	26	32.5

TABLE-66: Families' participation in community activities.

No participation in other groups (e.g., local administration, political) was reported.

Six families considered the visit of the local priest a form of support. Two families referred that they have hospital beds on loan, one from the local religious organization and the other one from a self-help group, respectively.

With the exception of physician and physical therapy services, and religious participation, the small numbers involved introduce major constraints for any statistical analysis. The overall use of community resources is included in one of the domains of the family coping index and is addressed in conjunction with it.

In order to clarify the determinants of physical therapy usage a stepwise multiple regression analysis (backward procedure) was performed. The procedure, which allows us to arrive at the best possible fit of the data, was run separately for each sex.

Eleven independent variables (age, maximum and current disability, patient education, maximum family education, number of years in Porto, maximum family number of years in Porto, number of household and non-household members, number of household and NON-household members contacting the patient at least once a week, and length of follow-up) were

entered, using the use of physical therapy services as the dependent variable.

For both sexes combined a r-square of 0.19 was obtained for all variables entered. A final r-square of 0.12 was obtained after the exclusion of all variables except maximum disability level and number of non-household members.

The next step involved similar testing for each sex (tables 67 and 68). These tables show that the best predictor for males is the current disability level in association with maximum education level (r-square=0.25,  $p=0.001$ ). For females the only variable significant at 0.1 level was the number of non-household members. A low coefficient of determination was observed (r-square=0.15,  $p=0.039$ ).

BACKWARD ELIMINATION PROCEDURE FOR DEPENDENT VARIABLE:  
PHYSICAL THERAPY

STEP 0 ALL VARIABLES ENTERED

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	11	2.90232361	0.26384760
ERROR	24	5.65323195	0.23555133
CORRECTED TOTAL	35	8.55555556	

F VALUE = 1.12 PR > F = 0.3887  
R-SQUARE = 0.33923263

-----  
STEP 9

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	2	2.12902718	1.06451359
ERROR	33	6.42652838	0.19474328
CORRECTED TOTAL	35	8.55555556	

F VALUE = 5.47 PR > F = 0.0089  
R-SQUARE = 0.24884733

	B VALUE	STD ERROR	TYPE II SS	F VALUE	PR > F
INTERCEPT	0.3122				
MAX. EDUC.	-0.0701	0.0398	0.6052	3.11	0.0872
CURR. DIS.	0.1688	0.0692	1.1586	5.95	0.0203

ALL VARIABLES IN THE MODEL ARE SIGNIFICANTE AT THE 0.1 LEVEL

SUMMARY OF BACKWARD ELIMINATION PROCEDURE

STEP	VARIABLE REMOVED	NUMBER IN	PARTIAL R**2	MODEL R**2	F VALUE	PR > F
1	MAX. PORTO	10	0.0000	0.3392	0.0001	0.9910
2	HOUSEHOLD	9	0.0002	0.3390	0.0074	0.9322
3	FOLLOW-UP	8	0.0009	0.3381	0.0352	0.8526
4	YEARS IN PORTO	7	0.0027	0.3355	0.1092	0.7436
5	CASE EDUC.	6	0.0070	0.3285	0.2929	0.5926
6	MAX. DISAB.	5	0.0115	0.3170	0.4971	0.4864
7	NON-HHOLD	4	0.0090	0.3080	0.3940	0.5349
8	SOC. SUPPORT	3	0.0061	0.3019	0.2739	0.6044
9	AGE	2	0.0531	0.2488	2.4325	0.1287

TABLE-67: (MALES) Stepwise multiple regression for dependent variable use of physical therapy.

---

BACKWARD ELIMINATION PROCEDURE FOR DEPENDENT VARIABLE:  
PHYSICAL THERAPY

STEP 0 ALL VARIABLES ENTERED

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	11	1.85333900	0.16848536
ERROR	32	6.39666100	0.19989566
CORRECTED TOTAL	43	8.25000000	

F VALUE = 0.84                      PR >F = 0.6008  
R-SQUARE = 0.22464715

-----  
STEP 10

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	1	0.80908720	0.80908720
ERROR	42	7.44091280	0.17716459
CORRECTED TOTAL	43	8.25000000	

F VALUE = 4.57                      PR >F = 0.0385  
R-SQUARE = 0.09807118

	B VALUE	STD ERROR	TYPE II SS	F VALUE	PR > F
INTERCEPT	0.3623				
NON-HHOLD	-0.0852	0.0399	0.8091	4.57	0.0385

ALL VARIABLES IN THE MODEL ARE SIGNIFICANTE AT THE 0.1 LEVEL

SUMMARY OF BACKWARD ELIMINATION PROCEDURE

STEP	VARIABLE REMOVED	NUMBER IN	PARTIAL R**2	MODEL R**2	F VALUE	PR > F
1	YEARS PORTO	10	0.0003	0.2243	0.0129	0.9103
2	MAX. PORTO	9	0.0005	0.2238	0.0221	0.8826
3	HOUSEHOLD	8	0.0007	0.2231	0.0299	0.8638
4	MAX. EDUC.	7	0.0017	0.2214	0.0777	0.7820
5	CASE EDUC.	6	0.0024	0.2190	0.1109	0.7411
6	AGE	5	0.0057	0.2133	0.2702	0.6063
7	FOLLOW-UP	4	0.0078	0.2055	0.3758	0.5435
8	CURR. DISAB.	3	0.0309	0.1746	1.5188	0.2252
9	SOC. SUPPORT	2	0.0199	0.1546	0.9664	0.3315
10	MAX.DISABIL.	1	0.0566	0.0981	2.7438	0.1053

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TABLE-68: (FEMALES) Stepwise multiple regression for dependent variable REHB. (use of physical therapy).

#### 7.3.4 Follow-up Length as a Confounding Variable

A reference is made here to the potentially confounding role of the different follow-up lengths. A regression analysis for the variables family coping index and length of follow-up showed no association between the two variables (table-69).

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#### DEPENDENT VARIABLE: FAMILY COPING INDEX

SOURCE	DF	SUM OF SQUARES	MEAN SQUARE
MODEL	1	1.44454728	1.44454728
ERROR	78	40.78014408	0.52282236
CORRECTED TOTAL	79	42.22469136	

F VALUE = 2.76                      PR >F = 0.1005  
R-SQUARE = 0.034211

---

TABLE-69: Regression analysis for family coping index and follow-up length.

#### 7.3.5 The Relationships between Individual and Family Characteristics and Family Adaptation

In order to clarify the complex role and the inter-relationships of the various variables on the overall family coping index, a stepwise multiple regression analysis was also performed. Demographic and clinical data presented above clearly suggested the presence of major differences between the two sexes. Tables 70 and 71, below, present these results.

BACKWARD ELIMINATION PROCEDURE FOR DEPENDENT VARIABLE:  
FAMILY COPING INDEX

STEP 0 ALL VARIABLES ENTERED

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	11	13.30052935	1.20913903
ERROR	24	5.79686434	0.24153601
CORRECTED TOTAL	35	19.09739369	

F VALUE = 5.01 PR >F = 0.0005

R-SQUARE = 0.69645783

-----  
STEP 7

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	4	11.71908896	2.92977224
ERROR	31	7.37830473	0.23800983
CORRECTED TOTAL	35	19.09739369	

F VALUE = 12.31

PR >F = 0.0001

R-SQUARE = 0.61364860

	B VALUE	STD ERROR	TYPE II SS	F VALUE	PR > F
INTERCEPT	2.3939				
NON-HHOLD	-0.2306	0.1066	1.1357	4.77	0.0366
HOUSEHOLD	-0.1854	0.0760	1.4159	5.95	0.0206
CASE EDUC.	0.3795	0.0744	6.1911	26.01	0.0001
MAX. EDUC.	0.1480	0.0610	1.4008	5.89	0.0213

ALL VARIABLES IN THE MODEL ARE SIGNIFICANTE AT THE 0.1 LEVEL

SUMMARY OF BACKWARD ELIMINATION PROCEDURE

STEP	VARIABLE REMOVED	NUMBER IN	PARTIAL R**2	MODEL R**2	F VALUE	PR > F
1	CUR. DISAB.	10	0.0007	0.6958	0.0545	0.8174
2	MAX. DISAB.	9	0.0039	0.6919	0.3192	0.5771
3	MAX. PORTO	8	0.0119	0.6800	1.0025	0.3259
4	YEARS PORTO	7	0.0020	0.6780	0.1654	0.6874
5	FOLLOW-UP	6	0.0142	0.6638	1.2387	0.2752
6	SOC. SUPPORT.	5	0.0219	0.6419	1.8870	0.1801
7	AGE	4	0.0283	0.6136	2.3689	0.1343

TABLE-70: (MALES) Stepwise multiple regression for dependent variable family coping index.



BACKWARD ELIMINATION PROCEDURE FOR DEPENDENT VARIABLE:  
FAMILY COPING INDEX

STEP 0 ALL VARIABLES ENTERED

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	11	11.22678067	1.02061642
ERROR	32	11.83045839	0.36970182
CORRECTED TOTAL	43	23.05723906	

F VALUE = 2.76 PR >F = 0.0123  
R-SQUARE = 0.48690915

STEP 5

	DF	SUM OF SQUARES	MEAN SQUARE
REGRESSION	6	9.99656295	1.66609383
ERROR	37	13.06067610	0.35299125
CORRECTED TOTAL	43	23.05723906	

F VALUE = 4.72 PR >F = 0.0012  
R-SQUARE = 0.43355421

	B VALUE	STD ERROR	TYPE II SS	F VALUE	PR > F
INTERCEPT	2.7426				
NON-HHOLD	0.1812	0.0756	2.0262	5.74	0.0218
HOUSEHOLD	0.2643	0.0853	3.3866	9.59	0.0037
MAX.PORTO	-0.0089	0.0051	1.0736	3.04	0.0895
CASE EDUC.	0.1501	0.0727	1.5058	4.27	0.0459
MAX. EDUC.	0.2377	0.0690	4.1850	11.86	0.0014
SOC. SUP.	-0.2774	0.0785	4.4092	12.49	0.0011

ALL VARIABLES IN THE MODEL ARE SIGNIFICANTE AT THE 0.1 LEVEL

SUMMARY OF BACKWARD ELIMINATION PROCEDURE

STEP	VARIABLE REMOVED	NUMBER IN	PARTIAL R**2	MODEL R**2	F VALUE	PR > F
1	AGE	10	0.0001	0.4868	0.0049	0.9447
2	CUR. DISAB.	9	0.0014	0.4854	0.0913	0.7645
3	YEARS PORTO	8	0.0080	0.4774	0.5309	0.4712
4	FOLLOW-UP	7	0.0261	0.4513	1.7480	0.1947
5	MAX. DISAB.	6	0.0177	0.4336	1.1626	0.2881

TABLE-71: (FEMALES) Stepwise multiple regression for dependent variable family coping index.

The procedures clearly confirm the expected sex differences. Patient and family education together with the number of household and non-household members are the best predictors of male family coping index ( $r\text{-square}=0.61$ ,  $p=0.0001$ ). For females a lower coefficient of determination was observed ( $r\text{-square}=0.43$ ,  $p=0.0012$ ). In addition to the variables found to be significant for males at  $p=0.1$  level, the number of weekly contacts by both household and non-household members and the maximum number of years in Porto, also contributed to the model.

The results point for both sexes the importance of education and of the number of household and non-household members available. However, a more complex predictive model is required for females. Despite the inclusion of two additional variables -- "family maximum number of years in Porto" and "number of contacts (at least once a week)", the model explains a smaller amount of the observed variation.

## CHAPTER 8

### CONCLUSIONS AND RECOMMENDATIONS

This study has examined socio-epidemiological aspects of cerebrovascular disease in Porto, Portugal, and explored family adaptation mechanisms associated with the various phases of the disease. Of particular importance in this context is society's construction of disabilities and its organized responses to the problem.

#### 8.1 THE SOCIAL CONSTRUCTION OF DISABILITY

Concern over disability has a long history which reflects the economy, level of technology, class interests, and ideology of the times. Frequently nations and communities have acted to protect those citizens judged to be the most valuable for the survival of the institution. Disability benefits have been generally determined by an individual's relative position in the labor force and the likelihood of his return to work after rehabilitation. It may be argued that policies and programs for the disabled

therefore, reflect the self-interests, economic concerns, and values of those in power.

All societies produce impairments related to their particular social organization and levels of technology. The diseases currently prevalent in industrial countries are chronic in nature and produce considerable impairment and socially defined disability before they finally kill. In these societies degenerative and man-made diseases like heart disease, stroke, and cancer have progressively replaced communicable disease as the primary causes of morbidity and mortality. These shifts in disease patterns are closely related to the socioeconomic transitions associated with modernization. Changes in the causes of death coupled with rising life expectancies also account for increased disability by creating a large infirm older population judged to be incapable of performing many social roles. Albrecht and Levy (1981:19) emphasize the social construction of disability:

Regardless of their incidence or prevalence, certain impairments are considered disabling only when they interfere with the individual's ability to perform expected social roles... The attribution of meaning to impairments is learned, culturally specific, and moderated by the individual's place in society.

Furthermore, disabilities are subjected to moral evaluations and selective social perceptions which, in some cases, are associated with the attribution of the

responsability for the impairment (e.g., venereal disease, drinking and smoking disorders).

In what regards social policies and programs associated with social problems, they are formulated within the context of competing social values, competing political interests, and multiple interpretations of the problem and its solution. For Greenwood (1985), disability dilemmas and rehabilitation tensions are a twentieth century inheritance. The situation is characterized by the presence of dilemmas which are present when determining and providing for the needs of disable persons and may take several forms: self-perceived and self-defined need versus bureaucratic standards and statistical definition; resource compensation versus resource enhancement; urban versus rural needs. Closely related to these perplexing problems are tensions in rehabilitation approaches: institutional and community approaches; individual functional improvement and environmental improvement.

We could argue, as Albrecht and Levy (1981:21) do that

government ideologies and policies actually shape the definitions of disability to achieve an acceptable fit between the perceived societal need and existing resources, value constraints, and social interests... Critics of governmental intervention note that the infusion of politics into the construction of social problems and development of policy depreciates the values of a purely rational decision-model of policy analysis. They prefer to rely upon such conventions as objective needs assessment, program design, and resource allocation to provide unbiased "open market"

guidelines. Yet, as we have argued, there is no value-free conception of any aspect of social policy, whether one is talking about disability determination or ascertaining who should receive care.

Another particularly important point to be considered is the generally recognized fact that the group that controls the construction of a social problem most often controls the policy response. For example, physicians for many years have been interested in providing acute care for patients with disability, but they had little interest in rehabilitation medicine because it was low-prestige work and not very profitable. As a consequence, rehabilitation services were built on a social service model and delivered by physical and occupational therapists, social workers, and psychologists. As demand for rehabilitation services increased and insurance benefits expanded, there was an incentive for physicians to enter the rehabilitative field. The designing of comprehensive rehabilitation programs, led hospitals and physicians to promote the incorporation of rehabilitation services into the medical model. Definitions of disabling conditions and appropriate treatment were expanded to include medical intervention and physician control. However, many disabilities are the result of social conditions and amenable to social service intervention. Medical care treatment, for example, is not going to solve low-income, social isolation, and architectural barriers

that are highly prevalent among the disabled. At issue is the conflict over bureaucratic supremacy between the medical (health) and social service sectors of the government. The clash involves ideological and theoretical differences concerning the nature of the problem and the required responses.

The medicalization of disability has brought both benefits and disadvantages (Albrecht and Levy, 1981:23). On one hand people in need can get quality medical care that would not be available under a strictly social service model. In addition, medical diagnosis provides the necessary mechanism for controlling the flow of patients in and out of services, which is of particular importance from an organizational viewpoint. Negative consequences include the assumption that physician based services are appropriate even when social conditions prevail. The medical model also contributes to take the responsibility for their actions away from the individual and their families as well as it may provide a rationale for some non-impaired persons to act as disabled.

In addition to traditional physical therapy, modern rehabilitation services include occupational and vocational therapy, speech therapy, therapeutic recreation, financial advice, psychological counseling, and a wide variety of care home services. These developments reflect significant changes in what regards the medical approach to

disabilities. Medical problems resulting from poliomyelitis or accidents used to be first treated in acute hospitals. Later the patients were passed to nursing facilities or sent home. As the impact of chronic diseases and accidents expanded, the definition of disability broadened to include a host of additional services beyond medical intervention.

In industrialized societies the socially acceptable response to the disability problem has been rehabilitation. As a consequence insurance benefits have been increased and rehabilitation programs expanded over the years. Yet, several authors point out that cost-benefit analysis for conditions caused by accidents and chronic illness suggest that prevention is a much more useful strategy (Terris, 1980; Russell, 1986). Therefore disability should be regarded basically as a public health problem rather than exclusively a medical problem. Nutritional, environmental, and behavioral changes should therefore be viewed as more important than potential medical cures of the developed condition.

## 8.2 Society and Stroke Care

Society's construction of disability is particularly evident in what respects stroke care. Much ambiguity characterizes current approaches, even when countries with similar development levels are considered. As it was



previously described two opposite views prevail. On one side we have those who consider that all stroke patients deserve hospital evaluation for diagnosis, although not necessarily for treatment. These authors also consider that the care of patients with a complete stroke is enhanced by concentrating medical and nursing facilities in one area, but this need not to be intensive or even acute (Norris and Hachinski, 1985:33). Hospital admission is also recommended by WHO and is considered essential in the United States, where it is thought that only 5% of the stroke patients remain at home (Robins and Weinfeld, 1981).

Another perspective is that shared by a large number of British authors who consider that admissions should be divided in two groups: (1) for diagnosis and (2) for treatment. These authors consider that with appropriate community support it is possible to considerably reduce the number in the latter group (Wade and Hewer, 1983 and Wade et al., 1985). Supporting this view, Cochrane (1970) noted that in South Wales 60% of all clinical strokes never went to the hospital, and that they were similar as regards to severity and case fatality to those hospitalized. The author concluded that the indications for hospitalization in the area appeared to be mainly social. Hewer (1972) also reported that patients from Great Britain's South West, supposedly admitted for treatment, often received little or no treatment. The average acute stroke inpatient received

approximately half an hour's physiotherapy a day and the average amount given on outpatient basis was one hour per week. He also found major limitations with regard to speech therapy, which in some places was totally unavailable. Hewer (1972:52) points out that according to his experience,

rehabilitation programmes offered by district general hospitals are unsatisfactory... I suspect that a similar situation exists in many acute district general hospital throughout the country.

The Geriatrics Committee Working Group on Strokes appointed by the Royal College of Physicians of London (1974:9) summarizes what is still a common situation:

From surveys and their own experience, Working Group members appreciated that strokes should not be wholly regarded as a hospital-based problem, but they realised also that some shortcomings in treatment must be the result of haphazard practice whereby some hemiplegics are treated at home, others in general medical, neurological, neurosurgical or geriatric wards, and because, as survivors, their fate depends as much on chance as on any established system of care. Some obtain excellent long-term rehabilitation and follow-up but most others are given none, or much less than they need. The services available to them are notoriously deficient in systematic assessment, standardized methods of treatment, and guidance by remedial and speech therapists with special knowledge of hemiplegia. Family support is deficient in advice, practical support and economics. Co-ordination of in-patient, out-patient and community services through special hospital units is an attractive possibility.

The situation is totally different in the developing world, where tertiary medical care and rehabilitation is in general out of question for the great majority of the population (Gish, 1979).

### 8.3 The Portuguese Situation

The current socioeconomic development of Portugal, at an intermediate stage between industrialized nations and the developing world, is a major determinant of present social and health sector approaches to health, disease and associated disability. The situation was extensively addressed in chapter 4, and particular reference was made to the severe and long lasting economic crisis that affects the country. Health and social welfare sectors have traditionally been extremely vulnerable to such crises and, therefore, it is not suprising to find that limited services and benefits are being offered to the great majority of the Portuguese population.

The current health situation of Portugal is also characterized by progressive reductions in communicable disease morbidity and mortality and marked increases in chronic degenerative disorders. This type of situation is one that requires organized efforts of both health and social sectors in order to achieve the best results from two possible approaches: (1) disease prevention and (2) minimization of the social consequences of chronic disorders.

Stroke is an excellent example of a problem that requires an integrated approach. However, despite being the country's leading cause of death and a major cause of morbidity and disability, national efforts aimed at its

control have been fragmented and, with few exceptions, predominantly based on medical models. This is the case of hypertension detection and control programs, which after initial community-based public health orientations, were subjected to major funding restrictions that led to significant program changes. Current approaches emphasize individualized clinical care, which despite the large numbers of physicians available in the country, is a sector affected by important organizational constraints. As a result the development of strong patient/physician relationships (of particular importance to compliance for anti-hypertensive regimes), is greatly neglected. In addition, the above described conflicts that affect the health/social services relationships in a wide variety of societies are particularly pervasive in Portugal. Contacts with key social sector personnel in Porto provided me with the understanding that current approaches are predominantly directed towards determining which of the sectors should be responsible for taking charge of the situation lacking integration.

This study also raises a number of issues which have practical implications of particular importance for Portuguese families, communities, and health care institutions dealing with cerebrovascular disease.

The data from this study confirm the importance of cerebrovascular disease in the study area. Comparisons with

other community-wide studies suggest that the prevalence in Porto is high, particularly among individuals aged less than 75 years. High frequencies of hemorrhagic stroke were found, confirming the potential role of uncontrolled hypertension which has been found to be particularly high in Portugal. In 1980, Miguel and Padua estimated that 31% of the population aged 25-64 was hypertensive and that only 6.7% was adequately controlled.

Lower than expected stroke rates were found among the older age groups, which may be explained by the fact that older patients may be treated at home and never referred to the ED. The presence of competing causes of death may also account for part of this pattern.

With regard to mortality, it was estimated that 39.2% of all stroke cases are dead within six months, the mortality being particularly high during the first 48 hours. These results are in accord with similar studies in the United States and other countries.

Another important characteristic of the study population is the current emphasis placed by families on hospital care and the unique role of the Hospital of Santo Antonio's emergency department (ED) during the initial phases of acute stroke. This role may be viewed as a mixture of the diagnostic functions suggested by Wade and Hower (1983), and of temporary admission associated with families' inability to provide the necessary home nursing care.

The process of active admission selection which occurs at the ED level was extensively documented. Few patients were admitted to a hospital ward exclusively for social or diagnostic reasons. In most circumstances patients were admitted for therapeutic interventions of both stroke and its complications. Only a small number of patients was exclusively admitted to benefit from physical therapy which hospital health professionals often describe as "starting late, lacking intensity and purpose, and being frequently initiated when the patient is near discharge." Few patients were actually transferred to the rehabilitation unit of the Hospital Rodrigues Semide or followed by the hospital's physical therapy out-patient clinic.

Compared with the results of the Monroe County Study (New York), hospital stays in Porto were found to be twice as long for patients who were eventually discharged, while for those transferred to another institution the average lengths of stay were nearly three times longer in Porto.

Families look to the health system, and in particular to its hospital component, expecting to obtain the care they need. Limited availability of community services, and the generalized belief that hospital care is the most appropriate to a quick and complete recovery, further accentuate hospital-oriented care seeking strategies. However the present system is not yet at a development stage that enables the provision of integrated rehabilitation

programs such as those currently available in most industrialized societies. Important components of the system are missing or not easily accessible (e.g., occupational and vocational therapy, speech therapy, home care).

The present situation may also be characterized by the presence of conflicting perspectives between the public and the hospital based health care system. The public views sheltering and therapy (including rehabilitation in general) as major hospital functions. Thus, it is not surprising to find that families have developed mechanisms to facilitate their access to the emergency departments. This is the case of address changes when preference for, or rejection by one of the city's Emergency Departments occurs. Rural patients confronted with the almost complete lack of diagnostic and rehabilitation facilities for stroke adopt similar strategies. As a result central hospitals are flooded with a large number of cases that in most circumstances could be managed locally. The exact effect of these care seeking strategies on the incidence rates presented above is unknown, since a significant proportion of these situations are not detected. According to this study 6.3% of the patients come from other areas of Porto, while 8.1% are from outside the city. If we assume that a similar proportion of patients from the study area uses the ED of the Hospital de S. Joao, only the group from outside the city will have a significant impact on the rates presented.

Frequently, these care seeking strategies are in conflict with prevailing attitudes regarding rehabilitation among health professionals. In Portugal, as in other societies, rehabilitation for complete stroke or other chronic disorders suffers from the long-established misperception that little or nothing can be done for the patient. Anderson and Kottke (1978:175) comment on this stating that

We have been bound by the concept from 19th century pathology that the lesion defines the patient. This has been taught in acute diagnostic and therapeutic medicine. What is done for the patient is what can be done to the pathology. If the lesion is permanent, nothing can be done for the patient.

Modern concepts emphasize the development of adaptative skills which will enable the individual to, as much as possible, resume independent and active life whether at home or in the work environment.

According to this philosophy, hospitalization may have major disadvantages. It may reinforce the expectation of "cure" as opposed to the development of new skills. On the other hand, care at home is usually thought to contribute to improvement of psychological and social adaptation of the patient and his family to illness, and lead to a closer involvement of the family doctor. (Wade and Hewer, 1985:305). Another disadvantage of hospitalization is emphasized by these authors, who note that many patients leaving hospital feel rejected and hopeless often believing



that "there is nothing more that can be done for me." If therapy is given in the patient's own home, the family and patient are inevitably more involved from the beginning and are likely to see rehabilitation less as a passively received process and more as an actively directed joint effort. This is in accordance with the positions of the movement initiated in the early 1970s that advocates increased activity on part of the client and his family (Sussman, 1972).

Further disadvantages are associated with the fact that patients themselves, once admitted, are usually reluctant to leave until much improved. Relatives similarly will be reluctant to have a disabled patient back, although they may have well been prepared to nurse him initially.

The situation with regard to physical therapy programs in Porto may be characterized as semi-chaotic. The very low correlations between various social indicators and the use of rehabilitative measures support this view, especially among females. Education was found to be the major predictor of use among males, while for females the only significant variable at  $p=0.1$  level was the number of non-household significant persons. Contrary to what we would expect no associations were found with disability, age, and other family variables. My participant observation as a health professional also suggested to me that the situation is remarkably similar to that described above by the Royal

College of Physicians' Working Group on Strokes (see page 310), where chance seems to prevail, rather than systematic organization of care and rehabilitation.

Qualitative and quantitative data clearly suggest that the phase immediately following stroke is the one that poses greatest challenges for families adaptative mechanisms. The case-histories presented in section 7.2 are illustrative. During this period the major objective of most families is to obtain acute hospital care. However, even when that is obtained, families have to deal with the patient condition at the time of discharge and make major adjustments. It is not surprising that hospital stays are often prolonged against the wishes of health professionals, due to the inability of the families to make the necessary adjustments. Of the families included in the community sample, 81.3% reported the presence of at least one caretaker (a person who is in charge of providing the care needed by the stroke victim), and nearly a quarter of them mentioned two or more caretakers. The vast majority of caretakers were females (80.2%) of whom 7.7% were aged 65 or more years. In addition, 26.2% of the caretakers stated that they had to adjust their working schedules. Some of them left employment completely to devote their time to caring for the stroke victim.

With regard to long term family coping abilities the majority of the families was found to be coping within

"average" levels. Only eleven families had family coping indexes below the neutral value of three, what was associated with limitations in more than one domain. Most families were found to have lower scores in only one or two domains, therefore balancing the overall score. Values above 4.5 ("coping well") were found in 10 families.

The best predictors of family coping abilities among males were education and the actual number of individuals available in and outside the household. A coefficient of determination of 0.61 ( $p=0.0001$ ) was found. For females a lower coefficient was obtained ( $r\text{-square}=0.43$ ,  $p=0.0012$ ) and the model included the same variables observed for males plus the maximum family number of years in Porto and the number of weekly contacts with the individual.

These results support the conclusion that for the study population education is a major determinant of coping abilities, and that men depend on all the available personnel inside their social support network in order to mobilize the resources available. The situation with regard to women, is less clear: more variables provide a less reliable model. It suggests that in addition to the variables found important for men two other variables are of particular importance -- the number of weekly contacts (which is a measure of the social support network functioning), and the number of years the family has lived in Porto.

The impact of illness on a family is still an area of limited and controversial information. Few health professionals or scholars challenge the proposition that illness or impairment in a family member has adverse effects on family functioning. Most agree that families of ill people generally function more poorly than families in which all the members are healthy. With the onset of an illness, the family's social life contracts and becomes primarily family-centered. Within this circumscribed existence the patient often becomes the focus of the family, with other family members forced into the background. Furthermore, most observers agree that the more severe and long lasting the illness or impairment, the greater the family disruption. However reasonable these propositions, empirical data to support them are slim and far from compelling.

#### 8.4 Recommendations

In order to make the following recommendations is necessary to make reference to the theoretical framework. This study clearly demonstrates that the present pattern of care in the city of Porto reflects cultural attitudes found in earlier ways of life, in which the role of the family was of utmost importance. Most of the patients studied were originally from rural areas. Cultural attitudes in the

family regarding coping and rehabilitation also result from the interaction of the family system with the curative and the other components of the health care system, which in this case as little to offer beyond acute care. "More active" or "more modern" approaches will require a greater effort and will only be realistic if more services are made available.

What we believe the data indicates is a situation in which the neutral level of adjustment (level-3) is reached by most families. Basic care needs are provided but little is done to help the patient resume a social active life. This also reflects what families understand as feasible to do under the present circumstances without having to challenge or extensively fight the current situation.

Two types of recommendations are presented here. The first set refers to emergency and other hospital care; recommendations 4 to 6 refer to community services.

Recommendation-1: The great majority of non-clinical problems and conflicts occurring at the emergency department are of a social nature. Often conflicting perspectives and expectations of the role of the ED are present. Social work at the emergency department has become a necessity for providing a less aversive and more supportive ED atmosphere. In addition to advocacy roles, social workers have an important function in helping families find and utilize a wide variety of resources that are often unknown

to the majority of the population and health professionals.

Recommendation-2: Discharge planning is of particular importance in the case of stroke patients. Currently this important component of care has been the exclusive responsibility of physicians. Often families disagree with the timing and/or type of discharge but they find themselves powerless. Discharge planning with the participation of all interested parties, including social workers, may contribute to reduction of gaps in care which often occur at the time of transition from hospital to community care.

Recommendation-3: The intermediate ED ward (here designated by OBS) would benefit greatly if a more dignified type of bed care was given to patients waiting clinical decisions. Although in most cases patients had not been formally admitted, it is my view that all effort should be made to provide the best possible care.

Recommendation-4: This research suggests that most families make major efforts to overcome bureaucratic and inequalities barriers that limit access to the emergency health care. These efforts are stressful and families are frequently concerned about possible legal consequences. In addition, health professionals are often distracted from their care functions to devote themselves to ascertain the patient's correct address. I understand that any changes in the current access policies to emergency departments may further deteriorate existing conditions. Efforts should be

directed towards eliminating current inequalities in care through the development of an appropriate primary care system, which would also contribute to the development of much needed prevention policies. While these solutions are not attained, administrative reasoning should take into consideration professional criteria and patient and family preferences.

Recommendation-5: This research supports the felt need for the development of intermediate care facilities such as those available in other western health systems. These units, often non-stroke oriented, provide comprehensive rehabilitative programs to those disabled but medically stable, at lower than hospital costs. This would also allow for the development of rehabilitation components currently missing or of very limited availability in Porto, including speech, vocational and occupational therapy.

Recommendation-6: Community programs to support these patients and their families should target particularly vulnerable families (e.g., economic and socially deprived). With the support of the local health, social and administrative sectors, coordinate home care services would provided the much needed and widely recommended home-based care that would enable early hospital discharge and improved family functioning. Such a home care system would make it possible to strengthen the integration of these families in the social fabric of Porto.

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