CHAPTER ONE

1.0 INTRODUCTION

Acquired immune deficiency syndrome (AIDS) and Human immune virus (HIV) have become a devastating disease around the globe. They have affected about 57.9 million people in the last two decades. Within this period, governments, non-government organizations, private sectors and civil societies are joining together in fighting HIV/AIDS epidemic. Marina¹ noted the victim’s stories of living with discrimination, with stigma, with pain, with loneliness and fear made me realizes that the full dimension of HIV and AIDS epidemic cannot be explained in laboratories or epidemiological studies. The people who understand it most, the people who have been infected as well as those around them, who care for them and love them, best explain it¹. In spite of the measures and strategies developed for awareness that is more effective to combat the spread, the story of the spread remains the same. The number of people falling victim to HIV/AIDS is increasing daily and it is threatening to cripple progress. Whereas there have been visible efforts by governments warning people about the danger of unprotected sexual relation and intravenous drug use, hence, the need for monitoring and evaluation of HIV/AIDS health education and promotion cannot be over emphasized.

This study derives from the conviction that a clear general perception of HIV/AIDS threat to life and development will provide the necessary format on which a formal study of

HIV and AIDS health education and promotion in Kuala Lumpur, Malaysia can be effectively undertaken.

Indeed, over the years, the emergence of HIV and AIDS as part of social health problem has become a dilemma. The disease once acquired will ultimately lead to death. Social factors, mainly lifestyle, significantly affect the extent to which the virus is transmitted, hitting the homosexuals or bisexual males, prostitutes, and intravenous drug users.

It is against this backdrop, therefore, that monitoring and evaluation of HIV/AIDS health education and promotion in Kuala Lumpur, Malaysia will be examined with a view to finding out how health education and promotion had helped Malaysians to overcome HIV and AIDS as social health problem. This work therefore, will discourse the origin/history of HIV/AIDS vis-a-vis health education and promotion.

1.1 BACKGROUND OF THE STUDY

It is believed that a clear background to the study of HIV/AIDS health education and promotion will provide the objective criteria that can sharpen one's appreciation of the fundamental problems involved in the monitoring and evaluating of HIV/AIDS health education, and promotion. This, in turn, will predispose an analyst toward a realistic appraisal of Malaysia's efforts toward prevention program of HIV/AIDS infection and spread.

Health Education has an ancient and complex history; its beginning can be traced to the very foundation of civilization. Much of the early history of the profession closely
parallels that of medicine and its associated sciences. In later times, particularly since 1800, the history of health education has taken on richness and character which is uniquely its own.

To the distant past when history began to fade into speculation, the earliest societies emerged from independent families into gatherers and hunters. Communities or people began to examine the forces that were shaping their lives the first. Two forces they experienced were illness and death. Although unable to identify the specific cause and effect relationship leading to illness and death, they were nevertheless able to determine that disease had some relationship to illness and death and therefore should be avoided. They also recognized that some members of the community lived longer than others. It was believed that people with great longevity must have had some special knowledge that enables them to remain healthy and alive. This belief is still reflected in the fact that people who survive into their 80s and beyond are frequently asked to reveal their secret of longevity. In primitive civilizations the survivors were respected and revered. Eventually the status of such survivors evolved to that of headmen or shamans whose role was to define and enforce the taboos of the culture. Compliance with taboos was believed to result in a longer and healthier life. Superstition evolved through taboos and mores to become laws that shaped public policy. The headmen gradually emerged ultimately become an institutional heads. The evolution of superstition into scientific fact and the role of shamans into what we call teachers, doctors, and other health specialists comprises the history of health education. The earliest traces of the history of health are found among paleontologist relics. They are composed of wall paintings, artifacts, and trephine skulls. The oldest written documents related to health are the Smith papyri

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1 Marina Mahathir, Ed Hidden Voices, True Malaysian Experiences of AIDS, Malaysia AIDS council Project 1999, P.1
dating from 1600 BC, which described various surgical techniques. "It described forty-eight cases in clinical surgery, from cranial fractures to injuries of the spine. ²

The modest document is followed by the Code of Hammurabi, which contains the earliest medical free-schedule, which serves as proof of an organized system of medicine 4000 years ago. Also are ancient writings particularly those of Homer credit, the good Asclepius with superior knowledge and ability in medicine.³

The Dark Age was replaced with vitality and dynamism of the Renaissance. The renaissance also has gradually lost its vitality and was replaced by an era of religious reformation. As the reformation ended, medical science and health care began on age of discovery and innovation more than anything else; this era after 1650 was characterized by the dominance of science and replacement of superstition with the analysis of cause and effect.⁴

Oxford Medical Dictionary describes health education as persuasive methods used to encourage people (either individually or collectively) to adopt lifestyles that the educators believe will improve health and to reject habits regarded as harmful to health or likely to shorten life expectancy.⁵

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Acquired Immune Deficiency Syndrome (AIDS) was recognized as a global threat by the World Health Assembly and the United Nations General Assembly in 1987 and by the Health Ministers at a summit meeting in London in January 1988.6

To find the source of AIDS, we need to look for the origin of HIV. What type of virus is HIV? HIV is said to be part of a family or group of viruses called lentiviruses. Lentiviruses other than HIV have been found in a wide range of non-human primates. These lentiviruses are known collectively as simian monkey viruses (SIV) where a subscript is used to denote their species of origin.7

So where did HIV come from? It is now generally accepted that HIV is a descendant of simian immune deficiency viruses bearing a very close resemblance to HIV—1 and HIV—2. The two types of HIV, for example HIV—2 corresponds to a simian immune deficiency virus found in the 'sooty mangabey monkey' (SIV), sometimes known as the green monkey which originates from Western Africa.8

Until 1999, HIV-1 was the most virulent strain of HIV. Its closest counterpart that had been identified was Simian (Monkey) immune deficiency virus that was known to infect chimpanzees (SIV CP2) but this virus had significant differences from HIV. In February 1999, it was announced that a group of researchers from the University of Alabama had studied frozen tissue from a chimpanzee and found that the simian viruses which carried SIV CP2 was almost identical to HIV-1. The chimpanzees came from a sub-group of chimpanzees known as pan troglodytes which were once common in West-central Africa. These researchers showed that chimpanzees were the sources of HIV-1 and that the viruses at some

6 Nancy Alexander (ed) Heterosexual Transmission of AIDS, Publisher, Alan R. Liss, New York, 1990, P.1
point crossed species from chimpanzees to human. However, it is not necessarily clear if those chimpanzees are the original reservoir for HIV-1 because chimpanzees were only rarely infected with SIV CP2. It is therefore possible that both chimpanzees and humans have been infected from a third, and yet unidentified primate species. It has been known for a long time that certain viruses can pass from animals to humans and this process is referred to as zoonosis. They suggested that HIV could have crossed over from chimpanzee as a result of a human killing a chimpanzee and eating it.

The human immune deficiency virus was unknown and signs or symptoms salient enough to be noticed did not accompany transmission. Although rare sporadic reports of AIDS and seroarchaeological studies have documented human infections with HIV prior to 1970, available data suggest that the current pandemic started in the mid-to-last 1970s. By 1980 HIV had spread to at least five continents which include North America, South America, Europe, Africa and Australia.

During the silent period, HIV spread was unchecked by unawareness or non-preventive actions, and approximately 100,000-300,000 persons may have been infected. The discovery period started in mid 1981 with the first description of AIDS in the United States. The recognition of a new health problem always had a remarkable stag (e.g. legionnaire's disease, toxic shock syndrome) and AIDS was no exception. The discovery in 1981-1985 was characterized by relatively rapid scientific advances in understanding of HIV/AIDS emerging from intense effort by a steadily expanding group of scientific

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8 Ibid.
9 Ibid.
investigators. The modes of AIDS transmission was defined before the virus was discovered.\textsuperscript{11}

The discovery of etiological agent permitted testing for antibodies to HIV which led to major discoveries, like the latency period infection from AIDS was seen to be long and measured in years. At the current stage of pandemic, the number of person infected with HIV in any population was discovered to exceed the number of persons with AIDS. The studies among different geographical population led to awareness of the global scope of HIV infection. Within the discovery period, the application of already existing scientific concepts and tools to the new problem rapidly provides information from which a realistic worldview of HIV/AIDS was constructed. Despite inevitable delays, this period was extremely productive and shortened the time from discovery of AIDS to global action. The history of AIDS began with global mobilization, which started immediately after, the first international conference on AIDS held in Atlanta, the United States in April 1985.

The AIDS context in 1985 and early 1986 was in many ways chaotic. As a result of small and occasionally inaccurate studies, many widely varying estimates were advanced on the scope of HIV infection particularly in Africa, coupled with the stigma attached to the affected countries by the world community. The ensuing climate of accusation and hostility among nations drastically reduced the open sharing of scientific information.\textsuperscript{12} In the mid-1990 and 2000, most nations were fully aware of the impact of HIV/AIDS spread. The Global Summary of the HIV/AIDS epidemic, December 2002 reported the number of people living with HIV/AIDS totals 42 million.

HIV/AIDS Total | 42 million
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Adults | 38.6 million
Women | 19.6 million
Children | 3.2 million

People newly infected with HIV in 2002 Total | 5 million
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Adults | 4.2 million
Women | 2 million
Children under 15 years | 800,000

AIDS Death in 2002 Total | 3.1 million
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Adults | 2.5 million
Women | 1.2 million
Children under 15 years | 610,000

As of January 1987, a total of 132,977 AIDS cases were officially reported to the World Health Organization from 143 countries. In Africa, the majority of cases have been reported from ten countries in Central, Eastern, and Southern Africa. In Americas, 87 percent of cases have been reported from the United States with more than 500 cases were reported from Brazil, Canada, the Dominican Republic, Haiti and Mexico. In Europe, of the 28 countries reporting AIDS cases, the largest numbers came from France, the Federal Republic of Germany, Italy, the United Kingdom and Spain, each of which has reported more than 1,000 cases. In Asia and Oceania, 27 countries have reported AIDS cases, and the largest numbers came from Australia, New-Zealand and Japan.

In October 1987, AIDS became the first disease ever debated on the floor of the United Nations General Assembly. The General Assembly recognized the enormous importance of social, cultural, economic, and political dimensions of AIDS and resolved to

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mobilize the entire United Nations system in the worldwide struggle against AIDS under the
leadership of World Health Organization.\textsuperscript{13}

But, it is very difficult to develop reliable estimates of the number of infected persons in
any group or country; hence AIDS and HIV infections were not randomly distributed. HIV
has infected different groups or sub-groups around the world at different rates and at different
times. Using the available information, three broad, but distinct patterns of infection could be
distinguished. While in all countries, the modes of HIV transmission are fundamentally the
same through sexual intercourse, blood contact and transmitted from mother to infant.

Details of personal and social risk behaviors in different areas have influenced the
distribution of infection. The patterns of HIV infection to some countries are explained thus:
Pattern I involves North America Western Europe, Australia, New Zealand, and many urban
areas in Latin America. In Pattern I areas, sexual transmission of HIV occurs predominantly
among homosexual or bisexual males, over 50 per cent of homosexual males in some urban
areas have been infected. Heterosexual transmission also occurs in these areas and is
increasing. Transmission through blood contact in Pattern I areas principally involves
persons with drug injecting behavior, as blood for transfusion and blood products have been
made essentially safe. Mother to infant spread is uncommon because relatively few women
have thus far been infected, but will increase as heterosexual transmission increases.

Pattern II areas include sub-Sahara Africa and parts of Latin America especially in the
Caribbean. In Pattern II, sexual transmission is predominantly heterosexual, up to 25 per cent
of the 20 years—40 years age group. Transmission through HIV contaminated blood
continued. While HIV screening of blood is not yet routine, drug-injecting behavior is rare in

\textsuperscript{13} ibid.
Pattern II. The use of un-sterilized needles or other skin-piercing instruments can contribute to HIV spread. HIV in Pattern II areas equally affects women; mother to infant spread is a major problem. In some areas, 5 to 15 per cent or more of pregnant women are HIV-infected. Between one quarter and half of the babies to be born from these infected women will be HIV positive.

Pattern III areas include Eastern Europe, North Africa, the Middle East and most countries in Asia and Pacific. In Pattern III areas, HIV appears to have been introduced more recently from the early to the mid 1980s. Thus far, only 1 percent of AIDS cases reported to WHO are from Pattern III countries. HIV infection has not yet penetrated into the general population of Pattern III countries.

The virus is present and is spreading and HIV infection is being increasingly recognized among persons with risk behavior such as homosexual or bisexual males, prostitutes and persons with drug injecting behavior. From 1986-1988, in practical terms, the implementing the global strategy had involved providing coordinated, technical and financial support to national AIDS programs with continued efforts to reach policy, scientific and technical consensus.

In January 1988, a world summit of ministers of health organized jointly by the government of the United Kingdom and the World Health Organization brought together an unprecedented number of Health Ministers to discuss national AIDS programs. The London Declaration on AIDS, which came from the summit, called upon all governments to inform

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14 ibid.
and educate their people about AIDS\textsuperscript{16}. During the 1988, this commitment was met and the declaration of World AIDS Day on 1\textsuperscript{st} December. World AIDS Day was concerned as a day of talk about AIDS, during which individuals, organizations and communities debated and considered how AIDS affect themselves, their communities, countries and the entire world. Events to highlight World AIDS Day occurred in every country throughout the world. As a result, the focus of World AIDS Day was on individuals families, groups and on specific programs and actions rather and to symbolize a world united against AIDS, facing uncertain future with realism, humanism and collective confidence.

In May 1988, the World Health Assembly considered and adopted a resolution entitled "Avoidance of discrimination in relation to HIV infected people and people with AIDS." The resolution urged countries to foster a spirit of understanding and compassion for HIV infected people and people with AIDS and to protect human rights and dignity of HIV infected person---to avoid discriminatory action against them and stigmatization of them in the provision of services, employment and travel. These actions are recommended in the interest of public health, to prevent HIV infection among persons whose behaviors place them at increased risk of exposure to HIV. They must be informed, educated, provided and helped to assume responsibility for preventing HIV transmission to others\textsuperscript{17}.

As of January, 1989, virtually all countries have established national AIDS committees through hundreds of expert missions. World health organization has provided support for technical assistant to over 145 countries that have established short-term (6 to 18 months) national AIDS plans and urgent technical and financial support has been provided to help these countries to start work without delay. An increasing number of countries as of 1st

\textsuperscript{16} ibid.

\textsuperscript{17} ibid.
January 1989, over 40 nations have developed medium term (1 to 5 years) plans for national AIDS prevention and control. The international agreement based on existing information has been useful in many areas including AIDS and work place, AIDS prevention and control in prisons, AIDS and drug users, Neuro-psychiatric aspects of HIV infection, AIDS and international travel. Thus, the global AIDS strategy had provided a framework for coordinated and coherent action against this disease and the strategy itself had evolved in response to new scientific information and policy perspectives, bearing in mind that extraordinary efforts against AIDS may yield a rich harvest of knowledge, personal and social to all.  

Health education and promotion are intertwined, i.e. symbiotic or complementary to each other. As it is believed that living a healthful life and observing those factors that can cause sickness, injury or death is health promotion. While Oxford Medical Dictionary defines health promotion as a program of surveillance planned on a community basis to maintain the best possible health and quality of life of the members of that community, both collectively and individually. Programs may include a blend of such personal services as health education, immunization and screening tests, with environmental monitoring of the atmosphere, housing, water and food supplies, as well as occupational hazards. But why health promotion? Before the mid-twentieth century, most of the sickness and deaths were caused by infectious diseases, which had acute onset and occurred in apparently random fashion among the population where little then could be done to prevent individual sickness. Hygiene education at that time focused on anatomy, physiology, and a few content areas such as contagion, alcohol education and personal cleanliness. Pedagogy consisted of didactic lessons aimed at helping people understand the disease process.

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18 ibid.
In the past 50 years, the major causes of death have shifted towards chronic diseases; which developed over a prolonged period of time and resulted largely from the negative aspect of people’s life styles. It was during this era that health educators learned the colorful title of “Warriors against pleasure”. It seemed as though anything that was fun and anything that tasted good was harmful to health. Therefore the primary word in the vocabulary of the mid twentieth century health educators was “Don’t eat sweets because they cause tooth decay”, "Don’t smoke cigarette because you will get lung cancer" and "Don’t have sexual intercourse because you might get pregnant.”

During the 1970s the new buzzword became health promotion and the educational approach adopted a whole new philosophy. The “don’t do this because” method of avoiding disease shifted to a more positive orientation that focused on quality of life. This change required health educators to call on a broad area of study known as behavioral sciences. If people were going to encourage others to make healthful lifestyle changes, it would be necessary to understand the principles of motivation, reinforcement and behavior modification. In the context of disease, prevention requires action to reduce or eliminate specific risk factors. Gradually, it became apparent that many contemporary illnesses could be linked to a person’s lifestyle.22

Health professionals, policy makers, economists and most importantly average citizens began to consider the possibility of disease prevention through personal activities that could actually raise one’s level of health beyond its present state. Health promotion takes place in a wide range of settings which includes the homes, schools, work sites and health

care facilities. A variety of techniques were employed to achieve the stated goals, among them are health education, risk reduction programs, environmental controls, mass media presentations, and activities that promote a healthy life style. Schools, colleges, professional associations, and voluntary health agencies, governments, business, labor unions, churches, synagogues, mosques, and private clubs, consumer and self-help groups sponsor these activities.23

Conclusively, HIV/AIDS as a modern health problem demanded positive informative approach especially in the teaching of health education as universal remedy or measure for overcoming HIV infection. Health education remains the necessary program in educating the general public on the issue of AIDS instead of letting emotions or fear dictate philosophy and policy. To date, the general public continues to have many misconceptions about HIV and AIDS. Consequently, HIV positive individuals suffer from discrimination, elimination from jobs and from sports. In some places, they were ostracized.24

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1.2 STATEMENT OF THE PROBLEM

Monitoring and evaluation of HIV/AIDS health education and promotion in Kuala Lumpur, Malaysia has become necessary owing to emergence of Human Immune virus (HIV) and Acquired Immune Deficiency syndrome (AIDS), which have created a modern health care dilemma. With AIDS as the greatest social health problem, the death toll continues to rise. The faces of those infected continue to change, social factors such as people's life styles significantly affect the extent to which the virus is transmitted, not even those working in an established system or those concerned with creation, evaluation, organization, storage, retrieval, and dissemination of information are exempted from HIV infection.

The stigmatization established around HIV/AIDS still produces concealment in people and such secrecy had not been overcome. The obstacles barring the use of dissection like morality, religion, and prejudice continue to be associated with AIDS. As a result, many individuals with HIV remain unidentified both in life and in death. The anonymity is often achieved and upheld through a desire on the part of the individual affected by the illness not to be identified as an HIV infected patient. The various agencies for health education and promotion appeared to have not been doing enough especially as regard to dissemination of health education instructional material to those who are at the risk of HIV infection. The pandemic has not forced the re-examination of cultural sensitive subjects like homosexuality, human sexuality etc which the society has historically chosen to ignore. The researcher feels it is imperative that people take time to analyze the pressure on them to act in particular ways and to understand how their own and clients perceptions of the syndrome may be influenced by cultural and social factors.
Individual lifestyle is rooted in HIV infection; as evidenced by people who often ignore warning about the danger of intravenous drug use and unprotected sexual relationships. Some individuals seem to disregard HIV as serious disease by promoting carelessness with regard to health care. Again, the system’s inability to develop comprehensive health education programs and at times, governments ignoring HIV as an emerging problem makes it worse. Among others are poverty which restrict the individual from seeking proper medical treatment, illiteracy makes the individual vulnerable to HIV infection; inhibitory social roles or cultural norms further restrict peoples ability or willingness to seek for health care; low level of education prevents them from assessing information about the disease; some parents lack obligation to their children.

The socio-psychological trauma following HIV infection perhaps is the reason why people are unwilling to go for HIV test. Coupled with non-availability of condom to the public for sex protection, non-teaching of drug and sex education and lack of sex education knowledge help to compound the problem. Inadequate counseling and health promotion in the concept of everyday life, vis-à-vis, shortage of health educators, including equipment for testing HIV and lack of clear-cut policy on the part of governments on the issue of HIV/AIDS are the major setbacks toward solving the problem.

Efforts to deal with the threat to public health posed by HIV infection will not depend on some magic bullet (i.e. solution) in the form of drug or vaccine. Health education must speak directly on the needs to a wide range of groups. It would be therefore unwise to produce one leaflet to be read by senior citizens and young people, while the problem naturally lingers on without solution. The feeling of 'not responsible to act for the general
good of the people' especially in preventing the spread of infectious disease such as
HIV/AIDS, could aggravate the situation.

Where there is no society participation in health education oriented issues because it
is not taken to be an essential pre-requisite for community development. Sustained behavior
change is difficult to bring about if people are treated as passive recipients of health
education messages. Health educators' failure to develop an effective health education
intervention around HIV/AIDS may offer no alternative other than to rely on a magic bullet.
The facilitators working in the field of HIV/AIDS disease think less in terms of ways the
education of the community could bring about lasting changes in behavior, neglecting the
physically disabled, and those with learning disabilities. It is worth noting in this respect that
advent of AIDS itself has led to the alienation of certain groups perhaps the most obviously
over looked are those whose cultural and /or linguistic background marks them out from the
norm.

Tina Wiseman contended that little or no attempt has been made to develop health
education strategies that are either culturally acceptable or linguistically appropriate to these
groups. She concludes that people with learning difficulties have also received little or no
attention by HIV education. Many of the strategies that presently exist assume a fairly high
degree of literacy amongst those they seek to involve\textsuperscript{25}. For many people, the sheer number
of words in a leaflet or poster may be daunting, how much more for those with learning
difficulties. Yet little or no attempt has been made to produce information in visual graphics.
Existing health education initiatives have also missed many young people. Some have had
too boring a feel to them; others have used inappropriate terminologies in consequence.
Some young people have been forced to fall back to their own resources, a situation which is worrying giving their probable high degree of sexual activity. Peter Aggleton noted that there is evidence that in the area of HIV education, many of the health education initiative are narrowly conceived and executed in haste without carefully considering its appropriateness to the present situation.\textsuperscript{26}

This study intends to undertake a descriptive investigative technique to tackling these problems by monitoring and evaluating the HIV/AIDS health education and promotion in Kuala Lumpur, Malaysia. Accordingly, the study will seek to answer the following questions:

What factors are responsible for ineffective and inefficient HIV/AIDS health education and promotion in Kuala Lumpur, Malaysia?

What methods of information dissemination are employed by AIDS organization in reaching the masses?

What benefits is the society hoped to derive from HIV/AIDS education?

What problems are facing an organization, which has no plan to train her health personnel?

\textsuperscript{26} Peter Aggleton edited, AIDS Social Representations-Social Practices. Publisher. The Falme press
1.3 OBJECTIVES OF THE STUDY

This study is premised on three central research objectives and is as follows:-

- To find out the problems militating against effective HIV/AIDS health education and promotion in terms of finance, personnel and mobility.

- To identify how the knowledge acquired from health education program helped to enhance Malaysians' awareness of HIV/AIDS as a social health problem.

- To ascertain the impact of HIV/AIDS health education and promotion among Malaysian students and how it is working in the school curriculum.

1.4 SIGNIFICANCE OF THE RESEARCH STUDY

This research is significant in many ways. Firstly, the issue of monitoring and evaluation of HIV/AIDS health education and promotion in Kuala Lumpur, Malaysia deserves investigation. Secondly, the devastating pattern of HIV/AIDS epidemic and spread has become a dilemma. Thirdly, the study will contribute to our understanding of the importance of monitoring and evaluation of HIV/AIDS health education and promotion programs. Finally it will contribute to the existing literature in social administration hence the relevance of this work.
1.5 SCOPE AND LIMITATION OF THE RESEARCH STUDY

"Monitoring and Evaluation of HIV/AIDS Health Education and Promotion in Kuala Lumpur Malaysia" are the scope of this study.

However, this work had not only become a victim of many limitations but also the attending problems in the library's lack of current research materials like textbooks, journals on health education, etc coupled with language barrier. Hence very few but relevant books are written in Bahasa Melayu and indeed difficult for the researcher to interpret and also difficult for the library attendant to provide a dint of translation into English Language which breed delay and had unexpectedly tried to undermine the great need of this work cum its subsequent long desire for completion.

Finally, the cost of transportation, logistics, and high cost of source materials and general problem of getting official documents from government officials, agencies, organizations equally slowed the pace of this research study.