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# PALLIATIVE CARE, ETHICS, AND THE JAMAICAN PARADIGM

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# ABSTRACT

Palliative care provides symptom control, social, psychological and spiritual care for terminally ill patients, and psycho-social support and bereavement care for their families. Ethics is the study of rational processes for determining the best course of action between conflicting values and choices. All medicine is practiced within a defined cultural setting and local beliefs about health and illness may determine particular solutions to ethical problems.

Culturo-religious beliefs and practices in Jamaica are linked historically to its people's African ancestry and to the syncretism of Euro-British values during slavery. The resulting socio-cultural and medical pluralism has presented an ethical dilemma concerning respect for the beliefs and wishes of terminally ill patients to seek care from magico-religious practitioners versus what is in the society's best interest.

# ABSTRAIT

Les soins palliatifs fournissent du contrôle contre des symptomes, de l'attention sociale, psychologique et spirituelle pour les malades en phase terminale, et du soin familial et soutien psycho-social pour des familles endeuillées. L'éthique est l'étude des processus rationnels qui déterminent la meilleure ligne de conduite parmi des valeurs et des choix contradictoires. Toute médecine est pratiquée dans un milieu culturel spécifique, et les croyances locaux concernant la santé et la maladie peuvent déterminer des solutions particulières pour les problèmes de l'éthique.

Les croyances et pratiques culturo-réligieuses à Jamaïque sont historiquement liées à l'ascendance africaine de son peuple et au syncrétisme des valeurs euro-britanniques pendant l'époque de l'esclavage. Le pluralisme socio-culturel et médical qui résulte présente un dilemme éthique lorsque le droit des malades en phase terminale de chercher du soin parmis des practiciens magico-réligieux, selon leurs croyances et souhaits, s'oppose à l'intérêt de la société.

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# INTRODUCTION

"There is something different about dying; it is distinct from other medical events".
(Battin, 72)

The practice of all medicine has evolved as a result of its setting within a unique cultural context, and valid attempts to analyze a particular medical system must include not only assessments of the social structure, social organization, and local beliefs system, but also how these relate, both historically and currently, to the total cultural context (Lock, 11). Concepts of health, illness, treatment, and the role of doctor and patient are all modified by cultural values.

Ethnomedicine denotes the concept that different societies view health care in different ways, and every society not only has its own belief systems but also its own set of solutions for life's problems (Roach, 3). In certain cultures, religious influences may determine the quality and character of an individual's life, and his or her perception of death. As a consequence, the conflicts brought about by differing belief systems may pose a real dilemma for some persons within certain societies.

Jamaica is a Caribbean country where religion plays a very important part in the lives of a majority of its inhabitants and represents a strong cohesive force among congregations of people (Leavitt, 66). Religion is intimately tied to the overall cultural and social life of the people and linked historically into their heritage and socio-political development. Religious pluralism has thrived and along with the social, economic and political changes through time, accounts for an enduring dichotomy of attitudes towards concepts of disease, disease etiology and health care in the Jamaican culture.

The history of Jamaica is essentially that of the coming together of a European people, the British and African people (Tucker, 14). The meeting of the two cultures on the slave plantations of Jamaica during the seventeenth and eighteenth centuries resulted in an insidious syncretism of culturo-religious beliefs, indigenous beliefs about how and why certain illnesses occur and from whom help should be sought, that have persisted until today.

Prior to the rise of modern medicine ("western-style"medicine, "scientific" medicine, biomedicine), most societies relied upon some form of magico-religious medical system in which religion, medicine and human mortality were closely intertwined (Miller-McLemore, 65). Such persons considered illness and health products of supernatural powers and evil human intent, but with the body/mind dualism philosophy of Rene Descartes and the development of the scientific model of medicine in most western countries there is no monolithic world view regarding the causation of illness and treatment (Mount [b], 30; Marty, 281). Indigenous beliefs and healing systems such as "obeah" in the West Indies have persisted and still influence many persons in some countries (Roach, 7).

A glance at the literature on a wide range of diseases shows that different theories about their causes, prevention, and treatment are held by both lay and professional persons (Fonaroff, 113). Some patients with terminal illness commonly turn to alternative therapies which may as yet be unproven or even medically unsound (Bulkin and Lukashok, 13).

Indeed alternative medicine may not be "alternative", as in a pluralistic society many persons may turn to this form of therapy first, or in addition to scientific medicine, rather than as a last resort (Roach, 39).

Jamaica, like most developing countries, suffers from a severe shortage of various biomedical personnel, and medical professionals that are able to emigrate often do so (Fonaroff, 113; Leavitt, 80). Few doctors work outside main towns, and specialist services are only to be found in a handful of parish capitals. Yet the practice of alternatives to biomedicine is prohibited by law despite the report that large numbers of people believe in and turn to these practices (Leavitt, 67). Some terminally ill patients in Jamaica are therefore presented with a dilemma: whether to resort to a system of care that is in keeping with their own African heritage belief system or to respect the law forbidding such practices.

Based on a British study, up to 55% of cancer patients in Britain may already have an incurable disease upon presentation to biomedical practitioners (Tate,140). Curative treatment is attempted for 45% of these patients, resulting in 30% obtaining long term cures while the remaining 15% (treatment failures) will move to the palliative arm of care. 70% of all cancer patients therefore require terminal care, and the concept of hospice has arisen out of a dissatisfaction with modern medicine's approach to such care (Mor and Masterson-Allen, 120).

By denoting an active treatment philosophy, the term "palliative care services" is now preferred to "hospice" which generally care for dying cancer patients (Gates, 5). Symptoms of an incurable disease are eased and controlled, the remaining powers and abilities are maintained and the patient and his or her family may then live as full a life as possible with palliative care (Oliver, 15; Latimer [b], 65). The aim is to help people to die well, in comfort and with dignity, by meeting their specific physical, emotional, social and spiritual needs (Grey, 215; Doyle, 92; Greenaway et al, 275). Services may be offered to any terminally ill patient who has opted not to continue curative treatment and may include patients with cancer; end-stage cardiac, lung, liver, and renal disease; AIDS; motor neurone disease, and end-stage Alzheimer's disease (Gurfolino and Dumas, 533; Grothe and Brody, 48; Fraser, 24; Foley et al, 22). Palliative care can therefore be a viable option for almost all terminally ill patients.

In view of all these important issues, this thesis examines the moral dilemma posed in the Jamaican paradigm: that of respecting the beliefs and wishes of terminally ill patients versus beneficence, providing for the well-being of patients in the public's best interest. I will also explore whether culturally appropriate palliative care may provide a possible solution to this dilemma.

In Chapter 1, I examine the salient issues relevant to respecting wishes in the Jamaican setting. Providing a background to the Jamaican context, I discuss the concept of self-determination and family values, and the attitudes, preferences and limitations of the local health care team. As religion is intrinsically interwoven with cultural issues in Jamaica, I present these two issues simultaneously, providing the historical context. I also provide insight into financial factors and complete the chapter by discussing the legal and moral issues related to society's interests.

Chapter 2 provides a literature review outlining the history of palliative care and the various models existing in some developed countries, from which I hope to identify features which might be of value to creating a model for Jamaica. Chapter 3 presents the results of a literature search for reports on palliative care services provided in various parts of the world, and the chapter ends with my tailoring palliative care to the specific Jamaican culture, utilizing information gathered from chapters 2 and 3.

In Chapter 4, I will examine the various ethical dimensions to all issues raised, including important ethical principles and values, the possible options to resolve the dilemma, and the consequences for each option. At the end of each major chapter, I will attempt to summarize the important issues raised therein. The thesis will end with a final summary and conclusion, which will include my recommendation for the resolution of the moral dilemma.

# CHAPTER 1: RESPECTING WISHES AND THE JAMAICAN PARADIGM

This chapter establishes the major ethical components in the dilemma for terminally ill patients in Jamaica. Of relevance are the principles of self-determination, respect for values, preferences and personal beliefs, the norms of culture, religion, law and the social and political realities in Jamaica. All these considerations are necessary to reach a practical and fair resolution of the particular moral dilemma.

## 1.1) Background to the Jamaican context:

The largest English-speaking Caribbean island, Jamaica belongs to the group of islands known as the West Indies. Approximately 140 miles long from east to west and 50 miles across at its widest point, the country lies 90 miles south of Cuba and west of Haiti, and about 600 miles south of Miami, Florida. Its topography consists mainly of flat, narrow coastal plains and mountainous regions, with nearly half of the island being over 1,000ft high and its Blue Mountain range ascending to a peak of 7,402ft. In the large rural areas therefore, transportation is a major problem.

More than 90% of Jamaica's 2.5 million people have African ancestors, being descendants of slaves taken from West and central Africa (Sobo, 22; Chevannes, 138). Although British English is the language standard, most Jamaicans speak a form of "Jamaican dialect" or "patois", a mixture of archaic English, Spanish, and various African languages (Barrett, 17). While 44% live in urban areas, the greater part of the Jamaican population lives, works and dies in the rural areas (Fendall, 1294). Since slavery was abolished only 160 years ago, the population in the rural areas comprise mainly peasant farmers who have only a rudimentary formal education (Fanaroff, 114).

During the 1970s, the Jamaican government initiated policies to provide health care for all citizens, but since then economic conditions have considerably worsened due to the worldwide economic upheavals, producing a substantial negative effect on the delivery of health services (Seivwright, 22). In 1987, the per capita yearly income was reported as U$1,000, and 20.8% of the labour force was unemployed (STATIN, 1988). With an annual inflation rate above 30%, Sloper claims that 60% of the population live below poverty level (Sloper, 1). As a relatively low income developing country, Jamaica cannot provide adequate biomedical services for all its people, and at present the public sector provides less than 30% while the private sector provides over 70% of all health care services (Golding, 110; Donaldson, 11; Fendall, 1296).

The present distribution of biomedical services is heavily weighted toward urban and coastal areas, and significantly more health dollars are expended on curative rather than preventive or supportive services (Marchione,227). Distributed across rural Jamaica are small health centres in which are located community health aides and a visiting staff nurse and public health nurse on certain days of the week. Only two palliative care services operate in Jamaica, both of which are located solely in the capital city. A British trained oncology nurse founded one facility, the Consie Walters Center for Cancer care, which operates a small six bed hospice on the grounds of the St. Joseph's Hospital, a private institution under the auspices of the local Catholic Church. Using a few nurses and volunteers, this facility also offers some home care of unspecified quality.

Also located in Kingston, the country's capital, the second facility is a small, private, non-profit organization with an office at the government's Hope Institute for Cancer. Its services are almost entirely domiciliary, with admitting privileges allowed to three beds at the Hope Institute. Here, the "physical model" of palliative care is provided by a retired Orthopaedic Surgeon and a part-time oncology nurse who meet once or twice per week to make home visits (Golding, 111). This program hopes to establish satellite services in some rural areas once the requisite human and financial resources can be realized.

### 1.2) Self-determination and family values

The principle of autonomy that North American bioethicists have emphasized is not well established in the Jamaican culture. Some principles and behaviours which operate in this country's upper and middle classes are neither established nor accepted as ideal among the larger peasant or working class society (Clarke,17). In the typical Jamaican setting many people may live together, and it is not uncommon to find a grandmother, a daughter and her child, another daughter and her common-law husband, and four grandchildren being together in one home (Sobo,147). Underpinned by a heritage of slavery, close interpersonal relationship dynamics therefore make decision-making a group process.

With the extended family being the norm, kin have historically assumed some responsibility for caring when one of its members fall ill. The family provides support and collectively dialogue with health care professionals where some individuals do not have much biomedical knowledge (Clarke,142). Rather than the Euro-American "individual" deliberation with emphasis on self, decisions, when made, will almost invariably reflect a joint deliberative, consultative process.

In providing full support and love, some say family relationships may enable individuals to advance their own personal interest (Nelson, 7). Jamaican families usually have common interests, and major decisions affecting the well-being of one individual are likely to have significant effects upon the well-being of others, whether socially, financially, or emotionally. Consequently, collective family decision-making about the welfare of one of its members could arguably be considered ethical in the particular Jamaican paradigm.

For the terminally ill, a good death should occur naturally, with support for spiritual needs and relief of symptoms (McCue,1039). In a true palliative care setting, the health care team could have a significant role to play in helping the terminally ill and their families accept the impending death, mitigate their fears, and assuage their feelings of sadness and loss. However in Jamaica most persons are not aware or fully informed of the nature and scope of palliative care, and so patients, relatives, friends and significant others make management decisions within a vacuum of knowledge.

Employees of the Ministry of Health estimate that 70% of Jamaica's population generally receive and accept most of its health information from indigenous practitioners and influential lay persons (Fonaroff,114). Conflicts may arise as indigenous beliefs about the etiology of most illnesses being due to "bad blood" or "obeah" (witchcraft) may be at odds with the teachings and practice of the biomedical team (Fonaroff,116). Also, because they are often unaware of warning symptoms, some cancer patients may be more inclined to first consult their local traditional healer and so will sometimes present to biomedical practitioners in a more advanced state requiring more palliative and less curative interventions. As terminally ill patients often opt for alternative methods once scientific interventions cease, the attitudes, preferences and limitations of the local biomedical team are therefore important in the analysis of this dilemma.

### 1.3) The biomedical team: Attitudes, preferences, and limitations:

"All medicine is palliation because we all have to die."
(Riley, 242)

The concept of palliative care is nothing new as it is not so long ago that some doctors regarded the care of the dying and the support of their families as an essential part of their practice, a role not easily delegated (Norris, 459). Preceding scientific medicine's ability to cure or put diseases into remission, caring for the sick and suffering was at the core of medicine's practice (Hauerwas [b], 23; Harrison, 528). The continuance of care to the end of life even when cure is not possible carries a strong ethical component, yet biomedical practitioners seem to fixate more on the detail of diagnosis, patho-physiology, and therapeutics than on the greater moral issue of "caring" for the patient (Fischer,106; Mount [a], 60).

Some have said that the physician has a responsibility to ensure that his hopelessly ill patient dies with dignity and with as little suffering as possible (American College of Physicians, 265). This may involve decisions such as when radical curative treatment should cease and palliative care measures begun (Ashby et al, 1322). Terminal care has to be individualistic as the same pathological trauma may affect people variously, and a specific strategy may be needed to deal with pain as well as adequately dealing with suffering (Petrie, 2; Patterson and Emmanuel, 1518). In fact, humans may suffer in different ways, ways that are not always considered by modern medicine (O'Rourke and Boyle, 311).

Some physicians are not trained, are not experienced, and are uncomfortable with the management of terminally ill patients (Kerr-Wilson, 113). Often, health professionals have little training in the techniques of breaking bad news, a proposition that is difficult under the best of circumstances (Oliver, 17). Indeed, the biomedical physician may be considered limited in his applications as although he identifies and ministers to our disease with causal explanations and scientific predictions, he does not show the way to the spiritual side of illness, nor perhaps offers much social or psychological support (Creevy, 68; May [a], 87).

Many Jamaican doctors come from a background of people among whom the use of folk medicine is an entrenched way of life. Yet, having been educated and socialized in modern medicine's concepts of disease, many of these doctors tend to hold to the system of meaning that they have internalized and understood, and so provide care only along that model (Griffith, 570). They tend to disregard native practices such as "obeah" as superstition, which they feel interfere with their patient's compliance with prescribed therapy (Morrow, 4; Laguerre, 50). Some have described their attitude as one of "benign neglect", since they may be well aware that folk medicine practitioners are sought after by not only the peasant class but also some of the affluent, yet they have failed to fully explore these practices, whether by scientific enterprise or anthropological studies (Barrett, 90). However, others have claimed that a few bio-physicians have been known to refer patients with serious cases of psychosomatic illness to some of the more reputable folk healers whom they believe would do a better job than themselves under the circumstances (Barrett, 91).

Beaubrun has argued that in a culture undergoing transition from magico-religious thinking to scientific pragmatic thinking, it is important that every doctor be taught the social anthropological background of the patient with whom he deals (Beaubrun, 52). Yet the majority of biomedical practitioners have ignored the influences which magico-religious belief systems have on some of their patients, and by only providing care along a physical model, they leave a void in the emotional, spiritual and social spheres which some believe is the domain of African folk medicine practitioners.

## 1.4) Culturo-religious factors in the Jamaican psyche:

> "And when I did come in the church road there, it was very late, two of us, me and me brodder. So we sort of walk pious like that in the road. Met a big bush in the topside, see a big thing just - just flash and drop in between the two of us to the bottomside, and I say I goin' knock 'im back, and me brodder says, "No, you leave it alone!". Well, we came to the gate, and I see me [dead] daddy. It was mi daddy. Yes, it was mi daddy. Him do so to me, three time. It was very late. It was very late, and that's why him do it so, just give me a sign like that." ("A Sign from Daddy", Folklore from Contemporary Jamaicans, p.40)

When one is describing the way of life of a people, one is really talking about culture; it involves those ways of knowing, imagining and doing things that people learn to regard as natural (Shkilnyk, 58). To examine culture is to examine the elements which shape human behaviours - the inhibitions which govern it from the inside; the rules that control it from the outside; the languages and philosophies that serve to edit a people's experience of life, and the customs and rituals which help to define how one person should relate to another. To understand the culture of Jamaican folk medicine therefore will require looking at the origins of the people and their methods of healing before and after they arrived on the island; to understand why many terminally ill patients have been attending Jamaican "bush doctors" for their emotional, social, and spiritual care will involve looking at the healing fraternity of the African medicine man going all the way back to antiquity (Barrett, 68; Roach, 10).

Jamaica's African roots originated in the vast expanses of West and West-central Africa, from among the lost homelands of Ebo, Guinea and the Congo from where the vast majority of slaves were brought to the island (Cooper, 34; Roach, 9). Dominant were the Ashanti and Fanti tribes, closely related in both origin and language, and the Yomba-Ibo people whose influences still predominate across the Caribbean (Barrett,16; Leavitt,64). Indeed, still a market centre in eastern Nigeria from whence came many Iboes to the island, "Mocho town" is the name of a famous community in Jamaica today (Barrett, 17).

Belief in the supernatural was an integral part of life in West Africa (Williams, 450). Along with counter-magic, witchcraft theory invoked various manual and vocal rites and dances, with soul-hunts, exorcism, and purification methods which might involve blood-letting, massages, baths and drugs (Ackernecht, 507). Amulets served as magical preventive methods and the society's medicine man was not only a magician, but might also have been a priest and sorcerer. Indeed, Ackernecht relates the African medicine man (or woman) to the modern day priest, while the African lay healer (usually a woman and midwife) was related to the modern day physician (Ackernecht, 508).

In pre-literate societies, the causes of disease could be either personalistic or naturalistic (Foster, 773). Correlated with personalistic etiologies were the beliefs that all misfortune, disease included, were explained in the same way; that illness, religion, and magic were inseparable; that the most powerful curers had supernatural and magical powers, and that their primary role was diagnostic. In naturalistic etiology belief systems, disease causality had nothing to do with other misfortunes; religion and magic were largely unrelated to illness; the principal curers lacked supernatural or magic powers, and their primary role was therapeutic (Foster, 773). Both systems may exist in a given society but usually one form predominates, and most people are committed to one system to account for the majority of illness (Foster, 776). In fact, these two disease etiology belief systems are present in the Jamaican society today.

Indigenous medicine must have fulfilled a role in order to have succeeded through time, and its effectiveness may have depended on many factors: the relative effectiveness of massage, blood-letting, baths, and cauterization; a number of native drugs which were effective (for example, opium, hashish, hemp, coca, cinchona, eucalyptus, sarsaparilla, acacia, kousso, copaiba, guaiac, jalap, and podophyllin); and remedies which may have acted through the mind and mobilized strong psychic forces (Ackernecht, 512). Magic medicine may satisfy a basic craving in humanity, a certain metaphysical need for the ideal, for dreams and for the unreal (Ackernecht, 516). If these explanations are plausible, then by satisfying a physical need, and by providing satisfaction through metaphysical participation, magico-religious medicine may never die in many pluralistic, non-western societies.

The focus of indigenous medicine has had to change with time: in the hunter/gatherers of ancient Africa infectious diseases posed a major problem, whereas in some societies today non-communicable diseases such as cancer present a challenge for healing (McKeown, 37). Yet certain practices remain the same: the wearing of amulets and "charms" to ward off the evil spirits causing illnesses has persisted (Williams, 540); the traditional magico-religious healer continues to be the equivalent of a doctor, philosopher, and priest (Braithwaite, 219); and many African beliefs determine the actions of many in the Jamaican society today (Williams, 448).

Jamaica's present history began when the Spaniard Christopher Columbus "discovered" the island in 1494, and for nearly two centuries there was continuous strife and poverty under Spanish rule. The native Arawak Indian population were decimated by enslavement and exposure to European diseases, and were replaced by slaves from Africa who were physically more suited for transportation and enslavement in the New World (Dechesnay, 293; Farmer, 281). Western style medicine and the Catholic religion were introduced into Jamaica by its Spanish settlers at the start of the 16th century, but Catholicism was prohibited from 1655 until 1792 upon capture of the island by the English from the Spanish (Dance, Preface).

English vessels began bringing African slaves to the island in 1666 for work on the estates and for transhipment to North America (Hill, 5). A kind of sorcery or witchcraft practiced in West Africa, "obeah" was likely imported directly and without change into the Caribbean region and reportedly flourished despite the attempts of the slave traders to control it (Morrow, 5; Roach, 10). "Obeah" practices were based on magico-religious theory, and European-trained, English medical practitioners, in supervising the health of the plantation and keenly observing and precisely describing what they say, noted the presence of magical death amongst the slaves (Morrow, 5). Plantation owners saw African beliefs and practices as an enemy and, as the "obeahman" was regarded as a rival to their own institutions of authority, the practice of "obeah" was made (and still remains) a crime in Jamaica (Morrow, 5; Barrett, 70). The established church also regarded "obeah" as sin, and the dual stigmatization (moral and legal) of the practice has persisted to today.

Established in Jamaica at the time were various forms of magico-religious practices: obeah, myal, ettu, revival, kumina, and spirit-possession (Cooper, 2). "Obeah" was "essentially a magical means whereby an individual may obtain his personal desires, eradicate ill health, procure good fortune in life and business, turn the affections of the objects of his love or lust towards himself, evince retribution or revenge upon his enemies, and generally manipulate the spiritual forces of the cosmos in order to obtain his will" (Morrish, 41). The words "myal" and "myalman" referred to that class of African specialists who, under spirit-possession (myal), could detect the evil influence of the "obeahman"; "myalmen" were the persons who prescribed the herbal cures for the healing of the bewitched, and were the descendants of African priests or priestesses (Barrett, 70).

As their practices had been outlawed during slavery, "myalmen" joined forces with "obeahmen" and functioned as a secret society to fight their masters with witchcraft. Their strong influence among the slaves remained unchallenged until the late 19th century as, for a period of nearly 200 years in Jamaica, the preaching of the Christian gospel had been forbidden to slaves (Barrett, 70) It was not until 1815 that, in order to oppose the non-conformists churches forming in the society, the Church of England reportedly began reluctantly to instruct the slaves in Christianity, a work continued by the Baptist and Methodists to make Christianity available to all island-wide (Barrett, 70).

Over one million slaves may have been off-loaded in Jamaica from the beginning of English colonization to 1807 when the slave trade was abolished by an Act of the British Parliament (Leavitt, 50). When full emancipation was granted to all slaves in 1838, the African descendants numbered in excess of 250,000 (Hill, 5). What followed was a period of economic decline as some freedmen refused employment on plantations, though the few who had been bequeathed land by sympathetic or grateful estate owners became peasant farmers (Holt, Preface xviii). The freedmen rallied around their religious practices and a dichotomy of values developed; one impulse tended toward an identification with and re-interpretation of their own remembered African culture, and the other tended towards coming to terms with their new situation and their previous master's image of them (Brathwaite, 244; Holt, 91).

During the days of slavery there was no shortage of doctors in Jamaica as, besides caring for the local English, doctors were paid by plantation owners to ensure that slaves were healthy to work (Braithwaite,145). In the post-emancipation period, as most freedmen were unable to pay for their services, the proportionate numbers of doctors declined steadily. Some freedmen had to resort to folk medicine as although the physician's fee was not unreasonable, the cost of imported medicine was high, estimated at 2,000% of the prime cost in England (Braithwaite,146; Laguerre,12). Since then, both western-style medicine and African folk medicine have co-existed, albeit quite uncomfortably, within the Jamaican society.

The missionary movement in both pre- and post-emancipation Jamaica was undoubtedly a strong force, bringing the themes of salvation, acceptance of the gospel, acceptance of the condition of slavery on ideological grounds, accepting the authority of ordained ministers, literacy, regular prayer, and the reported "de-Africanization" of the believer in significant areas of beliefs and values (Carnegie,15). Yet the Christian religion was not the kind most people admired and the two African religious cults which reportedly brought out the soul of the emancipated Jamaican were the "Kumina" and the "Pocomania" (Barrett, 25). The word "Kumina" derives from an ancestor possession cult of the Ashanti people and the possession crisis in Kumina (known as myal) involved the spirit or "duppy" of an ancestor actually taking control of the dancer's body with the latter losing control of speech and faculties (Barrett, 25). "Duppy" is an African word still used today in west coast African languages, and the dancing and singing in this form of revival is both an art form and a type of ceremonial prayer in Jamaica (Dance, 35; Leavitt, 65).

A syncretism of "Kumina" and Christianity, "Pocomania" is a brand of Jamaican religion which emerged out of the 1860 revival of religious enthusiasm then sweeping the island one generation after the emancipation of slaves (Barrett, 27; Holt, 290). At the time undergoing declining membership, internecine conflict, and challenges to European doctrines, faiths and controls, the regular church denominations disdained and feared these revivals in which people reportedly had visions, went into trances, threw themselves on the ground, jumped from windows apparently unhurt, went for 3 to 4 days without food, and much to the dismay of the authorities, did no work (Holt,290). Due to its high-activity dances, "trumping", drumming, and possession, "Pocomania" (small or "little mania") came to be regarded by some Jamaican elite as a slight case of madness (Williams, 448; Barrett, 27).

Nettleford carefully distinguishes between "Pocomania", which he classifies as a religious syncretism with more of an African heritage, and the more generic nomenclature

"Revivalism", into which he states relatively more of Christianity has been syncretized (Nettleford,18). Nevertheless, emerging as a cultural resistance to missionary Christianity while providing a link between pure African religion and Christianity in Jamaica, both "Pocomania" and "Revivalism" are still amongst the most important of the "native" religions on the island (Barrett, 27).

By the end of the 19th century, the churches of the Jamaican freed people reportedly became venues for the fostering of community, the legitimization of alternative world-views, and the articulation of political solidarity (Holt, 291). Indeed, the Native Baptist Church nourished the islands syncretic blending of Christian forms and rituals with African beliefs and values, such that "myalism" flourished and its practice did not bring about automatic expulsion from the church's membership.

Here in the 20th century, Christianity enjoys the prestige as the "religion of advanced civilization" or Christendom in western colonial history (Nettleford,19). Official church membership is high and nearly all Christian denominations have churches in Jamaica; the Church of England heads the list and is followed in order of size by Baptist, Wesleyan, Presbyterian, Roman Catholic, Moravian, Church of God, Adventist, Congregational, Salvation Army, and numerous smaller bodies (Simpson, 160). Pentecostal, Evangelical and numerous non-denominational churches also abound (Dance, Preface).

Political leaders have repeatedly declared Jamaica to be a "Christian country" but still some say Africa "rules" in the ongoing assertion of faith among a mass of people who, though present in the congregation of some orthodox Christian denominations, continue to be a source of indigenous forms or religious expression (Nettleford, 19). Indeed some practicing Christians attend Fundamentalist churches whose activities are said to provide them with deep personal satisfaction, despite many middle class residents regarding them as a form of "uneducated" religion, indicative of an undisciplined, superstitious, and inferior working class (Austin, 232).

Reflecting the African culture, leaves (herbs) have an important place in the Jamaican revivalist cults, and "bush" teas and "bush" baths may be prescribed by obeahmen, revivalist leaders, and others who attempt to cure illnesses, redress injustices, and overcome misfortunes (Simpson,170). Healers may be placed in two categories: religious and herbalist. Religious healing is based on animistic beliefs and is symbolic and magical in nature, while the herbalist is the "medicine man" or "bush doctor" who utilizes the healing power of herbs (Roach, 37). In fact the Jamaican "obeahman" may be used to effect healing or "private workings", the latter merging into areas of "black magic" at times as he or she delves privately into areas that no longer can be classed as religion. Indeed, although a few see acts of "revivalism" as religion and "obeah" as magic, many see such beliefs as overlapping almost constantly (Simpson,189).

A misrepresentation of the social reality is a popular view that only certain individuals use African folk medicine (Laguerre, 5). Whether one sees the phenomenon as a residue of beliefs originating in time immemorial and persisting in a family, or as a part of the ethos of community life, the practice of African folk medicine is deeply entrenched in Jamaica. The social reality is that, for reasons deeply rooted in their culture, many terminally ill patients have attended Jamaican "bush doctors" for their emotional, social and spiritual care for a very long time.

### 1.5) Financial issues and the Jamaican paradigm:

In any evaluation of the efficiency of health care systems, financial issues are of a primary concern (Dossetor and McDonald, 39). In the biomedical model, health care for the terminally ill is a very costly venture, with the treatment of malignant neoplasms comprising the most expensive intervention (Back-Friis, Norberg, and Strong, 263). Indeed, in scientific medical care, the allocation of cancer resources is highly concentrated on the earlier trajectory of the disease while little priority has been given to early palliation to effect a better quality of life (Wodinsky, 25).

Resources given to other branches of biomedicine greatly outbalance the human, organizational, and financial resources presently provided for terminal patients (Toscani, 33). Yet justice would dictate that dying patients have access to care equal to others (Latimer [a], 331). In addition, the supportive care provided by palliative care services may have a direct impact on reducing overall health care costs, as home care may be less expensive than institutional care (Wodinsky, 26). Even more important, it has been strongly recommended that governments ensure that the pain and suffering of terminally ill patients be well controlled first before they fund high-cost, high technology developments in diagnosis and treatment (Roe, 28).

Physicians should recognize when anti-tumour treatment may have ceased to have any rational basis for its continued administration (Krakoff, 817). Indeed, some say physicians may do very little curing as it is the power of the body to heal itself that has so far given physicians much of their glory (Van Eys, 27). Consequently, only in those diseases by outside agents which overwhelm the body's natural defensive mechanisms may a physician's ministrations really make a distinct difference to affect the course of the disease.

Prevention, early detection, treatment, and palliation for terminal diseases such as cancer all fall along a spectrum of continuity of care (Ashby and Stofell, 1322). Policy makers and planners therefore need to develop service models which include the appropriate criterion of quality of life while doing cost-effective analysis of the caring for terminally ill patients in the various stages of their disease (Viney et al, 157).

Undergoing serious economic decline over the past decade, Jamaican has marked unemployment, a trade deficit, short term debts that exceed foreign exchange reserves, and a large foreign debt which inhibits the country's ability to import much needed drugs (Leavitt, 59). The high cost of modern biomedical technology puts most equipment beyond the purchasing power of both the Government and the private sector, and a significant part of the high cost of training western-style physicians is consequently borne by medical students and their families, resulting in high fees that some working class persons cannot afford. Care of terminally ill patients has therefore been assigned a low priority by the Jamaican Government, and only the Hope Institute for Cancer, a 29 bed "treatment" institution serving the whole of Jamaica, provides any special in-patient bed facility for cancer patients.

According to the Medical Register of the Jamaican Medical Council, to date no physician in Jamaica has received any formal training in palliative care, nor are any palliative care services widely available beyond the sometimes poor attempts at pain control in some hospitals. Indeed, Jamaica's physicians do not consider palliative care to be attractive either financially or academically; the average patient or his or her family would not be able to afford to pay for in-patient palliative care; and the state would presently be unwilling to add this service to its already overstretched health services (Golding,110). In addition, once discharged from hospital, only privileged members of the upper class may be able to afford to hire any therapist privately or pay for good home care (Leavitt, 89). The psychosocial and spiritual aspects of care are therefore not provided in biomedical hospitals and once therapeutic interventions cease, terminally ill patients are discharged with liquid morphine medication and the cursory, dismissive statement "we are sorry, but we have nothing else to offer".

Emotionally devastated and financially embarrassed, some terminally ill patients go home with very little option. If their pain exacerbates, with no medical advice on how to adjust their morphine dosages, some urban dwellers may have to incur a costly taxi drive to the nearest hospital's emergency department, but rural inhabitants have no such recourse and may therefore experience unrelieved suffering. With important physical, emotional, spiritual, and social needs, and with very little financial resources, not surprisingly some terminally ill patients may therefore choose to turn to the much less expensive "bush doctor" /"obeahman" to try to relieve their suffering.

## 1.6) Societal interests: Legal and Moral Issues

Reflecting to a very important degree the urban, industrial, material, and affluent character of western culture, western style medicine has a powerful effect on national elites in many societies (Bates and Weisz, 5; Wear, 12). Indeed biomedicine gets much of its political power to heal from being deeply ingrained in the values and priorities of the middle and upper middle classes. Wherever there is increased urbanization, industrialization, technological advancement, and the affluence with which these are associated, western-style medicine is likely to flourish. However, wherever other forms of medicine are widespread and deeply rooted in the culture, and biomedicine is not given monopoly by the state, medical pluralism exists and prevails through time (Bates and Weisz, 5; Lock, 2).

The peasant class in Jamaica is politically, ideologically, and culturally controlled by the upper and middle classes who sometimes exploit their lack of formal education (Besson, 354). In African folk medicine, permission to heal is granted by the folk, but since the social and political power rests ultimately with the social elite who covertly direct the state, the fate of folk medicine practitioners rests ultimately on the values and attitudes of the ruling class. Despite some receiving African cultural values in their early upbringing, the ruling class as a whole does not support or value African folk medicine as it is a local phenomenon and its heritage derives from slavery.

The prohibition of the practice of any form of African folk medicine (termed by some "obeah" ) dates back to the Old Slave Law of 1760 (Barrett,74). It reads in part:-

> "...after the first Day of January which will be in the year of our Lord One Thousand Seven Hundred and Sixty one, Any Negro or other Slave who shall pretend to any Supernatural Power and be detected in making use of any Blood, Feathers, Parrots' Beaks, Dogs' Teeth, Alligators' Teeth, Broken Bottles, Grave Dirt, Rum, Eggshells, or any other materials related to the practice of Obeah or Witchcraft in Order to delude and impose on the Minds of others shall upon Conviction thereof before two magistrates and three Freeholders suffer Death or Transportation, anything in this Act or any other Act or any other Law to the Contrary notwithstanding, etc."
>
> (Barrett, 74)

The present law was enacted in 1938 as a modification of the Old Slave Law of 1760. It reads:-

> "Section 2. 'Any person practising obeah' means any person who, to effect any fraudulent or unlawful purpose, or for gain, or for the purpose of frightening any person, uses, or pretends to use an occult means, or pretends to possess any supernatural power or knowledge; and 'Instrument of Obeah' means anything used, or intended to be used by a person and pretended by that person to be possessed of any occult or supernatural power."

The penalty under Jamaican Law for practising "obeah" is contained in Section 3, which reads in part:-

> "Every person practising obeah shall be liable to imprisonment, with or without hard labour for a period not exceeding twelve months, and in addition thereto, or in lieu thereof, to shipping... "
>
> (Barrett, 74)

With respect to government and the liberty of its people, Mill stated that the sole justification for the State restricting a person's liberty is to prevent harm to others (Mill, 143).

While Mill's statement may be simplistic with regard to the rights of individuals and those of society, it nevertheless points to the need to determine the interests of all parties concerned, in order to balance any conflicts which might arise. The liberty afforded individuals under the ethical principle of autonomy may be restricted under Mill's Harm principle, not only for an individual's own protection but for the welfare of others. However in the Jamaican context, legal moralism complicates the issue further, as the law has been used in the past to enforce the moral attitudes of slave owners and this legislated moralism has remained in force up to today.

Like many others, Capron has argued that law and morality need not be connected (Capron, 377). Indeed, morality only becomes related to the law when it is enacted into law, that is, in codified morals (Capron, 378). Historically a society's morality, including that of organized religion, has had a profound direct and indirect impact on society's legal rules, nevertheless each generation needs to scrutinize its own laws to decide which ones may be archaic or unjust, and which are germane and aught to be retained. Unfortunately this process of legislative review has not taken place with regard to the practice of "obeah" in Jamaica.

Enacted to protect the welfare of society, laws regulating the practice of medicine in some societies have been evolving over time. Modern medicine was professionalized in France and England during the 19th century, thus providing the legal basis for its members to control their own entry requirements, conduct their own examinations and enforce their own discipline (Wear, 7; Sidarous, 2). At that time the 'unorthodox' practices of those practitioners not on the Medical Register were still allowed, but by the second half of the 19th century scientific medicine emerged, thereby helping to increase the status of the medical profession and leading to its further differentiation and stratification (Wear, 10). Since then unorthodox practitioners have been further marginalized and have come to be regarded by some as charlatans, and in Jamaica such practices have been made illegal.

Jamaica's legal system is that of common law arising from the British tradition, whereby Judges make law by case precedents and other areas of law are dictated by statutes (Gilmore, 1040; Waddams, 87). The Law is designed with the intention of serving the community by setting minimum standards for behaviour, including institutional and individual relationship, with the expansion in some jurisdictions this century to provide minimum assurances of human well-being (Schneider, 16). Societies having specific health laws may use them to expose inequities and inefficiencies which may exist in their particular health care system (Annas, 565). However Jamaican law has not evolved to these levels of sophistication and does not reflect the current mores and values of the broader society.

The Jamaican Medical Act of 1972 states that no person shall be registered as a medical practitioner unless he:-

A i) has qualified as a medical practitioner from the University or from any other institution approved by the General Medical Council of Britain;

ii) has qualified as a medical practitioner from an American or Canadian institution approved by the Council and is licensed to practice in the country in which he so qualified, or

iii) holds a medical qualification other than those specified in paragraphs (i) and (ii) of this sub-paragraph;

B has done a year's internship after so qualifying; and

C has passed any examination referred to in subsection (2) which may be set by the Council.

(The Medical Act 1972, 558D)

The Administrative Agency for this piece of Legislation is the Medical Council of Jamaica, which was most recently constituted under the Medical Act 1976 to "protect the public by regulating the conditions of medical practice in the island and prescribing the procedure to be followed in respect of disciplinary proceedings against registered medical practitioners in relation to professional misconduct" (A Guide to Medical Ethics,1). The Council has no legal jurisdiction over non-registered practitioners and therefore refers any such complaints received to the Director of Public Prosecutions (DPP) and to the Commissioner of Police.

Kept by the Registrar of the Medical Council, the Medical Register was instituted so that persons (the lay public) may be able to distinguish between qualified and unqualified practitioners. The Medical Council prohibits any association between its registered physicians and any other type of practitioner, and therefore states " a doctor who improperly delegates to a person who is not a registered medical practitioner, functions requiring the knowledge and skill of a medical practitioner is liable to disciplinary proceedings" (The Medical Council of Jamaica, 8).

The exclusion of all non-registered practitioners from the "practice of medicine" on the island is made even more clearly under the heading "Censure, Suspension, and Striking off the Medical Register":

> "A registered medical practitioner shall be deemed to be guilty of conduct that is disgraceful in a professional respect, if he: employs or permits a person not registered under this Act, to attend or treat or perform services which require professional skill upon any patient, or by his presence, advice, assistance or co-operation enables that person, whether acting as an assistant or otherwise, to do any act which would constitute the practice of medicine."
>
> (The Medical Act of Jamaica, Section ii.2[h])

Under item 12: Non-Traditional Practitioners in the Annual Report of the Medical Council of Jamaica, April 1, 1990 - March 31, 1991, the Council recorded its concern over the apparent increase in "the number of individuals without standard medical training who were offering therapy of various kinds to the public". Under Section (ii) other Unorthodox Practitioners, it also expressed concern about the activities of "other practitioners", notably reflexologists, about whom both the DPP and Commissioner of Police had been contacted. Similarly in its report of the subsequent year, it recorded that four complaints had been received against persons deemed to have been practising illegally and noted (under Item 10: Non-Traditional Practitioners) that the Council had referred to the Commissioner of Police and the DPP two sick leave certificates issued by non-registered practitioners, but that nothing further had been heard up to then (Annual Report of the Medical Council of Jamaica, April 1, 1991 - March 31, 1992).

Despite these referral of complaints by the Jamaican Medical Council, there apparently has been no action by the security forces, perhaps due to a shortage of police personnel or possibly to their having developed some measure of tolerance towards "unorthodox" practitioners until they have been shown to have caused serious harm. Despite any possible level of tolerance however, the law remains on the book, and at present folk practitioners would still be deemed to be breaking the law and therefore liable to be so charged.

Despite being viewed as "natural" with an absence of side-effects by some, some herbal medicine is regarded by others as dangerous with the ability to kill if not skillfully managed, and there has in fact been some documented evidence to this effect. Brody reported that during the 1940s and 1950s, Jamaican women used "bush medicine" to induce abortions (Brody, 110). Morgan described epidemics of partial paralysis associated with the consumption of an ethanolic extract of Jamaican ginger (Morgan, 1864). In addition, due to folklore and lack of knowledge, Huxtable has stated how the intentional consumption of the Senecio and Crotolaria species as herbal tea, the cause of the high incidence of primary liver cancer in black Africans, has posed a major public health and cultural problem in many areas of Africa, and in particular, Jamaica (Huxtable, 3).

With its medical description originating in Jamaica in association with the drinking of certain "bush remedies", paediatric veno-occlusive disease has been of almost epidemic proportion in the island (Huxtable, 3). Indeed, one survey of paediatric inpatients at the Tropical Metabolism Research Unit in the University Hospital, Kingston, Jamaica, demonstrated that 71% of these children had been treated with herbal remedies before their presentation to the medical services (Michie, 31). Drunk in an oily suspension, the red powdery extract from the seeds of the annatto plant (a well known food colouring) is used as a folk remedy for diabetes mellitus in Jamaica. Yet detailed investigations on this extract yielded a purified substance which was demonstrated to cause hyperglycemia in "anaesthetized mongrel dogs, with damage to mitochondria and endoplasmic reticulum mainly in the liver and pancreas" (Morrison et al, 184). These findings therefore would perhaps question any open-ended advice on the generalized use of wild plants for ingestion, and point to some potential dangers of these informal medications in the Jamaican setting.

In spite of this, health-related concerns over the state of one's blood is typical among descendants of the African diaspora (Sobo, 36). As a result the practice of cleansing it using "bush teas", commonly known as purifiers, is well entrenched in Jamaica. Prepared by a person going into the scrubland and collecting leaves from a wide variety of plants, or by receiving them from a "bush doctor", "bush teas" are then boiled and subsequently infused. A brew's bitterness is supposed to indicate its effectiveness, and the very bitter Cerasee tea is among the island's favourite. Teas of ground Bissy are also said to remove strong toxins and most of the teas brewed for breakfast are presumed to have a blood-purifying action (Sobo, 36).

As a result of these beliefs, in the rural areas, African folk medicine gets very little competition from biomedicine, but in urban areas they may be said to exist in a somewhat symbiotic relationship, as a few urban folk healers may sometimes use patent medicine and will often refer their complicated cases to the general hospital or to a biomedical practitioner (Laguerre, 4; Fonaroff, 120). Therefore, with the abhorrence of folk medicine by some members of the social elite and the State, and the embracing of it by a majority of the working class, medical pluralism continues to exist in Jamaica.

## Summary: Chapter 1

Significant economic hardships and poverty exist in Jamaica, with a major problem of transportation especially in rural areas. The majority of inhabitants of the rural areas are peasant farmers with a rudimentary education, little if any knowledge of palliative care, and for whom no palliative care services exist. Most of these persons have deep cultural magico-religious beliefs and may routinely rely on their illegal local "bush doctor" or "obeahman" for a significant part of their health care. With limited financial resources, biomedical physicians' disinterest in providing good palliative care, and Jamaica's legislated moralism concerning African folk medicine, most terminally ill patients find themselves in a quandary when discharged from the treatment hospital with the words "there is nothing more we can do for you".

# CHAPTER 2 : PALLIATIVE CARE IN SOME DEVELOPED COUNTRIES

Very little knowledge of palliative care presently exists in most parts of Jamaica, and so information on the nature and scope of its services will be required if this form of care is to provide a possible answer to the dilemma of terminally ill patients in that country. This chapter therefore provides a historical perspective to palliative care, and as this care has become specialized to some extent with the provision of care in various settings, I also examine various models which have evolved in some developed countries.

## 2.1) LITERATURE REVIEW: THE HISTORY OF PALLIATIVE CARE

Despite his limited capabilities, the Hippocratic physician was unquestionably committed to restoring the health and alleviating the suffering of his sick patients (Cowley et al, 1476). The Hippocratic Corpus stated the following:-

On the Art (iii):

> "First I will define what I conceive medicine to be. In general terms, it is to do away with the suffering of the sick, to lessen the violence of their disease, and to refuse to treat those who are over mastered by their diseases, realizing that in such cases medicine is powerless." (Prioreschi, 341)

In earlier times in most cultures, dying people remained at home, unless they died by accidents, execution or on the battlefield (Thorpe, 915). Indeed, during the middle ages in Europe dying persons presided over the ritual surrounded by family and friends. However this natural acceptance of a biological reality became lost by the mid-nineteenth century, and regrettably many persons now regard health care institutions as the best place for persons to die (Thorpe, 915).

Describing an interaction of caring, the Latin term "hospice" meant both host and guest, and to provide care for pilgrims returning from Africa, a hospice existed in the port of Rome over two millenniums ago (MacCormack, viii). In the medieval period the term "hospice" referred to a place of shelter for weary travellers returning from crusades where respite and comfort were provided (Gurfolino and Dumas, 533). Whereas this theme has persisted, the focus is now on the care of the dying. Indeed, in Europe a number of homes were specifically designated in the mid-nineteenth century to provide care for such persons, but it was not until the second half of the twentieth century that the concept of hospices was broadened to include "the control of pain combined with the spiritual, emotional, and psychological care of the individual" (Gurfolino and Dumas, 533).

Deeply affected by dying soldiers in great pain while working as a nurse and social worker during World War II, Cicely Saunders entered medical school to pursue her goal of easing the pain and suffering of dying persons (Magno [a],72; Saunders, 70). Then, while working in a traditional London hospice with a specific vision of improving depersonalized care, Dr. Saunders realized that patients dying in pain were being denied the full benefits obtainable from the practice of modern medicine (Pollard, 97). Consequently, while experiencing difficulty in convincing her colleagues, Saunders nevertheless generated enough spiritual, medical, and organizational support for her concept to realize the financial resources necessary to open the 55-bed St. Christopher's Hospice in Sydenham, London in 1967 (James and Field, 1363; Ford, 15). This event subsequently represented the symbolic start of the "modern" hospice movement (Rogatz et al, 500; Mount [b], 28).

With the commencement of a community based service two years later, the emphasis shifted from in-patient facilities to home care whenever possible (Clark, 995). Palliative care programs subsequently expanded across the United Kingdom, Europe, the USA, Canada, Australia and other English speaking countries during the 1970s and 1980s, and there are now over 2600 palliative care beds in 140 hospices and units in Great Britain (McNamara et al, 1502; Bruera,7; Schipper, 38).

Many pioneers of hospice in North America learned their first lesson in caring for the terminally ill at St. Christopher's Hospice, and the first hospice in the USA was started in New Haven, Connecticut in 1974 (Magno [b], 74; Rogatz et al, 500). Initially institution-based, palliative care in that country now also occurs in patients' homes with affiliation to hospitals, nursing homes and other institutions. Indeed, over 1800 hospice programs were operating in the USA in 1994 (Gurfolino and Dumas, 533).

> Hospice/palliative care may presently be defined as:
>
> "specialized health care, supportive in nature, provided to a dying person. A holistic approach is often taken, providing the patient and his or her family with legal, financial, emotional, or spiritual counselling in addition to meeting the patient's immediate physical needs. Care may be provided in the home, in the hospital, in specialized facilities (Hospices), or in specially designated areas of long-term care facilities. The concept also includes bereavement for the family." (From the Dictionary of Health Services Management, 2nd edition)

Palliative care continues to give care to patients, their families, and other care givers who may be eventually exhausted by terminal illness and may therefore need such solace. With adequate and total holistic care, patients may "live until they die", without pain, in peace, and with dignity (Miller, 127). As individual family members must work through and recover from their grieving, good care also extends into the period of bereavement to ensure the likelihood of family recovery and adaptation (Foley and Hannigan Whittam [b], 52). Seeing that all these services are important to "good" palliative care, we now need to examine the various forms, scope, format, and models under which such care may be administered.

## 2.2) MODELS OF PALLIATIVE CARE

### I) The Locale and Personnel of Palliative Care:

Palliative care may be provided in the patient's home or in an institution, and the varied programs may be classified as follows:

(a) Day Care Units , free standing or attached to a hospice;

(b) Community based home care, with no affiliated inpatient unit;

(c )Community based home care, with hospital affiliation;

(d) Hospital based program without an identified inpatient unit;

(e) Hospital based program with an inpatient unit;

(f) Specific Hospice facility, with or without a home care component; and

(g) Conventional care (non-hospice) hospital

(Dawson, 83; Clark, 995; Mor and Masterson-Allen, 122).

Programs may meet the physical and emotional needs of the terminally ill patient and their family to varying degrees, and may be inhibited by : (a) a shortage of care givers; (b) a lack of understanding of the dying person's needs; (c ) the time lag between curative treatment and the onset of palliative care; (d) the extent of family involvement; (e) any lack of teamwork among care givers; and (f) any lack of specialized training for staff members in palliative care (Burucoa, 31).

Due to its philosophy of physical, psychological, social, and spiritual care, palliative care programs need a number of specialist care givers whose teamwork provide the basis for such holistic care, and a large palliative care team may comprise the following:-

1) A physician with experience in the management of terminally ill patients, and particularly with patients in severe pain;
2) A psychiatrist;
3) Professional nurses who subscribe to the palliative care concept;
4) Pastoral/spiritual counsellors, i.e. clergy experienced in palliative care counselling;
5) A medical or psychiatric social worker;
6) Therapists, including music, occupational and physiotherapists;
7) Nursing Assistants and home health aides;
8) A nutrition consultant;
9) A secretary and receptionist; and

10) Volunteers, family members, friends and sitters.

(Mercadante et al, 38; Rogatz et al, 501; Roe, 30; Kerr-Wilson, 113; Quick, 56; Twycross, 78; Ajemian and Mount, 19; Mandel, 37; Parkes, 252).

Unfortunately most teams are not this extensive, and local resources will dictate their composition. Careful selection of the team therefore, accompanied by effective support and backup, good communication and co-ordination, and proper financial provisions, will be essential to an effective palliative care program (Roe, 30).

ii) Some Institutions of Palliative Care:

Concern for a patient's quality of life may render admission to an institution imperative, and for terminally ill patients, such care may be sought from an acute care hospital, a hospice, or even the geriatric department of a local hospital (Severs and Wilkins, 361; Rutman and Parke, 23). In some institutions, care for terminally ill patients may be directly provided by specialized palliative care teams, while in others, the services of such specialized teams may be essentially consultative, assisting specialists or family practitioners with the care of their terminally ill patients (Kerr-Wilson, 113; Lickiss et al, 34). Consequently, highly trained palliative care staff are used expeditiously, while patients remain in a familiar environment.

Despite the growing trend of community based home palliative care programs in some developed countries, there has been an increase in the proportion of terminally ill patients living in institutions or being admitted to hospital in the 12 months preceding their death (Cartwright [a], 81; Thorpe, 916). However, this may not be surprising, as inadequate social support may exist for many elderly persons in their communities, and care givers may become overwhelmed by the preponderance of complications which may afflict such persons at the final stage of life.

Institutions that provide palliative care may therefore play a vital role in palliative care programs (Ajemian, 33; MacDonald [a],41; Wilkes, 169). Whereas the manner of their utilization will vary from society to society, the physical, social, and psycho-spiritual support obtainable in some facilities may greatly contribute to a better quality of life for persons in the terminal stages of life.

### iii) Home Palliative Care:

Palliative care provided in the home has the potential for optimizing the quality of life for patients and their families, with the possibility for cost reduction in publicly funded health care systems (Lubin, 18). Indeed, home palliative care may often provide more privacy, dignity, and family closeness, with care for patients occurring in familiar, comfortable surroundings, and patients having more time to spend with their families and to work through the grieving process.

In recent times home health care has grown to include IV therapy, parenteral nutrition, changes of the patient's dressings, and patient education in some locales, and even speech, occupational, and physical therapies can be provided within homes in some communities (Hohl, 52; Monroe, 252; Marcant and Rapin, 68). However in order to assist patients effectively at home, one needs to take into account the various environmental, cultural, economic, and religious factors which may differ in all societies (Mercadante et al, 39).

In some communities, home care programs were initiated to cater to patients requiring full hospital care but who preferred to remain at home (Beck-Friis, Norberg, Strang, 259; Cartwright [b], 271). Such care provide the best of two worlds: qualified specialist care being given within the privacy of the patient's own home. Being at home, patients may choose their own company, solve some of their own problems, and eat and sleep when they desire. Family care givers are more actively involved and are in command, and this allows them a tangible way of saying goodbye while initiating the process of mourning. However, the emotional needs of some family members may exceed that of the patient, and there may be anxiety, the feeling of being trapped, financial strain, physical and emotional burnout and an inability to cope (Birenbaum and Robinson, 101; Beck-Friis and Strang, 5; Davies et al, 20). So in a well functioning home care program, support must be available to the patient and family night and day, and where the family unit breaks down, the patient may not be able to remain at home (Kinzbrunner, 793; Johnson, 43).

For those patients without the support of relatives or friends, home care may still be possible through the use of home health aides if these persons are available. Home health aides may sometimes provide genuine friendship, and their intimate, physical, and personal care of the patient can be invaluable to the palliative care team in their ongoing assessment of the patient's quality of life (Stephany, 71). Thus, with either outside help or the help of family and friends, a number of patients with advanced terminal disease may be successfully managed at home (Norris, 458; Muzzin et al, 1202).

### iv) A Comparative look at Palliative Care in Homes and Institutions:

> "The belief that terminal care in the home is more beneficial to family life than hospital may not be an accurate reflection of what families experience."
>
> (Birenbaum and Robinson, 101)

Illness often transforms the home and family life; it can make familiar domestic settings alien, confuse family roles, promote deception, detachment, and even resentment in some families (Ruddick, S11). Less well-to-do families may inhabit too few rooms, have too many children, or have neighbours in too close proximity to realize any idealism of home care. In addition, within the home, visiting hours may be continuous, and the terminally ill may be constrained to improve on any grumpy, pessimistic ways or keep up pretenses for the sake of worried children, spouses, or friends (Ruddick, S12).

Dying may be agonizing and a source of distress for many carers. Terminal patients often suffer from weakness, pain, vomiting, bedsores and shortness of breath, and many carers may develop symptoms of insomnia, weight loss, nervousness and anxiety (Jones et al, 250). Indeed, carers are likely to be nursing a dying relative for the first time in their life, and all of their needs may not be supported (Minton et al, 649). Further, some terminal patients who are messy may prefer their caring to be done by impersonal professionals, and may even be concerned about the lingering effects which a home death may heap on the surviving family members still living there (Ruddick, S14). Under these circumstances therefore, we should be very wary of any simplistic assumption that home may be the best place for the terminally ill to die.

> "Consignment to the total institution and to the rigors of treatment there often disrupts the patient's sense of his own body, rips him out of his ordinary community and identity, and disconnects him from the over-arching order, rhythm, and meaning of his former life." (May, 8)

Whereas stand-alone hospices, by and large, are better tailored to provide for the needs of terminally ill patients, some hospitals or nursing homes may be more designed to physically cater to the convenience of their staff and their machinery than to the physical comfort and convenience of their patients (Seale, 147; Twycross, 79). In fact, conventional care (non-hospice) hospitals score poorly in assessments of basic needs satisfaction, psycho-social support, and over all program satisfaction, when compared to home palliative care and hospitals with affiliated hospice (Dawson, 83). Other shortcomings included inadequate numbers of palliative care beds, difficulty in gaining admission for persons needing long term care, too early discharge, and over treatment of some dying patients (Cartwright, 271). Also, hospitals rarely allow for the full expressions of family grief, rage, or love (Ruddick, S14).

In addition to all these considerations, however, there is evidence to suggest that palliative care provided at home may be less costly than in other settings (Rogatz et al, 502;

Twycross, 79). As financial considerations are important in most health care systems irrespective of whether they are privately or publicly funded, this might therefore be the most important determinant of the locale of care.

v) Partial Palliative Care:

> "Partial palliative care is, for better or worse, the most commonly evolving model of care for the dying." (Latimer [c], 107)

Differences in the philosophy of care, financial constraints, and the perceived need to tailor palliative care to particular settings or populations, provide some of the main reasons for the emergence of partial palliative care programs. Although the concept of a full palliative care program may be still subscribed to and may be even planned for sometime in the future, economic constraints may determine that only a part of a full palliative care service can be funded at a time (Latimer [c], 108). Also, some palliative care teams may have philosophical objections to certain parts of the traditional palliative care system. Further, some teams might deny the need for a specialized physician consultant role, or for psychosocial or pastoral care. Indeed, some persons may wish to tailor palliative care to a particular setting, and this may be justifiable if such a population has special needs in caring (McNeil, 30). Nevertheless, the essential elements of palliative care programs (symptom control and emotional support for the patient and family) must be maintained in all adaptations in order to validate the use of the term palliative care.

A partial palliative care program exists where an interdisciplinary care team provides consultative care in a scatter-bed fashion throughout an institution or by community outreach, but where no backup specialized palliative care inpatient facility exists. Whereas this model provides direct patient and family care, and may in fact be very cost-effective, these teams may be only partial in their composition, and more may be expected of them than what they can actually accomplish (Latimer [c], 108).

Even more scantily comprised teams may exist. The "physical model" team may comprise nurses and physicians but lack the psycho-spiritual components provided by the clergyman, the social worker and volunteers (Latimer [c], 108). The mainly "psycho-social" model may comprise nurses, pastoral carers and social workers, but lack a physician consultant. Unfortunately however, minimal staffing does not often allow for off-hours coverage, nor for the continuity of skill, personnel, and philosophy which larger numbers of palliative care staff can provide.

Partial palliative care programs may also exist where no readily available palliative inpatient beds exist for those requiring admission from home, where there is insufficient funding of home care programs to provide for good quality care at home, or where skilled palliative medical consultation is unavailable whether in the home or ambulatory clinic settings (Latimer [c], 109). Partial palliative care may also exist if it is provided by others not trained as palliative care providers, as at times well-meaning health professionals may commence practising palliative care without grasping its entire concept. As a result, their care may exhibit deficiencies of skill, knowledge, interpersonal communication, or philosophical intention (Latimer [c], 109). Nevertheless, these various partial models of care ( especially that provided by the consultation/collaborative care teams), may be the most effective way of reaching the greatest number of patients and colleagues, and so partial palliative care programs must therefore simultaneously ensure high standards of care and safety (Latimer [c], 109).

As palliative care emerges as an important field in medical care, it is becoming increasingly apparent that such care needs to occur in a wide range of settings, e.g. in hospital, hospice, nursing home, or the patient's home (James and MacLeod, 8). Catering to the particular patient's physical and psychosocial needs and those of their family also forms an important part of such care. Consequently, in a model of good palliative care we will need to be concerned not only with its physical location, but also with the features of caring, the routines, rules, and the pertinent aspects of culture (Suzuki et al, 39; Tong and Spicer, 27; Kai et al, 1158).

## SUMMARY: Chapter 2.

A form of care for the dying, palliative care involves the control of physical symptoms, accompanied by psychosocial and spiritual support for the terminally ill patient and his or her family. The patient may live comfortably until he or she dies, in peace, without pain, and with dignity, while the family may be provided with respite and bereavement services. In some developed countries, this program may be provided in the home, in hospital, in hospices, or in specially designated areas of long term care facilities.

Whereas palliative home care may allow for more privacy, dignity, care in familiar surroundings, family closeness and the working through of the grieving process, admission to a care institution may be necessary where problems are too difficult to be effectively managed at home. Indeed, the physical, social, emotional, and spiritual support provided in some facilities in certain developed countries may contribute greatly to a better quality of life for some terminally ill persons. However, where such care may be too costly and may not be covered by health insurance, care for these persons may have to take place in the home setting and will therefore need to take account of the environmental, economic, religious, and culturo-specific factors existing in that particular society.

# CHAPTER 3 : PALLIATIVE CARE AND CULTURE

Concepts of illness vary across time, place, and among peoples, and so palliative care may differ in various countries from those models employed in some developed countries. To discover how palliative care may vary across different cultures and what problems may be encountered, this chapter reviews the literature on palliative care from different settings, reports on how religious beliefs may alter views on sickness and death, and explores some cultural concepts of pain, death, and bereavement. I conclude the chapter by suggesting how palliative care may need to be tailored to fit the particular Jamaican situation.

## 3.1) REVIEW OF THE LITERATURE: CULTURAL ASPECTS TO PALLIATIVE CARE

### I) Culture: Common Boundaries and Contrasting Influences

> "Culture may be defined as values, norms, beliefs, and practices of a particular group that are learned, shared, and guide thinking, decisions, and actions in a patterned way."
>
> (Pickett, 104)

Care for human beings may have certain special features. These features include:

1) that human beings are capable of concern for other people's well-being, needs, and survival;

2) that care has been important to human survival, development, and the meeting of life events such as illness, disability and death;

> 3) that human care is universal, but there may be diverse expressions, meanings, patterns, and methods of action in care giving;
>
> 4) that expressions, patterns, and styles of care assume different meanings in differing cultural contexts; and
>
> 5) that providing specific local care requires culturally based knowledge and skills to be not only effective but also relevant to the people of diverse cultures.
>
> (Pickett, 105)

Consequently, understanding a particular culture is vital to tailoring palliative care to meet the specific needs of dying patients in a defined cultural setting. For example, in some cultures the expression of anger at a terminal illness may be unacceptable, yet in the dominant American culture ventilation of one's feeling of anger at a terminal illness is normal and may even be actively promoted (Pickett, 104). Moreover, the display of grief reactions may vary across cultures. Some western cultures place a high value on individualism, self-determination, personal happiness, and self-actualization motivated by personal achievement, while some non-western societies ( e.g. in Africa, Asia, Latin America and many indigenous [aboriginal] societies) place emphasis on family togetherness and emotional interdependence which is a part of their extended family system (Olweny [a], 26). Here, personhood is identified within the context of the family and one's ethnic origin, and cannot be extricated from kinship or community. Hence illness and death are major social events and the entire community may be expected to share in any grief. So in order to relate palliative care to local settings, we may need to anticipate any problems which might impede the delivery of palliative care.

### ii) Palliative Care in different cultural settings:

> "There are many countries in which effective symptom control for patients dying from cancer is inhibited by stringent restrictions on opioid drugs, by social and professional custom, by lack of exposure to suitable examples of good palliative care, and by poverty or political instability."
>
> (Workshop on Global Palliative Care, 78)

Varying demographic and socio-economic circumstances and differing concepts of illness may affect the delivery of adequate palliative care in different locations around the world. Consequently, a review of the literature on palliative care services provided in various settings across the world has revealed some common problems.

First, many palliative care services have been established in locations that make delivery of care difficult. For example, a service established in La Viga, Colombia, was located too far away from the city, making access by patients' families difficult (De Lima and Bruera, 43). Yet, in some parts of Africa, there was a perceived need for palliative care services to be established outside urban settings. It was suggested that traditional healers in those societies could be trained to offer palliative care services in their local communities (Olweny [b], 21). However, in another example, a palliative care service in Poland found that home care was problematic because (probably due to their particular socio-economic situation) most potential family care givers had to work (Corr, 54).

Second, many palliative care services in developing countries lack essential financial resources. For example, in La Viga, Colombia and other Latin American countries there is a lack of adequate financial resources for palliative care programs along with a relatively high cost of some drugs (Stjernsward et al, 11). Indeed, narcotic drugs which are essential to proper pain relief in palliative care are relatively unavailable in even some European countries (Schipper, 38).

Third, palliative care programs in many countries must deal with the problem of widespread misinformation about cancer and other illnesses (Corr, 54; Luczak et al, 40). Akin to the present situation in Jamaica, a lack of adequate information about palliative care also poses a problem in La Viga, Colombia and insufficient education of medical personnel on cancer pain management is prevalent in other Latin American countries, in Poland, and in Palermo, Italy (Stjernsward et al, 11; Luczak, 40; Mercadante et al, 40).

Fourth, many palliative care programs have been hindered by concerns about widespread drug abuse, and this has led to bureaucratic restrictions on opioid use in many Latin American and European countries. This situation may be no different from that existing in Jamaica where only specially registered physicians (and not pharmacists) are allowed to purchase opiates. These physicians must record and give account for the use of every drop of these drugs.

Fifth, in some countries, palliative care programs may have to compete with various forms of alternative therapy. Mercadante and others saw the choosing of alternative therapy to palliative care as a problem at Palermo in southern Italy, where local healers were consulted and magic potions taken to influence the patients' recovery (Mercadante et al, 40).

In fact, among Zulu-speaking South Africans two forms of therapy apparently exist. Mtalane and others state that terminally ill Zulu-speaking South African patients consult their traditional healers for the spiritual aspect of their illness, while also seeking western medical treatment for the physical element (Mtalane et al, 144).

Despite the assorted problems identified in each of the aforementioned locations, however, these reports all indicate that the concept and delivery of palliative care in these various cultural settings have almost all been modeled on that existing in the U.K., U.S.A. and Canada (Richard and Lassauniere, 36; Chaturvedi, 256; Whitaker, 59; Chan and Woodruff, 69). The reports from Africa and Italy illustrate some deviation from the western concept of the causation and effect of illness, and therefore may indicate a desire by some of these patients for alternatives to western medical treatment.

### iii) Religious beliefs and Palliative Care:

Spirituality is said to be the integrating (and perhaps creative) aspect of the total person that influences as well as acts in conjunction with other aspects of the person (Grey, 215). A broader concept than religion, spirituality includes more philosophical ideas of belief, and may provide a way of making sense, meaning, and significance out of life and death. In fact, religion has been described as a practical expression of spirituality involving a framework of beliefs which may be pursued in rituals and religious practices (Grey, 216). Therefore, whilst some religious persons may find meaning through their specific beliefs about God and their religion, other persons may find meaning in other endeavours such as philosophy, art, politics, meaningful work, or creative expression (Grey, 218).

However, not everyone agrees that spirituality is a part of human functioning, and those who deny the existence of spiritual needs are most generally those who reject religion (Welk, 17). Indeed, whereas the use of religious words or rituals as a part of their care may not be necessary for some believers in spirituality, yet others may feel that a religious structure to their care is very important.

Historically, religious beliefs have helped to shape particular cultures of care, and within the North American culture, Lebacqz has argued for physicians to hold the Judeo-Christian concept of "humility in health care" in a higher esteem (Lebacqz, 292). In fact, bioethical debates about health care in North America have often appealed to Christian virtue ethics (Cahill, 265).

So, overtly or covertly, religious beliefs may play a very important role both in the practice of palliative care and in many individuals' decisions about palliative care. They may influence end-of-life decisions by:-

a) helping to shape an individual's world view;
b) providing form for that individual's personal beliefs;
c) giving rise to moral principles and rules; and
d) shaping the character and dispositions of particular communities (Hamel and Lysaught, 61).

Whereas some patients and their families may choose palliative care to facilitate their dying at home, others may make such a choice because this concept best suits their religious traditions, and matches the way they have lived their lives. Such traditions may orient "the patient's beliefs about the value of life, the scope of human responsibility for life, and the meaning of suffering and death" (Hamel and Lysaught, 61).

Nearly all of the world's religious traditions view death as the passage of one life to another. In both Christianity and Islam, if one has led a virtuous earthly life, the afterlife is one of peace, wholeness and freedom from pain and suffering (Hamel and Lysaught, 62; Hauerwas [a], 164; Byock, 9). Approximately one third of the world's population professes one form of Christianity or another, and for them death is a mere step to the "fullness of life" (Green [a], 26). As a consequence, Christians who receive palliative care may wish to be visited at intervals by their own clergyman, and so this person may in fact form an important adjunct to any diminished staffing which may exist in the physical model of palliative care (Green [a], 27; Golding, 111).

Other religions may also have specific views regarding modern medicine, the healing of the sick, ritual practice, care of the terminally ill, suffering, and death (Green [b] 33, [c] 37, [d] 45, [e] 44, [f] 59, [g] 57; Hamel and Lysaught, 62). Palliative care can therefore best serve the needs of terminally ill patients and their families of various religious backgrounds and ethnic origins, by first saying to them "you tell us what you want our care to be..." (Gates, 42).

### iv) Some Cultural Concepts of Pain, Death and Bereavement:

Cultural differences may affect the way pain is perceived by a terminally ill person. In some cultures of southeast Asia for example, pain may be regarded as retribution for misdeeds performed in the past (Olweny [b], 20). In some western cultures, on the other hand, most persons believe that pain may indicate physiology that has gone wrong and which therefore needs to be corrected. In fact, a firm control of one's distress in the face of adversity is strongly encouraged in some societies. Consequently, in light of varying attitudes such as these, care for terminally ill patients must be mindful of cultural differences.

Some persons fear death because they are not convinced of their existence in an afterlife, or because their religious persuasions convince them that they will have to face a final day of reckoning. According to Judeo-Christian beliefs, failure of this ultimate test would carry the penalty of forever burning in hell. However, such a concept is foreign to most African societies where it is believed that those about to die will automatically go to join their ancestors (Olweny [b], 20), and so in this context persons may not regard "appropriately practiced" palliative care as a very depressing undertaking.

The bereavement counselling provided in full palliative care programs is also reflective of the bereavement support offered in some African societies. In such communities, the community provides the bereaved person with companionship and support for weeks to months until they are perceived to have come to terms with their loss (Olweny [b], 20). In other societies, however, such neighbourly or community support may not be readily available or forthcoming. Clearly, therefore, some societies may have a greater need for different aspects of palliative care services.

## 3.2) TAILORING PALLIATIVE CARE TO FIT THE SPECIFIC JAMAICAN CONTEXT

Whereas for decades biomedical practitioners have been concerned primarily with disease processes, medical anthropologists and others have been more concerned with the wider implications and perceptions of illnesses. Disease denotes the objective abnormalities in the structure and function of body organs and systems, while illness has been described as the subjective response of the patient to feeling unwell. Included here is how the person and his or her family interprets the reasons for the illness, how it affects the person's daily life and what treatment, if any, is sought. In fact, disease may occur without any illness (e.g. early cancer), and illness may occur without disease (e.g. anxiety). Consequently some healers may not only attempt to cure the physical disease, but might also address the illness of which the disease forms only a part (May,104).

During its relatively short history, western scientific medicine has taken a particularly secular and mechanistic approach to the study and treatment of disease and illness. Against the highly technological focus on diseases this century, the modern palliative care movement came into being to provide a more holistic approach to caring for the dying patient. However, despite its attempt at providing care within the physical, social, emotional, and spiritual spheres of the patient's existence, because it is modelled on the western philosophy of a scientific approach, palliative care consequently does not attempt or may be unable to provide an answer to the Jamaican peasant farmer's question of "why me and not someone else?".

With their African heritage going back to the days of antiquity and without much exposure to western cultural influence, less well-educated Jamaicans have always had deeply held magico-religious beliefs which have served over time to answer such questions and to provide hope of a magical or spiritual cure. In fact some Jamaican folk have not yet separated their religious beliefs from their secular activities, and their world is a sacred one at the centre of which is a spiritual force, power, or will (Barrett,102). Consequently, if palliative care is to be truly holistic and cater to all the needs of the particular Jamaican terminally ill patient, it must attempt to address these issues while perhaps also providing some hope for a miraculous healing.

This element of hope may be important to both folk and other forms of care. Kubler-Ross has maintained that even when faced with the terminal phase of their lives, the majority of her patients still left the possibility open for some last-minute cure (Kubler-Ross, 139). This thread of hope apparently kept some of them going through weeks and months of suffering, thereby maintaining their spirits through difficult times. In fact, they reserved their greatest confidences for those doctors who allowed for such hope. Nevertheless, this element of hope would seem to clash with the present philosophy of palliative care which encourages the patient to accept his or her illness as being terminal, and simply to seek to live out the remainder of his or her life in physical and psycho-spiritual comfort.

Along with endeavouring to address metaphysical questions and shifting its philosophy to allow for the hope of a miraculous cure, of even greater importance within the particular Jamaican setting are palliative care's efforts in symptom control and psycho-socio-spiritual nurturing. Physical symptoms ( severe pain, dyspnoea, nausea, vomiting, constipation, bowel obstruction, mal-odour, and so on) might in some instances be overwhelming for Jamaican family care givers, and so specialist palliative care management would likely be particularly helpful here (Storey [b], 748; Jacob et al, 31; Foley et al [a];

346; Dudgeon, 48). Indeed, a palliative care service, inclusive of a physician, nurses, home health aides, and volunteers, could help families greatly by providing appropriate medication, pertinent advice, and essential physical care to ensure the control of a patient's perplexing symptoms and anatomical lesions. Moreover, no evidence exists that the Jamaican "bush doctor" or "obeahman" provides any effective relief or even temporary respite from these physical symptoms.

Relationships with family and friends are important while conflicts are uncomfortable and undesirable, thus the reconciliation of conflicts and the resolution of any unfinished business with friends and family members may be a great priority for the terminally ill (Welk, 16; Bourke, 122). Personal, domestic, legal, and financial matters may need to be put in order and so the social arm of palliative care may also have a role to play on the Jamaican scene. When necessary, a social worker may help to arrange for physical assistance to those persons with inadequate or no support from family care givers, even though this is uncommon in the Jamaican setting.

Providing emotional and psychological support to the terminally ill patient and their family is extremely important within the present concept of palliative care (Welk, 15). Euro-American culture has stressed the notions of personal privacy, individual responsibility, the fear of depersonalization, dignity in dying, and not wanting to die alone. Indeed in those cultures, death always occurs "in the context of others". Whether the patient is surrounded or abandoned by loved ones, and or is mourned or ignored, his or her death is always understood and related to the presence or the absence of others (Bulkin and

Lukashok,13). While such values do not necessarily carry the same level of importance for Jamaican patients, the psychological aspects of cancer pain (e.g. anxiety, depression, sleep interruption and mental exhaustion) are very important, and would likely benefit from the attention of palliative care (Storey [a], 5).

This is not to say that most Jamaicans identify with psychological problems. Griffith has described how, in one Jamaican church-based tripartite clinic catering to spiritual, psychological, and orthodox medical needs, psychological counsellors were poorly utilized (Griffith, 570). Not only did biomedical practitioners fail to detect or deliberately ignore psychological problems, but both patients and staff were uncertain about what role psychological counsellors could play. In addition, the Jamaican society as a whole did not encourage anyone acknowledging that they might be having psychological difficulties (Griffith, 570). His interviews repeatedly showed how these patients failed to understand the concept that the mind itself could require therapeutic attention, or that psychological counsellors might perform the needed therapeutic intervention without professing some links to God and religion.

Whereas middle-class educated Americans tend to psychologize somatic experiences and separate their distress into mental and physical categories, some non-western cultures (including Jamaica) have always tended to express emotional distress in somatic terms (Kirmayer,174). In fact, this calling attention to the physical body's supposed pain or discomfort lets others know that the person is in some form of mental or emotional anguish, the main intention being the evoking of an appropriate social response. However, rather than offering psychological interventions to address such distress, medical and psychiatric care in Jamaica would perhaps instead have to be offered either through the orthodox medical modality, or via the various magico-religious settings which are said to work on the mind.

Believers in spirituality regard it as the most central, deepest, and most complex of human needs; they also find it a way of making sense, deriving meaning, and finding significance in life (Welk,17). Further, spirituality may be used not only to make sense of death, but also to see through it to find life and peace. Consequently, in attempting to address spiritual needs, palliative care seeks to resolve what might otherwise be a source of great suffering for terminally ill patients.

Whereas beliefs in spirituality and religion are integral parts of everyday life, the particular syncretism of African revival and Christian beliefs in Jamaica may dictate that spiritual care for a majority of lay persons may have to take the form of magic rituals in order to match the local appeal of the Jamaican obeahman. Such care may indeed have to include revival singing, praying, and testimony, or even Holy Ghost possession, the shouting or speaking in "tongues", and healing through the laying on of hands (Griffiths, 571). Therefore, in attempting to address the specific spiritual needs of the ordinary Jamaican rural peasant farmer, palliative care may need to allow for or even make efforts to link with or provide avenues for African revival religious expressions.

Palliative care services may need to offer to link with revival groups in the patient's community and be willing to invite them into the patient's home to perform African revival religious services and prayers. Such acts would help to convince terminally ill patients and their relatives that local palliative care services are willing to go beyond traditional biomedical care in order to cater to an individual's needs or desires. Moreover, psychologically and spiritually, such deeds may greatly produce a significant improvement in the terminally ill patient's quality of life.

Given the multidimensional approach and the inter-disciplinary staffing required for good palliative care, would Jamaicans be able to afford this method of care? Some would, but perhaps the majority would not. At present, funding for any such program would have to be entirely private as the economic problems in the public sector have severely impaired health service development, especially those of the nature of primary care and care of the elderly (Eldemire et al, 42). Whereas a significant portion of employed persons have health insurance, the large majority of the self employed and unemployed do not. Indeed, among the patients presenting to private practitioners, only 20% of urban dwellers carry any form of health insurance, a policy that is virtually non-existent among the rural peasant folk. Further, there are as yet no provisions under the various Jamaican health insurance schemes which would facilitate the multidimensional aspect of care existing in the present North American palliative care programs.

To be effectively delivered in Jamaica, palliative care services would most likely have to be home based, with a small number of identified in-patient beds to provide respite for family care givers and care for those patients with symptoms too difficult to manage at home. In addition to perhaps being the least costly, home care also allows for care in very familiar surroundings, the family closeness to which Jamaicans are accustomed, and the working through of the grieving process, if or when the inevitability of death is finally accepted. With their very limited financial resources and their lack of an organized and efficient method of public transportation, without such a domiciliary service persons in the rural and semi-urban areas would otherwise be denied the services of palliative care.

In this particular culture of care, the establishing and maintaining of any effective palliative care program would require the setting of realistic goals for symptom control, quality of life, and culturally relevant methods of action. Despite the local appeal of the "bush doctor"/"obeahman", persons may choose palliative care if its specific local concepts and goals suit their own traditions and matches their particular outlook on life (and death).

## Summary: Chapter 3

Concepts of illness vary across cultures, and cultures may be shaped by various religious beliefs. Diverse expressions, meanings, and methods of action may therefore exist in the giving of care. Consequently, palliative care will require specific knowledge and skills advised by culture, and the setting of realistic goals which are relevant in the particular cultural context.

A review of the literature on palliative care services provided in various parts of the world has identified a number of common problems. However, the large majority of these services have been modelled on palliative care programs existing in the most developed nations. Unfortunately the concepts, values, and philosophies of these "western" cultures are deeply ingrained in their medical systems, and so these may not be wholly transferable across cultures worldwide.

To be tailored to the particular Jamaican setting, palliative care will need address local metaphysical questions and provide hope for a miraculous healing. Symptom control is likely to be imperative but the need for social support may be minimal due to the existence in most cases of a strong, supportive extended family structure. Palliative care may also be needed to alleviate some psychological aspects of terminal illness, including denial, anger, anxiety and depression, but as Jamaicans stigmatize psychological problems and somatize emotional distress, the route of care would probably have to involve either conventional biomedical drugs, or participation in defined magico-religious rituals.

A deep seated belief in spirituality is part of the Jamaican heritage, and magico-religious rituals may have much significance in the psyche of the Jamaican culture. Only partial palliative care administered in the home may be affordable to some Jamaicans, and therefore in tailoring palliative care to the particular Jamaican context, the specific needs of the individual local patient must be first sought and identified.

## DISCUSSION : ETHICAL CONSIDERATIONS

We live in a culturally and philosophically diverse world in which it may be difficult to maintain a consistent ethical approach to care while respecting cultural differences (Roy, 5; MacDonald [b]; 44). Differing belief systems and solutions may pose a real dilemma for some persons within certain societies. Further, as technology continues to rapidly evolve, the practice of western "scientific" medicine with its accompanying value system may now greatly differ in both form and substance from that practiced in many non-westernized, developing countries.

Secular values are highly visible in most industrialized societies, with media hype and massive advertisements of cars, implements, and cosmetics being the order of the day. Western values promote the idea of working towards "progress" and technological perfection, and hence many individuals in these societies become obsessed with utilizing the tools of capitalism to make themselves comfortable in the world. The technological advances in medicine have further contributed to the enhanced feeling of comfort and security for many of these persons, as a long life, aided if necessary by medical innovations, is presumably assured. In other less technologically advanced societies where philosophies and values may be quite different, many individuals separate themselves from a secular pre-occupation, adopt good preventive health care measures, and work instead towards achieving an inner peace. Many others, unable to work their way out of poverty, or to have access to even basic levels of health care, may simply resign themselves to their life of physical deprivation and suffering, with the hope that an after-life exists which will be better.

In a majority of societies around the world, religious beliefs have assuaged the suffering of many, and in the Jamaican culture, many Christians believe that suffering is their lot in life. Consequently, they symbolically link their suffering with that of Christ on the Cross, regarding it as a necessary and inevitable part of life for them on earth. However, whereas many Christians might have adopted this mental attitude to mitigate their anguish, some may not subscribe to this view, and so with any introduction of palliative care services to alleviate suffering, some terminally ill Christians might wish to seek its services.

For some persons, illness may be a form of punishment, or the devil in the form of an enemy which must be fought. Others may regard illness as yet another challenge in the travail of life, or a physical weakness they should try to overcome. As a result, the meaning attributed to an illness may influence the coping behaviour adopted by the afflicted. Invariably, one's socio-economic status, education, access to information, religious faith (if any), ethnic background and culture influence one's attitude to terminal illness, and hence the outlook one brings to an encounter with a healer, or one's attitude when facing impending death.

In fact, illnesses may have multidimensional qualities. According to Good and Good:

> "An illness or symptom condenses a network of meanings for the sufferer: personal trauma, life stresses, fears and expectations about illness, social reactions of friends and authorities, and therapeutic experiences. The meaning of illness for an individual is grounded in - though not reducible to - the network of meanings an illness has in a particular culture: the metaphors associated with the disease, the ethnomedical theories, the basic values and conceptual forms, and the care patterns that shape the experience of the illness and the social reactions of the sufferer in a given society."
>
> (Good and Good, 176)

Therefore, given the vast differences in therapeutic experiences, social climate, and cultural values which exist between industrialized and developing countries, the meaning attributed to particular illnesses may show great variation, both in context and significance.

Reared in an overwhelmingly Christian society, a majority of Jamaicans view terminal illness and subsequent death as an unfortunate person's destiny. Describing such events as unfortunate perhaps reflects the African heritage of the personalistic etiology belief system in which the cause of a disease and misfortune were linked. With the syncretism of Christian beliefs, Jamaicans may also regard such events as destiny, whereby somehow that particular person had been chosen for the affliction, an affliction which others in the community were unlikely to get.

For the majority of Jamaicans, all life is controlled and directed by a higher power, and man has not the right nor power to question the wisdom of the all-knowing, omnipotent God. Such beliefs sharply contrast with an apparently growing attitude in some industrialized societies that the old acceptance of destiny has gone, unfortunately replaced by a new belief that modern technological advances can halt (or indefinitely postpone) the inevitability of death. Such attitudes have therefore made care for the dying and their families very demanding, and often very difficult (Doyle et al, Foreword,v).

With this widespread belief in Christianity and destiny, it should be relatively easier for Jamaican patients to accept the services of palliative care. In fact, palliative care services might seek the support of churches in patients' communities in order to work together in a loose alliance for the patients' benefit. However, palliative care teams need not include the services of a minister or priest as, traditionally, churchgoers develop close ties with their particular pastoral leaders, and are often reluctant to be ministered to by a strange pastor. Indeed, whereas a small handful of private hospitals provide pastoral counsellors whose services would help to provide spiritual care while the patient is hospitalized, nevertheless, once the patient is discharged from hospital, he or she often prefers to return to his or her own particular pastoral leader.

This notwithstanding, however, while many Christians may view terminal illness and any accompanying suffering as their lot in life and may be therefore unlikely to demand that the medical team fight their disease against all odds, many persons who subscribe to magico-religious beliefs may be less likely to accept terminal illness as destiny. Such persons may regard terminal disease as an enemy to be fought, and may be more likely to hope for or seek a miraculous cure. Therefore, in order to appeal to various persons with different attitudes, local palliative care services may have to broaden the traditional palliative care philosophy to allow African folk rituals at a person's request.

Unfortunately, due to the deeply ingrained prejudices existing between the social classes in Jamaica, palliative care services would have to be careful not to be stigmatized by too close an association with magico-religious or revivalist practices, or to be viewed as only being associated with the practice of Christianity. To establish and maintain a broad-based appeal, a middle-of-the-road path respecting and involving all religious beliefs and practices would have to be taken. Therefore, inevitably, the spiritual support given and the nature of the care provided would be determined by the beliefs and needs of each individual patient.

Perhaps because of the fervent belief in a higher power controlling events on earth, no one has overtly requested, or argued for, assisted suicide or euthanasia in Jamaica. To seek to take your own life for whatever reason, thereby usurping God's power and perhaps shortening the days he might have intended for you to spend on earth, would most certainly incur his wrath, and your soul would probably then be condemned to burn forever in Hell's fire. So whereas terminally ill persons may wish relief from any severe suffering, spiritual beliefs, including a personal desire for an after-life with God, would render suicide or euthanasia taboo.

Characteristically, religious skepticism is supported by some biomedical scientists who demand solid evidence for any proposal or postulation about occurrences in the world. Any idea which cannot be proved in some physical way may be systematically rejected. In truth, biomedical science does not attempt to explain "spiritual phenomena", nor address issues such as whether a God exists. It does not address questions about man's purpose on this planet (if one exists), or proffer any explanations for the meaning of life. Yet, accompanying science's search for answers using its scientific tools to separate "fact" from "superstition", the relative importance of the unclear, the unexplained, and the enigmas of the world have dwindled, and life has lost much of its mystery.

The biomedical reductionist model of health care separates the mind from the body, and addresses the biological needs of the sick person. For this model of health care, the issue is the disease process rather than its meaning to the patient. All diseases are reduced to their physiological elements, then a standard procedure is applied to the problem. Diseases can be objectively studied and evaluated, but meaning is difficult to evaluate quantitatively. In a typical model of medical evaluation, data is gathered based on a set of questions asked, and phenomena which fall outside the frame of reference are excluded. Consequently, whereas psychosocial and cultural information provide important personal knowledge about the sick individual, such information is not considered relevant to the disease being evaluated. In the bioclinician's world therefore, explanations of phenomena that are not easily reconciled may be excluded, and questions concerning the meaning of illness may be considered unorthodox (McNeil [b], 95). Moreover, typically, many biopractitioners take a negative view of any of the patient's cultural beliefs which conflict with their own, especially when such beliefs may cause interference with the practitioner's prescribed treatment.

Unfortunately, however, sick individuals cannot isolate their disease from their person, and they do not live in a vacuum. Their disease affects their relationships, their very being, and may significantly change their life plan and goals. In fact, the psychosocial effects of a severe, debilitating disease may be much more disruptive to the afflicted and their family than the ravages of their physical disease (McNeil [b], 17). Cancer is one such organic disease with possible dire psychosocial consequences; it may impose monumental stress to which many persons may not be able to adapt. Consequently, terminal cancer may be a problem not only for the patient, but also for his or her entire family.

Care for some terminally ill patients may require a great deal of support, and twenty four hour nursing care may be required. Under such circumstances, the supportive role of relatives is often essential to any successful care for patients in the home setting. In fact, the importance of the emotional support of the family cannot be overstated, and in those societies where health care is not augmented by a strong social welfare program, or where auxiliary nursing staff are difficult to obtain in the home, the proper physical care of the patient in that location without the presence of relatives may be virtually impossible.

In many cultures, families may be widely dispersed, as individual family members may move to distant and sometimes foreign locations, often seeking jobs and a better quality of life. Often therefore, in such situations, some terminally ill patients have only a few family members in close vicinity, and so their care may become onerous and stressful. Bye and large, Jamaican families are a lot more fortunate in this regard. Living on a relatively small island with only 2 main cities, and with few prospects for outward migration, most family members are almost always close at hand. In fact, with the large and extensive network of relatives present in most family structures (many parents having up to 12 children as recently as 30 years ago), almost invariably terminally ill patients will have adequate physical help for their care at home.

Jamaican families traditionally are very supportive, family bonds are very strong, and invariably emotions run very deep. Families will not only quickly assume care for members who fall ill, but often will toil ceaselessly for long periods of time in an effort to bring comfort to the afflicted. Moreover, due to the large size of most families (and relatively high unemployment), physical and emotional burnout of individual family members is less likely to occur, as "turns" are more easily taken in the care of the terminally ill relative.

Unfortunately, in the standard western models of palliative care, the bio-psychosocial and spiritual care given to the patient and family is only provided towards the end of the terminal illness, and not when the frightening diagnosis was pronounced, or its harsh treatment begun. Further, little, if any, attention may be paid to what the illness means to the patient or his or her family. We should encourage palliative care personnel to expand their traditional concepts to include the interpretation of the possible meaning an illness has for the patient at the earliest possible moment, and should teach them some specific techniques used in the social sciences to help elicit such details with an aim to reducing their patients' suffering. This approach would assist care personnel to better understand their patient's behaviour, become better teachers, and improve compliance, especially where sick persons may have blended health care values, background experiences and beliefs, which may hinder their care (McNeil, 7).

The healer needs to develop a meaning-centered approach to illness, which would thus help him or her to understand cultural concepts of illness. Preferably, terminally ill patients and their care providers should have a clear and common understanding of the illness and the suffering involved, as this would greatly enable an improvement in the quality of care provided for such patients. Whatever the meaning attached, and the causative factors associated with a terminal illness, enhancing the person's quality of life within their particular cultural setting is the ultimate goal, and this should be paramount in all models of palliative care.

Consequently, the delivery of palliative care ought to be fully cognizant of the deeply entrenched magico-religious belief system in Jamaica; this cultural model would reveal what issues are of most concern to the patient, help to explore the rationale behind the patient's behaviour, and form a therapeutic alliance aimed at total care. Due to the high value placed on family and kinship, and the invaluable support which most terminally ill patients obtain from their immediate and extended family support system, such a cultural model of palliative care should have both an immediate impact, and long term success in providing good, palliative care services to terminally ill patients in Jamaica.

In light of all this, then, how can we best resolve the dilemma posed in the Jamaican paradigm? In this classic case of principles conflicting, the principle of autonomy is at odds with the principle of beneficence. An ethical approach to solving a particular dilemma may in fact require a delicate balancing act. On one hand, rational arguments may be provided for respecting the personal beliefs, religious values, the emotions, and personal wishes of terminally ill patients which have existed so far in a vacuum of knowledge about palliative care. On the other hand, the laws and codes of the local health care system should reflect fairness and Jamaica's particular social, political, cultural and economic circumstances, with the state protecting the best interests of patients (Beauchamp and Childress, 327). As persons may have many different reasons and sources for their values and moral inclinations, we will therefore have to adopt a comprehensive, integrated approach in seeking to resolve any dilemma in this morally pluralistic society.

Should we respect the terminally ill patient's belief in African magico-religious theory and his or her wish to opt for "obeah" practices once scientific interventions cease? In the Jamaican context, family dynamics render decision-making a group rather than an individual process, and so "respecting the wishes of terminally ill patients" would in fact be respecting the democratically derived decisions of patients and their relatives. Consequently, if families collectively decide to transport these patients to the "bush doctor"/"obeahman", should society oppose their desire?

By and large, Jamaica's social elite do not support or value African folk medicine, the practice of which may still lead to criminal incarceration under Jamaican law. Indeed, some biomedical practitioners regard "obeah" as superstition, and the Jamaican Medical Act permits only the practice of scientific medicine. Despite this, however, Jamaica's security forces may have developed some measure of tolerance towards "unorthodox" practitioners, once they do not clearly cause harm. Nevertheless, evidence has been documented of some harm being caused by the use of certain bush remedies.

All this notwithstanding, at present Jamaica's bio-physicians only function in the physical sphere of their patients' lives, leaving unfulfilled gaps in their patients' emotional, spiritual, and social spheres. As the belief systems of the local revivalist religion and that of "obeah" as magic overlap, these may serve to fill the void left by biomedical practice. Indeed, the practice of African folk medicine is deeply entrenched and pervasive especially in rural Jamaica where there is much poverty, little formal education, very inadequate biomedical services, and significant transportation problems.

Ethics has been said to be the study of rational processes for determining the best course of action in the face of conflicting choices. In the Jamaican paradigm, therefore, we need to decide what would be ethical; that is, we need to determine what would be the best course of action between respecting the beliefs and personal wishes already stated, and fairness in restricting individual liberty to protect the public's interest.

Since ethical principles are in conflict, in order to recommend acceptable courses of action, the short and long term consequences of each specific option are very important. A predominant ethical principle, beneficence in medicine, ensures the good of the patient by requiring that we protect him or her from harm while taking efforts to secure his or her well being (Suzuki et al, 39). Thus beneficence embraces at its minimum, the principle of non-maleficence, which is the duty to remove or limit the possibilities of harm (Pellegrino and Thomasma, 26). Enacted in 1938, the present Jamaican law prohibiting the practice of African folk medicine is designed presumably to protect patients from any harm which may come from the "obeahman". However, the supposed beneficence of this law may be questioned, in light of the present conflict existing in the Jamaican paradigm.

The principle of autonomy underscores the right of patients or their surrogates to choose between available options in determining the course of their care (Byock [b], 1). It invokes the duty of respect for persons and gives strength to the arguments for respecting the personal beliefs, religious values, and personal wishes of terminally ill patients in the Jamaican paradigm. In the present dilemma, therefore, this principle is in direct conflict with that of beneficence.

Moral and ethical principles and theory may be invoked to enhance the good of the patient, but "good" may not be a monolithic concept (Pellegrino and Thomasma, 74). In order of increasing importance, these authors have described four concepts of the good of the patient:

> 1) The biomedical good: that which can be achieved by medical interventions into a particular disease state;
>
> 2) The patient's best interests: his/her subjective assessment of the quality of life which the intervention may produce, and whether or not it is consistent with his/her life plan, goals and aims;
>
> 3) The good of the patient as a person: grounded in his/her capacity as a human being to reason, to choose and to express choices in speech with other humans; and
>
> 4) The ultimate good: taking into account the patient's view, if any, of the meaning and destiny of human existence, the world, and his/her God.
>
> (Pellegrino and Thomasma, 81)

Apparently, Jamaican society has been preoccupied with the biomedical good and the weighing and balancing of the particular benefits and harms which biomedical and folk medicine interventions might cause to the patient. The terminally ill patient's subjective analysis of his or her quality of life and his or her own personal goals are not appreciated or acknowledged (Cella, 9). Indeed, no apparent respect is shown for that person's human capacity to reason and make rational choices based on his or her own particular life plan or the person's own emotional or social needs. Most certainly there is no cognizance of the terminally ill patient's ultimate good within the Jamaican paradigm, whereby the patient's metaphysics and world views are incorporated, with a general societal appreciation of or respect for the person's magico-spiritual beliefs and particular view of the world.

To be fair, of major concern in respecting a person's beliefs and personal wishes are questions of whether patients understand relative levels of health care competence, whether they are in a position to make a decision based on this information, and whether in fact they have all the necessary information upon which they can make logical choices. However, any decision simply to compel terminally ill persons not to visit or utilize the services of their local "obeahman" may be difficult to sustain, as freedom of choice may only be justifiably restricted when it can be shown that unregulated choice would cause serious harm to the individual or to other people. Although we should not place an absolute value on individual choice, for any of the state's paternalistic policies to be justified we would have to clearly demonstrate the harmful effects of the practice to be restricted. Indeed, if there is an alternate way of accomplishing the same end without the restriction of civil liberties, then such a choice would be almost obligatory in a western society where civil liberties are highly respected (Munson, 277). In Jamaica however, civil liberties are not deeply entrenched in law and not enough recognition or respect is given to the ultimate of the terminally ill patient.

In Jamaica, the state's paternalistic policies are enforced by legislation. Although the Jamaican law encourages or enforces minimal morality, the law is not "neutral"; that is, it may not be blind to social class and so on. So we therefore need to examine the limitations, frustrations and entrenched unfairness which may be present within that society's legal institution. Consequently these laws may need to be changed, and we would have to incorporate the present values and norms of the Jamaican society to make the new laws relevant.

Would palliative care services be able to provide an answer to the dilemma in Jamaica? In Jamaica, most persons are unaware of the nature and scope of palliative care. In reality, 70% of the population receive and accept most of its health information from either indigenous practitioners or influential lay persons. Further, the average patient and his or her family cannot afford in-patient palliative care and would be hard pressed to pay for good palliative home care, which provides not only good symptom control but also emotional, social, and spiritual support.

On a practical level, a palliative care service would have to convince patients in Jamaica that it can do a better job than what presently obtains; it would have to tell patients that, not only would their particular religious beliefs be respected, but that the service would liaise with their specific spiritual leader in order to promote their care. Whereas palliative care teams need not work specifically with "obeahmen", they should be willing to permit magico-religious rituals to occur at the patient's bedside. Further, the palliative care service would have to promise patients that it would augment the physical care provided by family members with trained experts to ensure that their symptoms are controlled and their quality of life improved.

Jamaican palliative care teams would have to be educated in the significance of the meaning of illness, and the history of Jamaica and African folk medicine, in order to appreciate why the latter appeals to certain sectors of the populace. Accompanying the widespread belief that events on earth are controlled by a higher power, some persons believe that the "obeahman" has connections to the supernatural world, connections which he can make to procure good fortune or misfortune, eradicate ill health, and provide protection. To persons with such magico-religious beliefs therefore, "obeah" would possibly do a better job of catering to their spiritual concern. For Christians, whose higher power comes in the form of Christ, their spiritual concerns would best be addressed by their minister or priest. Consequently, palliative care services would perhaps best make a difference by facilitating the individual's desired spiritual care, and augmenting it with any needed emotional support and physical care.

How then do we resolve the dilemma in the Jamaican paradigm? Ethical considerations dictate that patients should have access to adequate pain relief, but with the present inadequacies in the biomedical services existing across Jamaica, most rural dwellers do not have this. This ethical consideration consequently strongly supports the implementation of more palliative care services to make this option more widely available across Jamaica. So at least in the short term, by adjusting the state's budgetary allocation to reflect this new emphasis, partial palliative care involving basic symptom control could be offered in the public health care clinics outside of urban centres for those rural dwellers financially unable to afford private care. In addition, general education as to the nature and scope of palliative care would be even more effective if it were to involve the public education of both influential lay persons and indigenous practitioners.

General education might entail informing lay persons about the philosophy of palliative care as discussed for the Jamaican context, the personnel involved, the locale of care, and support at home. Members of the palliative care team might be better suited for this undertaking, although health education officers employed by the government might also be briefed to provide such education. Further, private and volunteer organizations such as the Jamaica Cancer Society might be lobbied to underwrite the cost of this educational program.

In view of all this, I recommend that:-

1) The society be educated about the possibility and principles of palliative care;

2) We respect people's personal beliefs in magico-religious theory, but restrict a terminally ill patient's options to only full evaluated, culturally appropriate, and demonstrably safe methods of care (e.g. palliative care, folk remedies shown to be safe); and

3) We change the laws and codes regulating the health care system to reflect the medical pluralism, socio-economic, and politico-cultural realities presently existing in the society.

To determine whether any, or all of these recommendations would be in the society's best interest, we need to examine the short and long term consequences for each recommendation. The emphasis in education of the society underscores the principle and values of beneficence. It may have the immediate consequence of persons becoming curious about, showing interest in, and becoming more aware of palliative care. In the short term, various families would likely place their terminally ill relatives in palliative care, compare its care with other "services" in their communities, and provide an empiric evaluation of the advantages and disadvantages of palliative care which would be then be spread by word of mouth throughout the society. In the long term, there would likely be cultural assimilation for palliative care, with its acceptance as a viable option of care for the terminally ill patient.

In respecting people's wishes but with limitations to only safe methods of care, the principle of autonomy is balanced by beneficence. Whereas some persons would probably initially resent such restrictions of their freedom, other concerned persons would probably welcome this. Quality of care would possibly be enhanced, and there would be increased confidence in the choices available. The long term effect would consequently be the entrenchment of a plurality of safe care. Indeed, folk remedies of a spiritual or psychological nature whose practices in the past have not indicated any deleterious effects could be categorized perhaps as safe, while remedies which involve ingestion of substances would be required first to undergo stringent scientific evaluation to ascertain any possible harmful effects on the body.

On the other hand, in unfettered autonomy, more people employ or resort to any method of care they wish, tested or untested. In the short term, such experimentation may be fruitful, or may lead to dissatisfaction or even harm for some persons. In the long term, whereas a few may find relief, some persons may continue to be harmed, and others, in their disenchantment, may continue their uninhibited search for alternative remedies of any sort. Although outlawed, the practice of "obeah" is tolerated in Jamaica. As a result, many persons have attempted "obeah" cures and some have been dissatisfied. This notwithstanding, however, many persons continue to explore and remain receptive to the many anecdotal claims of other remedies present in the society.

In changing the laws to reflect the medical pluralism, the biomedical community would probably protest immediately while practitioners of alternate and folk medicine would rejoice. Thereafter, less policing would be required from the state, folk practitioners would no longer be stigmatized, and there would likely be a gradual acceptance by the biomedical community. In the long run, the present legislated moralism existing in health care would be abolished and there would likely be a relatively tolerant co-existence of biomedicine and folk medicine, as occurs in some similar paradigms (Bates and Weisz, 5; Lock, 2).

Are there significant burdens in any of these recommendations? Educating the society through influential lay persons has great benefits with very little burden, perhaps the only burden being the costs incurred in an educational program. Respecting personal beliefs but restricting a person's options to only safe methods of care embraces many important principles and values, and both short and long term benefits greatly outweigh any burden that might arise. Also by updating and regularizing the health laws, there would be a maximizing of the good for the benefit of society, and any resulting burden would be minimal.

To resolve an ethical dilemma, it is usually best to find a common ground, an acceptable compromise within the milieu of varying points of view. Consequently in this dilemma, the best course of action would be the combining all three recommendations in order to be fair to all parties and protect their best interests.

# FINAL SUMMARY AND CONCLUSION

Harsh socio-economic problems prevail and grossly inadequate palliative care services exist in Jamaica, a country where few people know about the concepts and principles of palliative care. For a very long time, many Jamaicans have turned to cultural magico-religious practices when biomedical cure for terminally ill patients was no longer possible. Nevertheless, folk medicine is still not only frowned upon, stigmatized, and marginalized, but its practice also remains illegal in Jamaica.

Palliative care services may be generally provided in the home, in hospital, or in specially designated institutions, and its principles include the control of physical symptoms, social, psychological, and spiritual care for terminally ill patients, accompanied by psychosocial support and bereavement care for family members. This notwithstanding, concepts of illness and care vary across peoples, places and cultures. Due to the complex set of circumstances existing in particular cultural settings therefore, establishing and maintaining palliative care programs will require the setting of realistic goals which reflect the particular cultural context.

In the Jamaican setting, palliative care may need to address metaphysical questions while also allowing hope for miraculous healing. While the control of physical symptoms may be greatly needed, psycho-social support may be of less importance. Indeed, spiritual comfort for a large percentage of the Jamaican common folk would probably best be provided through the performance of religious rituals. Unfortunately only partial palliative care may be affordable to the majority of Jamaicans, and so in tailoring care to the particular Jamaican setting, the specific needs of the local patients must first be sought and identified.

Biomedical science is said to be a cultural dimension of western development, and Jamaican scientists should avoid any arrogance or hubris in their practice of scientism (Nettleford, 77). Indeed, biomedical students and physicians who understand that scientific medicine has been shaped by the particular western culture will be better able to guide their patients in discussions about biomedicine and alternate forms of therapy. In fact, if in the end the patient chooses an alternative to biomedicine, the bio-physician ought not to simply abandon the patient, but rather should leave the door open for such a patient to return to his or her care at any time.

The "unorthodox" practitioner ought not to be condemned as even biomedical doctors sometimes may follow particularly traditional courses for treatment rather than those that have been empirically proven (Williams, 448). In fact, some authors have encouraged the upgrading of the skills and the incorporation of local healers into existing health care systems. However, this path may risk losing the legacy of traditional knowledge while probably rendering access to the folk healer more expensive for rural folk (Olweny [b], 21; Laguerre, 89).

In truth, since the establishment in Jamaica of the Faculty of Medicine at the University of the West Indies in 1949, some research has been carried out on folk medicines used by Jamaican healers, but much more work needs to be done (Barrett, 90). More research should be undertaken to provide systematic evidence of the efficacy of such remedies, their active principles, their modes of action, any short or long-term toxicity, and the requirements for their standardization (Laguerre, 89). Nevertheless, since these remedies are rooted deep in the Jamaican belief-culture and any changes may only occur over generations, those who work closely with the people, are concerned with their health care, or who may be seeking or hoping to serve them should listen more carefully to their history and give more respect to their cultural beliefs (Morrow, 6).

In this thesis, I have illustrated the peculiar circumstances existing in the island state of Jamaica, providing an insight into its culture and the multidimensional problems to be found in the society. I have identified a particular moral dilemma faced by terminally ill patients in that setting, and have explored various ways of resolving their specific plight. The services offered by palliative care are among the best options available for such end-of-life care, and using an ethical approach I have made specific recommendations which I think will benefit these patients and the good of the Jamaican society generally.

Unfortunately, as we move toward the 21st century, Jamaica is still trying to survive the severe turbulence of the world economy, and the Jamaican government is presently preoccupied with charting a way forward which would ensure its own survival. The ensuring of respect for civil rights and changing legislation to make them more relevant is not deemed a priority, and most members of society are so absorbed with maintaining their daily existence that there is little societal pressure on the government to update the laws.

It may therefore take some time for all the changes I have recommended to come to fruition but I think such changes are inevitable. Within the Jamaican society are small but nevertheless vocal groups of lawyers, sociologists, and anthropologists who continually bring to light some of the inequalities and social injustices, while informing of changes taking place all over the world. Over time, therefore, with repeated discussions and the development of a generalized societal concern for the particular plight of terminally ill patients, there should be an eventual evolution towards providing adequate care for terminally ill patients in the Jamaican society.

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