

# Pediatric Advanced Care Team (PACT): A Model for Caritas Baby Hospital in Bethlehem, Palestine and a Paradigm for Developing Nations

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## Abstract

Muslims believe that human life is sacred and that it belongs to God. Therefore, all human life must be treated with dignity and respect. Muslims are also very realistic and know that all beings will die one day. The Quran is clear that death is a transition from the present existence to a future life. It is also a tradition among Muslims that they prefer to die at home. To address this issue among children, the Pediatric Advanced Care Team (PACT) has been designed as a model for palliative care and hospice care for pediatric patients living in Palestine. PACT intends to educate patients and their families regarding treatment, improve dialogue and communication with medical professionals, provide patient care, and assist families during the grieving process. With the implementation of PACT the dignity and respect of all human life, even in the last moments, would be protected and the greater good would be promoted.

## INTRODUCTION:

All of humanity is born into this world and one day returns to the earth. This is a fact that is unavoidable to all that are living, and one problem that is often ignored until death is near. Towards the end of one's life, palliative care and hospice care are remedies for those suffering with terminal illnesses. However, patients that are recommended palliative and hospice care are reluctant to begin treatment out of fear instilled from society. In many cases, these options are believed to be the worst-case scenario as medical professionals forgo curative treatment in favor of care to improve the quality of life. In developing and developed nations alike, there are cultural, religious, and social values held by patients and their families that restrict the caregiving

and grieving process. In addition, there is often a lack of communication between physicians and patients in regard to the treatment plan, which leads to mistrust and a less noble death that impacts all involved.

Developing nations such as Palestine show an extensive need for palliative care. Of the 58 million annual worldwide deaths, 45 million of these deaths are located in developing countries.<sup>1</sup> There is an estimated 27 million people in poor nations that would benefit from palliative care, and this number is continually growing as chronic diseases such as cancer remain prevalent.<sup>1</sup> In order to address this issue, the Pediatric Advanced Care Team (PACT) is an initiative designed to be a model for palliative and hospice care in Palestine and other developing nations. This team is initially

centered around Caritas Baby Hospital in Palestine, but PACT is encouraged to be replicated in other developing countries. Without prominent palliative and hospice care services, beds in Caritas Baby Hospital are currently being occupied by terminally ill patients for extended periods of time. Combined with cultural and religious restrictions, medical professionals in Palestine often struggle to provide treatment that does not impede upon the patient's values. PACT intends to educate patients and their families regarding treatment, improve dialogue with medical professionals, provide patient care, and assist families during the grieving process. The implementation of PACT will be further discussed in the last section of the paper.

### **CASE STUDY:**

A 24-year-old male known as CJ was first admitted to Caritas Baby Hospital for a known case of methylmalonic acidemia (MMA) and chronic renal failure. Methylmalonic acidemia is a rare and severe genetic disorder that involves autosomal recessive inheritance. In autosomal recessive inheritance two copies of an abnormal gene are present.<sup>2</sup> Since both of CJ's parents were unaffected by MMA but passed on the genetic disorder to their offspring, they are said to be carriers of MMA. A carrier has one normal copy of a gene and one abnormal copy of a gene.<sup>2</sup> When two carriers reproduce, there is a one in four chance of the offspring inheriting an abnormal copy of a gene from each parent.<sup>2</sup> In CJ's case, his mother had eight children, four of which were aborted. Notably, one of his siblings had MMA, and ultimately passed away from the disease. In around 60 percent of methylmalonic acidemia cases, a mutation occurs in the MMUT gene, which alters the gene's ability to properly produce an enzyme called methylmalonyl CoA mutase.<sup>3</sup> A normal methylmalonyl CoA mutase enzyme works with vitamin B12 to process certain proteins, lipids, and cholesterol.<sup>3</sup> With an altered enzyme, toxic and acidic compounds build up in the body, which could result in coma or even death if left untreated.<sup>3</sup>

Due to methylmalonic acidemia, CJ was noted to experience hypoactivity, reduced oral intake, general weakness, and metabolic acidosis. Metabolic acidosis for CJ involved the buildup of acidic compounds in his body. With a high number of acidic compounds, CJ had an abnormally low pH in his cells, which is a prominent inhibitor of oxidative phosphorylation.<sup>4</sup> Even though CJ was able to breathe in oxygen, cells in his body were unable to use the oxygen and perform oxidative phosphorylation. Since oxygen is essential

for all aerobic animals, an inability to utilize oxygen is a serious danger to the health of a patient.<sup>5</sup>

In order to treat CJ, doctors provided CJ with two 6-mL doses of 30 % L-carnitine, 1 tablet of Alpha-D3, 20 mg of Nexium, and 100 mg of Allopurinol PO every 24 hours. In terms of these medications, the administration of Flagyl, Allopurinol, and Nexium are quite notable. For example, Flagyl is a broad spectrum antibiotic that is used to prevent infection. The prescription of Flagyl indicates that CJ's immune system is extremely vulnerable to infection. In addition, Allopurinol was given to CJ to prevent gout. Since CJ is experiencing chronic renal failure, he is not metabolizing uric acid properly. Without normal processing of uric acid, the compound builds up in the body. A high level of uric acid in the blood is responsible for forming crystals around a joint, which is a main characteristic of gout.<sup>6</sup> Furthermore, Nexium was provided to CJ to inhibit proton pumps in his stomach. Since CJ is unable to perform oxidative phosphorylation, Nexium helps reduce the buildup of excessive stomach acid. Even though these medications help manage the effects of MMA, there is no cure for this devastating disease. However, enzyme replacement therapy could potentially treat diseases like MMA in the future through correcting the mutated gene responsible for MMA.

Even though CJ was discharged from Caritas Baby Hospital after his first admission, CJ has recurrent admission to Caritas Baby Hospital. In the last few months of 2019, his admission has dramatically increased due to the late stage condition of his disease. With the inability to metabolize oxygen and the lack of functioning enzymes, CJ is destined to experience multisystem organ failure. Since organ transplantation is expensive and will not prevent his organs from failing again, CJ has a terminal prognosis. With a terminal prognosis, it is clear that CJ is approaching the end of his lifetime, and that any current treatment will not cure his disease. Through using a bed in the Caritas Baby Hospital, CJ is preventing children with treatable diseases from getting the help they need. Without access to a bed, children that can be treated are dying. Ultimately, no one benefits from terminally ill patients preventing access to healthcare for children in need.

### **CULTURAL/RELIGIOUS AND SOCIAL ISSUES IN PALESTINE:**

Despite the diversity of sects and cultures in Palestine, the vast majority of the population belongs to the Islamic religion. However, each religion promotes a universal notion

of spirituality that vitally influences parts of one's personality. In terms of palliative care, spirituality affects the way in which patients cope with their illness, and spiritual care is as important to the families as to the patients themselves. Furthermore, spirituality helps patients find "inner strengths" and to "think positive," which consequently empowers them to deal with the suffering resulting from their terminal illness.

In Palestine, an extensive amount of people believe in God and in the inevitability of death, along with the notion that death and illness are God's will that cannot be avoided or stopped. In addition, the belief of eternity through the presence of an afterlife is exemplified by some individuals. For these individuals, personal conduct in the temporary life on earth will be either rewarded or punished. This belief helps patients to cope with illness and die in peace through the promise of looking forward to being rewarded in the afterlife. Furthermore, illness and suffering are accepted as a way of atonement for sins. Illness and suffering allow people to become closer to God, which strengthens their faith and makes them appreciative of their finite time on earth.

In terms of patient care, the prevalent religious beliefs in Palestine do not conflict with the necessity of giving all efforts to relieve suffering. When parents experience the traumatic death of their young child, they often express resentment towards God. However, the local community and extended family members forbid these feelings to be expressed as they believe that doing so is considered to be a sin. As health care providers, it is our role to give them the space to express their understandable feelings of anger that resulted from the death of their beloved child.

Along with allowing individuals to grieve, health care providers play a significant role in providing treatment. For people that need treatment, seeking treatment for illness is religiously permissible, and the necessity of pursuing treatment increases with the higher severity of a disease. However, using opioids as pain killers to reduce the level of pain, and not as a medication, is also religiously permissible, but not mandatory. For example, if a Muslim decides to tolerate the pain and to not take pain medications, it is believed that he will be rewarded more in the afterlife. Therefore, different methods of treatment provide varying religious implications in Palestine.

Even though many treatment options are available in Palestinian society, religion prohibits euthanasia or killing a

patient as a means of mercy. Instead, it encourages seeking medications, which compels doctors to rigorously look for appropriate medications to treat the patient and make their life comfortable. Since it is believed that a person is entrusted with their own life, decisions made by the person, family members, and doctors must aim to protect the individual's life rather than end it. Moreover, Christianity and Islam both prohibit direct euthanasia, and the culture of both Palestinian Muslims and Christians is nearly the same in respecting life as a gift from God. Through this belief of a precious sense of life, direct euthanasia and suicide are both considered sins and not practiced by the Palestinian society.

At the cultural and social level, Palestinian cultural values are mainly derived from religion. Culture is an important determinant in healthcare because of its influence on lifestyle, beliefs and values, the perception of individuals' quality of life and palliative care, the interaction with the healthcare system, and decision making throughout illness and end of life. Despite the undergoing changes in the social structure in Palestine, the Palestinian family has an extended structure rather than a nuclear structure. Children live with their parents until they are old enough to get married and expand their families, and they maintain proximity to their parents even after marriage. As a result, family members gather frequently for different social and religious occasions. Due to the presence of the extended family structure, other prominent cultural values include the care of the weak and ill individuals in families. In caring for individuals that are weak and ill, decision making by the family is collective and involves parents, spouses, and older members (brothers, sisters, grandparents, etc.). Evidently, family and familial bonds are sacred in Palestinian society.

Since familial bonds are sacred, it is the family's duty to take care of the ill members. The family fulfills this essential responsibility through being there for ill members in weakness and pain, towards the end of life, and in the time of death. The basis of what constitutes a "good death" in Palestinian society is for terminally ill individuals to be surrounded with their family preferably in their home, and having the ability to say goodbye to their family before they leave. One of the common practices for Muslims and Christians at the end of life is the reading of verses from the Holy Qur'an or the Bible to patients, which allows them to experience comfort.

In some cases, family members prefer to take the patient home to be around them to provide comfort and company.

However, in our experience at Caritas Baby Hospital, most families are terrified to take their child home to die. Parents are often scared in these situations, as they fear seeing their child dying and not being able to do anything for him/her. This feeling of helplessness in these situations is often mitigated for parents through having their children die at our hospital.

Among Arabs, there exists a common desire in parents to appear strong and to please others at all costs. In order to accomplish this, Arab parents bear physical pains, hide emotions, maintain familial leadership, and perform their proper duties and roles. Arab parents often avoid asking for help or showing signs of weakness, as they believe they are maintaining their dignity. Therefore, this factor may be a challenge for us as a health care provider, as we must provide psychosocial intervention for helping parents accept the sickness of their children.

### **PALLIATIVE CARE AND HOSPICE:**

Traditionally, medical care has had two mutually exclusive goals: either to cure disease and to prolong life or to provide comfort care. Given this dichotomy, the decision to focus on reducing suffering is made only after life-prolonging treatment has been ineffectual and death is imminent, usually by days or hours.<sup>7</sup> As a result, one of the best kept secrets in a hospital today in the United States is palliative care and hospice care. In 2006, we estimated that of the 2.4 million Americans that die each year, about 80% end their lives in hospitals attached to the latest advances in technology; 300,000 die at home under hospice care.<sup>8</sup> However, these numbers have gotten better due to education about palliative care and hospice. The New England Journal of Medicine reported that between 2003 and 2017, there were nearly 35.2 million annual deaths in the United States. Of these natural deaths, 29.8 percent occurred in hospitals, and 30.7 percent at home. This analysis shows that deaths at home have surpassed deaths in the hospital. This gap may be small but it has been narrowing for years and many believe it will continue in this direction.<sup>9</sup> The reasons why more people do not receive palliative or hospice care range from the patient's fear of abandonment and the unknown, the family's denial of the inevitability of death of their loved one, and physician's denial of medicine's limitations. Unless the options of palliative or hospice care are given to patients the fears that people have of dying--fear of dying alone and fear of dying in pain--will continue to make the dying process one that lacks dignity and respect.

#### *Palliative Care:*

Palliative care comes from the Latin word *palliare* which means to cloak. It is a form of medical care or treatment that concentrates on reducing the severity of the symptoms of a disease, or to slow the disease progress, rather than provide a cure. Occasionally, it can be used with a curative therapy, providing that the curative therapy will not cause additional morbidity. The goal is to relieve suffering and improve the quality of life for patients with advanced illnesses and their families through scientific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services.<sup>10</sup> The World Health Organization (WHO) in 1990 defined palliative care as "the active care of patients whose disease is not responsive to curative treatment." This definition stresses the terminal nature of the disease.<sup>11</sup>

#### *Hospice Care:*

Hospice care is viewed as part of the philosophy that we call palliative care. Hospice is a centuries old idea coming from the Latin word *hospes* meaning guest. Originally, it referred to the offering of a place of shelter and rest or what we refer to as "hospitality" to weary and sick travelers on a long journey. Over the centuries it developed into a philosophy of care that recognizes death as the final stage of life and seeks to enable patients to continue an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality, surrounded by their loved ones. Hospice care like palliative care affirms life and neither hastens or postpones death. The focus of hospice and palliative care is to treat the whole person rather than the disease; it emphasizes quality rather than quantity or length of life.<sup>12</sup> In addition, emphasis is placed not only on the well-being of the patient but also on the well-being of the family caregivers. Hospice personnel provide care for the patient and the family 24 hours a day, 7 days a week.

The history of hospice and palliative care dates back to ancient times. Some say the first hospice experience appears in the New Testament with the parable of the Good Samaritan (Luke 10: 29-37). The Good Samaritan bandaged the wounds of the man beaten and lying along the roadside, then took him to the closest inn and paid to have the man ministered to by the innkeeper. Others believe the first recorded hospice opened in 475 AD in Syria by Fabiola, a

Roman woman and follower of St. Jerome, as a place of rest for the traveler, the sick and the dying. During the next 1500 years, hospices provided care for those on a journey. In the 19th century a religious order established hospices for the dying in Ireland and London.<sup>13</sup> “Until the 20th century, most people spent their last days at home, surrounded, cared for, and comforted by family and friends. That tradition faded as hospitals became places of healing in many Western countries.”<sup>14</sup> The modern notion of hospice began in 1967 when Dr. Cicely Saunders founded St. Christopher’s Hospice in London. She is regarded as the founder of the modern hospice movement. As a physician, Saunders dedicated her life to the care of the dying and planned a model hospice that would provide exemplary palliative care and would incorporate teaching and research programs. She avowed the regular giving of strong narcotics, including heroin and the Brompron cocktail mixture of morphine and gin, as the proper regimen to ensure that a pain-free patient could maintain quality of life in the last days. St. Christopher’s demonstrated the superior reliability and efficacy of oral morphine over heroin and reported the absence of tolerance and addiction in cancer patients, even with long-term use.<sup>15</sup>

The hospice movement in the United States began in the 1960s but the first hospice to provide services was the Connecticut Hospice in March 1974. “In 1982, Congress created the Medicare hospice benefit, reserving such services for terminally ill Medicare beneficiaries with life expectancies of six months or less ‘if the disease runs its normal course.’ Effective with the enactment of the Balanced Budget Act of 1997, the Medicare hospice benefit was divided into the following benefit periods: 1) an initial 90-day period; 2) a subsequent 90-day period; and 3) an unlimited number of subsequent 60-day benefit periods as long as the patient continued to meet program eligibility requirements. Beneficiaries must be re-certified as terminally ill at the beginning of each benefit period.”<sup>16</sup> The relatively generous Medicare reimbursement for hospice treatment has increased hospice usage in the United States. The 1989 Congressional mandate increased reimbursement rates by 20% and tied future increases to the annual increase in the hospital market basket. From 1984 to January 2006, the total number of hospices participating in Medicare rose from 31 to 2,884—a more than 90% increase. Of these, 1,648 are freestanding, 672 are home health agency-based, 551 are hospital-based, and 13 are skilled nursing facility-based.<sup>17</sup> The first hospital-based palliative care program in

the United States began in 1989 at the Cleveland Clinic. This was in response to the recognition that restrictions on hospice eligibility imposed by the Medicare Hospice Benefit prevented adequate care for seriously ill and dying patients in acute care hospitals. In response, there has been a dramatic increase in hospital-based palliative care programs, now numbering more than 1200.<sup>18</sup>

Hospice programs provide services in various settings: the home, hospice centers, hospitals, or skilled nursing facilities. The number of hospice programs in the United States has continued to increase from the first program in 1974 to more than 4,100 programs today.<sup>19</sup> The majority of the growth is in small free-standing programs. 93% of agencies reported that they are Medicare certified; nearly 3 out of 4 hospice programs are accredited by either the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), Community Health Accreditation Program (CHAP), Accreditation Commission for Healthcare (ACHC), or other accrediting agencies. 67.6% of programs reported nonprofit (501c3) status while 27.2% reported for-profit status. Government-run programs account for 5.2% of all programs.<sup>20</sup> The criteria for hospice care under the Medicare benefit requires that patients acknowledge they are in the dying process and are willing to forego insurance coverage for life prolonging treatments and that two physicians certify that the patient has a life expectancy of six months or less. Studies have shown that referral to palliative care programs and hospice results in beneficial effects on patients’ symptoms, reduced hospital costs, greater likelihood of death at home, and a higher level of patient and family satisfaction that does conventional care.<sup>21</sup>

The principles that constitute the National Hospice Organization’s “Philosophy of Hospice” include:

1. Hospice implies acceptance of death as a natural part of the cycle of life.
2. When death is inevitable, hospice will neither seek to hasten it nor to postpone it.
3. Patients, their families and loved ones are the unit of care.
4. Psychological and spiritual pain are as significant as physical pain, and addressing all three requires the skills and approach of an interdisciplinary team.
5. Pain relief and symptom control are appropriate clinical goals; the goal of all intervention is to maximize the quality of remaining life through the provision of palliative therapies.
6. Care is provided regardless of ability to pay.<sup>22</sup>

The principles of hospice and palliative care are based on a

shift in the patient's treatment from curative to palliative care. This shift rarely takes place at a specific moment. "Just as the disease treatment is a process, so to is preparing a patient for the time when treatment for cure is no longer an option. Preparing a patient begins with an honest discussion of the disease and its outcomes."<sup>23</sup> Physicians have the ethical responsibility to be honest with their patients about their medical condition. When there are no further treatments to cure the disease, the patient must be informed of this fact but must also be given the option of palliative care and hospice care as a treatment. "Presenting hospice as a medical option for treating a terminal illness can help with many unknowns—'fears of uncontrollable pain, nausea, vomiting, embarrassment and especially abandonment' that often accompany end stage diseases."<sup>24</sup> The focus of hospice is to provide services to both patients and their families to assist and support them during the dying process. The family of the patient and others involved with the patient can be crucial in any hospice discussion and care plan. In many cases the patient may be ready to accept hospice care but family members and friends are not. At times, they can even coerce the patient into continuing aggressive treatment even though the burdens outweigh the benefits. That is why the family should be included in these discussions whenever possible but always with the patient's consent. Many times all the family needs to hear is that the patient has accepted the diagnosis of the terminal condition and that it is his or her choice to accept hospice care.<sup>25</sup> Hospice treats the patient and the family as a unit and unless both parties understand the principles and the goal of hospice, the services offered will fail to be beneficial to all parties concerned.

Hospice services are offered by a multidisciplinary team whose emphasis is to maximize comfort for the terminally ill patient and support the family members and other loved ones. The hospice team consists of physicians, nurses, health care aides, spiritual counselors, social workers, volunteers, ancillary therapists and bereavement counselors. The services offered by the hospice team include: pain and symptom support, spiritual care, home care and inpatient care, respite care, family conferences, bereavement care [Examples can be found in Appendix A, B, C] The services offered are extensive and wide-ranging. For example, hospice care integrates complementary therapies with conventional care such as relaxation therapy, massage therapy, music therapy and acupuncture to relieve symptoms and other causes of pain. Trained bereavement counselors offer support and guidance for patients and family members.

This support continues for up to a year after the death of the patient. The most common concerns found among those in a terminal condition are: fear of pain, loss of independence, worries about family and feeling like a burden. The hospice team provides comprehensive palliative care aimed at relieving symptoms, treating depression in patients and giving social, emotional and spiritual support to both the patient and the family.

### **PACT SERVICES:**

"A paradigm shift of viewing palliative care or hospice as a gift instead of seeing it as giving up has the potential to change the way we experience advanced age."<sup>26</sup>

Medical care has revolutionized treatment for illnesses while redefining hope for patients and families. In 2017, the Institute of Health Metrics and Evaluation (IHME) determined the worldwide number of years lost from serious illnesses such as cardiovascular disease and cancer to be 365.87 million and 233.51 million, respectively.<sup>27</sup> In some situations, the utmost care and support is required to meet the growing needs of suffering individuals. These layers of professional treatment are known as hospice and palliative care, which have been mistakenly interchangeable to the general public. Both options intend to improve the quality of life, but hospice care exclusively applies to those with terminal illnesses. Although inconsistent, medical professionals define terminally ill as the certain lack of restorative health with a limited life expectancy that varies from months to days.<sup>28</sup> In contrast, palliative care still allows for the continuation of curative treatment as patients experience life-threatening illnesses. While hospice care is utilized during the end stages of life, palliative care can be helpful in any stage of illness. In both circumstances, measures are being taken by medical professionals to dispel misconceptions while educating affected families and caregivers.

The Pediatric Advanced Care Team (PACT) is a model developed specifically for Caritas Baby Hospital in Bethlehem, with the intention of providing a framework for palliative care throughout many developing nations. The team is comprised of a physician, nurse, social worker, and pastoral care member. Currently, pediatric intensive care unit (PICU) and neonatal intensive care unit (NICU) beds in Caritas are occupied by terminally ill patients which prevents resource allocations to other patients in need of care. Unfortunately, hospice care is viewed negatively in Palestine and has been suppressed by religious intervention.

The goals of PACT are as followed: educate patients and family members on the diseases, offer support services, establish trust between members of PACT and patient/family, and save medical resources at Caritas while these terminally ill patients are taken care of at home and are allowed to die with dignity and respect.

*Misconceptions:*

Reservations on morphine have been embedded in society, with its most common associations being synonymous with death. In popular media that depicts war, morphine syrettes are often glorified when injured soldiers are inflicted with mortal wounds. In war movies such as *Saving Private Ryan*, morphine is administered to soldiers suffering from major blood loss. An example of such instance involves a soldier no longer feeling the pain from his injuries. The soldier appears to be in a trance and quickly dies shortly after, further conditioning individuals to fear the prescription of morphine. While the Centers for Disease Control and Prevention lists the number of deaths in 2017 at around 2.8 million, only 28,000 of these deaths were caused by opioid overdoses.<sup>29</sup> In most of these opioid cases, the cause of mortality stems from recreational abuse rather than an error from a medical professional. Still, modern culture believes the purpose of administering morphine is to result in a swift and painless death. In a case study from Mercy Catholic Medical Center (MCMC), a patient undergoing end-stage breast cancer has continually refused hospice care treatments such as morphine. While the family has been active in decision making, they continue to ignore the advice of the palliative care manager. The fear of morphine and the belief of its death-accelerating ability have led to reluctance and distrust when communicating with medical professionals. While abuse of morphine can lead to death, a normal dosage serves solely to reduce pain experienced by the patient. Based off the family's religious convictions, they believed that God would heal her and continued exploring curative treatments. Unfortunately, the pain that resulted from cancer care and curative treatment efforts were far greater than the options presented by MCMC advisors. The ethics committee of MCMC met to create a resolution for this issue while ensuring the consent of both the patient and family members were met. Much of this dilemma falls on how investigators could provide better support, education, and awareness towards all involved.

As seen in the MCMC case, religion can become a challenge when choosing medical treatment. Followers of Islam have a

strong belief that the prophet Muhammad determines the factors surrounding one's death. Muslims are derived from a polythitic group, resulting in divisions of opinions regarding medical care. In a recent survey, there were 50 percent of Muslim physicians that were unsure if the removal of feeding tubes is permitted by their religion.<sup>30</sup> In addition, 50 percent of Muslim physicians are unsure on whether brain death is equivalent to true death. This provides great conflict when determining whether patients should be withdrawn from life support. Due to these beliefs clashing with medical expertise, medical professionals are often challenged when determining treatments while keeping in mind the beliefs of the patient. On the same note, practicers of Christianity will place their trust in God even when their illnesses are defined as terminal. Religion plays a crucial role in unifying much of the world, but it often allows for irrational decisions to be justified solely from faith alone. It is human nature to envy and believe in miracles, but this should not be done to discredit medical advisors when they present undesirable advice.

One purpose of PACT is to provide effective educational programs to both patients as well as their families. While morphine is not the only treatment related to hospice care, it still invokes fear in prospective families of hospice and palliative care. Religious beliefs often muddle the situation, making it difficult for medical professionals to gain consent when deciding treatment. Providing proper awareness on the situation is important, but additional education is necessary to dispel misconceptions while providing solutions that do not discredit the religious views of the family. Also, this can be seen to resolve confusion on techniques that families may have initially thought to have gone against their beliefs. To help the PACT Team talk to families about the use of morphine and why it is acceptable under the Principle of Double Effect see Appendix D.

*Support:*

The knowledge surrounding death is often overlooked by much of the population, regardless of age. This lack of awareness that persists into adulthood incites the need for greater education on the topic at an earlier age. As a child develops, their perspective of death shifts from one of little meaning to a permanent state. However, many teens can struggle with death based off their past experiences while they attempt to shape their own identity.<sup>31</sup> Since death has been labelled as a threat, many will cope with this fear by believing that they are immortal or exempt from death.

Religion once again serves a remedial function through providing purpose in life and an existence following death. A study on self-related outcomes reports that low levels of death fear and denial are correlated with significantly higher levels of self-esteem and well-being.<sup>32</sup> Because our time is limited, most fear rather than embrace the end and will thus have reservations when discussing end-of-life treatment.

While the terminally ill are often distraught while facing the reality of death, many will often have to face this battle alone. The National Center for Health Statistics reported that an estimated 60 percent of nursing home patients never had visitors.<sup>33</sup> While cellular communications have strengthened the network of human interactions across the world, it has also neglected the final stage of life. Care from the family has slowly been replaced by institutionalized medical treatment, even though both together provide a symbiotic relationship; trained professionals provide the best care for the suffering individual while the family allows individuals to retain their humanity. Researchers have shown that patients towards the end of their lives value resolution with family, pain management, an active role in treatment decisions, planning for death, affirmation, and sharing the views on life to others.<sup>34</sup> Abandonment of the terminally ill negatively influences the extension of life as well as the dying process brought about by medical advancements. The financial and emotional burden can be too overwhelming for caregivers, leading to less involvement in the dying process.

While many realize the necessity of quality care to affirm the lives of patients, caregivers are wary of the growing costs now correlated with end-of-life treatment. On the contrary, hospice care and similar forms of treatment are designed to prevent out-of-pocket costs while the fees are almost entirely covered by health insurance.<sup>35</sup> The United States additionally revised the Medicare Advantage program in 2018 to apply to some non-skill in-home care services.<sup>36</sup> This provides federal financial support towards services including companionship, housekeeping, and respite care. However, this still does not cover additional expenses from additional care services seen in assisted living or nursing homes. Some institutions, including MCMC, provide extra services free of charge. Having these additional services covered, such as skilled care and assessment, allows for continued support while reducing the stress placed upon the grieving families. It is apparent that medical institutions prioritize the well-being of the patient and provide financial relief as much as possible to allow for proper treatment. Overall, these programs should

start to be viewed as support for not only the patient, but also towards the family members assisting in the dying process.

While PACT is intended to provide hope to all parties involved, it also serves to help patients and families better understand and cope with their illness, treatments and ultimately with death. The hope of this model is to provide the best quality of life to patients, which is supported through family members serving an active role in treatment. Financial burdens are relieved under this model, as PACT covers all the costs of treatment and care. Further education, financial support, and care at home are intended to reduce burdens placed upon patients and family members while ensuring the best care has occurred.

#### *Communication:*

The news of a loved one being diagnosed with a life threatening or serious illness is devastating for all involved. The choice in becoming a caregiver is even harder, as one has to handle the emotional burden of watching a loved one suffer while becoming an outlet of hope and positivity. While treatment from a medical professional is intended to be curative or pain-relieving, it is just as important to ensure that the well-being of the caregiver is taken into consideration. The Family Caregiver Alliance reported that 11% of family caregivers have seen a reduction in their own physical health.<sup>37</sup> Also, the Alzheimer Association found in 2014 that the physical and emotional burden from caregivers of dementia patients resulted in an estimated \$9.7 billion in healthcare costs.<sup>38</sup> The toll of this process on those indirectly affected by illnesses stresses the need for an active relationship between physicians and caregivers. However, some families rightfully have reservations when discussing options with medical professionals.

While medical professionals are trained to be impartial, there still remains racial bias that plagues the field. In a study surveying 543 family physicians, two nearly identical scenarios were described regarding osteoarthritis treatment.<sup>39</sup> The only difference between each imaginative case was one individual being African American while the other was Caucasian. Unfortunately, there was strong evidence showing a preference of the physicians to determine that the Caucasian individual would lead to a more cooperative environment. In another study, women were less likely to receive an analgesic for acute abdominal pain, even though pain scores were comparable between the sexes.<sup>40</sup> This medical bias is seen once again in studies showing marital



status significantly affecting the treatment prescribed to patients. This only further supports the stigma that medical professionals treat patients differently based off of race, gender, and socioeconomic standing. Having these biases provides even more impediments when trying to establish a healthy communication between all involved in patient care. While greater strides must be taken in properly educating those seeking medical assistance, it is also imperative to provide more training to physicians to reduce medical bias and allow for more transparency.

To explain the future outlook of medical treatment to patients and their families, physicians under PACT will utilize meetings with all parties. Information is allowed to be shared between everyone involved while the potential concerns of patients and family members are also stressed. However, literature revealed that there was a lack of extensive parameters surrounding the conduct and utility of family meetings with palliative care.<sup>41</sup> As a result, researchers refined the guidelines of family consultation, therapeutic communication, and single session therapy. Important parameters included a friendly environment, involvement of a social worker, offering meetings based on need, and additional formal training needed for conducting these meetings. While implementing all these guidelines may serve as a challenge, they establish family meetings as an opportunity to clarify and establish goals for future care. Despite the prospective benefits of family meetings with guidelines, medical professionals should avoid using this as a tool to debate the status of the patient. This would further complicate their relationships with patients and family members.

PACT is comprised of a physician, nurse, social worker, and pastoral care member to provide expertise in ethics and patient care. At the same time, this variety of professionals should reduce the biases seen from each member while encouraging a more open dialogue between PACT, the patient, and family members. Communication between all involved in treatment is done to keep all individuals fully aware of the current and future states of care. Having an active and healthy dialogue allows medical professionals to better understand the circumstances of both the patients and caregivers. This allows for both proper quality care towards the patient but also alleviates the emotional burden seen from caregivers during this process.

#### **Medical Services:**

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness.”<sup>42</sup> There are two important parts to this definition; first, is the distinction that palliative care improves quality of life rather than quantity. Second, is the inclusive definition where patients and their families are the focus, rather than exclusively focusing on the patient. A child that is recommended palliative care services can strain the well-being of both the patient and their families. Part of this challenge is that there is nothing ‘normal’ about severe illness, especially for children. In most cultures around the world, children are expected to outlive their parents. Therefore, any deviation from this belief may be met with frustration and confusion. This is one of the main reasons why life-limiting pediatric disease can be so devastating. The role palliative care would play would be one that offers expert knowledge in communication, pain management and an interdisciplinary approach to helping not only the patient, but the patient’s family as well.

#### *Communication*

The first and most important step to any medical therapy is clear communication between providers, patients, and their families. Early initiation of these discussions is particularly important in pediatric palliative care as needs may be met with surprise and denial. By involving palliative services as early as the time of diagnosis much of the stress and fear associated with a devastating diagnosis can be alleviated. However, “Parents and children may infer that a discussion of issues such as do not resuscitate orders or comfort care is equivalent to “giving up.” Such inferences may inhibit family members from voicing fears and concerns about the burdens of life-prolonging interventions and the dying process.”<sup>43</sup>

These challenging conversations with patient and families must emphasize empathy and respect. It is important that the implications of specific treatment options and long-term complications be discussed. Difficult topics such as cardiopulmonary resuscitation, advanced directives, and goals of care need to be communicated early on in the care continuum, ideally prior to any care being provided. While desires of patients and families may evolve throughout the palliative care process, there is at least a communication framework in place to assist in future conversations.

#### *Treatment Options*

Central themes of palliative care include a holistic approach to patient care and improving quality of life. Pediatric palliative patients have unique pathology and therefore require individualized palliative treatment modalities. Palliative care utilizes effective treatments against serious medical conditions including, but not limited to, cancer, complications of prematurity, genetic disorders, neurologic disorders, and cardiopulmonary disorders. Some specific symptoms palliative care therapy aims to treat include pain, dyspnea, constipation, nausea, fatigue, anxiety, depression, loss appetite, and difficulty sleeping.

The first paradigm for treatment is pharmacological methods. The benefit of pharmacological therapies is that they are generally cheaper, more ubiquitous, and less resource-dependent than interventional options. Oral medications can be taken via pill or liquid forms. These may be short acting or long acting to provide sustained analgesic effect. These may include anti-inflammatory medications like NSAIDs and steroids, or analgesic medications like opioids. Adhesive patches are another modality as a pain-alleviating treatment. Some examples of these adhesive patches include a lidocaine patch and a fentanyl patch. Moreover, injections can be delivered as an injection subcutaneously or directly intravenously. Patient-delivered analgesia uses a pump which a patient may control to deliver medications at a rate they desire. All these medications described above have direct pain-alleviating effects, however, there are also many classes of drugs called adjuvant analgesics which assist in pain and symptom control. These include antidepressants to modulate mood and nerve pain, anticonvulsants to control seizures, and muscle relaxants to avoid painful muscle spasms.<sup>44</sup>

Interventional palliative care modalities generally require a more specialized care model. However, many of these options provide effective treatment when pharmacotherapy is ineffective. For example, adequate pain control cannot be achieved in 10-20% of patients with advanced cancer by pharmacological methods alone.<sup>45</sup> In these cases, there are alternatives usually delivered by pain management experts. Interventional procedures include neuraxial techniques like epidural and intrathecal injections. Neurolytic techniques including nerve blocks or cauterization are also effective in certain circumstances. Additionally, traditional surgical modalities unrelated to the disease itself can be utilized. Examples include surgical fixation or removal of affected limbs, removal or ablation of non-essential damaged organs,

and radiation therapy as a means of neuropathic pain control.

Additionally, palliative care can offer options for the caregivers as well as the patients. The palliative care provider can offer therapy for the grieving loved ones by listening and providing a place where families can feel safe to express their fears and hopes. Through palliative care it can be possible to provide guidance during a difficult time. By focusing not only on the medical diagnosis, but also the impact both emotionally and spiritually that a diagnosis will have on the patient and their family, the palliative care team can help to ease the suffering of these people.

### *Interdisciplinary Techniques*

As the international demand for pediatric palliative care continues to grow, it is important to develop and implement multidisciplinary teams to address its complex needs. Doctors and nurses provide a portion of care along the interdisciplinary palliative care continuum. However, there are many experts from a variety of disciplines that have been shown to be effective providing care directly or indirectly in pediatric palliative care situations. These include art therapists, music therapists, physical therapists, occupational therapists, nutritionists, pharmacists, respite providers, social workers, chaplains, case managers, and social workers. Exercise, art, yoga, relaxation, massage therapy and other services help children to cope with the stresses of hospitalization and treatment. Palliative care can also offer pain management, caregiver support, social support and spiritual support. Through the use of palliative care, the overall experience of treating someone who is gravely ill can be drastically improved.

### *Overall*

The role of palliative care experts is most influential when experts are allowed to participate in the care of patients early on in the diagnosis. However, their role is not limited to those that are dying, or those that will die immediately. Palliative care experts can offer many services and treatments not only to those that are terminal, but also to those who face challenging diagnoses that require more care beyond what the typical medical team can provide. At the same time, palliative care is a medical subspecialty, and experts are intimately aware of the medical aspect of a diagnosis. Along with a medical understanding of a diagnosis, palliative care experts often focus on treating the emotional toll the diagnosis may have on not only the patient but the patient's families. Ultimately, palliative care

compliments medical care and can ease the transition to end-of-life care if necessary. It can also treat those with chronic disabilities that require more than just standard medical care. In the case of Caritas Baby Hospital, involving palliative care in taking care of severely ill children may enhance the care they are receiving.

## **IMPLEMENTATION:**

The Pediatric Advanced Care Team (PACT) is an initiative designed to be a model for palliative and hospice care in Palestine and other developing nations. Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care that focuses on providing pain management and relief from the symptoms and stress of a serious illness. It is provided by a specially-trained team of doctors, nurses and other specialists who work together with your other doctors to provide an extra layer of support. The goal is to improve the child and family member's quality of life.

To do this, the palliative care team will:

- Relieve your symptoms and distress
- Pain Management
- Help you better understand your disease and diagnosis
- Help clarify your treatment goals and options
- Understand and support your ability to cope with your illness
- Assist you with making medical decision
- Coordinate with your other doctors

### *PACT Team Members*

The team is comprised of a physician, nurse, social worker, and pastoral care members. Dr. Issa Abed Rabo, Wafa' Musleh, Nagham, Hazar Hiba are the members that will implement PACT at Caritas Baby Hospital in Bethlehem, Palestine. The team could also be expanded to include an additional physician and nurse to assist with patient care. In addition, pastoral care members will be selected with the help of the religious reference of the family. PACT would also benefit by having a Muslim Clergy member as a team member, as they would be more experienced in the religious impact of medical treatment for Muslims.

### *Criteria for Identifying Potential PACT Patients*

Patients that will be selected for PACT should have been treated for their illness at Caritas Baby Hospital, and have an established relationship of trust with the hospital. The primary physician treating the patient should document the condition of the patient to be terminal in order for the PACT

team to intervene. In addition, there should be no available alternative treatment option for the patient's condition. When all of these conditions are met, the patient is eligible for PACT services.

### *PACT Services*

PACT provides a variety of palliative and hospice services that are intended to benefit patients, families, and caregivers. For example, hospice services are similar to home healthcare services, but also include:

- Spiritual services
- 24-hour care or on-call care
- Respite care to give the caregiver a break for up to 5 days while the nurse provides care at Caritas baby hospital.
- Volunteer Services - volunteers from Bethlehem University can be utilized as volunteers to assist in respite care for patients.
- Bereavement support
- The choice of having a death attended by hospice staff

Along with hospice services, PACT is centered on other services:

- **Pain Management** – Treatments to help with pain and discomfort
- **Symptom Management** – Treatments to aid with anxiety, breathing, nausea and other symptoms
- **Medication Coordination** – Allows the proper medication to be available when needed
- **Medical Equipment Coordination** – Provides the necessary equipment for comfort management
- **Registered Nurse Visits** – Scheduled to meet your individualized hospice care plan
- **Nurse Aide Visits** – Scheduled to aid with personal care: bathing, feeding, dressing and other duties
- **Medical Social Services** – Counseling and emotional support with social and financial issues
- **Spiritual Services** – Assist and support patient and family with spiritual needs and facilitate interaction with community clergy
- **Unlimited Bereavement Services** – Unlimited bereavement services to all hospice family members

In terms of pastoral care services, a potential commitment service can be utilized to treat the predominately Christian and Muslim patients encountered at Caritas Baby Hospital. For Muslims, the most fortunate thing a Muslim can say before death is to declare the Shahadah (testimony of faith). This should be the last thing a Muslim says before death, and someone from the family can help a dying Muslim to say it if they are struggling to do so. The family of the Muslim patient may read anything from the Quran as well, as long as it does not cause the patient any annoyance. In

addition to the Quran, for a Christian child the Pastoral Care member of the team could use **The Rite of Christian Commitment to the Terminally Ill** [See Appendix E], which could also be adapted for a Muslim child.

#### *PACT Team Meeting Schedule*

Physicians will have regular rounds on inpatients. A weekly meeting will be implemented for PACT members to discuss the status of care at the home and hospital for each patient. At the meetings, each member of PACT will be able to share their updates on patients and to suggest any alterations to the care provided to the patient. In addition, PACT members will meet weekly with the families of patients to update them on the status of the patient, and to listen to the concerns of the family. This will allow for an optimal level of care and support for both the patient and family members.

#### *Financial Costs of PACT*

In terms of the costs for PACT, medical equipment and medication are required. At least two hospital beds will be needed to begin to implement the services provided by PACT. Transportation services for medical staff and patients are covered by existing systems at Caritas Baby Hospital. The cost of the PACT team is already covered by team wages. In addition, Caritas Baby Hospital already has hospital beds and medication in inventory, but the additional costs necessary to implement PACT are listed in Table 1. The estimated costs for PACT were based on the projection that 10-15 patients per month would utilize the PACT services. To assist with the costs of the implementation of PACT, a \$5,000 grant has been graciously provided to Caritas Baby Hospital by the Saint Joseph's University Institute of Clinical Bioethics.

**Table 1**

Costs of PACT Implementation

Equipment	Cost/Unit	Quantity
Manual drop regulator (single use)	\$10	50 per year
Feeding pump	\$1500	2 devices
O2 generator	\$1300	2 devices
O2 bottle (5 L.) +regulator	\$350	2 devices
Suction pump	\$340	2 devices
Pulse oximeter	\$700	1 device
Thermometer device	\$400	1 device

## **CONCLUSION:**

The Palliative Care/Hospice Program known as PACT at Caritas Baby Hospital can serve as a paradigm for all developing nations. Understanding the challenges that are

faced in Palestine can better prepare other nations to overcome the negative aspects of the dying process and concentrate more on the positive aspects. Many of the challenges faced in the Palestine will be present in other nations. Death and dying has social, cultural and religious dimensions among all types of peoples. Lessons learned in Palestine can be adapted to other cultures and religions and many of the challenges faced in Palestine can be overcome by preparing people to face dying and death realistically and providing comfort measures as an integral part of end-of-life care. With the proposed implementation of the Palliative Care and Hospice Program at Caritas Baby Hospital, the dignity and respect of all human life, even in its last moments, would be protected and the greater good would be promoted.

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