

# Adult Palliative Care/Hospice Program in Arcatao El Salvador: A Paradigm For Developing Nations

P A Clark, N Mathew, B Buragamadagu, D Morales

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## Abstract

The main goal of this paper is to create a palliative care/hospice program that could be implemented in Arcatao, El Salvador and could serve as a paradigm for palliative/ hospice care in other developing nations. First, we will need to develop a Home Palliative Care/Hospice Team that will consist of a nurse, social worker, and pastoral care member from the community of the Arcatao. With the help of the medical team in El Salvador, we could then begin to outline the need for such a program in this area. This will tell us how many people may need palliative /hospice care and if this population would be open to take part in the program. This program would also allow us to examine any cultural/religious issues surrounding palliative care/hospice and any differences between palliative care and hospice in this area. This paper will mainly focus on the design of the program and how we will incorporate several important aspects of palliative/ hospice care.

## INTRODUCTION/BACKGROUND

Chalatenango is a department, a municipality, and a city (the capital of the Department of Chalatenango), located in Northern El Salvador. The territorial extension is approximately 131.05 km<sup>2</sup> as rural land and approximately 75 km<sup>2</sup> as urban land. Chalatenango includes the St. Bartolome parish, which is in the town of Arcatao in the Diocese of Chalatenango, with a population of approximately 3,000 people. Arcatao is located in a small hollow between several low hills on the border of the Republic of Honduras. During the El Salvadoran Civil War, the town of Arcatao was greatly impacted and lost many of its young adults to the war, leaving the town inhabited mostly by older adults, women, and young children. In regards to the access to health care currently in Arcatao, there is a Medical Dispensary at the service of the community, that is open 5 days a week and there is a health unit called Fosalud that attends to medical needs on weekends. In the case of medical emergencies, cases are referred to Chalatenango. The two main hospitals in the Department of Chalatenango are: Hospital Nacional Dr. Luis Edmundo Vasquez and Hospital Nacional De Nueva Concepción. As a Bioethics Institute Research Fellow, it has been brought to my attention that many communities in

Latin American countries have zero or inadequate end-of-life care. In Latin America alone, more than one million new cancer cases and 600,000 cancer deaths occur each year [1]. Seventy-eight percent of the adults worldwide who need end-of-life care live in low-to-middle income countries (LMIC's) [1]. Also, within these countries, palliative care is often limited to privileged, urban centers. We will start in Arcatao, El Salvador because currently we have a strong connection with the Parish (San Bartolomé Mártir de la Liberación) there as well as a strong connection with the Jesuit University of Central America in San Salvador, El Salvador. We are also collaborating with the Saint Joseph's Parish in Seattle, Washington, who have a 30-year relationship with the parish in Arcatao. In order for this research project to be feasible, we will need to develop the program to meet the needs of a developing country because of the limited financial, educational, and health-related resources. With that in mind, we also have to consider the importance of tailoring the program to the Latino culture, which is the formal or informal expression of the people of Latin America that involves different customary practices and/or religious practices, in El Salvador. This program will not only help from a healthcare standpoint, but will also aim to strengthen the solidarity within the community, so that the

community may come together to take care of one another. The foundation for this program will be rooted in Catholic Social Teaching, which highlights the importance of the whole individual, and the common good, as a tool for reducing inequality and social injustice in the world. Grounded in human dignity and the innate social dimensions of human life, the common good consists of all the conditions of society and the basic goods secured by those conditions that allow individuals and groups to achieve human and spiritual flourishing. The social teaching of the Catholic Church insists that the human community – including governments, public and private organizations, and individuals – must be actively concerned with promoting the health and welfare of every one of its members so that each member can contribute to the common good. In turn, the hope is that this idea of solidarity and common good will radiate from one community to another. This paper, we hope, will serve as a blueprint for the program we wish to implement. This program will be a joint effort with a team from Saint Joseph's University, a research fellow in the Institute of Clinical Bioethics, a medical resident and Bioethicist and a team in Arcatao -nurse, pastoral care, and social worker. The outline for the program will incorporate several integral aspects of palliative/hospice care.

### **CASE STUDY**

J.T., a 58-year-old Hispanic man, was diagnosed in April 2002 with prostate carcinoma, initially detected as a result of an elevated prostate-specific antigen (PSA) screening procedure. J.T. underwent a radical prostatectomy; however, subsequent PSA levels remained elevated. External beam radiation therapy was initiated and completed in July 2003, with subsequent PSA levels in the normal range. In 2007, J.T.'s PSA was elevated and leuprolide was initiated. This controlled his disease for a few months. At that time, bicalutamide was initiated. When the bicalutamide was no longer effective, J.T. began docetaxel as a single chemotherapy agent. J.T. tolerated treatment with few minor allergic reactions, but his PSA remained in the 40 ng/ml range for the next eight months (a PSA above 10 ng/ml indicates very high risk). PSA results in July 2008 jumped to the 220s. Despite the administration of mitoxantrone, a subsequent PSA result was 750 ng/ml. J.T. developed metastatic disease to his lung and right iliac crest. In November 2008, J.T.'s oncologist recommended additional treatment with estramustine and steroids. At that time, J.T.'s quality of life was diminished by progressive generalized weakness and fatigue, cytopenias with bruising, and bone pain. In January 2009, J.T.'s wife took him to the hospital

because he "just wasn't acting right." She reported that he had been having increased pain and she did not think he had been taking his medication as prescribed. On admission to the oncology unit, two units of packed red blood cells were transfused in response to a critical hemoglobin level of 6.8 g/dl. J.T. slowly recovered, but his pain continued because his current medications had become ineffective to the progressive cancer and he appeared depressed. His wife and adult sons expressed their frustration to the oncology nurse at not knowing what to do or how to help. After a lengthy discussion, which focused on J.T.'s healthcare options, the nurse contacted the oncologist and obtained an order for a palliative care consult. The purpose of the palliative care consultation was to provide and coordinate support and pain management. In this instance, the palliative care social worker arranged for a family meeting to develop a care plan that would manage J.T.'s care needs. At the meeting, the palliative care physician stated that J.T.'s symptoms and pain could effectively be managed. A discussion occurred regarding the goals and wishes of the family; these were kept appropriate by the palliative care physician and linked with J.T.'s expected disease trajectory. J.T. did not have an advance directive and the palliative care team social worker offered assistance by explaining all options, including the meaning of a Do-Not-Resuscitate order (DNR), and provided the necessary paperwork. J.T. chose to continue estramustine and steroids for the treatment of his prostate cancer. The palliative care physician added new medication orders to treat his pain rather than to cure his disease. He was placed on 40 mg of extended release oxycodone every 12 hours with an as needed dose of immediate release oxycodone 10–20 mg every six hours for breakthrough pain. He was set on a scheduled time for a bowel regimen, which included senna and docusate. Within 72 hours after the medication changes, J.T. expressed a decrease in pain. Although the antidepressant had not begun to take effect, J.T. reported an overall sense of well-being and a feeling that he and his family were better prepared for the events to come and more open to discussion about admission into an appropriate hospice program [2].

### **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 [3]. As a result, one of the best kept secrets in a hospital today in the United States is palliative

care and hospice care. From a global standpoint, the number of adults in need of end-of-life care is greater than 19 million, with 78% of these patients living in (low- and middle-income countries) LMICs. In the Americas, it has been estimated that 2,588,117 people need end-of-life care, of whom roughly 40% have cancer [4]. Pain is experienced by 55% of patients undergoing anti-cancer treatment and by 66% of patients who have advanced, metastatic, or terminal disease [5]. This can be relieved in most cases through medicines and other treatments. In comparison, 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 [4]. 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 [6]. 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 the overall 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 may lack dignity and respect. Furthermore, prior to developing any palliative/hospice program, it is essential to make a clear distinction between these two types of end of life care.

### **A. 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 [7]. 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 [8]. Finally, the World Health Organization, goes on to explain that Palliative care overall:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients' illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications [8].

### **B. 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 [9]. In addition, emphasis is placed not only on the well-being of the patient but also on the well-being of the family caregivers. Usually if possible, 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 475AD 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 [10]. “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” [11]. 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 [12].

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” [13]. 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 [14]. 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 [15].

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 [16]. 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 [17]. 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 [18].

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 [19]

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 too 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" [20]. 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" [21]. 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 [22].

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. 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.

As we stated, over time, the goals of medicine have come to focus on: pain and suffering relief, the promotion of health and the prevention of disease, the postponement of death and the promoting of a peaceful death, and the cure of disease when possible, and the care of those who cannot be cured [3]. This palliative care/hospice program will focus on the latter, with an emphasis on providing care for the whole individual (physical, emotional, and spiritual support) as well as the patient's family. The program we will develop in Arcatao, El Salvador will provide palliative hospice care for the terminally ill that will help manage pain and provide support for the patient and family. We will aim to provide a compassionate, integrative, holistic approach to health care that specifically addresses the physical, emotional, educational, cultural, and spiritual needs of each patient, their family and caregivers when curative treatment may no longer be an option. At the forefront of our program, will be a vision of a community in which people-in-transition and those who love and support them have access to proper palliative care and support when they need it, wherever they need it and whoever they are. And as stated in the Constitution of the World Health Organization (WHO), "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition". [6] Next, we will elaborate on each of the 8 aspects of the palliative/hospice care program.

### **CULTURE IN LATIN AMERICA**

A person's attitude toward death and bereavement is shaped to a large extent by their cultural heritage, religious practices, and family unit. Other factors such as birth region, education, and income level also influence how the patient perceives illness and makes health decisions. The University of Washington Medical Center published a paper called "End of Life Care: The Latino Culture" which seems to

adequately reflect the El Salvadoran culture [22].

In the Latino culture, there is a complex relationship between health and illness, as well as the physical, mental, and spiritual parts of a person's life because there are many aspects that go into patient decisions such as family involvement, which is considered very important in Latino culture. The family-centered model of decision making, which will be the focus of our program is highly valued and at times may be more important than patient autonomy. In the Latino culture, this is called *familismo*, which is characterized by interdependence, affiliation, and cooperation [23]. Relatives participate in the spiritual and physical care of their ill family member. The family may be apprehensive about giving technical care without receiving education and training.

The family may prefer to hear about medical news before the patient is informed so that they can shield the patient or deliver the news gradually. If the patient gives informed consent, meeting the family members first is critical in order to strategize how to communicate news about the illness. This is in stark contrast to the United States, if the patient does not want to make his or her own medical decisions, we let them know a Durable Power of Attorney for health care needs to be prepared. However, in El Salvador, this is done in a slightly different way. Through our team in El Salvador, we were informed that when a person arrives at a hospital or clinic they open a legal document, "un expediente clinico," which serves to store and protect the patient's detailed health information such as their past medical history, telephone number, address, etc. In this document, they also ask the patient to name a person that the patient wishes to make medical decisions on his/her behalf in the case of a medical emergency and that person is the only person that can make decisions if the patient is incapable of making the decision for themselves (see Appendix A).

Some patients and their families prefer to take care of their loved ones at home at the end of life. This tends to be the case in many Latin American countries. The patient may believe that the hospital setting is impersonal or that the routine disrupts the family's ability to take care of their loved one. In fact, a major study published in *Cancer*, the peer-reviewed medical journal of the American Cancer Society, finds that people in home hospice have longer survival rates than people with similar conditions receiving palliative care in hospitals [24]. It is important to explore the patient and family's understanding about treatment choices including the option for care at home at the end of life

because ultimately the patient deserves the dignity and respect to determine where they spend the end of their life. Enlist the aid of Social Services to explore available options and feelings about hospice care.

The patient and family may believe that God determines the outcome of illness and that death is a natural part of the life process, as many Latinos are predominantly Catholic. Latin America is home to more than 425 million Catholics – nearly 40% of the world's total Catholic population [25]. Because of this acceptance, the patient and family may not seek health care until the condition worsens significantly. This outlook may also allow the patient to tolerate a high level of pain because pain is perceived as something that you live with as part of the human condition. This is elaborated on in the *Declaration of Euthanasia*, from the Congregation for the Doctrine of the Faith, which states that according to Christian teaching, suffering during the last moments of life, has a special place in God's saving plan; it is in fact a sharing in Christ's passion and a union with the redeeming sacrifice which He offered in obedience to the Father's will [26]. Therefore, one must not be surprised if some Christians prefer to moderate their use of painkillers, in order to accept voluntarily at least a part of their sufferings and thus associate themselves in a conscious way with Christ crucified (cf. Mt. 27:34). This belief can also serve a protective role by preparing the patient and family for grief and death.

### **A. Rituals**

Prayer and ritual may be a part of the end-of-life process for the patient and their family members. Family members may use prayer or bring special amulets and rosaries (prayer beads) while visiting a dying patient. The family members may request that they keep candles burning 24-hours a day as a way of sustaining worship. Electric candles will be available for patients and families if needed. The patient and the family may display pictures of saints. Saints have specialized and general meanings for Catholics in that by praying to them they are asking for their help and to ask God for help on their behalf. For example, St. Peregrine is the patron saint of cancer, St. Joseph is patron for the dying, and Saint Raphael the Archangel for healing. Some families may want to honor their deceased relative by cleansing the body. There may be a belief that a person's spirit is lost if they die in the hospital rather than the home setting. Furthermore, the sacrament of the sick is important for people who are Catholic but it can only be celebrated by a priest. Other rites like the Rite of Christian Commitment to The Terminally Ill

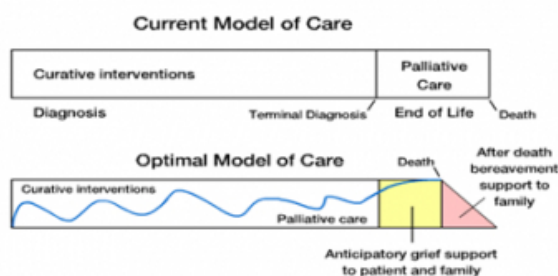
have been designed to allow lay ministers to help patients and family members from a spiritual perspective (see Appendix B). A priest or lay minister may be asked to perform these rituals when a person is close to death. If the patient is Catholic, asking about their preference and plans for this ritual is very important.

### EFFECTIVE EDUCATIONAL PROGRAMS FOR PATIENTS AND THEIR FAMILY

One main purpose of the palliative/hospice program is to provide effective educational programs to both the patients as well as their families. The principles of hospice and palliative care are based on a shift in the patient's treatment from curative to end of life care. Contrary to popular belief, this shift rarely takes place at a specific moment, and the dying process is different for each individual. An example of an optimal model care is seen in the figure below:

**Figure 1**

Stanford Overview of Palliative Care: Models of Care



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 are crucial in any hospice discussion and care plan. In many cases, the patient may have already come to terms with their condition and reality of death, and may be ready to accept hospice care, while family members and friends might not be. Many times, they can even coerce the patient into continuing aggressive treatment even though the burdens outweigh the benefits. That is why it is crucial for the family to 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. 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. With this in mind, it is important that effective educational programs be

present and this will be done in Arcatao at the San Oscar Arnulfo Romero day home, the base of operations for the "Casa Hogar Project."

In Arcatao, the community is currently working on building the San Oscar Arnulfo Romero day home, that will serve as a place that has enough recreational and occupational space for the elderly to receive the supportive care that they may require, such as practicing agricultural work, physical therapy, exercise, and socializing among people of the same age. In addition, it will serve as a space for community assemblies and to create a connection between the adults and the youth of the community. Ultimately, this day home will be in collaboration with several different institutions present in the community, and will serve as our base of operations for our palliative care/hospice program.

The "Casa Hogar project" is seeking to improve the quality of life of the elderly in the San Bartolomé parish, through assistance, promotion, and rehabilitation. The project will mainly aim to serve elderly adults over 70 years of age as well as those with serious illnesses, and in some cases patients with physical disabilities. The holistic vision of the project is to provide the elderly with food, occupational therapy, psychosocial workshops, and through this, integrate the hospice program to make sure patients are able to receive the necessary healthcare and supportive healthcare services they might need. The Casa Hogar project "San Romero de America" is divided into phases, which will help to create a space where older adults can be together during the day and return to their homes during the afternoon, a technician will be hired to provide occupational therapy, workshops or other activities for the elderly, and the technician will be responsible for working on an assistance plan for the "San Romero de América" home. In addition, the plan is to have a nurse who will monitor the health of adults and tend to their therapies and treatments. The staff at the home will be able to provide effective educational programs and instructions about proper medical care to the patients and their families. If the patient for some reason is not able to receive medical care at the San Oscar Arnulfo Romero day home, our team in Arcatao will also visit the patients in their home and provide the necessary palliative/hospice care services. A person will also be hired to prepare food according to the diet recommended by their health and the participation of the community will be promoted to take part in this program.

### SUPPORTIVE CARE

Supportive care is not simply characterized as pain or



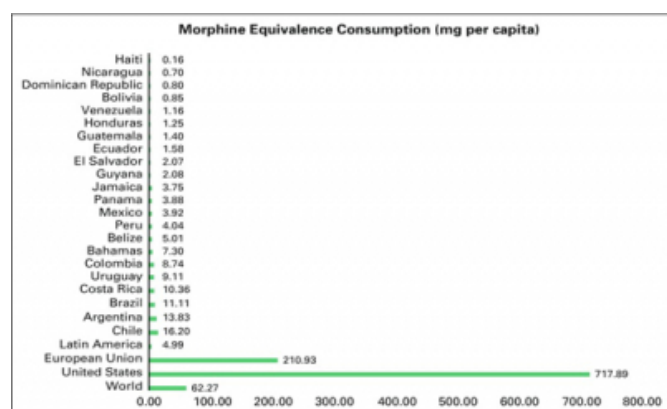
symptom management, but also focuses on providing hope, emotional, and spiritual support that can help manage the stress that can weigh on a patient and their loved ones.

First, because of the fact we will be developing a program in a LMIC Latin American country, our pain medications will be limited and an alternative form of pain management will be necessary. Ideally, the first choice of pain management for our program will be non-pharmacological pain interventions such as music therapy, breathing techniques, spiritual practices, massage therapy, repositioning, because not only are they beneficial but they are also cost effective and easily taught. This will all be possible through the “Casa Hogar” project. If pharmacological interventions are necessary, the patients will be put on an appropriate medical plan guided by our structural protocol for choosing the right pain medication (refer to Appendix C & D). In the following section we will look at plausible options for pharmacologic intervention in a developing country such as El Salvador.

By way of example, the average morphine-equivalent consumption of opioids in the European Union and the United States is 42 and 143 times higher, respectively [1].

### Figure

Consumption of opioids in morphine equivalents, 2013.



The truth is many of these pain medications, especially opioids, require availability and affordability, which is often not the case in a developing nation such as El Salvador. Initially, we believed medical marijuana would be both an affordable and effective alternative, however after further research, medical marijuana is illegal in many Latin American countries including El Salvador. However, in a recent article, the UN reclassified cannabis as a less dangerous drug, so in the near future, medical marijuana might be an affordable option for pain management. Another possible option that is important to mention, is the use of

liquid morphine made from morphine powder, boiled and filtered water, and a preservative to indicate the strength of the dose. This model was developed in Uganda by a group called Hospice Africa, with the goal of finding pain management for African countries with very minimal funding. The project is quite remarkable in the sense that not only is it inexpensive but it is also not addictive and easy to produce. Dr. Merriman, Founder of Hospice Africa says this drinkable morphine has not fostered addiction in Uganda. "It's so diluted," she says. "It's not going to give you a high. They have to take an awful lot to get any form of a high" [27]. The advantage to liquid morphine is that by grinding it into powder and diluting it, minimizes the cost, its addictive properties, and has been found to still be a very effective form of pain management. Today the price is about \$2.50 for a week's supply in Uganda, which is much more financially limited than El Salvador, and if El Salvadoran government policies allow this, it would be a huge step for palliative/hospice care there. This is not a certain arrangement so we will explore further options in order to find the most effective, sustainable, and plausible form of pain medication for the community of Arcatao, El Salvador. Also, nonsteroidal anti-inflammatory drugs (NSAIDS) will be financially supported to help with less severe pain and muscle/bone pain such as arthritis.

In addition, hope, emotional, and spiritual support will be provided to the patient in conjunction with the San Oscar Arnulfo Romero day home. Our team in Arcatao will consist of a nurse, a pastoral care worker, as well as a social worker. While the nurse is responsible for pain management, the social worker is responsible for the overall support of the patient and family. They can assist with financial planning and advance directives as well as emotional support and counseling. Furthermore, the pastoral care worker is responsible for providing spiritual support to all patients and family members requesting such support. They can serve as a bridge between the patient/family and their personal house of worship.

### COMMUNICATION GUIDANCE

Communication between all involved in the care of the patient, within the bounds of patient confidentiality, will allow everyone to be fully aware of the current and future plan of care for the patient. Complete trust and transparency between the parties involved is crucial and will help build trust between the team and the patients. As stated before, in the Latino culture family is very important and decision making is characterized by interdependence, affiliation, and



cooperation. The family-centered model of decision making will be at the center of developing our program in order to build the best patient-medical team relationship possible.

The University of Washington Medical Center has established the following communication criteria that we wish to implement regarding Latino Culture and end-of-life care: [22]

1. There are a variety of Latino cultures. In addition, there is diversity in the religions practiced by Latinos. In Latino culture, Catholicism, Christianity, and other religions may provide religious means of dealing with life and death for your patient. With this in mind, it is crucial to ask the patients and family members about their preferences and rituals to better understand their needs. A good strategy to learn more about the patient is to have informal conversations with the extended family. Extended family members may be more available and approachable than the immediate family during times of grief.

2. *Respeto* (respect) is an important concept in the Latino culture. Respect implies that relationships are based in common humanity, where one is required to establish respect – it is not assumed. Older patients may prefer to be called *Señor* (Mr.) or *Señora* (Mrs.). It is important to also ask patients how they prefer to be called. To develop an effective therapeutic relationship, the doctor and other health care providers need to be brought into the extended family circle. This is accomplished by gaining trust and showing respect.

3. Grieving is considered a natural part of the life process. Use of clear and specific language will help the patient and family better understand the prognosis and make decisions about palliative care. The patient and their family members may not be assertive or aggressive when communicating with doctors and clinical staff. They may not want to have any direct disagreement. As a result, important issues and problems may not be discussed, unless dialogue is initiated.

In this type of palliative care/hospice program, it is crucial to have proper communication that is focused more on the patient's goals and needs, rather than their medical condition. Oftentimes, we focus so narrowly on a patient's health and safety that we lose sight of their human-ness, their wellbeing, and their purpose that makes them whole. This patient centered, end-of-life care, is well exemplified in Atul Gawande's book, "Being Mortal." In his book, Gawande emphasizes the importance of asking four key questions in

order to ensure the dialogue between a patient and doctor, addresses the needs of the patient. The four questions are as follow:

1. What is your understanding of where you are with your health?
2. What are your worries for the future?
3. What are your hopes and priorities?
4. What are you willing to sacrifice, and what are you NOT willing to sacrifice? [28]

For example, in the book, Gawande recounts a story of one of his patients that, when asked these questions, said he would like to continue treatment as long as he can eat ice cream and watch football on Sundays. If he couldn't watch football or eat ice cream then he would like to forego treatment.

Gawande's book illustrates that oftentimes, making the decision of when to continue treatment to prolong a patient's life or when to cease aggressive treatment is difficult, however, it is crucial that we ask the patient what their goals and needs are so that they get the proper care consistent with those goals. It is also important to note that these questions go beyond just end of life situations and patients' answers to these questions can change over time. In short, asking these simple questions ensures our recommendations and services parallel those of our patients and their individual needs and wants.

### **CONTINUITY OF CARE**

Continuity of care is concerned with quality of care over time and is the process by which the patient and his/her care team work together in the patient's ongoing health care management toward the shared goal of high quality, cost-effective medical care [29]. Sustaining early palliative care access and continuity for all patients facing serious illness requires diligent collaboration and follow up. Continuity of care is concerned with quality of care over time. Not only does it enable providers to have an improved relationship with their patients but also enables them to work more effectively and, most importantly, it results in improved clinical outcomes. Integrated palliative care, or bringing together administrative, organizational, clinical, and service aspects in order to realize continuity of care, has the potential to improve continuity of care experiences which are often at stake within the context of palliative care [30]. According to a qualitative study with patients and family caregivers in five European countries, patients and family caregivers most likely experience continuity of care by having a small number of trusted health care professionals who are available, provide multidisciplinary care where medical and allied health care professionals consider all

relevant treatment options and develop an individual treatment plan for each patient collaboratively, and regularly transfer information to all health care professionals involved [31]. This dynamic will fit in perfectly with our small multidisciplinary team in Arcatao and will help ensure the residents in Arcatao will get the best care possible.

### **CARING FOR THE CAREGIVER**

Caring for a loved one or friend is not an easy task, and it isn't something that most of us are prepared or trained to do. Caring for the caregiver is just as important as taking care of the patient, both may experience grief. It is also important to mention that grief comes in many different forms and is experienced differently by every individual. And although there are many differences to the grieving process, it is crucial to understand Elizabeth Kübler-Ross' five stages of grief, the most commonly observed stages experienced by the grieving population, in order to better understand the needs of patients and their caregivers. In her book "On Death and Dying," Kübler Ross introduces her 5-stage grief model, based on her work with terminally ill patients, and makes it known that these stages are non-linear and some people may not experience certain stages or none at all.<sup>42</sup> The 5 stages are explained in Dr. Christina Gregory's article "The Five Stages of Grief: An Examination of the Kübler Ross Model" as follows:

1. *Denial*- a state of shock, where dealing with a situation or bad news is denied. In the denial stage, the person might not be living in 'actual reality,' rather living in a 'preferable' reality that helps to pace these new emotions of grief, and denying them or suppressing them, helps them from becoming overbearing too fast. Surprisingly, it is the denial and shock that really help people to cope and begin to overcome their grief.

2. *Anger*- Once the person begins to understand the reality of the current situation, usually anger might begin to set in. This anger may be directed at family or friends, and they might feel enraged by the fact that this has happened to them. This stage is usually accompanied by questions such as "why me?" and "life's not fair." However, unlike most situations, where we are told to control our anger, in this stage, anger serves as a natural step in the healing process and it is important to not suppress those feelings. The direction of anger toward something or somebody is what might serve to bridge the person back to reality and connect them with those around them.

3. *Bargaining*- In this stage, sometimes when something bad

happens a person may try to make a "negotiation" in order to try and avoid the grief. Many times, it comes in the form of trying to make a bargain with God, for example, "God, if you take away my cancer, I'll promise to give more money to local charities." Ultimately bargaining is a stage of false hope, where the person is desperate to get their life back to how it was before the grief event, they are willing to make a major life change in order to get back toward normality.

4. *Depression*- Depression is often most commonly associated with guilt and is characterized by strong feelings of sadness that involve coming to the realization the person or situation is gone or over. In this stage, the person might seem withdrawn from life, not want to get out of bed, and/or experiencing feelings of hopefulness.

5. *Acceptance*- Considered the final stage of the 5-stage grief model, in this stage the person begins to accept their new reality and that most importantly, the situation is something they can deal with and will be okay moving forward. This person's emotions may begin to stabilize and they may begin to re-engage with family and friends if they haven't done so. This stage will involve good days and bad days, but is ultimately a period of adjustment. [32]

In palliative care, the person begins to understand their loved one can never be replaced or if they are the patient, come to terms with their illness, but most importantly they move, grow, and evolve into their new reality. It is also important to note that these stages can also apply to caregivers as well.

In addition, our palliative/hospice program will support caregivers by providing access to a pastoral care worker, social worker, volunteer and bereavement support which will continue to be available after a loved one's death at the San Oscar Arnulfo Romero day home. In addition, because the day home provides a place where families can drop patients off to get the medical attention they need in the morning, this will provide time for the caregivers to have respite care. Respite care provides temporary relief for a primary caregiver, enabling them to take a much-needed break from the demands of caregiving a sick, aging, or disabled family member [33]. Respite care can take place in their own home, even if it's for just a few hours a week. The focus of respite care is that it can help ease the burden of family caregiving and help to relieve stress, restore energy, and promote balance in a caregiver's life.

### **TRANSITION INTO HOSPICE**

"Just as the disease treatment is a process, so 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 [10]. Physicians have not only a medical responsibility to the patient but also an ethical responsibility to be completely honest with their patient and assure confidentiality regarding their medical condition. This responsibility requires that health professionals act in accordance with the core ethical principles: Autonomy, the patient must be allowed to make informed decisions about his/her own care. Beneficence, promote the course of action that is in the best interests of the patient. Justice, to treat all people fairly and equitable and the just allocation of healthcare and resources.

Nonmaleficence, the obligation to not inflict harm on others. When curative treatment is futile, the patient must be fully informed of this fact but must also be given the option of palliative care and hospice care as a form of 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” [19]. Our program will make it our priority that the patient, their loved ones, and the health professionals collaborate and decide when hospice care should begin. Hospice care is appropriate when treatment is no longer medically beneficial, the patient is expected to live 6 months or less and the patient agrees to move to non-aggressive treatment. Ideally, this will be done by our team in Arcatao, and when the patient moves into hospice care, the team will set up a schedule to visit the patients at least once a week if they are not able to travel to the San Oscar Arnulfo Romero day home.

### **BEREAVEMENT COUNSELING**

Everyone grieves in their own way and at their own pace. Some people recover from grief and return to normal activities within a six-month period, though they continue to feel moments of sadness. Others may feel better after about a year. Sometimes people grieve for years without seeming to find even temporary relief. Grief can be complicated by several other conditions such as a person's level of dependency on the departed and depression. In reality, the grieving process often involves many difficult and complicated emotions as mentioned in the 5- stage model of grief.

Yet joy, contentment, and humor do not have to be absent during this difficult time. This is why our program will offer bereavement counseling at the day home through the “Casa

Hogar” project. This bereavement counseling will include self-care help, recreation, and social support that will be vital to recovery. Feeling happiness does not mean a person is done mourning, but is part of normal daily living.

Promoting a sense of community will also provide a great support base for the families going through bereavement counseling.

### **FINANCIAL SUPPORT**

One of the foundational values of any hospice and palliative care program is that no one should be devoid of pain/symptom management at the end of life because of financial circumstances. Each person deserves dignity and respect with end-of-life care, while doing everything possible to assure relief from distressing symptoms. Palliative care is a human right, and the International Human Right to Health from the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12.1 (1966) calling for the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health” [34]. Government funding will be difficult because hospice programs will need to further integrate into the El Salvadoran healthcare system and prove their value to the overall system in the coming years. As a result, we will focus on getting the support of NGOs and contact organizations such as the World Bank group, IAHP (International Association for Hospice and Palliative Care), to help us either to fund the sustainability of the project or direct us to organizations that can help us. Regardless, there are many programs and services that would be willing to help. The parish in Arcatao has a 30-year relationship with St. Joseph’s parish in Seattle and they are committed to implementing this program financially. The Institute of Clinical Bioethics at Saint Joseph’s University in Philadelphia awarded our project a \$5000 grant from the Morris Foundation, which will help to aid the “Casa Hogar” project, in attaining medicine, wheelchairs, and any other necessities, etc.

The following is a list of resources need for implementation of the project:

**Table**

Resources	Quantity	Cost/unit
Portable bathroom	5	\$99.00
Shower chairs	4	\$56.50
Wheelchairs	10	\$452.00
Crutches	12	\$29.00
Canes	12	\$14.69
Walkers	10	\$59.99
Materials for Physical Therapy		\$13.56
Physical Therapy Exercise Ball	8	\$33.90
Thermometer	2	\$35.00
Blood pressure Cuffs	2	\$56.25
Stethoscope	2	\$40.00
Glucose Tests	4	\$46.00
Physical Therapy Weights	8	\$9.09
Height and Weight Scale	1	\$508.50
Digital Scale	1	\$101.70

*List of Needed Resources for Older Adults*

It will be the responsibility of the Arcatao Community and their partners in the US to help fund and implement the program.

## CONCLUSION

Although this program is mainly focusing on bringing palliative/hospice care to a developing country, it will also serve to build a stronger sense of community and shine light on the importance of palliative/hospice care. All human life is inherently valuable and the role of hospice nurses, physicians and all other staff is to alleviate suffering and provide comfort for the sick and dying. It has been widely advocated that palliative care should be delivered on the basis of need, not diagnosis or prognosis. With that in mind, we continue to move forward, both in research and development, in order to implement this program in Arcatao,

El Salvador and hopefully in other Latin American countries.

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**Author Information**

**Peter A. Clark, S.J., Ph. D**

**Nimmy Mathew, M.D.**

**Bhanusowmya Buragamadagu, M.D.**

**Daniel Morales**