Growing Pains: Palliative Care in Indonesia and Papua New Guinea

All characters, organizations, and plots described within the case are fictional and bear no direct reflection to existing organizations or individuals. The case topic, however, is a true representation of circumstances in the Papua New Guinea and Indonesia. The case scenario is complex and does not necessarily have a correct or perfect solution, and thus encourages a judicious balance of creative yet perceptive approaches.

The authors have provided informative facts and figures within the case and appendices to help teams. The data provided are derived from independent sources, may have been adapted for use in this case, and are clearly cited such that teams can verify or contest the findings within their recommendations, if it is pertinent to do so. Teams are responsible for justifying the accuracy and validity of all data and calculations that are used in their presentations, as well as defending their assertions in front of a panel of knowledgeable judges representing different stakeholders.
Introduction

Ruth Somare, the Secretary of the National Department of Health in Papua New Guinea (PNG), had seen her country’s health status improve greatly during her lifetime. She remembered hearing the stories Lana Somare, her mother, told about the toll infectious diseases had on their family members, including Lana’s own battle with tuberculosis during her childhood. These stories prompted Ruth to pursue a career in medicine. After studying medicine in Indonesia, Ruth returned to PNG to work as a physician. Her skills caught the attention of officials in the Department of Health, leading to her current position.

Two years ago, Lana was diagnosed with terminal breast cancer. Since the diagnosis, she has been in tremendous pain and has faced great difficulties finding hospice facilities and general pain management relief, including reliable and safe sources of opioids. Even as Ruth reflected on the great improvements in health care that have been made in PNG, Ruth remained deeply troubled by the lack of available palliative care services in the country. Upon further investigation, Ruth discovered that the scarcity of palliative care resources was a troubling trend not unique to PNG but one that affected other countries in the region as well, including Indonesia. She expressed her concerns to both her boss, the PNG Minister of Health, as well as the Minister of Health of Indonesia, who was one of her medical school classmates. Moved by the gravity of the problem and the passion with which Ruth spoke, both leaders made a commitment to make access to palliative care a national priority.

Prompt

As a world-renowned international consulting group on palliative care, you have been chosen to respond to a request from the governments of Indonesia and PNG. The government leaders have recognized the growing public health concern as millions of their citizens suffer from diseases whose final stages can involve substantial pain, especially HIV and various types of cancer.

Each consulting group is tasked with developing an innovative palliative care program to address this need. Choose one country, either Indonesia or PNG, to which your palliative care program will be targeted, and appropriately justify your choice. Country leaders and public health officials have a focused interest in improving accessibility of palliative care treatment to their citizens suffering from chronic pain; your program does not need to be governmental policy, but it must demonstrate active collaboration with current governmental entities and activities. Appropriate economic considerations are required, as the health systems in these two countries are at a crossroads; they are both in the accelerated transition phase of the GAVI support transition, due in part to strengthening economies. Legal issues will also be central, particularly regulations of opioid medications and considerations of the legality of physician assisted deaths. Furthermore, your plan must encompass physical and emotional aspects of palliative care, while also considering the religion and culture of the country for which it is developed. Attitudes surrounding death vary vastly between cultures, and your program must demonstrate sensitivity towards your target population and the variability within that population. Additionally, the appropriate use of opioids is a key component to quality palliative care and related treatment, and thus opioid availability and
usage guidelines in Indonesia or PNG are important considerations. A panel that includes experts in public health, chronic disease, and palliative care will judge your program.

Funding will be guaranteed for the first three years of your program, as promised by Basuki Sutrisno, a celebrity that commonly donates to health care related charities, and each of the governments. Each respective government has promised fifty percent of yearly funding, and this will be matched by Mr. Sutrisno to reach the full funding level. If your team chooses to work in Indonesia, you will be provided USD 10 million for each of the first two years and USD 5 million for the third year. If you choose to work in PNG, the amount will be scaled by the ratio of national spending on health care, so you will receive USD 4 million the first two years and USD 2 million the third year. The funding is only guaranteed for the first three years, so each consulting group must include a plan for long-term sustainability and growth.

Background on Palliative Care

What is palliative care?

The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” It is a form of care that is integrative, involving many different disciplines to address the physical and mental needs of the patient. Somewhat unique among medical fields, palliative care also has an explicit focus on support for the family of the patient in addition to care for the primary patient. The United Nations (UN) recognizes palliative care as a human right, and opioid analgesics are included on WHO’s list of essential medicines. The WHO estimates that approximately 40 million people need palliative care worldwide each year, and 78% of these are in low and middle income countries.

International status of palliative care

Worldwide, palliative care has had a unique place in many cultures. However, the ideal for end-of-life care has taken a number of forms, often dependent on location-specific contextual factors. Although a model based on hospice care has emerged in the United States and Europe, these principles may not be acceptable everywhere. An open discussion around death with the patient, a central part of hospice care, is not necessarily practiced in all cultures. Discussions of palliative care can be complex and are heavily influenced by the belief systems of the patient, the patient’s caregivers, and clinician. Furthermore, cultural and religious upbringing are central to an individual’s belief system.

Greater than 5.5 billion people (83% of world’s population) in more than 150 countries have low to no access to morphine and other narcotic medications. According to data from the International Narcotics Control Board’s (INCB) 2015 Availability Report, more than 75% of the world’s population has limited to no access to proper pain relief treatment for conditions including cancer, HIV/AIDS, cardiovascular disease, diabetes, surgery, and injuries, among many other medical...
Based on WHO and Worldwide Palliative Care Alliance (WPCA) estimates, 377 adults per 100,000 will require palliative care at the end of life, but 18 million people still die in pain each year.7,8

**Opioid regulations and governing bodies**

The UN 1961 Single Convention on Narcotic Drugs is a major governing treaty in the international control of opioid analgesics. It recognizes that narcotic drugs are indispensable for the relief of pain and suffering and that narcotic drugs should be made available for such medical purposes. The INCB was established at the Convention to oversee compliance of the determined laws and regulations, as well as monitoring implementation of international drug control conventions.9 In addition to the INCB, the other governing bodies addressing opioid use include: the UN Commission on Narcotic Drugs, which leads the international drug policy development; and the UN Office on Drugs and Crime, whose responsibility is to coordinate global action related to drugs, crime, and terrorism.10 Additionally, Millennium Development Goal Eight aimed, in part, to encourage access to affordable, essential drugs in developing countries.11

**Access to Opioids**

Despite current regulations, “90% of the global consumption of morphine, fentanyl, and oxycodone registered in 2009 occurred in Australia, Canada, New Zealand, the United States, and several European countries.”12 This highlights the limitations of current regulations, as widespread availability of opioids in low and middle income countries remains poor. There are a variety of factors contributing to low availability of opioids, including most notably a fragmented supply chain; unfavorable political, clinical, and patient views towards the drugs; a fear of creating opioid addiction and dependency; and a lack of sufficient health care system funds in many countries.13

The opioid supply chain is starkly different between developed and developing countries. In high-income countries, the primary wholesale market is controlled by a few national firms, whereas developing countries often have hundreds or thousands of firms controlling small shares of the same market.14 This fragmented system often translates to higher costs, for all actors in the supply chain including the consumer, and creates a market for cheaper drugs of questionable quality.14 The availability of potentially low-quality drugs can have devastating consequences — treatment may not be fully effective, there may be unknown side effects, or adverse events may occur because of the low quality of the medication. The most inefficient and expensive component of the chain of supply is the last leg, the distribution to the pharmacy.14

Badan Pengawas Obat dan Makanan (BPOM) is the primary governing body in control of distribution licensing of all prescription medications to be distributed in Indonesia.15 Further, large pharmaceutical distributors control wholesale distribution of drugs, which requires special licensing from the Director General of Pharmaceuticals and Medical Equipment (DGPM).15 In PNG, the supply chain is made up of “a tiered structure of Area Medical Stores, provincial transit stores, provincial hospitals and rural health services … using a ‘pull’ or demand system coordinated by the Medical Supply Branch of the Ministry of Health.”16 There is no regular assessment, on any government level, of pharmaceutical policy in PNG.
**Potential for Opioid Misuse**

Globally, there has been a lack of detailed reporting in regards to the use and misuse of opioids. However, there has been a significant increase in sales of opioids over the years. Annual global sales of Oxycontin, for example, soared from USD 48 million in 1996 to USD 2.8 billion in 2012. While there is limited information on global use, there was a greater than 300% increase in opioid prescriptions in the United States from 1991-2009. A dramatic spike in opioid production has consequently led to high rates of prescription drug abuse; in 2011 alone, over 1.2 million emergency visits in the US were due to unauthorized prescription drug use, and there are around 17,000 deaths per year due to prescription drug abuse. Officially declared a national epidemic by the CDC, opioid abuse is a very serious public health issue in the United States.

**End of Life Decisions**

Decisions surrounding end of life care can be difficult and emotional for patients, their families, and health care providers. Physician assisted death, also known as assisted suicide, physician aid-in-dying and patient administered hastened death, “refers to the practice where a physician provides a potentially lethal medication to a terminally ill, suffering patient at his request that he can take (or not) at a time of his own choosing to end his life.” There are individuals and groups that staunchly oppose this practice in any case, while others believe that physician assisted death should be allowed when the patient is a consenting, mentally competent adult. Cultural and religious beliefs play a large role in shaping individuals’ positions on this issue. The legality of the practice varies both between and within countries. Nonetheless, it is an issue that demands consideration when designing a palliative care program.

**Background on Indonesia and Papua New Guinea (PNG)**

**Demographics, Economies, and Health**

Indonesia and PNG provide two distinct historical and cultural contexts, where changing economies and disease distributions have led to an increased need for palliative care. These countries do not currently have robust palliative care infrastructure, although they both have many people who would benefit from such services. Both countries have made economic gains in the past few decades and are transitioning out of GAVI eligibility, complicating their current health care budgets. The end of GAVI funding means they will need to commit increasing amounts of their health care budget towards vaccines, which could affect the availability of funds for chronic diseases and other conditions.

These two countries have a unique relationship, predominately due to their shared border on the island of New Guinea (see Appendix A). The borders are porous and not entirely secure, and many citizens enjoy frequent travel across the border. Their border history is also smattered with conflict, from inappropriate military force to the stealing of vital resources such as food and medical supplies. Despite these differences, Indonesia and PNG are close neighbors with many similarities.
in terms of economy and health care issues.

One source of financing for health care in Indonesia and PNG has come from international partners. The Global Fund for HIV, Malaria, and TB is a partnership organization that provides financial support in over 100 countries for the three diseases listed in its name. The Global Fund awards funding based on a country’s income level in a disease-specific manner. According to the Global Fund, Indonesia currently has 51,000 people on antiretroviral therapy and, to date, has received a total of USD 691 million of the USD 906 million for which it signed, with USD 237 million of the received total (of USD 292 million signed) allocated specifically to AIDS (see Appendix B). In contrast, PNG has 21,000 people on antiretroviral therapy. To date, it has received USD 35 million out of the USD 43 million earmarked for AIDS care and USD 197 million in total funding of the USD 230 million for which it signed. Both countries remain eligible for funding through the Global Fund for HIV, TB and Malaria.

Indonesia

Indonesia has the 5th largest population in the world, with an estimated 258 million inhabitants (see Table 1). They also have the largest Muslim population in the world, with 88% of the population practicing Islam. Demographically, they have a young population; twenty-five percent of the populace is between the ages of 0-14 years old. This age structure is beginning to change however, with a total fertility rate of 2.13 and a life expectancy of 70.1 years for males and 75.5 for females. In Indonesia, total expenditure of health makes up 2.9% of the country’s USD 861 billion GDP.

The current health care infrastructure and health care access in Indonesia is in a state of development and transition; 2016 marks the second full year of Jaminan Kesehatan Nasional (JKN), the country’s universal health care system. As of November 2014, nearly 130 million Indonesians had insurance, including middle-income level citizens who had previously been excluded from prior forms of social health insurance due to their incomes. The new plan covers medical care, as well as hospital stays and ambulance services. However, the system often leaves citizens with little choice of provider or location of care. Additionally, Indonesia’s geography consists roughly of 17,000 islands, 6,000 of which are inhabited; this immediately creates an added challenge to the development of health care infrastructure and the provision of care. Citizens in remote, rural areas of Indonesia often have difficulty accessing the care they need, unless they are able to afford travel to another island with sufficient health care resources. Furthermore, there is an overall lack of providers relative to Indonesia’s population. The doctor-to-patient ratio is 0.2 per 1,000 patients, which is one of the lowest in Southeast Asia and puts it among the 44% of WHO Member States that have less than one physician per 1,000 patients.

PNG

PNG is a smaller country, with a population of 6.8 million people. The populace is 96% Christian, although some indigenous practices are still practiced widely. The age distribution is skewed even more heavily towards a younger demographic than Indonesia, with 34% of the population between 0-14 years old and a total fertility rate of 3.1. Despite this, there are still almost 650,000 inhabitants over the age of 55, and the average life expectancy is 65 for men and 69.5 for
PNG's total health expenditure is 4.3% of their USD 17 billion GDP. PNG has its own challenges pertaining to health care delivery, availability, and existing infrastructure. The PNG topography is diverse, with mountains and deep valleys that create geographical divides. This has led to a variety of indigenous peoples living throughout the country who may not have easy access to their current health infrastructure. Rising incomes have led to a shift toward Western lifestyles followed by a shift in the disease burden towards chronic conditions, including various types of cancer. The PNG National Health plan focuses on providing care for poor and rural populations, with clearly defined goals, such as Vision 2050 — to be among the top 50 countries in the UN Development Program’s human development index by 2050. Their health policy has also defined minimum standards for general health facility infrastructure and staffing, as well as standard equipment lists. The health plan in PNG focuses on decentralization, and provision of care at province, district, and local levels, in addition to a nationally-run referral hospital. However, there is still a shortage in the number of hospitals, both publically and privately operated. Churches play an important role in the delivery of health care services, operating 46% of health centers in the country, primarily in rural areas.

### Table 1: Demographics and Economies

<table>
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<tr>
<th></th>
<th>Indonesia</th>
<th>Papua New Guinea</th>
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<tbody>
<tr>
<td>Population</td>
<td>258 million</td>
<td>6.8 million</td>
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<tr>
<td>Population Under 15</td>
<td>25%</td>
<td>34%</td>
</tr>
<tr>
<td>Population Over 65</td>
<td>5.17%</td>
<td>3.05%</td>
</tr>
<tr>
<td>Fertility (children born/woman)</td>
<td>2.13</td>
<td>3.1</td>
</tr>
<tr>
<td>Life Expectancy</td>
<td>Female: 75.5</td>
<td>Female: 69.5</td>
</tr>
<tr>
<td></td>
<td>Male: 70.1</td>
<td>Male: 65</td>
</tr>
<tr>
<td>Gross Domestic Product (GDP)</td>
<td>USD 861 billion</td>
<td>USD 17 billion</td>
</tr>
<tr>
<td>Health Expenditure (% GDP)</td>
<td>2.9</td>
<td>4.3</td>
</tr>
<tr>
<td>Physicians Per 1000 People</td>
<td>0.20 (2012)</td>
<td>0.06 (2010)</td>
</tr>
<tr>
<td>Main Religion</td>
<td>88% Muslim</td>
<td>96% Christian</td>
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</tbody>
</table>
Cancer and HIV are two of many conditions that can lead to the need for long-term medical management, including the provision of palliative care.

**Cancer**

Historically, international aid money has targeted infectious diseases; however, the prevalence of chronic conditions has increased in many developing countries as people live longer and lifestyles shift. The worldwide risk of dying from cancer by the age of 75 is 10.5%, with both Indonesia and Papua New Guinea having comparable risks. In both countries, the five-year prevalence for females is higher than the corresponding figure for males (Table 2). The most frequent cancers in Indonesia, as of 2012, were breast, lung, and colorectal; PNG’s leading cancers are lip, oral cavity, and cervix uteri (see Appendix B).

**Table 2: Cancer Epidemiology**

<table>
<thead>
<tr>
<th>Risk of dying from cancer by age 75 (world average is 10.5%)</th>
<th>Indonesia</th>
<th>Papua New Guinea</th>
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<tbody>
<tr>
<td>9.7%</td>
<td>13.3%</td>
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| 5-year prevalence (per 100,000)                             | 357.7     | 385.5            |

| Sex specific 5-year prevalence                             | Female: 449.8 | Male: 263.6       | Female: 544.7 | Male: 228.9 |

**HIV/AIDS**

Although HIV treatment has been heavily funded, programs have focused primarily on providing antiretroviral therapy to patients. Less attention has been paid to those living with HIV, and the additional problems they may have beyond combatting the virus. PNG and Indonesia both have a relatively low prevalence of HIV, although this translates to a large number of people in need of care due to their large populations. According to 2015 UNAIDS estimates, the prevalence of HIV among adults aged 15 to 49 in PNG is 0.8% compared to 0.5% in Indonesia.
Palliative Care in Indonesia and PNG

Indonesia

The focus of health care in Indonesia is shifting towards non-communicable diseases, especially as the country’s population continues to age. Indonesia has 12,500,000 adults over 65, and this number is expected to increase 7-14% by 2050, per the World Bank’s estimates. Expansive growth of infrastructure will be required to support the aging population as their disease burden for certain age-related conditions increases, including palliative care services for those living with terminal diseases. To distinguish infrastructure available in different countries, Lynch and colleagues designated six different levels of palliative care service categories. Level 1, the lowest level, has no known hospice-palliative care activity. The highest level, 4b, requires advanced integration where palliative care services are well established and utilized within the health care system. Indonesia has most recently been classified as level 3a: isolated palliative care that is not fully integrated into mainstream health care services.

A palliative care plan was established in 1990 when three hospitals were appointed to evaluate the use of oral morphine as pain relief. Since then, public, private, and faith-based organizations have come to the table to join in efforts to improve palliative care. There are plans to open more than ten new hospitals by 2017, reaching those previously unable to access care due to location and cost. Further plans include development of a 500-bed palliative care center focusing on pain relief and management of terminal, chronic conditions, as well as a 100-bed cancer hospital. Three doctors in West Jakarta are being chosen specifically to receive palliative care training. It is hoped that this will encourage continuous growth of infrastructure and practitioners available to provide palliative care. Another form of existing Indonesian infrastructure related to palliative care is Rachel’s House, a non-profit organization that provides palliative care to children living with cancer or HIV. The organization provides home-based palliative care free of charge. The government and health officials have clearly recognized the country’s need for palliative care and are attempting to create solutions for these problems, in the form of outpatient services, increasing accessibility to opioid medications, and an overall increase and improvement in quality palliative care treatment.

Despite this history, access to palliative care is still limited, with only 7 cities on the 3 major islands having any palliative care infrastructure in place. In addition to a lack of providers, limited knowledge of palliative care practices by general health care providers has also been a major barrier in cancer management, as well as limited use of opioids for pain management in palliative care treatment. Infrastructure is lacking, and needs to be addressed before improvement in palliative care treatment can occur throughout Indonesia.

Papua New Guinea

In PNG, infrastructure for palliative care has been non-existent. Despite the approximately 10,000 people that die annually from cancer, only recently have plans for a new palliative care facility, the first of its kind, been announced with funding from the Australian government. With some activity related to palliative care but no current provision, PNG is rated as a level 2 country by Lynch and colleagues in their tiered designation. The 2014 revision of the national drug policy recognized the poor distribution of medications and an inability to maintain them in rural areas due
to a lack of trained pharmacists. All of these factors highlight a large gap in health care infrastructure for palliative care in PNG, as well as the opportunity to have a large impact if these needs are addressed.

References


Appendix A. Map of Indonesia and Papau New Guinea

https://commons.wikimedia.org/wiki/File:Indonesia_Papua_New_Guinea_Locator.svg
Appendix B. The Global Fund Statistics

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<thead>
<tr>
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<th>Indonesia</th>
<th>Papua New Guinea</th>
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<tbody>
<tr>
<td>Total Funding Allocated (all three diseases)</td>
<td>US$691,552,779</td>
<td>US$230,306,739</td>
</tr>
<tr>
<td>AIDS Funding received</td>
<td>US$237,483,191</td>
<td>US$35,362,874</td>
</tr>
<tr>
<td>AIDS Funding allocated</td>
<td>US$43,967,123</td>
<td>N/A</td>
</tr>
<tr>
<td>Number of people on antiretroviral therapy</td>
<td>41000</td>
<td>21000</td>
</tr>
<tr>
<td>Antiretroviral therapy retention rate</td>
<td>67%</td>
<td>N/A</td>
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Appendix C. Cancer Incidence

Indonesia

![Cancer Incidence Graph for Indonesia](image)

PNG

![Cancer Incidence Graph for PNG](image)
Acknowledgements

The Emory Global Health Case Competition Leadership Team gratefully acknowledges the dedication and contributions of each of the Writing Team members.

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Jessie Preslar, Emory University School of Medicine/Rollins School of Public Health (Chair)
Mwangala Akamandisa, Laney Graduate School
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Dr. Robert Bednarczyk, Rollins School of Public Health *(Faculty Advisor)*
Dr. Deborah McFarland, Rollins School of Public Health *(Faculty Advisor)*

The Case Writing Team also recognizes valuable inputs and expert reviews from Drs. Jeffrey Koplan and Robert Breiman.

The Emory Global Health Case Competition Leadership Team gratefully acknowledges the logistics and planning team, with special thanks to: Rebecca Baggett, Kelsey Patel, Jessie Preslar, and Karla Umana.