# Relieving extreme physical pain in humans – an opportunity for effective funding

Jonathan Leighton

Executive Director, Organisation for the Prevention of Intense Suffering (OPIS)

Started 7 August 2018, last edited 11 October 2018

**Summary** 

<u>Introduction</u>

Ethics of relieving suffering

Scale

<u>Neglectedness</u>

**Tractability** 

Cost-effectiveness

Project Burkina Faso

Further research

Conclusion

# Summary

Relieving extreme physical pain is one of the highest priority interventions according to both suffering-focused and other ethical frameworks. Millions of people suffer every year from moderate to extreme pain that could be relieved with inexpensive oral morphine that they are unable to access, due in many cases to overly strict government regulations, as well as lack of medical training, inefficient distribution channels and social attitudes – all of these linked to largely unwarranted fears of dependence and misuse. We consider this a cause area of high scale/importance, moderate neglectedness and low tractability, with an estimated overall rating of 23, according to the standard criteria and scale widely used within the effective altruism (EA) movement. A brief cost-effectiveness estimate suggests that, given the importance of relieving extreme suffering, advocacy and education projects to promote increased morphine access, such as in small-to-medium sized countries like Burkina Faso or Guatemala where OPIS has begun collaborations, could be of competitive effectiveness to benchmark EA interventions.

## Introduction

There has been increased attention recently to the problem of lack of access to morphine and other opioid medications for people suffering from moderate to severe physical pain – an issue that has been likened by a UN special rapporteur to <u>torture</u> by omission and that affects millions of children and adults each year, especially in low-to-middle-income countries (LMICs). The

issue has been raised in EA circles (esp. Lee Sharkey's excellent analysis, also Peter Singer's article and Michael Plant's EA Global London 2017 talk on increasing world happiness) and received media coverage as a result of a comprehensive 2017 Lancet Commission report (NYT article, Guardian article). The Organisation for the Prevention of Intense Suffering (OPIS), a think-and-do tank with close ties to the EA community, has taken action on this issue, holding a panel event at the UN Human Rights Council in March 2018 to promote access to morphine as a human right, preparing a guide to the issue in several languages which is being used by palliative care associations around the world, and recently establishing collaborations with national palliative care associations in Burkina Faso and Guatemala to promote access to morphine - especially the easily administered, immediate release oral form. In this document, I examine the case for funding projects to facilitate access to morphine from an EA perspective, including an initial reflection on the underlying ethics and value system. I do not claim to have an entirely unbiased stance in this document, given OPIS's existing involvement in the issue and our interest in eliciting funding. However, I should note that our initial interest in the issue arose from both ethical and EA considerations, and in this document I have attempted to be transparent and objective in relating the facts.

Much of the emphasis in this document is on the potentially highest impact interventions that can relieve the most common systemic bottlenecks to expanding access to morphine. As governments play a central role in limiting or facilitating access, there is a particular focus on advocacy to gain government support for the issue that can lead to changes in regulations and legislation that currently hinder access, an increase in training and education, improved supply and distribution, and communication to destigmatize use of morphine. However, some interventions to improve access can also potentially be carried out locally without necessarily requiring the support of central governments or changes in regulations. These interventions, while smaller in scale, may be greater in tractability. Many of the considerations discussed in this document apply to local interventions as well.

# Ethics of relieving suffering

The EA movement is united by a desire to promote effective ways of "doing good", but there isn't a consensus on what "doing good" means. Even in a community that has a strong consequentialist orientation, there is moral uncertainty, including, for example, about the merit of different strains of utilitarianism, what constitutes well-being, the degree of disvalue of suffering, the value of existence, the role of deontology and the moral status of non-human animals. Human-focused interventions may promote increased well-being, which in many cases can be considered equivalent or similar to reducing suffering, and they may also save lives. Benchmarks for EA interventions, such as Against Malaria Foundation and Malaria Consortium's SMC Program, have typically been given top rankings in large part because of their cost-effectiveness in saving lives, although they also spare many more people from the suffering of the disease itself. Animal-focused interventions tend to focus mainly on well-being by preventing animals from coming into existence who would have been tortured on factory

farms. There is therefore currently some accepted flexibility in the EA community in the interpretation of "doing good", with a common focus on effectiveness within an area of interest.

Nonetheless, according to virtually all ethical theories, alleviating suffering has high importance. This includes classical utilitarianism, where a single instance of extreme suffering could even be given overwhelming preponderance over the "same quantity" of bliss, depending on the weighting scheme; prioritarianism, which gives greater weight to those worst of; and of course negative utilitarianism, which explicitly places the moral emphasis on relieving suffering.

OPIS operates according to the <u>ethical view</u> that what matters ethically is the prevention or relief of suffering, with a very strong emphasis on extreme or unbearable suffering (<u>Tomasik</u>). This perspective does not conflict with the subjective value of happiness (beyond the relief of suffering and frustration, i.e. "hedonic zero") and even bliss to those experiencing it, but it denies the ethical *urgency* or importance of bringing into existence such states. This framework also attributes ethical significance to saving lives, but the argument is based rather on the associated impact on suffering – physical or mental – of those directly affected and others who would be impacted by their deaths. It also, in principle, facilitates a more direct comparison, on the basis of suffering averted, between interventions meant to save lives and interventions means explicitly to avert suffering. This comparison is especially important for the "scale" dimension of the "scale, neglectedness, tractability" heuristic triad of EA thinking.

The phenomenology of happiness and suffering is complicated by imprecise language. Increasing the happiness of someone who is suffering to some degree may actually mean the same thing as reducing their suffering. As a rule, most EAs do not focus on creating more blissful states in people who are already happy. On the other hand, the use of the term "suffering" to cover a wide range of mental states might lead to the conclusion that suffering so extreme as to make life literally unbearable is merely quantitatively different from the suffering of a stubbed toe, when it could be argued that these states are of a qualitatively different nature and do not lend themselves to a simple numerical tradeoff with states of lesser suffering. Although it might be unintuitive to claim that extreme/unbearable pain is infinitely more urgent than more moderate pain (and therefore demands a huge reallocation of resources to even a small number of such cases), it is also not obvious that there is a simple linear relationship between these two kinds of suffering. But even if extreme/unbearable suffering is considered to be only quantitatively different than mild or moderate suffering, the relative weight of such suffering is arguably considerable, and could even be orders of magnitude more negatively valued than other levels of suffering.

The agony of extreme physical pain and the effectiveness of morphine in relieving it is what attracted us to this cause area and why we consider it to be of such great importance (guide).

## Scale

The importance of the problem lies most significantly in the inherent urgency of relieving extreme physical pain, and also in the number of people affected, even in smaller lower-income countries. According to the Lancet Commission report, at least 61.1 million people experienced severe health-related suffering (SHS) in 2015. A rough estimate from the report is that up to one half of these experienced physical pain requiring morphine, or about ~20-30 million patients/year. A lower bound estimate of total SHS days per year is 6 billion days worldwide, of which 5.1 billion days occurred in LMICs. Pain accounted for about 20% of total SHS days, with mild pain about three times more common than moderate to severe pain. Therefore moderate to severe pain represented ca. 5% of total SHS days. This gives a lower bound of 300 million days (822'000 person-years) of moderate to severe pain worldwide, of which 250 million days (685'000 person-years) in LMICs. A single small-to-medium-sized country such as Burkina Faso or Guatemala represents roughly 1/300 of the latter figure.

The vast majority of people in LMICs lack access to palliative care and pain relief. The global shortfall of morphine-equivalent opioids for palliative care is estimated to be 48.5 metric tons, according the Lancet Commission report. The main issue is not the cost of morphine, but rather strict government regulations and lack of medical training on pain relief, as well as inefficient distribution channels and social attitudes, that severely inhibit the prescription of morphine and the ability of patients to obtain it. Underlying these obstacles are largely unwarranted fears of dependence and misuse.

The Lancet Commission report does not distinguish between moderate and severe pain, and so we do not have a precise estimate of the number of days of severe pain, although they clearly represent a significant fraction of the total. The report also does not cover suffering from other causes than 20 diseases with potentially fatal outcomes, such as from chronic pain, and therefore the figures only represent a subset of the total number of patients, total days of moderate to severe pain and total morphine needs.

A separate analysis of morphine needs (Scholten) used as a reference for "adequate" consumption levels the quantities of morphine and equivalents consumed in the top 20 countries of the Human Development Index (HDI). This estimate has its own limitations, including a potential skewing by overconsumption in a few countries, notably the US. Nonetheless, the estimates give a potentially more accurate picture of the real shortfall in morphine treatment based on what would ideally be needed to effectively relieve moderate to severe pain from all causes, potentially increasing the overall shortfall by as much as *two orders of magnitude*.

The urgency of relieving severe physical pain reveals the serious limitations of the "QALYs gained" approach to measuring scale of impact. A person with terminal cancer treated with morphine for two months might remain highly disabled and in a very poor state of health, and gain only a fraction of a QALY, yet be spared two months of agony. As one of the most

important health interventions possible, the scale of this problem cannot be represented on a QALY scale. On the other hand, we can easily quantify the scale of the problem as ca. 685'000 person-years per year of moderate to severe pain (which includes extreme/unbearable pain) in LMICs worldwide, and ca. 2000 person-years per year of moderate to severe pain in a single small-to-medium-sized LMIC.

It is impossible to directly compare this issue with issues such as existential risk because of the different value scales. The 80'000 Hours scale rates curing cancer as a 12 because of the QALYs gained, but from the perspective of preventing extreme suffering, curing cancer would merit an even higher rating. I would assess the scale/importance of the issue to be high, within 2 orders of magnitude of a health intervention such as curing cancer, because it would ease the worst effects of cancer and also of other diseases and conditions. This would suggest a worldwide scale rating of about 10.

## Neglectedness

There are international, regional and national palliative care associations and other organisations promoting palliative care within medical systems, holding conferences and advocating for improved access to morphine, and also seeking to apply pressure within the UN system. These include International Association for Hospice & Palliative Care (IAHPC), Worldwide Hospice Palliative Care Alliance (WHPCA) and International Children's Palliative Care Network (ICPCN) as well as the Pain & Policy Studies Group (PPSG) at the international level, and regional associations such as the African Palliative Care Association (APCA), the Latin American Association for Palliative Care (ALCP), Pallium India, Asia Pacific Hospice Palliative Care Network (APHN) and the European Association for Palliative Care (EAPC). Human Rights Watch has also made access to morphine a key cause area and has carried out numerous investigations and reports at the global and country level. However, given the scale and importance of the problem, it is still relatively neglected. National palliative care associations in lower income countries generally have scarce resources and are run on a voluntary basis by a physician carrying out other activities. They are therefore often not equipped to carry out extensive advocacy campaigns and educational programs.

For example, OPIS has begun a collaboration with Hospice Burkina, the palliative care association of Burkina Faso, a country with a population slightly larger than the Netherlands, to promote morphine access in the country. The association consists of about two dozen volunteers but does not have a regular source of funding to carry out advocacy. OPIS is also in the early stages of a collaboration with the Guatemala Palliative Care Association, with the goal of carrying out an advocacy campaign to help promote the recommendations of a recent <a href="Human Rights Watch report">Human Rights Watch report</a> documenting the very difficult situation in the country. Again, the local palliative care association has limited means at its disposal to raise awareness of the issue. The Open Society Foundations, one of the most prominent international funding organisations for palliative care programs, operate only in selected countries. It therefore appears that a focus on supporting efforts in a single country can have a major impact on total resources devoted to the

problem locally during the period of intervention, within the same order of magnitude of existing efforts. Based on estimated worldwide figures, I would estimate the neglectedness rating at about an 8 or 9 on the 80'000 Hours scale, or moderate.

## **Tractability**

A major obstacle in many countries is the existence of Kafkaesque regulations that severely limit the ability of doctors to prescribe and of patients to acquire sufficient quantities of morphine. Each country has its own unique hurdles, in some cases clearly identified, in others less so. Invariably, political will to resolve the issue and establish effective strategies is key to achieving a comprehensive, sustainable solution. In some countries, local efforts to educate doctors in prescribing and administering morphine and, more generally, in palliative care can also lead to increased levels of use. However, in all countries with regulations that severely curtail the ability to prescribe or to obtain morphine, a change in government regulations is a necessary condition for significant scale up.

Persuading governments to change policies is possible, but it requires the right approach and some luck, which may also include good contacts in the government. It therefore remains a risky endeavour. However, the importance of the problem means that even, say, a 10% success rate of advocacy campaigns in several countries would still have high impact.

General awareness of this issue remains low among the general public worldwide. Awareness campaigns including social media and outreach to journalists have the possibility to raise interest.

It is also important to note that impact in this cause area is systemic and sustainable, as it changes the operating rules and capacity of the medical system, thereby ensuring the alleviation of suffering of patients in the future as well (on the assumption that the cost of medicine is covered). This is the case even for changes that may require a few years to be implemented and rolled out, such as the establishment of new education and training programs.

Again, the actual cost of the morphine itself is not a significant obstacle. Morphine is relatively cheap, and although lower income countries typically pay 4 times the lowest international bulk prices, the cost of a 30-day, 100 mg/day treatment would be about \$36 at current prices (ca. \$0.0120/mg; \$9 at the lowest international price of ca. \$0.0030/mg; calculated from Lancet Commission report figures). Furthermore, as regulations are relaxed and prescriptions are increased, it will also be easier to justify international health spending to help cover the cost of morphine, such as a World Bank-led fund, as proposed by the Lancet Commission. The report estimated the total cost of meeting the global shortfall of morphine for palliative care at \$145 million at the lowest international prices – more than 99% of this in LMICs, and representing only 0.009% of healthcare expenditures in these countries.

It is entirely plausible that a focused, multi-pronged campaign in any one country, especially in collaboration with an ambitious local partner, could help to persuade a government to seriously address the issue of morphine access, revise regulations and legislation, and promote medical training. These kinds of advocacy projects appear to be rare and would represent not just an increase in resources but the use of resources for neglected activities. A doubling of resources in any one country for a period of several months might therefore be expected to solve 1-10% of the problem in that country, giving a tractability rating of about 4 or 5 according to the 80'000 Hours scale, or low.

The summed up scale/neglectedness/tractability ratings yield a 23, comparable to other interventions rated as effective.

## **Cost-effectiveness**

As for the scale/neglectedness/tractablity analysis, any estimates of the cost-effectiveness of interventions to promote access to morphine are inherently uncertain, due both to uncertainty about the real impact of an advocacy or educational campaign, and to the inherent difficulty of comparing it with interventions with a different kind of impact. Nonetheless, we can make some estimates and draw some comparisons.

As a starting point: the Malaria Consortium's SMC Program is currently estimated to save a life for \$2000. Given that about 500 times more people contract malaria than die from it every year, this amount would probably spare 500 children from contracting the disease, or \$4 per child spared. The main symptoms of malaria are high fever, flu-like symptoms, headaches, muscle aches, abdominal pains and a general feeling of unwell. There is, unfortunately, currently no universally used health metric for suffering, and the standard metric of disability weight, used to calculate DALYs, is not a reliable proxy for actual suffering, as the perception by healthy individuals of degree of ill health, as represented by the disability measure, could be greater than actual suffering, as appears to be the case with malaria, or could vastly underrepresent it.

Nonetheless, the disability weight (Global Burden of Disease, 2015) of severe malaria is 0.133 (0.088-0.19), though it can climb to 0.402 (0.268-0.545) if it causes severe motor impairment. On average, a malaria patient probably suffers moderately, but in most cases it would probably not be considered extreme suffering. Perhaps the greatest suffering associated with malaria is the emotional suffering endured by a parent who loses a child to the disease.

In contrast, the disability weight for terminal stage cancer *with strong medication to avoid constant pain* is 0.54 (0.377-0.687); without strong medication the pain is often agonising. The mother of a 17-year-old Guatemalan high school student with brain cancer, interviewed by Human Rights Watch, said: "The pain was so intense [at some points] that he would grab his hair screaming and run through the streets calling for help." This level of extreme pain is arguably in another category than moderate pain – the kind of suffering that no one should ever be allowed to experience if at all possible. Added to this physical suffering, in many cases, is the

emotional suffering of a close relative, such as a parent who watches helplessly as their child screams in agony.

In a small- to medium-sized country like Guatemala, at least 5500 people with cancer or HIV/AIDS suffer annually because they cannot access low-cost opioid medications. (This figure is from the <a href="Human Rights Watch report">Human Rights Watch report</a>; another report by the Guatemala Palliative Care Association estimates the number of cancer patients living with untreated pain at ca. 40'000.) A significant fraction of them suffer extreme pain. Many more suffer chronic pain of other origins that is not adequately treated. The measures needed to ensure access have been properly documented, but a key to instituting the needed measures is a change in government policy. A multi-pronged advocacy campaign aimed at influencing government policy would have a significant chance of bringing about this needed change.

We can take a somewhat arbitrary, upperbound figure of \$50'000 to run a project that includes an extensive, well-designed advocacy campaign, media outreach and a workshop with government health officials. Let's assume that the project has only a 5% chance of persuading the government to change its policies to eventually make morphine accessible to 50% of those in need, taking a very conservative figure of 5000 people in need per year (based only on palliative care). The expected cost of the intervention would therefore be \$40 per patient spared intense suffering, spread out over 10 years. Given the degree of suffering involved, this appears a reasonable intervention, not just compared to overall healthcare spending, but also compared to other interventions evaluated as most cost-effective.

There are also possible knock-on effects of successful countries exporting their experience and know-how to other countries in the region and influencing policy, such as the case of Vietnam and Kerala (India). The total effect of a successful project and campaign may therefore be significantly larger.

# **Project Burkina Faso**

OPIS's collaboration with Hospice Burkina, the recently formed palliative care association of Burkina Faso, offers an example of how concerted, well-timed support for local efforts might play a major role in influencing government policy. Hospice Burkina is planning a national conference in early 2019 to bring together stakeholders, including top government officials, to sensitise them to the need for palliative care and access to morphine, and to identify current obstacles and practical solutions. An international organisation such as OPIS has an important role to play in lending credibility to local efforts. More substantively, we have the potential to bring in new perspectives and strategic advice, help to design the program for effectiveness and create communication tools such as documents and videos that can outline a pathway to success.

## **Further research**

As we develop the concrete details of projects in each country, currently including Burkina Faso and Guatemala, as well as new contacts with Mozambique, we will be investigating further and seeking to answer the following questions, to determine how to approach the government and also how much effort and resources to put into raising public awareness and obtaining media coverage:

- What is the history of past attempts to raise the issue of access to morphine with the government?
- Who are the key politicians and policymakers with influence on the issue?
  - What are their current positions on the issue, if expressed?
  - What are their main policy-related concerns?
  - What other interests do they have (private interests, political expediency)?
- Who are the key stakeholders in the country?
  - O How much influence does each have?
- How sensitive and responsive is the government to public opinion?
  - o Is an awareness campaign likely to have a positive influence?
- Are there any other factors that need to be taken into account in designing a program?
- Is there any point in proposing pilot studies to test out expanding access to morphine on a smaller scale, as a way of reassuring governments? Or is this needlessly complicated when the evidence already exists?
- What evidence is there for the usefulness of public awareness campaigns on similar issues to support changes in legislation? Is there any evidence that it can be counterproductive?
- What body of evidence can we prepare and provide to government ministers to demonstrate to them the success of programs elsewhere to increase morphine access, including the lack of negative consequences?
  - Collect summaries from successful projects in Uganda, Kerala, Romania and elsewhere

#### References:

 Embedding EA Thinking in Government Decisions Beyond the OECD: <a href="https://www.eaglobal.org/talks/embedding-ea-thinking-in-government-decisions-b">https://www.eaglobal.org/talks/embedding-ea-thinking-in-government-decisions-b</a> eyond-the-oecd/

#### Conclusion

For EAs who are interested in reducing some of the worst kinds of human suffering, funding country-specific advocacy and education projects aimed at facilitating access to morphine, such as those planned by OPIS in Burkina Faso and Guatemala, offer an opportunity to change policy that, while risky, may have an expected cost-effectiveness competitive with other effective healthcare interventions.

Derek Foster.		

Thanks for valuable input to Lee Sharkey, Jonas Vollmer, Trevor McCarty, Olivier Bertrand and