

**Original Article**

# Six Key Approaches in Open Society Foundations' Support for Global Palliative Care Development

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**Abstract**

**Context.** Between 1998 and 2021, the Open Society Foundations (OSF) network invested around US\$50 million in supporting the emerging field of palliative care worldwide, funding different approaches and interventions to advance its objective of putting palliative care on the global public health agenda.

**Objective.** To describe six approaches that were instrumental to the successes of Open Society Foundations' support in building the global field of palliative care. A robust discussion of lessons learnt is unfortunately not possible because Open Society Foundations did not commission a rigorous evaluation of the impacts of its investments.

**Methods.** This article describes these six approaches: Investing in versatile palliative care leaders at national and regional level; investing in palliative care champions within the OSF network; proactively engaging the World Health Organization (WHO) in efforts to promote palliative care; developing tools and skills to improve palliative care financing; using a human rights-based approach; and supporting self-advocacy by people with palliative care needs.

**Results.** Deep, long-term investments in national and regional champions from the palliative care community and OSF's own network built palliative care leaders with well-rounded skills, knowledge and opportunities to develop their own networks. The active engagement and involvement of the WHO in efforts to advance palliative care enhanced the credibility of palliative care as a discipline as well its champions, whereas the human rights approach resulted in more diverse strategies to overcome barriers to palliative care. The focus on palliative care financing and self-advocacy showed significant promise for impact.

**Discussion.** The approaches and strategies described helped a nascent palliative care field develop into a health service that is increasingly integrated into public health systems. Other funders and national governments can build on OSF's long term support for the palliative care field and support further integration of palliative care within public health to increase access. *J Pain Symptom Manage* 2022;000:1–11. © 2022 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

**Key Words**

*Palliative care, Hospice, Philanthropy, Leadership development, Human rights, Health financing, World Health Organization, Health systems, Self-advocacy, Public health, Networks, Champions*

**Key messages**

This article describes six approaches that were instrumental to the successes of Open Society Foundations' support in building the global field of palliative care.

**Introduction**

Between 1998 and 2021, the Open Society Foundations (OSF) network invested around US\$50 million to build the field of palliative care worldwide, seeking to place palliative care on the public health agenda to

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reduce needless suffering of people with life-limiting illnesses and their families. It funded many different approaches to advance its objective of ensuring access to palliative care for all. A list of publications that describe OSF supported palliative care initiatives is provided in Table 1.<sup>1–32</sup> This article focuses on strategies that have not been described in detail previously, discussing the origins of each approach, its evolution, and preliminary reflections on their effectiveness.

### Overview of OSF's Palliative Care Initiative

OSF first became involved in palliative care in 1994 with a US\$45-million effort to transform the culture of death and dying in the U.S. through Project on Death in America (PDIA).<sup>33</sup> In 1998, in response to requests

from OSF's national and regional foundations, a global palliative care initiative was established, later named the International Palliative Care Initiative (IPCI). Over the following 23 years, OSF's Public Health Program (PHP), which hosted the initiative, and at least 23 national and regional foundations funded palliative care initiatives in Africa, Asia, Europe, Eurasia, and Latin America. Table 2 lists the palliative care coordinators at OSF's national and regional foundations who supported the palliative care initiative over the years. Fig. 1 shows the geographic distribution of grants made between 2000 and 2021.

IPCI's strategy was based on the World Health Organization's public health model for palliative care and a Palliative Care Roadmap for introducing a new field of medical care into national health strategies.<sup>3</sup>

Table 1  
Past Publications Documenting OSF-Supported Initiative to Advance Global Palliative Care

Title	Authors	Date
Funding for Palliative Care Programs in Developing Countries	Callaway M, Foley KM, De Lima L, et al	May 01, 2007
World Health Organization Public Health Model: A Roadmap for Palliative Care Development	Callaway M, Foley KM, Connor SR	August 2017
The International Palliative Care Initiative	Callaway M, Foley KM	February 2018
Pain and Policy Studies Group: Two Decades of Working to Address Regulatory Barriers to Improve Opioid Availability and Accessibility Around the World	Cleary JF, Maurer MA	February 2018
Palliative Care for Tuberculosis	Connor SR	February 2018
The Worldwide Hospice Palliative Care Alliance	Connor S, Gwyther E	February 2018
Advancing Hospice and Palliative Care Worldwide	De Lima L, Radbruch L	February 2018
Legal Support for Palliative Care Patients	Ezer T, Burke-Shyne N, Hepford K	February 2018
Palliative Care and Human Rights: A Decade of Evolution in Standards	Ezer T, Lohman D, de Luca GB	February 2018
Leadership Development Initiative: Growing Global Leaders. Advancing Palliative Care	Ferris FD, Moore SY, Callaway M, Foley KM	February 2018
Promoting Palliative Care Internationally: Building Leaders to Promote Education, Practice, and Advocacy	Malloy P, Ferrell B, Virani R, Mazanec P	February 2018
International Children's Palliative Care Network: A Global Action Network for Children with Life-Limiting Conditions	Marston J, Boucher S, Downing J	February 2018
Treat the Pain Program	O'Brien M, Schwartz A, Plattner L	February 2018
Palliative Care Development in Tajikistan.	Abidjanova N	February 2018
Hospice Palliative Care Development in Hungary	Csikos A, Busa C, Muszbek K	February 2018
Palliative Care Development in Mongolia	Davaasuren O, Ferris FD	February 2018
Palliative Care in South Africa	Drenth C, Sithole Z, Pudule E, et al	February 2018
Palliative Care in Moldova	Gherman L, Pogonet V, Soltan V, et al	February 2018
The Palliative Care Journey in Kenya and Uganda	Kamonyo ES	February 2018
Palliative Care Development in Georgia	Kiknadze N, Dotsenidze P	February 2018
Palliative Care in Vietnam: Long-Term Partnerships Yield Increasing Access	Krakauer EL, Thinh DHQ, Khanh QT, et al	February 2018
Palliative Care in Rwanda: Aiming for Universal Access	Krakauer EL, Muhimpundu M-A, Mukasahaha D, et al	February 2018
Palliative Care in Kazakhstan	Kunirova G and Shakenova A	February 2018
Palliative Care in Romania	Mosoiu D, Mitrea N, Dumitrescu M	February 2018
Palliative Care Development in Kyrgyzstan	Mukambetov A, Sabyrbekova T, Asanalieva L, et al	February 2018
Development of Palliative Care in Armenia	Papikyan A, Connor SR, Amiryan D	February 2018
Forging a Vision of Excellence in Palliative Care in Central and Eastern European and Former Soviet Union Countries	Radbruch L, Ling J, Hegedus K, Larkin P	February 2018
Palliative Care—Albania	Rama R, Çarçani V, Prifti F, Huta K et al	February 2018
Palliative Care Development in Ukraine	Tymoshevska V and Shapoval-Deiniga K	February 2018
Advancing Global Palliative Care over Two Decades: Health System Integration, Access to Essential Medicines, and Pediatrics	Lohman D, Cleary J, Connor S, et al.	March 2022
Progress update: Palliative care development between 2017 and 2020 in Eurasia	Lohman D, Abidjanova N, Amiryan D, et al	April 2022
Progress update: Palliative care development between 2017 and 2020 in five African countries	Luyirika E, Lohman D, Ali Z, et al	May 2022

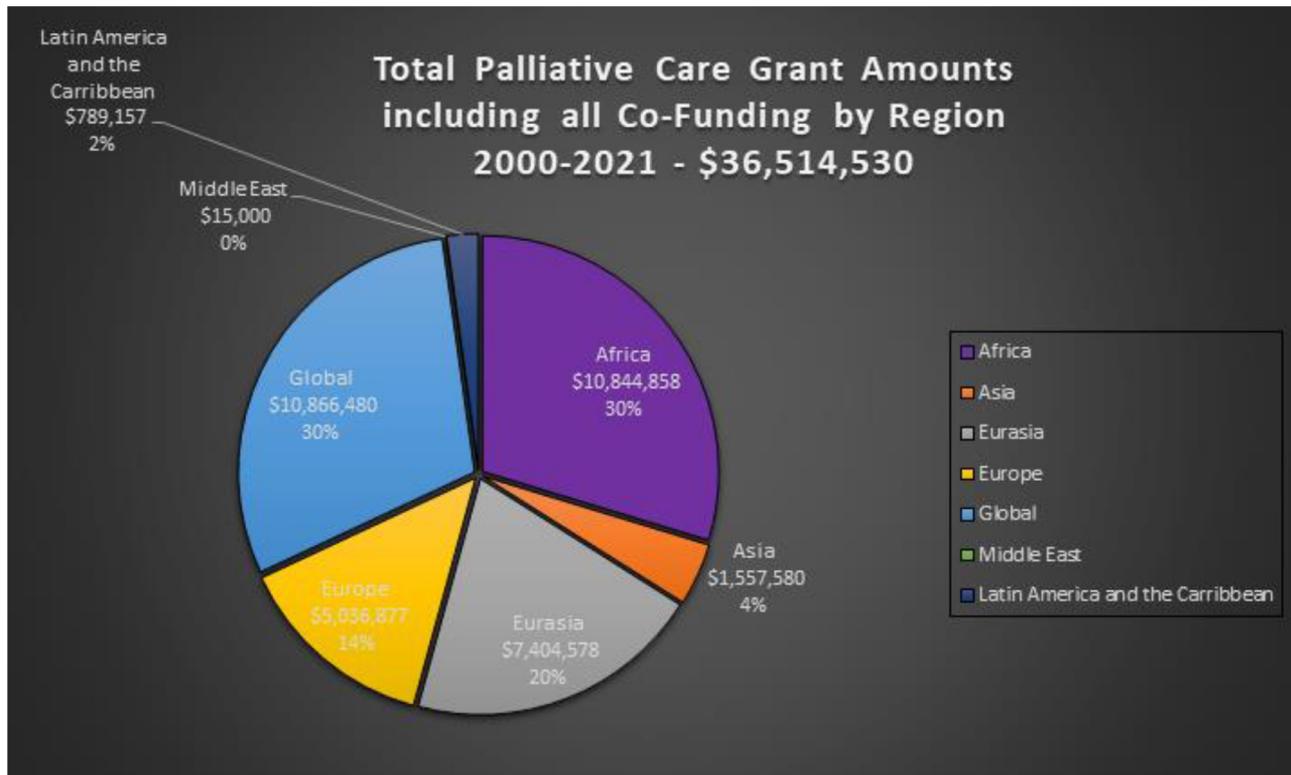


Fig. 1. Geographic distribution of OSF palliative care grants\*\* The numbers in this graph are approximate and include only OSF grants. It does not include staff salaries, benefits or travel or cost of convenings and consultants. It also does not include grants by other parts of the OSF network made without participation of the Public Health Program.

The strategy centered on four major components: policies that advance palliative care; adequate availability for essential medicines (especially opioids); education of health care professionals, policymakers, and the public; and country-specific implementation. Throughout its existence, IPCI pioneered additional approaches that, when successful, were incorporated into its core strategy, including an increasing focus on palliative care as a legal and human right issue.

Table 2

Palliative Care Coordinators at OSF's National and Regional Foundations

Country	Name
Albania	Valbone Mane
Armenia	David Amiryan Anaida Papikyan
East Africa	Aggrey Aluso Emmanuel Kamonyo Geoffrey Opio
Georgia	Nina Kiknadze
Kazakhstan	Ainur Shakenova
Kyrgyzstan	Aibek Mukambetov
Lithuania	Virginija Ambrazeviciene
Moldova	Liliana Gherman
Tajikistan	Nigora Abidjanova
Ukraine	Kseniya Shapoval Victoria Tymoshevska

In 2014, following the retirement of its directors (MC and KMF), PHP restructured IPCI from a stand-alone initiative to a cross-cutting thematic priority. Funding was significantly reduced and priorities shifted to increase support for civil society organizations to publicly advocate and campaign for palliative care, and hold governments accountable when they failed to ensure its availability.<sup>34,35</sup> In 2019, PHP decided it needed to shift support to newly emerging public health issues and implemented a multiyear exit strategy to end its funding for palliative care in 2021. The exit strategy included multiple years of funding for grantees to help them transition but not for an independent evaluation of the palliative care initiative's impact.

OSF's palliative care investment resulted in major advances in palliative care development in many countries and globally, including the introduction of palliative care policies, the revision of restrictive drug control regulations, the integration of palliative care into health worker curricula, and the inclusion of palliative care into universal health coverage. Following on to the JPSM supplement of February 2018 ("Palliative Care Development in Resource Limited Countries," Volume 55, Issue 2, Supplement, S1-S180),<sup>2-23</sup> three new papers summarize this work and its impact between 2017 and 2021.<sup>24-26</sup>

Table 3  
Examples of Impact of Palliative Care Leaders

Dr. Zipporah Ali, Kenya	Dr Ali is the founding executive director of the Kenya Hospice and Palliative Care Association and a graduate of the International Pain and Policy Fellowship and the Leadership and Development Initiative. Her work has been instrumental in Kenya's progress in the implementation of palliative care. Her advocacy contributed to dramatically improved availability of oral morphine for adults and children, the integration of palliative care services into 60 public hospitals throughout Kenya, and the inclusion of palliative care in Kenya's universal health coverage pilot program. She also played a key role in securing the inclusion of palliative care in the core undergraduate and graduate-level medical curricula as well as the undergraduate nursing curriculum.
Dr Ludmila Andriishin, Ukraine	Dr Andriishin is a long-term beneficiary of and contributor to OSF's Salzburg seminars and grantee of OSF and the International Renaissance Foundation (OSF's Ukrainian foundation). She is the founder of the first hospice in Ivano-Frankivsk (1996); the first palliative care training center (2005); the first pediatric palliative care ward (2013); and the first home care unit (2013) in Ukraine. She is one of Ukraine's chief palliative care advocates who has trained countless health care workers in palliative care at the hospice she runs. She has also played a critical role in the integration of palliative care into national health policies through her leadership in the palliative care community, media advocacy, and collaboration with government actors.
Dr Marta Ximena Leon, Colombia	Dr Leon is a long time palliative care advocate in Colombia and a graduate of the International Pain and Policy Fellowship and the Leadership and Development Initiative. She is leading palliative care advocate in her country who pioneered the first mandatory palliative care course for medical students in Colombia, served as an adviser to the Senate committee on health on Colombia's palliative care law and to the Ministry of Health on policies to improve opioid availability, including through the inclusion of opioids in the National List of Essential Medicines.
Dr. Daniela Mosoiu, Romania	Dr Mosoiu is the founder of the Romanian palliative care association, and a long-term beneficiary of and collaborator of IPCI. As a result of her work, Romania include palliative care as a compulsory topic in medical school curricula (2000) and recognized palliative care as a subspecialty for doctors. Supported by OSF, she spearheaded a successful effort to change Romania's highly restrictive drug regulations in 2005 and later conducted a groundbreaking costing study that paved the way for integration of palliative care into the national health financing system, a process that continues as of this writing in collaboration with the ministries of health, social welfare and Romania's insurance house. She also established a regional training center that graduated and supported hundreds of palliative care providers in the Eastern European and Eurasian regions.

### Selected Approaching and Interventions

#### *Investing in Clinician Leaders as Change Agents*

Following on the success of PDIA's strategy,<sup>34</sup> IPCI chose to invest in clinical leaders as a core component of its approach, seeking to engage health care professionals, mostly physicians, as change agents. This tactic set it apart from other PHP initiatives that focused on civil society leaders, but was based on the calculation that without clinical leaders it would be impossible to roll out palliative care, even if civil society demanded it. Indeed, Clark and Wright had found that clinician champions had been critical to advances in Europe.<sup>36,37</sup>

IPCI recognized that these champions required versatile skills: They needed to be clinicians with strong knowledge of palliative care but also effective advocates in the medical, public health, and health policy fields. They needed to have excellent communication, public policy and advocacy skills; be competent stewards of their own organizations; and be able to formulate and communicate a clear vision for palliative care in their setting.

To help palliative care leaders develop these skills, IPCI supported clinical training programs, scholarships to conferences, leadership development initiatives, study visits, mentorship programs, and supported the organizations of these leaders financially. For more than 22 years, OSF organized a series of Open Medical Institute Salzburg Seminars to train more than 1000

doctors, nurses, and some public health officials and lawyers in palliative care.<sup>11,38</sup> The International Pain and Policy Fellowship (IPPF) focused on equipping fellows with knowledge and skills to identify barriers to opioid analgesics use in their countries and engage policy makers on them.<sup>4</sup> The Leadership Development Initiative focused on developing general leadership skills of participants, creating networks of palliative care leaders, and linking them to resources.<sup>10</sup>

This commitment to developing leaders was a key factor in the success of OSF's palliative care initiative. A 2010 external evaluation of IPCI found that "without a 'cohort of champions,' it 'would not have been possible to make such progress' in the development of the palliative field worldwide," and noted important ripple effects as "the 'champion' takes their expertise back into the community to work with other international experts to educate health care decision makers and 'build the field'."<sup>39</sup> Table 3 describes the work of several of these leaders.

#### *Investing in Foundation Champions*

IPCI also invested significant resources in developing a strong group of internal palliative care champions. Since OSF is a network of semi-independent national and regional foundations that tend to collaborate closely and co-fund work of mutual interest, IPCI saw strong, collaborative relationships with network colleagues as critical to its success.

IPCI used several approaches to develop strong, substantive relationships with foundation staff. First, it created ample opportunities for them to learn about palliative care and attend conferences, go on site visits to centers of excellence, and offered extensive and direct teaching and mentoring. Secondly, IPCI entrusted foundation staff with significant responsibilities and space to grow, even as they were still learning about palliative care, creating a strong sense of partnership. Third, IPCI leadership invested significant time and energy in developing strong professional and personal relationships, regularly visiting countries, conducting joint field visits, and strategizing together. IPCI encouraged national and regional staff to take on substantive roles as strategists, innovators, and advocates, both within the OSF network and externally.

Over time, national and regional foundations staff became not just knowledgeable about and committed to palliative care but, in many countries, they became leaders in national palliative care communities with extensive networks, coordinating initiatives, and a detailed grasp of strategic objectives and tactics. As such, they did not just fund palliative care but helped steward their countries or regions toward key policy changes and integration of palliative care into national health systems.

In our analysis, the strong commitment and active engagement of national and regional foundations staff were critical to OSF's successes in advancing palliative care in many countries.<sup>15,19–21,24,25,27,29,30,33</sup> In addition to making grants, local foundation staff used their deep knowledge about their countries, the political context, the health care systems, and the palliative care communities to identify and seize opportunities that otherwise would have easily been missed. National and regional foundations staff developed collaborations across countries that enabled sharing of successes and challenges and joint learning, resulting in important innovations and breakthroughs. Finally, national and regional foundation staff played a critical role in securing sustained funding for palliative care as they helped secure funds from their foundation budgets for palliative care.

### *Collaboration with the WHO*

From the outset, IPCI listened to its stakeholders in the OSF network who strongly argued for the importance of engaging the World Health Organization (WHO). As many governments look to the WHO for guidance on both health policy questions and clinical practice, collaboration would lend legitimacy to the work of IPCI and its grantees and mobilize important technical expertise.

As noted, IPCI placed the WHO public health model for palliative care, which envisions the integration of palliative care into existing health systems, at the center of its strategy.<sup>3</sup> Its grant making strategy

addressed each of the model's key components: policy, medicines availability, education and implementation (although after 2015 education was deemphasized). The WHO's clinical and policy guidance on cancer pain furthermore played a central role in training of health workers and advocacy to improve availability of oral morphine.<sup>40</sup> IPCI also engaged the WHO's essential medicines department in the International Pain and Policy Fellowship.<sup>4</sup>

IPCI financially supported a number of WHO projects. In 2002, it funded a technical consultant in the WHO's cancer unit to work on integration of palliative care into national cancer control programs in Central and Eastern Europe and the former Soviet Union. Moreover, it supported the WHO to develop or revise several policy and clinical guidance documents on palliative care,<sup>41–44</sup> and paid for translations of various guidance documents into other languages.

IPCI worked with the WHO to co-host workshops with government officials, palliative care experts, and other stakeholders. For example, the organizations co-organized various regional workshop in Central and Eastern Europe on national opioid policies, cancer control programs, and palliative care in the early 2000s.<sup>45</sup> IPCI collaborated with the WHO's STOP TB program to develop palliative care models for drug resistant tuberculosis and train clinicians.<sup>5,46</sup>

Finally, IPCI supported grantees to advocate and collaborate with the WHO. The International Association for Hospice and Palliative Care worked with the WHO to include a section on palliative care in the WHO model list of essential medicines<sup>7</sup>; the Worldwide Hospice Palliative Care Alliance and the WHO have published several editions of a Global Atlas of Palliative Care<sup>47,48</sup>; and the palliative care community extensively advocated for and collaborated with the WHO on a World Health Assembly resolution, which, for the first time, instructed the WHO to integrate palliative care throughout its program of work.<sup>49</sup>

The investment in partnership with the WHO has had a number of impacts. It helped achieve the progress described in articles on Eurasia<sup>24</sup> and Africa<sup>26</sup> by lending credibility to the work of national-level advocates, opening doors with government officials, and giving advocates practical tools to use in advocacy toward and collaboration with national governments. It also resulted in increased—though not always consistent or sufficient—WHO commitment to palliative care, as demonstrated by the integration of palliative care into universal health coverage, the WHO's current top priority,<sup>50,51</sup> and its hiring palliative care experts at several points to help operationalize its palliative care work.

### *Palliative Care Financing*

Achieving adequate financing for palliative care services is as challenging as it is important. In much of

the world, palliative care services are funded primarily through charitable donations or philanthropic grants, rather than through regular health financing modalities, such as national or state budgets, social security or other insurance pools. As a result, providers often face intense fundraising pressures and significant resource uncertainty that impede the stability and sustainability of services, as well as their reach.

Thus, financing of palliative care through regular health financing schemes was essential to OSF's objective. While in the early stages the priority generally rested with training clinicians, setting up services and educational programs, and working toward policy changes to facilitate a broad roll out of palliative care, financing invariably became a key challenge as the priority shifted from building the foundations of palliative care to sustaining and integrating it into health systems.

Advocating for financial integration of palliative care, however, posed significant challenges for many of the palliative care advocates OSF supported: As medical doctors, they generally had only a limited understanding of health economics and of research methods for assessing cost or cost effectiveness. Moreover, data on the cost of palliative care services was often not collected at all or in a manner that did not allow for proper analysis, interpretation, or comparison.

To address these challenges, OSF convened an expert meeting in 2007 to identify tools to document palliative care costs, outcomes and cost effectiveness, and develop a research agenda on palliative care financing<sup>52</sup>; supported the publication of the findings of this meeting and articles documenting research methods and financing models of specific countries;<sup>53</sup> funded partner organizations to conduct budget monitoring and advocacy for integration of palliative care into financing mechanisms; and funded detailed costing studies in countries like Romania and South Africa that were subsequently used to drive policy change.<sup>68,69</sup> After the adoption of the Sustainable Development Goals in 2015, OSF increasingly supported country-level advocacy for the integration of palliative care into publicly funded universal health coverage plans and the development of a costed minimum essential package of palliative care services by the Lancet Commission on Pain Relief and Palliative Care.<sup>70</sup>

Since 2007, significant progress with palliative care financing has been made in low- and middle-income countries. In the early 2010s, Romania and Rwanda integrated palliative care into their national health financing systems.<sup>27</sup> In the early 2020s, Moldova and Ukraine followed suit, and Armenia included support for 10 services in its health budget.<sup>24</sup> In 2019, Kenya launched a publicly funded universal health coverage pilot in four districts that included palliative care.<sup>26</sup>

These countries have created models and palliative care financing data that can be used to inform similar advances elsewhere.

Moreover, new tools are now available to policy makers and advocates to guide integration of palliative care into health financing systems, including the minimum essential package<sup>70</sup> and various research tools.<sup>56–60</sup> Finally, a growing body of literature analyses on the costs and cost effectiveness of palliative care suggests that investments in palliative care can result in significant reductions in other health care costs.<sup>48</sup> While the majority of these publications emanate from high income countries, similar findings are increasingly reported from low and middle income countries.<sup>71–76</sup>

Adequate financing is one of the most significant barriers to moving from isolated provision to broad, generalized provision of palliative care services. Our experience suggests that palliative care financing—particularly through public or insurance-based financing mechanisms—should be an integral part of palliative care advocates' strategy from the outset so that when financing becomes critical to further progress in the palliative care rollout valuable time and momentum is not lost due to a lack of knowledge, connections or tools. Advocates will benefit from developing health financing competencies; developing connections with health financing experts and decision makers; collecting data on the costs and cost effectiveness of palliative care; and reviewing the pros and cons of different payment systems. Improvement of the peer reviewed evidence base allows for a significantly more convincing case for domestic financing than was the case in the early 2000s.

### *Focus on Human Rights*

Human rights have always been a core value of OSF. In the area of public health, it has supported grantees to take—and often define—a human rights-based approach to a diverse set of issues including harm reduction, mental health, access to medicines, sex work, and palliative care.<sup>77</sup>

While palliative care advocates began using human rights rhetorically in the 1990s,<sup>78</sup> it was not until IPCI started supporting partners to take a human rights-based approach that they became a practical tool for advocacy and coalition building. IPCI supported work to develop the concept of a right to access palliative care; pioneered legal services for people with palliative care needs; and funded human rights organizations to start working on palliative care.

These investments resulted in a rapidly growing understanding of the human rights-based approach to palliative care and its practical potential. It led to a series of groundbreaking publications exploring the legal foundations for palliative care as a human rights<sup>79</sup> and examining specific legal obligations of

governments<sup>80–82</sup>; the development of human rights-based advocacy for palliative care<sup>83</sup>; widespread acceptance among palliative care providers of the importance of addressing the legal needs of patients and families<sup>8</sup>; and the broadening of the community of palliative care advocates, as human rights organizations joined traditional palliative care champions.

These developments had a profound effect on palliative care advocacy. Human rights organizations brought advocacy expertise that palliative care advocates generally lacked; they helped translate human rights obligations into advocacy asks; and their comfort with a naming-and-shaming approach introduced an element of public pressure on governments that had often been absent previously.<sup>83</sup> At the global level, human rights advocates were instrumental in securing victories at the Commission on Narcotic Drugs and the World Health Assembly.<sup>25,83</sup>

The palliative care community was broadly supportive of efforts to engage human rights advocates. A 2010 evaluation listed potential advantages identified by the palliative care community, including bringing in new audiences and making more forceful recommendations to states.<sup>39</sup> But some concerns were also expressed: in particular, that human rights groups “may easily end up on the wrong side of the government” which could damage the work of palliative care champions. Particular concerns arose in the early 2010s when PHP decided to launch a campaign on torture in health care settings, with access to pain treatment as one of its priority issues. Palliative care leaders expressed concern that using the term “torture” in palliative care advocacy could alienate governments or result in medical personnel being labeled as “torturers.”

In practice, collaborations between palliative care and human rights advocates generally went smoothly. In countries like Armenia and Ukraine, close partnership on research and advocacy strategies and messaging resulted in significant breakthroughs without alienating government interlocutors. In fact, a review of these collaborations by Human Rights Watch staff noted that the “combination of their [palliative care advocates’] technical knowledge, credibility, and contacts, along with our rights-based approach and advocacy expertise, generated synergies that helped develop the political will needed to address... structural barriers to palliative care.”<sup>83</sup>

### *Self-advocacy*

In the 1980s and 1990s, determined self-advocacy by people affected by HIV transformed the global response to AIDS, resulting in unprecedented commitments to a worldwide roll out of HIV prevention and treatment services.<sup>84</sup> Since then, groups affected by a

variety of other health issues have confirmed the potential of self-advocacy.

The palliative care community has long understood the potential of self-advocacy but has often struggled to effectively empower and engage self-advocates. In contrast to the HIV field, where people affected by the disease generally lead advocacy organizations, physicians and other health workers dominate the palliative care field and people with palliative care needs were often seen as too ill, making self-advocacy “very hard.”<sup>85</sup> Moreover, cultural perspectives around death and dying were strong impediments to self-advocates speaking out about palliative care.

To appeal to public sentiment, the voices of people affected were used but these people did not themselves play a prominent role in organizing, strategizing or advocating for palliative care. For example, at a press conference to release a Human Rights Watch report in Ukraine, the story of Vlad Zhukovsky, a young man with brain cancer who suffered from untreated pain, was prominently featured.<sup>86,87</sup> His story succeeded in making an otherwise abstract issue relatable and resulted in official commitments to change drug regulations, thus demonstrating the power of the experiences of people with palliative care needs.

In 2015, based on a consultation with partners PHP’s palliative care subtheme concluded that self-advocacy by people with palliative care needs or their relatives was “an essential element of moving the issue from the overlooked fringes of health care to a political imperative to alleviate unnecessary suffering.”<sup>88</sup> Under its new strategy, the subtheme began to specifically fund activities by palliative care organizations to mobilize these voices. It supported a workshop on self-advocacy at the 2016 African Palliative Care Association conference; organized the participation of self-advocates at a 2017 seminar; and made a series of grants that included self-advocacy initiatives.<sup>88</sup>

These activities resulted in a rapid increase in engagement of self-advocates in the design, planning and delivery of palliative care advocacy. Ergene, an organization in Kyrgyzstan, built a partnership with a network of cancer survivors to raise awareness of palliative care and engage government officials on access to oral morphine; the African Palliative Care Association organized a small grants competition for self-advocacy projects; the Worldwide Hospice Palliative Care Alliance invited a palliative care recipient to help it develop its new strategy, reserved two seats on its board for people with palliative care needs, organized a network of self-advocacy ambassadors, and worked with partners in Ethiopia and South Africa to strengthen the public voice of people with palliative care needs.<sup>89–92</sup>

These initiatives have resulted in some early successes. Most prominently, WHO Director General Dr. Tedros responded to outreach from Lucy Watts, a

palliative care user, by meeting with her in London and committing to champion palliative care.<sup>93,94</sup> Since then, palliative care advocates have been able to organize multiple events with Dr. Tedros, which has significantly increased palliative care's visibility.<sup>95</sup> In October 2021, Dr Tedros released a statement on World Hospice and Palliative Care Day, a first, calling on countries to do more to ensure adequate availability of palliative care.<sup>96</sup>

While self-advocacy remains limited, these projects clearly demonstrate that people with palliative care needs can play a significant role in palliative care organizations and in advocacy. Palliative care organizations can benefit from actively engaging self-advocates and donors from funding activities to facilitate a key role in palliative care organizations for them.

### Conclusions

Twenty years ago, palliative care was either unknown or in its infancy in many low and middle income countries. Today, buoyed by improved evidence of its effectiveness and a strong community of advocates, palliative care's limited availability in many places is seen as a public health, legal and human rights crisis that needs to be addressed. As the former stewards of OSF's investments in palliative care, we believe that the approaches and strategies described above were instrumental in developing bringing about this change. Through deep, long-term investments in national and regional champions from within the palliative care community and OSF's own network, a generation of palliative care leaders emerged with well-rounded skills, knowledge and networks to effect change. Engagement of the WHO and using a human rights approach to promote palliative care have demonstrated their effectiveness while a focus on palliative care financing and self-advocacy are newer tactics that show significant promise and deserve further investment. It is our hope that other funders, national governments and global leaders will build on the experiences of OSF's wide ranging, long term support for palliative care. With a robust advocacy community and an expansive base of strategies, policies and guidance, the table is set to facilitate knowledge transfer and create innovative approaches to provide care and reduce needless suffering of those with life limiting illnesses. Finally, we hope that other funders will commission rigorous evaluations of future investments.

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