African Palliative Care Association
APCA
Relieving Pain and Suffering

African Palliative Care Association

Successful Advocacy for Palliative Care: A Toolkit

ISBN 978-9970-204-04

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UKaid
from the Department for
International Development

Help the
Hospices

This publication was made possible through funding from UKAid from the Department of International Development (DFID) through Help the Hospices, UK. The content of this publication is, however, the sole responsibility of APCA and does not necessarily reflect the views of either DFID or Help the Hospices.

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Foreword

The need for effective palliative care service provision across Africa has never had such a high priority. By 2009, an estimated 22.5 million people in sub-Saharan Africa were living with HIV and AIDS, 67 per cent of the global burden of the disease. Moreover, cancer rates in Africa are expected to grow by 400 percent over the next 50 years. For the overwhelming majority of Africans who currently endure these and other progressive, life-limiting illnesses, access to culturally appropriate holistic palliative care (that includes effective pain management) is at best limited, and at worst non-existent.

Consequently, through a collaborative approach with local national palliative care associations and its champions across Africa, the African Palliative Care Association recognised the need to develop advocacy materials and resources to address issues related to palliative care access, including drug availability.

This resulting toolkit is a practical guide intended to assist users to become advocates for palliative care in a practical and effective way. It is not necessarily a resource to read from cover to cover; rather, it can also be used selectively to each reader's needs to engage audiences and ensure that there is a real understanding of the need for palliative care. It should also be read in conjunction with the supplementary resources listed at the end of each of the toolkit's sections.

Sections 1-5 provide the background to becoming an advocate by introducing the subject and providing advice and guidance on implementing an advocacy campaign, measuring the campaign's impact, working with the media, and elaborating upon the public health approach to palliative care development. Section 6 subsequently provides the reader with four key factsheets that can be reproduced as handouts and used to engage key stakeholders in productive dialogue.

We hope that all those working in palliative care on the continent will find this a useful resource in their advocacy work as they seek to improve access to holistic palliative care for all in need.

Dr Faith Mwangi-Powell MSc Econ PhD
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African Palliative Care Association

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
ARV	Anti-Retroviral
HBC	Home-Based Care
HIV	Human Immunodeficiency Syndrome
IEC	Information, Education And Communication
M&E	Monitoring And Evaluation
MER	Monitoring, Evaluation And Reporting
NGO	Non-Governmental Organisation
OVC	Orphans And Vulnerable Children
PRA	Participatory Rural Appraisal
TV	Television
WHO	World Health Organization

1. Introduction to advocacy

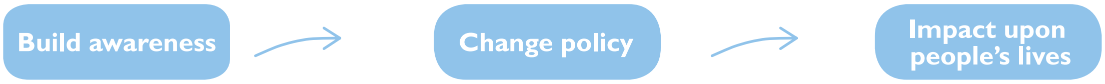
What you need to know

Advocacy is the effort to influence change through forms of persuasive communication. This change could be geared towards public policy, personal behaviour and attitude, political and public debate, or legal change. In broad terms, advocacy works at two different levels:

Attempting to influence policy directly, and;
Developing the capacity of others to undertake advocacy.

For the former, which is the focus of this section, the process of advocacy can be seen as a model of change in people's lives that is constituted by an impact chain that follows the pathway below:

Figure 1: The advocacy impact chain



Advocacy is not synonymous with information, education and communication (IEC) campaigns but the two normally go together. For example, in order to change regulations that limit access to effective pain management medications for people with life-limiting illnesses, the public, politicians and policy makers must be informed and educated on palliative care. Consequently, IEC becomes an integral part of effective advocacy.

Advocacy and palliative care

Advocacy for palliative care can be defined as seeking to influence policy makers to design, adopt, implement or change existing policies and practices to ensure the availability of palliative care for all in need.

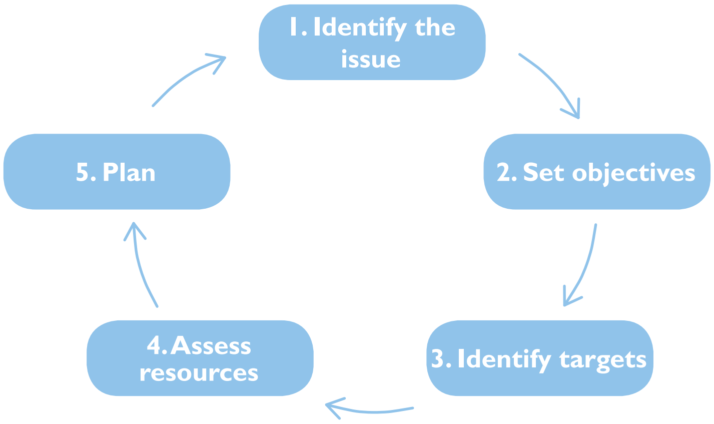
The World Health Organization (WHO)

Advocates for four foundation measures for palliative care scale-up: i.e. government policy; education; drug availability (especially oral morphine); and implementation (Stjernsward et al., 2007). However, while these measures are critical, in many parts of Africa they are not in place. Consequently, advocacy has a crucial role to play in ensuring these measures are adopted and implemented. The African Palliative Care Association (APCA) views sustained advocacy as a critical means by which the above measures can be achieved by securing the political and financial commitment of governments.

Planning advocacy

Planning advocacy work is similar to any other project or programme planning. As Figure 2 shows, the advocacy planning cycle is comprised of a series of steps, some sequential and some running in parallel, all of which may change their order according to the progress achieved (Mansfield et al., 2003). It is also a recurrent process, with ongoing monitoring and evaluation (M&E) that results in the regular updating and adjustment of the plan as the work progresses.

Figure 2: The advocacy planning cycle



Step 1: Identify the issue

Step 1 helps to identify the problem that needs to be addressed. It is a critical first step and one that needs to include those people affected by the problem. For example, if the issue is poor access to medications, patients can participate in planning the advocacy agenda. Patients provide expert knowledge of the situation and help in prioritising issues that concern them directly.

Questions that can support Step 1

- What is the problem? Is it serious? Is it urgent?
- What are the effects of the problem? Who is affected by it?
- Does it exert a great effect on certain groups? If so, who and how?
- What are the roots of the problem?
- What is the role of the policies and practices of the national government?
- Are the patients and other stakeholders able to participate in decision-making?
- Who has the power to do something to bring about change? Government, policy makers, other stakeholders, churches, businesses, community leaders, traditional healers?
- Has this problem has been addressed before? What was the outcome?
- What risks are there in getting involved in advocacy?
- What methods can be used to address the problem?

At the organisational level it is important to ask the following questions:

- What financial and human resources are available to do what needs to be done?
- How does this fit with the organisational strategy?
- How would this campaign fit with the organisational profile?
- Are you or your organisation best placed to do this?

Step 2: Set objectives

Setting objectives helps to provide clarity to the aims of the advocacy and assist in the planning and designing of advocacy activities. In the long term, clear objectives will also enable the effective evaluation and monitoring of the advocacy work. These objectives should follow the SMART formula:

- **S**pecific – what exactly do you want to happen?
- **M**easurable – Will you know when you have achieved it by M&E?
- **A**ppropriate – To your vision, mission and aim.
- **R**ealistic – In relation to your potential capacity and experience.
- **T**ime-bound – In relation to when the work will be done.

The objectives also need to have:

- **Short-term goals:** Ones that can be achieved in the near future.
- **Long-term goals:** Ones that can be achieved over a longer period of time.
- **Content goals:** Concrete changes that need to occur.
- **Empowerment goals:** Changes that need to be seen in the affected community to enable them to control their livelihood.

Step 3: Identify targets

The next step is to identify those most likely to be advocacy partners and those who might stand in the way of achieving the advocacy aims. The latter becomes the intended targets and it is important to determine what exactly needs to be done to influence those in the way in order to effect change. The targets can be defined as follows:

Group 1: Those directly affected by the situation, such as patients and families.

Group 2: Those responsible for creating the situation or with formal responsibility for finding a solution, such as government, policy makers, and politicians.

Group 3: Those concerned for the welfare of others and other interested groups, such as non-governmental organisations (NGOs), church groups, business and the media.

Group 4: International players, such as donors, and other NGOs.

It is important to have a clear understanding of the internal hierarchies of the organisations being targeted as this can determine your approach. Assistance can be sought from people who are familiar with the target organisation to achieve this end. For example, advocates may begin to lobby the wrong government department before properly establishing who the appropriate government decision-maker is. This may result in delayed advocacy work and yield no positive results.

It is worth noting that when identifying targets, secondary targets (i.e. people with the capability to influence authorities) are also crucial. These include the media, members of parliament, donors, faith leaders, traditional healers, government departments, human right organisations, community leaders, NGOs and trade unions. For example, the media can support advocacy work by advertising it, whilst human rights organisations can support it by dealing with issues that impact upon human rights.

What you need to know:

- Who are the organisations and the communities that need to be targeted? What do they know about the issue? What is their attitude towards it? What influence or power do they have over the issue?
- Is the message clear enough to be understood?
- What level of government should the advocacy work target?
- What other actors will be able to influence them (e.g. donors, NGOs)?

Regarding working with the identified targets, some important tips are suggested below:

- Spoon-feed them materials, statistics, and facts.
- Do not patronise or under-estimate them.
- Make yourself invaluable.
- Gain their trust.
- Make face-to-face contact.
- Remember their time constraints.
- Offer them a service they value.
- Know when to stop!
- Be the ‘humble expert’.

Step 4: Assess resources

Successful advocacy work requires resources such as people (i.e. human resources, which can include both staff and volunteers), money, skills and information. Other resources can include access to media and to distribution networks (e.g. newsletters, e-mail databases).

Resources might also include people with specific advocacy skills, such as negotiation experience, understanding of decision-making structures, leadership and diplomacy.
It is important to ensure that there is a differentiation between resources already available and resources that are needed in the future.

Step 5: Plan

Planning should not be too rigid; it needs to be flexible, though as specific as possible. The possibility of making changes should be incorporated into the plan.

Once the overall advocacy strategy has been developed with a clear methodology and activities, it is important to create an action plan that links timelines and resources, budgeting and personnel. The action plan should consist of a specific set of activities with a timeline, as well as agreeing from the outset of the project who will do what, when it is to be done, with whom, and what types of additional inputs, besides people, will be needed.

Advocacy activities can often have a greater impact if they are timed to coincide with other actions or events that will help the advocacy work. For example, politicians may be willing to make bold statements during election times.

More specifically, when planning for an advocacy campaign, the following should be incorporated:

- Clear goals, objectives and activities;
- Indicators for measuring activities;
- A timeline describing what you going to accomplish and when;
- An identification of key stakeholders and how they are going to be incorporated into your strategy;
- A clear division of labour letting all involved know what their job is;
- A specific method of gathering and disseminating convincing information to reach the target audience;
- A method for monitoring and modifying the campaign;
- A mechanism for evaluating your progress, and;
- A contingency plan if your main strategies are ineffective.

Key points

- Advocacy attempts to influence change through forms of persuasive communication.
- Palliative care advocacy seeks to influence policy makers to design, adopt, implement or change existing policies and practices to ensure the availability of palliative care for all in need.
- In the five-step advocacy planning cycle, identify the problem that needs to be addressed, including the people affected by it.
- Set objectives to provide clarity to the aims of the advocacy and assist in the planning and designing of advocacy activities.
- Identify potential advocacy partners and those who might be barriers to your aims.
- Assess your required resources, including people, money, skills and information.
- Plan but do not be too rigid; create an action plan that links timelines and resources, budgeting and personnel.

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2. Implementing the advocacy campaign

This is the point at which the planning stops and action begins and can be seen as a five-step process: (i) collecting and disseminating relevant information; (ii) raising awareness and concern; (iii) organised action; (iv) facilitating engagement; and (v) networking.

Step 1: Collecting and disseminating relevant information

Persuasive, relevant information enlightens decision-makers, providing them with evidence that demonstrates why change is necessary. In this respect, the information you need to collect and distribute falls into three categories:

a. Information about the problem;
b. Information about prevailing public opinion, and;
c. Information on possible solutions to the problem.

It is important to anticipate what information is necessary to advocate effectively and to ensure it is clear and accurate. You therefore have to think ahead; what do decision-makers need to be convinced of?

In order to determine public opinion on a problem, you can conduct studies to determine what the affected people and the general public think. Such information is helpful when approaching decision-makers who are more receptive to hearing the collective voice of a majority of their citizens, and as such likely to listen to possible solutions.

The possible solutions you offer need to be simple courses of action for decision-makers so that their enactment can be facilitated much more quickly. The aim of collecting information about the problem, assessing public opinion on it, and identifying possible solutions, is to (i) make sure the relevant decision-making authorities are aware of the public's displeasure and, importantly, that (ii) you are willing to assist them in addressing that problem.

Step 2: Raising awareness and concern

Raising awareness can be achieved through:

- Engaging in activities such as education campaigns, workshops, and following media strategies. Education activities help to inform vulnerable groups of their rights, how these rights are being violated and what remedies and recourses are available to them.
- Development of petitions and letters addressed to decision-makers (or those with influence upon them) and signed by multiple people to help demonstrate public support or displeasure.
- Celebrations of special events (e.g. World Hospice and Palliative Care Day) also increase public awareness. At such celebrations, it is important to include high ranking officials, influential community or NGO leaders and members of the public in any speeches and marches, etc.
- The media, using press releases, radio and television spots to convey your message to the public. Other possible techniques that involve the media can include:
    - ◦ Inviting journalists on field trips to learn about an issue;
    - ◦ Recording of speeches by high officials to inform the community about promises made, hence holding officials more accountable, and;
    - ◦ Making telephone calls to media houses about a known law violation that you think they would be interested in reporting on following their own investigations.

Step 3: Organised action

Organised action can be an effective way to implement an advocacy campaign. Such actions, if well planned, can pressure decision-makers into changing a policy or, more likely, entering into a negotiation process. Organised actions can include peaceful demonstrations and marches of large numbers of people who rally for, or against, an issue. These demonstrations need to be held at strategic or symbolic locations, such as in front of your country's house of parliament. For a successful demonstration or march you need to:

- Inform people you want to attend far in advance;
- Network properly with other organisations so many interested groups know about the event, and can help with preparations and attendance;
- Choose an appropriate day, like a weekend, so more people can attend;
- Inform the media about the event far in advance and follow them up to ensure they come;
- Select a good target – e.g. current draft legislation, and not necessarily the entire target problem;
- Make the event exciting, with banners, information to hand out, speeches, chants and petitions, and;
- Follow up the event with a press conference or organise new supporters around further campaigns.

Step 4: Facilitating engagement

Once the public and influential organisations are aware of a problem and have identified possible solutions, decision-makers may be more willing to discuss the issue. Some of the techniques used to engage decision-makers in useful dialogue include:

- *Open debates* – that bring together various actors involved in an issue along with members of the public. Such debates allow stakeholders to express their views and hear arguments they would not normally encounter. Local leaders should always be invited and lobbied to attend such events and publicly articulate their perspective. This is what in Uganda is typically referred to as '*Ebimeeza*' (i.e. an open forum). By holding such open discussions, decision-makers are more likely to be held accountable for their actions.
- *External exposure visits* – these can be arranged at a national and local level by sending decision-makers and community leaders to other countries to show examples of best practices. Such visits both afford you the dedicated time to talk to the decision-makers and give stakeholders the opportunity to have a physical exposure to the issue at hand.
- *Engaging the affected community* – so they are aware of your objectives and are convinced of the necessity of the advocacy campaign. The following strategies can be important in engaging the community:
    - Create connections with the community to understand their actual needs;
    - Engage the community from the beginning of your advocacy campaign;
    - Put community members in key leadership positions as a way of empowering them, and;
    - Involve the community in implementation; keep them actively involved by inviting them to demonstrations, lobbying activities, and meetings, etc.

Step 5: Networking

Networks create broad-based support for a specific issue and help strengthen an advocacy campaign. The existence and coordination of networks within a sector is a good indication of its strength. You should identify if a network already exists in your sector and think about including it or its members in your campaign.

Key points

- The advocacy campaign should concentrate on solving the problem identified.
- Collect and disseminate persuasive, relevant information to enlighten decision-makers.
- Raise awareness and concern (e.g. via educational campaigns, petitions, event celebrations, the media, etc).
- Undertake organised action (e.g. peaceful demonstrations and marches based around a clear issue).
- Facilitate engagement with decision makers (e.g. via open debates, exposure visits, and engaging affected communities).
- Include existing networks and their members in your campaign, if appropriate.

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3. Advocacy and monitoring, evaluation and reporting

Determining the extent to which advocacy has been efficiently and effectively implemented and reported upon requires a monitoring, evaluation and reporting (MER) system. The component parts of a MER system can be defined as:

Monitoring: the systematic collection and analysis of information over time to track the *efficiency* of a project in achieving its goals. Monitoring provides regular feedback that helps one track costs, personnel, implementation time, organisational development, and economic and financial results to compare what was planned to what actually took place.

Evaluation: the systematic collection and analysis of information to assess the *effectiveness* of the project in achieving its goals. Evaluation provides regular feedback that helps one analyse the consequences, outcomes and results of actions (i.e. what impact was made).

Reporting: the systematic, timely and integrated reporting of operationally useful information at periodic intervals. Reporting is critical in that it helps one inform oneself and others (e.g. partners, donors and other critical stakeholders) on the progress of a project, as well as the challenges encountered, successes achieved, and lessons learnt from implementing it (McCoy et al, 2005).

Why do MER for advocacy?

There are a number of reasons:

- External accountability: funding agencies are entitled to know if their money is being spent correctly, and is value for money.

However, MER is additionally critical to your project itself for:

- *Foreseeing problems and mitigating risk*: as part of a well planned project cycle;
- *Monitoring progress*: to ensure that the project is proceeding as planned, or if necessary corrective action needs to be made in its implementation to ensure its success;
- *Determining impact*: did the project make the change it anticipated achieving?
- *Learning*: as a project lead but also as an organisation, from the successes and failures, so future success can be ensured;
- *Building credibility*: documenting and sharing the success of the project, and justifying inputs into advocacy to donors and its beneficiaries, means future advocacy work can be justified.

Work plan: Inputs, outputs, outcomes, impact and indicators

Central to any advocacy project is a work plan. A M&E work plan needs to be flexible and explicit, clearly showing the steps to be used to monitor a project's activities and assess the progress achieved in attaining its goal and objectives. One must understand and agree upon what needs to be measured and how it will be measured. Crucially, it is important not to collect excessive data, or data that have minimal relevance to the project. The data should be appropriate, feasible, relevant and essential (Family Health International, 2004).

Work plans are typically presented in a tabulated format, as below, and comprised of inputs, outputs, outcomes and impact.

Figure 1: M&E Work Plan Template

Month:							Year:	
Activities	Indicators				Data source	Data method	Data collection frequency	Responsible person
	Inputs (a)	*Outputs (b)*	*Outcomes (c)*	*Impact (d)*				

Inputs are the project resources to be used; often simply the number and type of staff involved and production costs; which lead to:

↓

Outputs, which are the products of activities to be undertaken in the project, which lead to:

↓

Outcomes, the impact you expect to achieve from each of your outputs, which lead to:

↓

Impact, how your project fits within the wider picture, showing how its results contribute to achieving the highest level and longest-term impact than can be anticipated for an intervention (e.g. increasing access to quality palliative care).

Underpinning these are the indicators necessary to demonstrate that each has been achieved.

Indicators

A unit of information which is measured over time so that change can be documented, an indicator provides evidence of the achievement (or otherwise) of activities. Advocacy projects, like most other projects, must have indicators which either its developers or donors have identified as necessary to measure. The indicators you select should be simple enough for each output, and not require excessive amounts of time or effort to collect.

When measuring your project's success, it is important to know that 'success' for one stakeholder could mean something different to another stakeholder. Consequently, you may need to consult a range of stakeholders (i.e. ultimate beneficiaries, local people and their organisations, staff involved, target audience, journalists and outsiders). This can be achieved by using such methods as: surveys, interviews, Participatory Rural Appraisal (PRA) techniques, video, and case studies.

Kinds of monitoring indicators

Monitoring the process of implementing advocacy activities enables you to answer questions such as:

- Are our techniques working?
- Are people being reached, and is the message relevant and understood by the targets?
- Are the most appropriate targets and channels being used?
- Are you involving and collaborating with the relevant people, organisations and bodies?

In monitoring changes arising from your project:

Monitor your target

- Record and observe changes in the rhetoric of your target audience. Maintain a file of their statements over time.
- What are they saying about you and your campaign?
- Are they moving closer to your position, adapting to, or adopting, any of your language or philosophy?

Monitor your relationships

- Record the frequency and content of conversations with external sources and target audiences.
- Are you discussing new ideas? Are you becoming a confidante or a source of information, advice or otherwise?

Monitor the media

- Count column inches on your issue and the balance of pro- and anti-comment.
- Count the number of mentions for your organisation and campaign.
- Analyse whether media is adopting your language.

Monitor your reputation

- Record the sources and numbers of inquiries that you receive as a result of your work.
- Are you getting to the people you wanted to get to?
- How and where have they heard of your work?
- How accurate are their pre-conceptions about you and your work?

Monitor public opinion

- Analyse the popular climate through telephone polling, or through commissioning surveys.

Kinds of evaluation indicators

Attributing success to your project in an area as complex as, for example, policy change (when there are multiple factors and actors involved) is a challenge. However, it is important to determine such questions as:

- Did you achieve your objectives?
- Is the situation improved?
- Are the target people involved in the project happy with the results?
- What needs to be done to sustain changes?
- If you did not achieve your objectives, what will you do differently next time?
- What can be learnt for future advocacy activities?

Examples of evaluation indicators showing the impact of the project include:

- Number of people targeted with information on issue X.
- Number of media outlets that publish material developed by your organisation.
- Number of organisations attending meetings / assemblies.
- Number of organisations involved in a coalition for issue X.
- Number and percent of (a) participants and (b) community residents providing funding to support your cause.
- Number of elected officials who publicly support your campaign.
- Number of legislative votes in favour of the project's position on issue X.
- Number of litigation in favour of the project's position on issue X.
- Favourable legislation / reform measures passed related to your project goals or development.
- Improved condition of population resulting from policy change X (Urban Institute and the Centre for What Works' Outcome Indicators Project, no date).

Examples of national advocacy indicators, as developed by APCA for its work around palliative care drug availability activities on the continent, include:

- Number of sensitization meetings held with: a) national HIV/AIDS bodies and councils; b) Ministry of Health personnel; (c) representatives from drug regulatory authorities.
- Number of palliative care country team members equipped with advocacy skills and carrying out advocacy activities.
- Number of countries with palliative care integrated into national health and HIV/AIDS policies.
- Number of cadres of health professionals licensed to prescribe morphine.
- Willingness of health professionals to prescribe opioids
- Country estimates for annual morphine consumption (in kilograms).
- Total morphine ordered annually by each country (in kilograms).
- Number of trained drug dispensers in each country.
- Availability of palliative care medicines in the country's essential medicines list.
- Availability of palliative care medicines in known palliative care service outlets, by type of medicine.
- Proportion of people living with HIV/AIDS who attend palliative care service outlets who were prescribed (and received) morphine.
- Number of organisations provided with technical assistance for palliative care and HIV policy development.
- Number of countries / governments with palliative care in their health strategies.
- Number of local health professionals with improved skills to assess and manage pain, fear of opioid addiction and poor patient compliance.
- Number of palliative care provider organisations brought together to share lessons learnt and best practices in HIV-related palliative care.

Figure 2 below outlines examples of possible palliative care advocacy indicators, how data could be collected and how often.

Figure 2: Example of a Completed Advocacy M&E Work Plan

Month:								**Year:**
Activities	**Indicators**				**Data source**	**Data method**	**Data collection frequency**	**Respon-sible person**
	Inputs (a)	*Outputs (b)*	*Outcomes (c)*	*Impact (d)*				
Changing public attitudes toward morphine	(i) # of TV spots aired	% of general public with knowledge of, and positive attitude to, morphine	# of patients prescribed morphine Availability of PC drugs in the country's Essential Drugs List Palliative care integrated into national health and HIV/AIDS policies	Improved quality of palliative care	(a) Documented commissioned work (b) National Essential Drugs List	(a) Audit	(a) End of advocacy period	Name
	(ii) # of radio spots aired				(c) In-depth interviews	(b) Survey of general public views	(b) Baseline and one-year follow-up	Name
	(iii) # of posters distributed				(d) Health care records	(c) Audit	(c) Baseline and one-year follow-up	Name
	(iv) # of flyers distributed				(e) Given the national level at which impact is exerted, project-specific contributions are difficult to attribute			Name

Data collection methods and analysis

There are several available data collection methods, which fall under two broad categories: quantitative and qualitative.

Quantitative methods: These record the numbers associated with projects and focus on what, and how often, different elements of a project are being carried out (e.g. the number of radio slots or the number of policy makers attending an advocacy meeting). Examples of such methods include: structured or semi-structured questionnaires; review of documents and existing data sets; workshop attendance registers, and satisfaction surveys.

Qualitative methods: seeking to determine how well the elements of a project *are* being implemented, these can provide evidence of changes in behaviour or attitude (e.g. how attitudes towards morphine use have altered, perceptions of an advocacy campaign). Examples of such methods include: in-depth discussion and focus group discussions.

Responsibility for data collection may rest with several people in the organisation, ranging from data capturers to senior personnel.

Data analysis

This need not be a complicated undertaking, but there might be occasions when expert assistance is required and should be sought. For example, some simple quantitative data analysis could include a basic tallying of numbers (e.g. number of communities reached by an advocacy project), and depicting that data in simple but visually attractive and easily understandable tables and graphs.

Key points

- Develop a MER system to determine if your advocacy work has been efficiently and effectively implemented.
- MER builds your credibility, documenting and sharing project successes that justify advocacy work.
- Develop a work plan with clear inputs, outputs, outcomes and impact indicators.
- Choose indicators that are simple enough to measure, and do not need huge amounts of time and effort to collect.
- Choose monitoring and evaluation indicators that track changes arising from the project, and which can show you achieved your objectives.
- Use data collection methods that best suit the needs of the project.
- Beyond presenting basic data, seek expert assistance for data analysis.

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4. Making headlines

How to work with the media - why is this important?

Everyone working in palliative care knows that the issues we work on are crucially important and deserve more media coverage than they get. But sadly, just having something important to say is not enough to ensure coverage. It is necessary to learn the rules of the game – to find out how journalists think and operate, and adapt accordingly. Media coverage is invaluable for publicising the issues you are passionate about changing, helping you influence policy. Effective use of the media is a critical tool in any advocacy campaign, enabling public health advocates to capture public attention on behalf of a particular issue or policy. The challenge is not just how to get into the media but how to get your message across in the way you want.

How to get coverage: develop a strategy and key messages

Work out why you want to have a presence in the media: what will you gain from it? How will it help you reach your goals? Then you can work out how it is best achieved.

Be clear in your aims. Know the difference between news and campaigning. Sometimes the media will support a particular campaign, especially if it's seen to be in the public interest or it exposes injustices. Generally, however, journalists see their role as objective, impartial reporters, and are wary of campaigning.

Work out the essence of what you want to say on a particular issue and decide your key messages. For example, a story on opioid availability in your country might have four key messages:

- The current state of availability;
- Why availability matters (i.e. the impact on people's lives);
- What needs to be done, by whom, to improve the current situation, and;
- What your organisation is doing to help bring this about.

Get to know the media

You need to become a media expert. This means becoming aware of who and what is out there. Subscribe to newspapers and magazines, listen to the radio, watch TV, surf the internet. Which magazines, newspapers, radio or TV programmes or online media cover the type of issues you want to cover? Expand your media use beyond your own personal tastes and preferences – you will often be surprised by what's out there, and may become aware of possibilities you did not know existed. What media does your audience read and consume? These outlets are the most important to you. You can target your audience directly or indirectly by rousing public interest as a way of reaching and putting pressure on policy makers. Visit the websites of the various publications and broadcasters and find out who their target audiences are, what their geographical reach is, etc.

Learn to think like a journalist

NGOs tend to think of what is important and what *ought* be said. For journalists, that something is important is not sufficient. It must also be interesting to their audience, and preferably unusual too. Ninety-nine per cent of the time, *meetings and workshops in themselves are not a story*! You have to be able to offer them something new and exciting. Instead of thinking about what the media can do for you, turn the question around: what can you offer them? Journalists need new stories or fresh angles on old ones. So what's new, interesting or unusual? What unique insights on an issue can you provide? Get to know what is a good story: study the media, the type of things published, ask yourself why? If you have an idea, ask: is this news? What is different? Why might anyone be interested? Consider different types of story, e.g. a news story (something that has happened, a current event), a feature article (e.g. a day in the life, a profile of a person or issue) or an opinion piece.

Build a media database

Take note of the names of journalists covering the kinds of issues relevant to your work, and get their contact details. Newspapers often provide the journalist's email address at the end of articles. If need be, 'phone the media organisation and ask for the relevant phone and fax numbers, and email addresses. Compile this information into a database that can be easily updated (and on a regular basis) and used for sending out press releases.

Build relationships

As with many things in life, it is often about who you know, as much as what you know. It is quick and easy to send out emails and faxes, but it is very useful to make 'phone calls to individual journalists too, when youhave an interesting story to offer. This gives you the chance to cut through the clutter and make a personal connection. Find out who is responsible for writing about what you do / your issue. What do they want? Offer a potential story, e.g. a new report out soon contains ground-breaking research. Making a call to check whether a fax or email has been received is also a good idea. Invite particular journalists to meet you and your team over coffee, lunch or breakfast – make this an informal getting-to-know-each-other occasion rather than using it to try and 'sell' a story or idea.

If they are interested in any story you suggest, follow up your verbal pitch with a formal written pitch within a couple of days, containing what stories and background information you can offer, and whether there are photos or case studies. If they do not want anything immediately, try to stay in touch: you might be useful to them in the future. If you have submitted a written pitch and had no response, follow up by 'phone. Remember yours is just one of hundreds of pitches journalists receive, so you need to remind them of it – and why it meets their needs. If you do hear from the media, work fast: journalists need to, to meet their deadlines, so you cannot afford to delay them. Respond to calls immediately. If you can make journalists' lives easier, they'll want to work with you again. If you do not hear from them, do not be afraid to ask for feedback – if a story is not used, find out why –this can inform your future media work.

Take advantage of opportunities

Do not think simply about articles or reports dedicated to featuring your organisation's work. Of course, it is great if you can get those, but there are plenty of ways to get your name and views out there, and the more of these opportunities you take advantage of, the better. Write 'Letters to the Editor', send short message service (SMS) messages to comment lines, and call in to offer your views on radio talk shows.

Give your story a human face

This cannot be emphasised enough. Tell unusual or emotionally powerful stories about ordinary people: patients and how they have been helped by palliative care; relatives and how they have benefited; volunteers and staff, and the inspiring work they do. These stories will show people what palliative care is, which works much better than trying to tell them. Nobody's going to remember the exact definition of palliative care. They will remember the story they heard about somebody's uncle who was in pain until your hospice stepped in to help. Remember that however powerful they seem, policy makers and highly qualified medical educators are people too, and you will have the biggest impact if you can tap into the underlying humanity we all share.

Keep your calendar up to date

Look out for regular dates on the social, political and development calendar that may give you a 'hook' for a story you can pitch to the media. Plan way ahead, and think about story ideas and angles that link to these in some way. Again, think creatively. Do not only pay attention to dates such as World Health Day and Palliative Care Day. Why not come up with a story for Women's Day, or Human Rights Day? But again, the mere fact that there is a 'Day' is not a story in itself. That is just your entry point. You still have to come up with an event that generates excitement, or a gripping story to tell!

Be creative; follow the news agenda closely and find ways to fit your issues into it. Anticipate journalists' needs, and offer new angles on everyday stories people can relate to. Hold a media event such as a workshop for journalists, e.g. with a high-profile speaker, celebrity ambassador and a panel discussion; or (if you are sure of attracting journalists) a press conference. Take reporters to visit projects and see success stories first-hand and meet people whose lives are affected by not having what you are advocating for. You could hold a competition, for students or schoolchildren – poster / writing. Use drama, hold a demonstration, look out for milestones such as key numbers, e.g. when the number of people in need of / receiving pain relief hits a landmark figure, e.g. one million.

Ditch the jargon

Leave the complex definitions for the academics. Tell stories that show, rather than try to tell, what hospice does or palliative care is. All your material should use plain, everyday language. Most non-NGO people do not know what 'empowerment' is, or what 'capacity building' means, or what 'OVC' (orphans and vulnerable children) refers to. You will communicate more effectively if you say 'training' instead of 'capacity building', give a practical example to show how you are empowering people, and say 'orphans and vulnerable children' in full. Do not overwhelm journalists with information, or you will drown your key messages. Too much data will make the reader lose interest. Try to present statistics in a way the audience can relate to, e.g. X number of people need morphine, that is the equivalent of the population of (a well-known city).

Get your organisation mentioned

This may seem automatic if you have given the journalist the lead and the information. But you need to make extra effort if you want your organisation to be named in an article or broadcast. Editors might argue that not naming organisations is part of their editorial policy and they cannot be seen to be anyone's 'tool'. Identify a spokesperson who can speak to the media – someone who is well informed, articulate and easy to get hold of (this need not be your director or chief executive officer). Try to make sure that they and interviewees such as patients or experts mention your organisation at least once.

Writing a press release

A press release is useful for announcing a new report or policy statement, drawing attention and helping make sure it is reported accurately. It is effectively a news story written from your perspective which a journalist can easily turn into an article, possibly adding other perspectives.

Press releases need to be short, simple, interesting and clear. Think about what you want to say: what's the *one key message* you would want a reader to take away from it? What do the issues boil down to? What will make your story stand out from the crowd? It must be one or several of the following: new, urgent, unusual or unexpected, timely, of human interest, a local perspective on a bigger story, or supported by a celebrity.

Once you know you have got a powerful subject you can start writing:

- Begin with the date and a gripping headline that will make the reader want to read on. For example, 'New study shows xyz' is more interesting than 'New study released on …'
- Use your opening sentence or paragraph to get across the single most important idea you want the journalist to take away. Do not begin with background, past history, complicated statistics, long names of official organisations or general philosophical points, which are off-putting. What will grip people, make them curious and want to read more?
- Support this with five Ws: who, what, why, when, where – and a H: how.
- Provide the rest of your information in a way that is easily followed, putting the most important points first. Make sure you include the name of your organisation, e.g. 'The study, carried out by (your organisation) asked …' Humanise the story with quotes from patients, campaigners or others. Where possible, show people as active citizens able to influence their own situation.
- At the end, write 'End', then give your name and contact details, and the contact details of people who may be able to help with interviews. Here you can add any notes that may be helpful to journalists, such as a brief description of your organisation and background material.
- Good images with compelling captions (i.e. that deliver extra information, rather than simply describing what the eye is already seeing) make people more likely to start reading an article. Offer photos if possible, and try to make sure your organisation is credited.
- Before you send your press release out to newspapers and broadcasters,

check it for accuracy. Ask colleagues to proofread it to ensure there no mistakes – fresh eyes will spot errors the writer cannot see. Make sure the names and titles are correct and check facts against reliable official sources.

- If sending your release by email, include it in the body of your message rather than as an attachment so it can be read straight away. Make clear what it is with a compelling subject line, e.g. 'Press Release: new study shows morphine could help 50,000 people in Uganda go back to work.'

Getting case studies and photos

Personal stories can provide that vital emotional hook for your audience, but it is vital that you have the permission of the people you are interviewing and photographing, and that you portray them with dignity. Ask yourself: would I want to be portrayed this way in the media? If the answer is no or you are unsure, then you need to change your approach.

Always get permission

Always ask people's permission before you interview, film or photograph them. Make sure they sign a consent form. Explain why you want their story and how it will be used; make sure they understand this and, if they are reluctant, do not push them. You can offer to change the reported name if necessary, to protect their identities (if you do, make this clear in your article or broadcast, and be careful not to give away the location in your writing or pictures). Take particular care to protect children's identities: never use their real names, and always get written permission from their carer. Remember to thank people.

Portray rounded, real people

Do not show people defined simply by their illness: bring personal stories to life by including background information about the person, name, age, family situation, occupation, and where they live. Use direct speech as much as possible, either by quoting the person or telling the whole story in their words. Identify the moment of change (e.g. when the person introduced to morphine could resume daily life – this is pivotal). Show what a difference this has made to them and their family.

Be innovative: make a video or photo diary that records someone's daily life before and after pain and symptom control. Highlight successful results and key challenges.

Use professionals

It is a myth that anyone can conduct strong interviews and take powerful pictures. If possible, use professionals with the necessary skills, e.g. a local freelance journalist and photographer. Brief them carefully on your needs and, if financial resources are scarce, ask them to support your cause by donating some pro bono work. Otherwise, agree a daily rate in advance and get them to sign a contract.

Writing articles

News

- Keep it brief: try to say as much as possible in the fewest words possible.
- Use everyday language: short, plain words, not long complicated ones (e.g. 'use' not 'utilise'). Avoid jargon, specialised language and too many abbreviations or acronyms.
- Keep the flow going by using active verbs, and verbs instead of nouns (e.g. 'Morphine will enable people with life-threatening illnesses to participate in the workforce', rather than 'Morphine will enable the participation of people with life-threatening illnesses in the workforce').
- Use positive examples – show how what you want will change people's lives for the better (present the audience with an opportunity), rather than overwhelm the audience with depressing stories of need (e.g. 'Morphine can help people participate in their communities', rather than 'Morphine can help people be less isolated').
- Edit: when you have written everything you think you need to say, go back and cut it. Then take a break, come back to it later and read and cut it again.

Opinion pieces ('op-eds')

An opinion piece is a great way to promote advocacy and campaigning messages: it does not need to contain news (though this can be helpful), because your main purpose is to express your opinion. Before you send an article, contact the editor and find out the chances of having a piece published, (e.g. 'Next week is World Health Day, do you have anything planned? I can provide a piece on … that may interest your readers'). Act well in advance – you should know within a few weeks if your piece will be published. Or the editor may decide to keep your piece and publish it on a quiet news day.

- Stick to guidelines about length and content. Write clearly in the style of the publication, keeping sentences short and to the point; never more than 25 words. Do not write in an academic style (unless for academic publication).
- Your audience may be politicians, highly qualified doctors etc, but also human beings – try to hit on that common humanity before you bombard them with arguments or demands. Bring human interest into your story wherever possible. Try to make your reader feel they can identify with people you are talking about.
- A good structure is to start with a story about an individual person. Point out that many other people are similarly affected, and then explain the nature and extent of the problem. Then describe what the solutions are, what your organisation is doing, what people can do to help themselves, and what your audience can do to support your cause. Be persuasive.
- Keep to the point. An editor might remove entire paragraphs: try to prevent this by keeping your piece tightly-knit so that it would lose coherence if a sentence or paragraph were removed.
- Give yourself a bio line: '(Name) is (job title) of (organisation)', and contact details if you want readers to be able to contact you or your organisation.

Giving a broadcast interview

There is no need to be nervous about appearing on TV or radio if you are well prepared. To this end:

- Research the broadcaster's audience and the journalist who will interview you. Tailor your answers and style accordingly.
- Know the story's hook and angle (i.e. the reason why the journalist is covering the story at all, and the perspective from which they are covering it).
- Prepare a strong key message, two or three startling statistics, a unique viewpoint, a human angle, and some new information that will interest the audience. Keep it simple: more in-depth analysis is for written media.
- Try to pre-identify any tricky questions and prepare a response to them. 'No comment' sounds as if you are trying to cover something up. Try the ABC technique: Address the question; Bridge to something more comfortable; Communicate the answer you want to give.
- Use the 'so what?' test. If what you plan to say does not sound exciting to you, it will not interest your audience either. How can you make your responses livelier?
- Rehearse – ask colleagues to throw questions at you, practice your responses a few times. Aim to sound as relaxed and friendly as possible, as if making an important point to a friend. Speak a little more slowly than you would in ordinary conversation.
- Remember to mention your organisation two or three times. Where possible start answers with '(name of org) believes that …' But make it sound natural and appropriate, not forced.
- Never go off the record. Even in casual conversation, do not tell a journalist anything you would not wish to be published or broadcast.
- Know when to say 'no': understand the implications of talking to the media. If you think it is not a good time, you do not have enough information or a story may cast your organisation or cause in a negative light, then tell the reporter you do not have anything to say at this stage. Try to follow up and offer something else instead.

Building a movement of support: social media

Online social media sites, such as Facebook, Twitter, YouTube and Flickr, allow you to reach mass audiences without having to go through traditional media outlets, such as newspapers or TV stations. They are also a good route for getting into the mainstream media – stories originating on social media can create momentum and be picked up by mainstream media, and most newspapers and broadcasters have their own online editions, including blogs (short for weblogs) and reader response forums. More and more people who are not professional journalists can now create and distribute their own media. This provides great opportunities for NGOs. You can write about anything from a council meeting to powerful personal stories, or awareness-raising events; respond to articles and events to generate online debate, or post photos and videos of events. Twitter is especially good for Africa because you do not need a computer to use it, just a mobile phone with an internet connection.

A blog can help you keep in touch with people you are trying to influence. Free blogging sites, such as blogger.com or wordpress.com, enable you to communicate very quickly with people across the world. To make your blog work as hard as possible:

- Give it an enticing title;
- Make it easy to read, with short entries (not more than 800 words);
- Be real, personal and chatty (but avoid jargon and slang);
- Use other media – video, photos, sound – to bring your blog to life;
- Keep it up to date – post new material at least once a week to keep readers interested.
- Promote it – by world of mouth, email and networking sites.

Key points

- Use media coverage to publicise the issues you are passionate about changing, helping you influence policy.
- Work out why you want to have a presence in the media to help you reach your goals.
- Think like a journalist: what makes a good story?
- Tell new, interesting or unusual stories about ordinary people.
- Tell stories that show, rather than try to tell, what hospice does or palliative care is.
- Give your story a human face: make it emotionally powerful. Ditch the jargon!
- Portray real people not their illness, always securing written permission to use their interview, photograph, etc.

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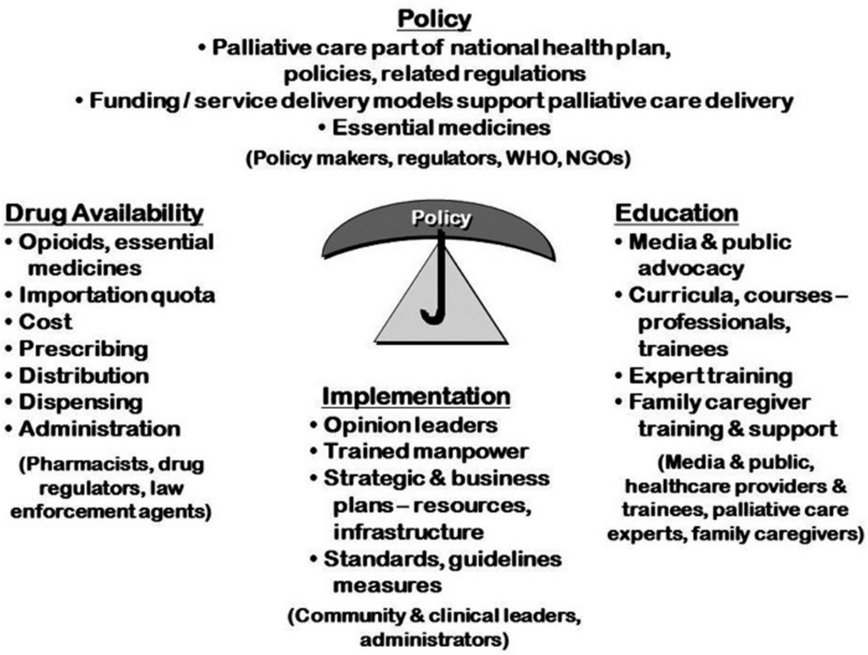
The Committee of Concerned Journalists (2007) How to Talk to the News Media. Available from: www.concernedjournalists.org/node/67.

Wingseed: http://wingseed.wordpress.com is a blog by media consultant Brett Davidson, aimed at providing ongoing resources and support to organisations involved in media advocacy.

5. The public health approach

In 1990, the WHO pioneered a public health system to integrate palliative care into existing health care systems comprised of three pillars, which was subsequently enhanced to four to include: (i) appropriate policies; (ii) education of health care workers and the public; (iii) adequate drug availability, and; (iv) implementation (see Figure 1 below).

Figure 1: The Enhanced WHO Public Health Model


Policy
• Palliative care part of national health plan, policies, related regulations
• Funding / service delivery models support palliative care delivery
• Essential medicines
(Policy makers, regulators, WHO, NGOs)
Drug Availability
• Opioids, essential medicines
• Importation quota
• Cost
• Prescribing
• Distribution
• Dispensing
• Administration
(Pharmacists, drug regulators, law enforcement agents)
Policy
Education
• Media & public advocacy
• Curricula, courses – professionals, trainees
• Expert training
• Family caregiver training & support
(Media & public, healthcare providers & trainees, palliative care experts, family caregivers)
Implementation
• Opinion leaders
• Trained manpower
• Strategic & business plans – resources, infrastructure
• Standards, guidelines measures
(Community & clinical leaders, administrators)

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For public health strategies to be effective, they must be incorporated by governments into all levels of health care systems and owned by the community. This strategy will be most effective if it involves the society through collective and social action. Those advocating for palliative care must, therefore, be familiar with the WHO's four pillars.

Policy and palliative care

The availability of appropriate policies is an important aspect of the public health approach to palliative care. Policies must be disentangled from laws / legal documents and implementation guidelines.

a) Definitions

Policy

A policy is typically a deliberate plan of action to guide and achieve rational outcomes and differs from a law. While laws can compel or prohibit behaviours (e.g. a law requiring the payment of income taxes), policies guide actions and oblige governments to support an issues at the national level. An example of a policy is a national health policy.

Law / legal document

Law is a system of rules, usually enforced through a set of institutions. It shapes politics, economics and society in numerous ways and serves as a primary social mediator in relations between people. Legal systems elaborate rights and responsibilities in a variety of ways. Law also raises important and complex issues concerning equality, fairness and justice. An example of a legal document is a Medicines and Poisons Act.

Implementation guidelines

Implementation guidelines for health are documents that seek to guide the implementation of national policies. An example of practice guidelines is a national health strategic plan.

b) National policies

There are several actions that health workers can take to support the development of national polices:

Advocacy

- Health workers can identify key policy makers in their countries and encourage them to undertake comprehensive policy review exercises (for guidance on such reviews, see African Palliative Care Association [2011]).
- Advocacy should be supported with clear information about what problems are posed by the current policies and feasible solutions on how these problems can be addressed.
- This should be seen as an ongoing activity and not a one-off exercise as policy reviews take time.

Education

- To support the advocacy agenda, it is critical to educate policy makers around the issues of palliative care, drug availability and accessibility.
- Policy makers should be provided with information on the clinical uses of medicines, the benefits for patients and also information on any legislation or policies that limit or prevent access to such drugs.
- Most importantly, policy makers must be educated about their role in
- addressing such policies.

Research

- Health workers must develop evidence-based information through research that can support the advocacy and educational issues mentioned above.

c) Examples of national polices

Countries might decide to have a dedicated national policy on palliative care or have a policy that is integrated into other existing polices. The latter can include: national health strategic plans; prevention polices or guidelines; national treatment or drug policies or guidelines; home-based care (HBC) policies; HIV/AIDS strategies, and; cancer control frameworks.

While both approaches are acceptable, often dependent upon a range of country-specific factors, any policy on palliative care must include issues around pain medication.

Education and palliative care

Palliative care education should target diverse audiences (e.g. policy makers, health care workers and the general public) to increase their awareness, skills and knowledge of, and change their attitudes to, palliative care.

In 2004 the WHO recommended that governments develop policies that include palliative care in training curricula for health workers at all levels, equipping them with the discipline's knowledge and core competencies. This is critical to integrating palliative care into existing care services at all levels. A vital target audience, however, are national leaders (both clinical and academic) who are responsible for developing polices around education.

Although palliative care education across Africa is not well developed, there are a number of educational initiatives that seek to address the holistic needs of patients and their families, with an emphasis on pain and symptom management, psychosocial, cultural and spiritual needs. These programmes range from short certificate courses, to diploma, undergraduate, and Masters level degrees. In some African countries, such as South Africa, Zimbabwe and Uganda, palliative care is incorporated into medical and nursing curricula and is examinable at both undergraduate and post-graduate levels. In other African countries, educational programmes to build the capacity of tutors and lecturers of health teaching institutions to teach palliative care are being implemented.

Despite these developments, however, a major challenge exists given there are still inadequately skilled human resources to support the development of palliative care across the continent.

Drug availability

Essential medicines save lives and improve health when they are available, affordable, of assured quality and properly used. However, lack of access to essential medicines remains one of the most serious global public health problems.

Essential medicines are defined as those that satisfy the priority health care needs of the population. They are selected with regard to disease prevalence, evidence of efficacy, safety and comparative cost-effectiveness. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford (World Health Organization Expert Committee, 2006).

African governments are urged by the WHO to institute policies on essential medicines for adults and children – that includes palliative care medicines (including opioids, such as oral morphine, for effective pain management as part of the WHO analgesic ladder) – that are supported by a policy on their importation to ensure that all can access medications that are affordable and effective.

Morphine is the strong opioid of choice in moderate-to-severe pain. Both immediate release and sustained release oral preparations are recommended to be included in a country's essential medicines list to enable morphine to be successfully used for both acute and chronic pain. In most parts of Africa, however, current legislation restricts the prescribing of opioids to doctors. Consequently, for example, in 2006 the vast majority of morphine was consumed in industrialised countries, whereas in Africa the regional mean was only 0.33mg per person compared with the global mean of 5.98mg (International Narcotics Control Board, 2008).

Given the poor physician : patient ratios in most African health systems, however, and the predominantly non-facility-based care received by rural populations, there is an emerging trend to alter existing legal provisions to enable other specially trained cadres (e.g. nurses) to prescribe opioids for patients in moderate-to-severe pain.

Implementation

Without effective implementation, the three additional components of the enhanced WHO public health model are redundant. Consequently, most African governments need to ensure there are sufficient funding and appropriate service delivery models in place to support the expansion of palliative care in their respective countries.

The primary mode of palliative care service delivery is HBC, which is predominantly dependent upon volunteers (Powell RA and Mwangi-Powell, 2008). In addition to addressing the issues of staff recruitment and retention, it is imperative that African palliative care providers ensure that the HBC services provide an acceptable standard of patient care. Of particular importance in this respect is the development and adherence to national quality care standards, developed by APCA (African Palliative Care Association, 2010). Moreover, to ensure widespread implementation, it is important that palliative care is integrated into all levels of the health care system, including the specialist, regional and district (as well as HBC) facilities.

Key points

- The WHO public health approach is comprised of: appropriate policies; education of health care workers and the public; adequate drug availability; and implementation.
- Public health strategies must be incorporated by governments at all levels of health care systems and owned by the community.
- Undertake comprehensive policy reviews as a starting point.
- Educate diverse audiences to increase their awareness, skills and knowledge of palliative care.
- Lack of access to essential medicines is a serious global public health problem.
- Morphine is the strong opioid of choice for moderate-to-severe pain.
- Specifically trained cadre (e.g. nurses) should be enabled to prescribe opioids for patients in moderate-to-severe pain.
- Governments must ensure sufficient funding and service delivery models to support palliative care expansion.

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6. Fact sheets: What you need to say

While advocacy methods are applicable to support any cause, it is important to have key facts and messages that support the cause. This section provides data that will support the advocacy agenda in the form of four fact sheets:

Fact sheet 1: What is palliative care?

Fact sheet 2: The need for palliative care

Fact sheet 3: Challenges to palliative care development across Africa

Fact sheet 4: Palliative care and human rights

Fact sheet 1: What is palliative care?

In the 1960s in the United Kingdom, hospices provided palliative care to people dying of cancer. Consequently, palliative care was defined as care provided for people who were not receiving any curative treatment for their illnesses.

In 1990, the World Health Organization (WHO) defined palliative care as the active total care of patients whose disease is not responsive to curative treatment and noted that control of pain, other symptoms, and of psychological, social, and spiritual problems were paramount. Although the WHO noted that many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with treatment, this definition of palliative care stressed its relevance to patients unresponsive to curative therapy and therefore implied that palliative care is just end-of-life care when all else has failed (World Health Organization, 1990).

In 2002, however, the WHO definition of palliative care was revised and noted that palliative care is an approach that improves the quality of life of patients and their families facing the problems 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 (Sepulveda et al., 2002). The new definition replaced the term 'terminal illness' with 'life-threatening illness', and broadened the reach of palliative care to all people suffering from chronic illnesses (such as cancer, cardiac disease, and HIV [Human Immunodeficiency Syndrome]).

The definition arose from a wide recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal, illness. This change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier stage in the disease trajectory.

WHO principles of palliative care

Palliative care:

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

The WHO also highlights the need for palliative care for both adults and children, stating:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multi-disciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, and even in children's homes (Sepulveda et al., 2002).

Possible confusion in terminology

Palliative care is often confused with terms such as 'supportive care', 'hospice care' and 'end-of-life care'.

What is supportive care?

To help clarify, it is useful to look at palliative care from two perspectives: one aspect that focuses on pain and symptom management, and the other that focuses on physical and psychological support. Care without pain and symptom management is known as supportive care.

What is hospice care?

Hospice care is a term that first came into general use in the 1960s with the opening of St. Christopher's Hospice in London, England. Hospice care is a philosophy of care that has been described as: care that is defined not only by the services and care provided, but also by the setting in which these services are delivered; care that treats the person rather than just their disease; care that highlights quality rather than length of life, and; care that can be provided in at one's home or in a special facility. From the hospice philosophy evolved the palliative care philosophy to meet the gaps in care for seriously ill and dying patients.

What is end-of-life care?

End-of-life care is an important part of palliative care, and refers to the care of a person provided during the latter part of their life, from that point at which it is clear that the person is in a progressive state of decline.

Palliative care

Palliative care is comprehensive care for people living with life-threatening illnesses and starts from diagnosis (clinical or otherwise) and continues throughout the disease trajectory and provides bereavement support after death. It incorporates the principles of hospice care, provides supportive care and also supports patients and families at the end of life.

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Fact sheet 2:
The need for palliative care

Defined as an approach that improves the quality of life of patients and their families facing the problems 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 (Sepulveda et al., 2002), the WHO has recognised palliative care as an essential component of a national response to HIV and AIDS, cancer and other diseases

There are at least four reasons that palliative care is relevant globally: disease burden; disease distribution; disease projections; and humanitarian reasons.

Disease burden

- In 2008 there were an estimated 12.7 million new cancer cases and 7.6 million deaths globally (Ferlay et al, 2010).
    - 2.3% of deaths worldwide were attributable to cancer (i.e. trachea, bronchus and lung cancers) (World Health Organization, 2008).
- In Sub-Saharan Africa, in 2008 there were an estimated 551,000 new cases of cancer, and 421,000 cancer deaths (Ferlay et al, 2010).
- In 2009 the prevalence of HIV/AIDS was estimated to be 33.3 million globally (Joint United Nations Programme on HIV/AIDS and World Health Organisation, 2010).
    - Adults living with HIV/AIDS – 30.8 million.
    - Women living with HIV/AIDS – 15.9 million.
    - Children living with HIV/AIDS – 2.5 million.
    - People newly infected with HIV – 2.6 million.
        - Adults newly infected with HIV – 2.2 million.
        - Children newly infected with HIV – 0.4 million.
    - AIDS-related adult and child deaths – 1.8 million.
- In Sub-Saharan Africa in 2009 there were:
    - Adults and children living with HIV/AIDS – 22.5 million.
    - Adults and children newly infected with HIV – 1.8 million.
    - AIDS-related deaths in adults and children – 1.3 million.

Disease distribution

- Fifty-six percent of new cancer cases and 63% of cancer deaths globally occur in developed regions (Ferlay et al, 2010).
- Sub-Saharan Africa accounts for two-thirds (i.e. 67%) of all HIV and AIDS cases (Joint United Nations Programme on HIV/AIDS and World Health Organisation, 2010).

Disease projections

- By 2030, nearly 21.4 million new cases of cancer will be diagnosed globally, with more than 13.2 million deaths (Ferlay et al, 2010).
- Low and middle-income countries are projected to account for 61% of all cancers worldwide by 2050 (Bray et al, 2006).
- By 2050, the prevalence of HIV/AIDS is projected to increase 278 million (UNFPA, 2003).

Humanitarian reasons

- The WHO estimates that at least 25% of HIV/AIDS patients and 80% of cancer patients suffer pain in the terminal phase of the illness (World Health Organization, 2004).
- Pain is experienced throughout the HIV disease trajectory (Mathews et al, 2000), with severe pain experienced by 80% of those with advanced HIV (Solano et al, 2006).
- Recent studies show that antiretroviral therapy has not eliminated the need for effective pain and symptom control, given that problems (sometimes treatment-related) persist (Collins and Harding, 2007; Harding et al, 2006).
- The International Society for the Study of Pain advocate for palliative care and pain relief as a universal human right.

Given the above, 80% of people in developing countries are estimated to require palliative care (World Health Organization, 2007).

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Fact sheet 3:
Challenges to palliative care development across Africa

There are a number of generic factors that exert a widespread adverse influence upon attempts to provide palliative care services for the majority of people in Africa. These include: diagnostic challenges; inadequate health and social care infrastructure; a paucity of trained palliative care professionals; negative drug environments; and logistical challenges to service provision.

Diagnostic challenges

- Late presentations of an illness to a health facility.
- Many HIV-infected individuals are reluctant and unwilling to seek medical assistance or to receive a HIV diagnosis due to the stigma that still surrounds the illness in many African countries, and the resultant social rejection.

Inadequate health and social care infrastructure

- Many African countries lack the health and social care infrastructure that is needed to ensure they can provide the care needed.
- Inadequate facilities, staff shortages and lack of medication are common and can result in a poor quality of care offered.

Paucity of trained palliative care professionals

- Shortage of general medical staff in many African countries (including very low doctor : patient ratios).
- Employment turn-over.
- Skills training deficits in palliative care in particular.

Negative drug environments

- In many African countries access to even the most simple pain-relieving medication – notwithstanding the strong painkillers (i.e. opioids) – and antibiotics to treat opportunistic infections is limited.
- Systemic challenges in the supply chain – from ordering to administering – are compounded by the lack of pharmacists in public health services, and the restriction of the powers of prescription to select group of professionals within the medical hierarchy.

Logistical challenges to service provision

- Topographical challenges facing effective palliative care provision cannot be understated.
- Dictated in large measure by the rurality of many African countries, and the remoteness of populations from existing institutional services (with visits to the nearest hospital potentially taking hours), home-based care is the prime modality of HIV palliative care provision on the continent.

Fact sheet 4:
Palliative care and human rights

Palliative care, including pain management should be a *right* of every person with a life- threatening illness. Guideline 6 of the International Guidelines on HIV/AIDS and Human Rights says:

> *'States should … take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services, and information for HIV prevention, treatment, and care and support … including preventive, curative and palliative care of HIV and related opportunistic infections and conditions' (United Nations High Commission for Human Rights, Joint United Nations Programme on HIV/AIDS, 2006).*

An unreasonable failure to provide adequate pain relief may constitute negligence. Breaches in reasonable pain care may be: an unreasonable failure to take an adequate pain history; an unreasonable failure to treat the pain adequately or, in the context of uncontrolled pain, an unreasonable failure to secure expert consultation.

What are palliative care rights?

Palliative care embraces human rights that are already recognised in national laws, international human rights documents, and other consensus statements. Palliative care rights include the right to:

- Pain relief;
- Symptom control for physical and psychological symptoms;
- Essential medicines for palliative care;
- Spiritual and bereavement care;
- Family-centred care;
- Care by trained palliative care professionals;
- Home-based care (HBC) when dying and to die at home if desired;
- Treatment of disease and to have treatment withheld or withdrawn;
- Information about diagnosis, prognosis, and palliative care services;
- Name a health care proxy for decision making, and;
- Not be discriminated against in the provision of care because of age, gender, national status, or means of infection (Open Society Institute, 2007).

Right to pain management

Chronic and severe pain are common in HIV/AIDS, as well as in other health conditions. Pain is experienced throughout the HIV disease trajectory (Mathews et al, 2000), with severe pain experienced by 80% of those with advanced HIV (Solano et al, 2006). Recent studies show that antiretroviral therapy has not eliminated the need for effective pain and symptom control, given that problems (sometimes treatment-related) persist (Collins and Harding, 2007; Harding et al, 2006).

According to the International Narcotic Control Body, under international human rights legislation, governments must address the issue of inadequate pain relief, a major public health crisis affecting millions of people every year.

Governments are requested to ensure that people have adequate access to treatment for their pain. At minimum, *governments must ensure the availability of morphine*, the mainstay medication for the treatment of moderate-to-severe pain, and that morphine is considered an essential medicine that should be available to all persons in need. However, the current situation in most developing countries (including across Africa) in terms of availability and affordability is quite the opposite, where pain treatment continues to be a low priority in healthcare systems palliative care commonly does not exist as a stand-alone national policy, or as part of health, cancer or HIV/AIDS national policies (World Health Organization, 2002).

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About APCA

The African Palliative Care Association (APCA) is a non-profit making pan-African membership-based organisation which was provisionally established in November 2002 and formally established in Arusha, Tanzania, in June 2004. Acknowledging the genesis of modern palliative care within the United Kingdom, APCA strives to adapt it to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, in collaboration with its members and partners, APCA provides African solutions to African problems, articulating them with what is the recognised regional voice for palliative care.

APCA's vision is to ensure access to palliative care for all in need across Africa, whilst its mission is to ensure palliative care is widely understood, underpinned by evidence, and integrated into all health systems to reduce pain and suffering across Africa. APCA's broad objectives are to:

- Strengthen health systems through the development and implementation of an information strategy to enhance the understanding of palliative care among all stakeholders;
- Provide leadership and coordination for palliative care integration into health policies, education programmes and health services in Africa;
- Develop an evidence base for palliative care in Africa;
- Ensure good governance, efficient management practices and competent human resources to provide institutional sustainability;
- Position palliative care in the wider global health debate in order to access a wider array of stakeholders and to develop strategic collaborative partnerships, and;
- Diversify the financial resources base to meet APCA's current funding requirements and to ensure the organisation's future sustainability.

www.africanpalliativecare.org

About Help the Hospices

Help the Hospices is the leading charity supporting hospice care throughout the UK. We want the very best care for everyone with a life-limiting illness.

Help the Hospices has an international programme that supports the development of hospice and palliative care worldwide, particularly in developing countries. Around the world, it is estimated that 100 million people would benefit from hospice and palliative care, but only a fraction receive it.

We work with our partners to provide a global voice on international hospice and palliative care issues. We provide resources to develop the capacity of hospice and palliative care services at national and local levels.

www.helpthehospices.org.uk

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APCA thanks DFID and Help the Hospices for funding the development of this publication.

PERSONEL NOTES