



Decent Care Values: A Demonstration in Palliative Care

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Executive Summary

Health care is in crisis worldwide, with millions suffering from life-limiting illness and disease. Many current health care models exclude or mute the voices of those they serve, resulting in sub-optimal care and outcomes. To begin addressing this need, Altarum Institute led the first research and demonstration project of Decent Care Values, an innovative, values-based model aimed at transforming and improving health care at three levels: **individual, social and systemic**; and seeking to bridge human rights principles with the practice of medicine to improve health care. The six values are: **Agency and Dignity** (individual), **Interdependence and Solidarity** (social), and **Subsidiarity and Sustainability** (systems). The six values form the underpinning of Decent Care Values, a unique model that constructs care based on affected people voicing what they need and want while living with life-limiting disease and illness.

In 2009, Altarum invested its own internal research and development funds, supplemented with support from the World Health Organization (WHO) to fund an initial endeavor focused on the role of Decent Care Values in palliative care services. Later, the project received additional support from the Diana, Princess of Wales Memorial Fund. The goal of this initial effort was to explore possibilities for using palliative care services as the platform on which to launch Decent Care Values in the care of people affected by cancer and HIV/AIDS. To inform the project, project leaders convened an international advisory committee comprised of leaders from health care systems and palliative care, WHO regional staff, USAID, funding partners, and people who live with or are affected by illness and disease.

In 2010, Altarum released an international application, which led to funding of two palliative care non-governmental organization (NGO) grantees, in Kuala Lumpur, **Malaysia** and Nairobi, **Kenya**, to demonstrate for the first time, in real-world settings, the implementation of Decent Care Values. Altarum provided ongoing support and on-site technical assistance and evaluation support to ensure that each grantee had the tools needed to be successful. The demonstration projects made significant improvements in their direct services to over **1,500 patients** and their families in Kenya and Malaysia. They also reported improved patient survival, satisfaction, and pain management, and enhanced relationships within health systems. In **Africa**, the grantee improved its capability to provide palliative care services and to deliver opioids, and established new partnerships with eight hospitals and the Ministry of Health. In **Malaysia**, the grantee's tools empowered affected persons and helped carers feel less isolated and better able to care for families; these tools are now being used by the Ministry of Health to create changes in the local care system.

The qualitative and quantitative evaluation results from the Decent Care Values in Palliative Care Services demonstration projects were significant both programatically and across continents, indicating the cross-cutting, cross-cultural relevance of the values to health care systems and services. Applying the abstract values of Decent Care to real-world applications within Kenyan and Malaysian cultures proved to be feasible and important. Although the two locations are radically different in populations, religion, economics, and culture, both found resonance and applicability of the values. This project has also demonstrated that using a values-based approach can facilitate change in a resource-poor or a resource-rich environment – it levels the playing field for all. Finally, the values provided a way for communities to engage in dialogue about what they need and what they value in health care settings to create paths forward to address needs and gaps at the individual, community and social levels.



Introduction

Decent Care Values (DCV) is an innovative, values-based model to transform health care at three levels: individual, social and systemic; and to bridge human rights principles with the practice of medicine. The six values are: Agency and Dignity (personal decision power and respect), Interdependence and Solidarity (connecting with providers and community), and Subsidiarity and Sustainability (aligning and influencing systems resources). The six values form a unique model that constructs care based on affected people voicing what they need and want while living with life limiting disease and illness.

The DCV philosophy of care was developed by the World Health Organization (WHO), international ethicists, people affected by life-limiting illnesses (affected people), philosophers, social scientists, and religious leaders to help create a framework within which people living with illness have the ability to construct, direct, and manage their care. The Decent Care Values in Palliative Care Services Project (Decent Care Values Project) builds upon the philosophy of Decent Care Values. The Decent Care Values Project features demonstration projects in organizations from the WHO regions of Africa (AFRO) and the Western Pacific (WPRO).

Decent Care Values directly address the disadvantage of marginalization at the individual level by asserting the rights and power of the individual to identify her or his own needs (agency and dignity). These values address the disadvantages of stratified and compartmentalized care by attending to the resources and strengths of families and communities (solidarity and interdependence). Decent Care Values address also the continuing disadvantages of inadequate resource allocation from policy and systems

levels through the values of subsidiarity and sustainability. Finally, Decent Care Values have the potential to address the disadvantages known to exist at health systems and policy levels, where lack of clear or unified values has created systems of care that exacerbate problems for vulnerable and marginalized people.

Global Demonstration Projects

Altarum Institute led the Decent Care Values Project using its own internal research and development funds, supplemented by grants and contracts with WHO and the Diana, Princess of Wales Memorial Fund. The project's goal was to use palliative care services for people affected by cancer and HIV/AIDS as the first health care arena for understanding the effects of Decent Care Values on the delivery of health services. An international advisory committee comprised of leaders from health care systems and palliative care, WHO regional staff, USAID, funding partners, and people who live with or are affected by illness and disease provided support and advised the project.

Applying Decent Care Values has untapped potential to redefine how care is constructed and delivered, and to improve the systems of care that serve all people, but especially those who live on the margins of society. For example, globally, the poor and marginalized are at greatest risk for HIV/AIDS. Despite the increased availability of anti-retroviral treatment, in 2008, 1,776,300 people died of HIV/AIDS. Cancer death rates are no better, it is estimated that globally, 7.6 million people die of cancer every year. Many people do not have access to palliative care, which focuses on pain and symptom control, psychosocial, spiritual, and

family support. Additionally, many people are not treated in a way that embraces the Decent Care Values, which reflect a holistic, integrated care system that centers on the affected person and supports them in their living or in their dying.

Why Palliative Care?

The WHO definition of palliative care is that it begins at a person's diagnosis and "is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness."¹

Palliative care was chosen as a particular focus for this work for two reasons. First, because in its focus on patient

preferences, excellent pain and symptom management, and on the entirety of the patients' experience, palliative care principles resonate closely with the values of Decent Care. Second, the 2009 WHO-Ford Foundation Global Consultation on Decent Care Values in Palliative Care Services held in Hammamet, Tunisia, found that palliative care practitioners were interested in and willing to test strategies to bring Decent Care Values to bear on their work.

The following sections of this report will address the background, goals and objectives for the DCV project; describe the demonstration project sites, the methodologies used, interventions selected, and results; and discuss the evaluation findings and their implications.

¹ World Health Organization. <http://www.who.int/cancer/palliative/definition/en/>. (Accessed February 10, 2010).

Decent Care Values in more detail



Agency and Dignity - Agency and dignity are, in many ways, the centerpiece of Decent Care. These are the values that focus on the inherent value that all humans share, the recognition of the unique needs each individual has, and the direct control and decision-making every

individual should have in the care he or she receives and how he or she receives it. At the root of the care process, every affected individual must be recognized as having the power – the agency – to construct, direct, and manage the care he or she receives (or elects not to receive).

Interdependence and Solidarity - Interdependence and solidarity are social values that focus on the unique relationship all individuals have to their particular social contexts and the communities around them. Interdependence and solidarity focus on the social nature of being cared for and caring for another – caring as a social process. The value of interdependence helps or benefits not only affected people and their families and communities, but also the caregivers who serve them. Solidarity focuses on the specific communities each individual identifies with and how people live together and advocate

for each other. Despite the many differences that separate individuals and communities, the real challenge is to find ways for individuals to stand by and with each other.

Subsidiarity and Sustainability - The final two values of Decent Care, subsidiarity and sustainability, draw attention to the systemic nature of the provision of care and to issues such as need assessments, resource allocation, health care models, and the short- and long-term development of access to care. The fundamental concept of subsidiarity is straightforward: The individuals or groups closest to problems "on the ground," who deal with the problems or issues directly and at the most fundamental level, should be the ones who help to resolve those issues or problems and help inform funding decisions. For a community, this means that care processes are developed and implemented directly around those needing or receiving care (the affected individual), and that those who receive care help develop their own care processes. Subsidiarity is also about creating and sustaining priorities that support Decent Care Values. There is one overarching challenge to sustainability in health care systems – sustainability does not mean sustaining the status quo. Rather, it means being open to, and aware of, who has access to care and who does not – sustainability does not close the door on these issues: It should always be an open and reflective process that places the affected individual and the goal of human flourishing at its center.



Background

On 15 April 2010, Altarum released a request for funding package (RFA) via Internet to more than 150 participants from the Decent Care Values global and regional meetings. Eligible organizations were invited to apply for up to \$15,000 US dollars to fund year-long demonstration projects in WHO global regions of the Western Pacific, Middle East and sub-Saharan Africa. We received 11 applications from the Western Pacific and sub-Saharan Africa regions. A review committee with representatives from the International Advisory Committee, project team and people affected by life-limiting illnesses was convened and selected two palliative care non-governmental organization (NGO) grantees in Kuala Lumpur, Malaysia (Hospis Malaysia) and Nairobi, Kenya (Kibera Community Self-Help Program (KICOSHEP)) to demonstrate for the first time, in real-world settings, the implementation of Decent Care Values.

Each applicant was invited to design a demonstration project to answer research questions about the impact of applying Decent Care Values in palliative care services. The demonstration projects participated in a year-long program of technical assistance and evaluation that enabled them to develop the skills and knowledge required to infuse their programs with Decent Care Values. The formative research gathered from the two demonstration projects aimed to expand the body of knowledge on DCV.

The Decent Care Values project was built around the following research questions:

1. How the application of Decent Care Values improves or changes palliative care services from the perspectives of affected people, communities, providers and health systems?
2. How can palliative care organizations apply the Decent Care Values of “agency and dignity” to improve or change their approach to working with affected people; has it improved the affected person’s ability to construct, direct, and manage the care he or she receives?
3. How can palliative care organizations apply the Decent Care Values of “interdependence and solidarity” to improve or change their approach to the social/community setting and resources; has this application improved or changed interactions among the components of the social systems that benefit the affected person, e.g. family, community systems, and health services?
4. How can palliative care organizations apply the Decent Care Values of “subsidiarity and sustainability” to improve or change their approach to resource allocation, health systems and policies; does the implementation of these values improve or change resource allocation, health systems, and policies?

How the demonstration projects were supported.

The Decent Care Values Project Team led by Altarum engaged in the following support activities to ensure grantees had the necessary tools to successfully implement the demonstration projects:

- Established a steering body of experts in Decent Care internally/externally, including an International Advisory Committee comprised of funding partners, regional partners, palliative care and Decent Care experts, and affected people
- Contributed and participated in three WHO sponsored regional meetings on Decent Care Values in palliative care (in sub-Saharan Africa, Middle East and Western Pacific)
- Created an organizational Decent Care Values self-assessment as a baseline tool to guide training needs and identify possible intervention areas
- Provided two technical assistance on-site visits, created tools and processes to support grantees with development of DCV interventions
- Created an evaluation/research plan, with cross-cutting data collection
- Created a cross-cutting pre/post test data collection tool
- Conducted evaluation site visits to gather interview and observational data

Overview Of Demonstration Project Sites

Hospis Malaysia Decent Care in Palliative Care Demonstration Grant

Hospis Malaysia (Hospis) applied for and received a grant from Altarum Institute to conduct a demonstration of the application of Decent Care Values in palliative care. Hospis is a palliative care organization based in Kuala Lumpur that features three key service components: home care, daycare, and teaching. In 2010, Hospis Malaysia served 1650 patients who had an average length of stay of 3 months.

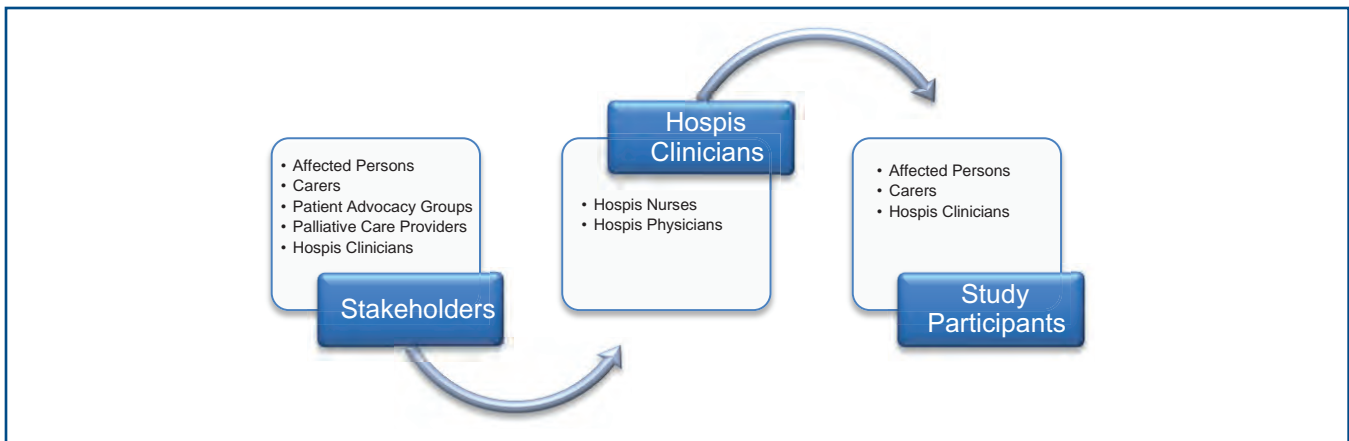
The demonstration project occurred in several phases, which included a needs assessment phase to understand individual needs, as well as barriers and facilitators to enhancing communication among patients, carers, and healthcare providers. Following the needs assessment, Hospis designed and implemented a Decent Care Values intervention. The program engaged stakeholders to develop organizational policies and implementation strategies based on the Decent Care Values.

The needs assessment process (documented in a March 2011 report) pointed to a gap in supportive services for informal caregivers (whom they refer to as 'carers'). Hospis found a need for information for and attention focused on caregivers. Hospis then developed a guide designed to provide such information and supportive tools for caregivers; the intended outcome was that caregivers would experience a greater sense of their own agency in dealing with the health and life issues of their loved one, and experience a greater sense of solidarity with the Hospis staff.

As detailed in the final Hospis report, "The carers' needs (identified from the needs study) were addressed by:

- Asking them to use a 'Distress Thermometer' to indicate their level and source of distress. Their distress levels will be assessed during each visit and whenever the needs arise. The carers are empowered to use this as a tool to initiate conversation with the nurses and other care providers.
- Providing information about Hospis Malaysia services such as who to contact during emergencies; equipment; and daycare service.
- Providing them resources (websites) to deal with: patients' physical and emotional problems; medications; family and friends; healthcare providers; daily living; finance; and uncertainty about the future.
- Encouraging the carers to seek advice from the Hospis Malaysia nurses whenever the needs arise.

Our hypothesis was that, by addressing the carers' needs, the care provided by the carers would also be improved and, hence, the quality of patient care would also be enhanced (Dignity – respecting patients' and carers' needs). Moreover, the resource materials would empower the carers (and patients) to be more in control of the physical, emotional and social challenges they face (Agency). The carers and healthcare providers, by using the resources materials, are working together to improve the care of the patients (Interdependence). By sharing information about community resources and support groups, it might encourage the community to harness its resources and provide support services for patients and their carers (Solidarity). By actively seeking feedback about services, input from affected people will routinely be used in service development (Subsidiarity)."



Hospis engaged on three continuous, interrelated fronts to develop and field its Guide.

- **Stakeholders.** Hospis broadly defined its category of stakeholders to include affected persons, carers, palliative care providers, and patient advocacy groups from around Kuala Lumpur, and Hospis staff. Stakeholders met twice during the intervention to discuss the development and implementation of the intervention as well as its implications for other service organizations.
- **Hospis clinicians.** Nurses are Hospis’ primary service providers, supported by physicians. Nurses engaged in discussions for the development of the intervention. They also provided feedback on the intervention in the early weeks of its implementation and then near the end of the intervention. Physicians provided feedback near the end of the intervention, but were individually involved in its development. Nurses and physicians implemented the intervention with carers and affected persons.
- **Affected persons and carers.** Affected persons and carers engaged with and provided feedback on all aspects of the intervention. They provided formal feedback on the elements of the intervention through the baseline and end-of-intervention surveys. They also provided informal feedback on the process of the study, both directly through comments on the instruments and the Guide, as well as indirectly through questions about the surveys and the Guide. Affected persons and carers were also included in the stakeholder group.

Kibera Community Self-Help Program (KICOSHEP) Decent Care in Palliative Care Demonstration Grant

KICOSHEP applied for and received a grant from Altarum Institute to conduct a demonstration of the application of Decent Care Values (DCV) in palliative care. KICOSHEP works at the community and national levels to help people cope with the effects of HIV/AIDS, providing special attention to the needs of women, people living with HIV/AIDS (PLWHA), young people, sex workers, grandmothers, and injecting drug users. It delivers integrated services to the community through various programs, which include building capacity and linking PLWHA to support groups and other institutions to help them build livelihoods and enhance positive living.

KICOSHEP’s Decent Care Values project focused on an initial assessment process and development of a Decent Care Values intervention. Through a needs assessment process, finalized in January 2011, KICOSHEP determined that it could improve its services to affected persons and their caregivers living in Nairobi’s slum communities. They found a need for increased knowledge and skill in their provision of palliative care. In particular, KICOSHEP needed to engage the wider health care community to a much greater degree so that its clients would experience a greater sense of their own agency in dealing with the health and life issues of their loved ones. It also needed to promote and encourage greater solidarity among the KICOSHEP staff.

As detailed in the final KICOSHEP report, the “needs (identified from the needs study) were addressed by:

- **Communication.** KICOSHEP has realized that many clients lacked skills to explain how they are doing with their illness and helping them at one point came very

difficult. Some even thought that they are a bother to their relatives, only thought the Doctor is the one who can assist when it comes to pain management.

- **Training.** KICOSHEP conducted training on communication explained the decent care values to the care givers, the patients and their families. KICOSHEP trained 70 patients, 30 caregivers on good communication skills, on how to pass on and get information from the clients.
- **Sensitization.** KICOSHEP has conducted two sensitization trainings on pain management and have undertaken to sensitize both children and adults of the different aspects of pain regarding their illnesses as trajectory changes on pain management.
- **Support Meeting.** KICOSHEP have conducted 6 support groups, one with clients who are non HIV positive and the other with HIV and cancer and other life limiting illnesses. It was found that clients are free to explain what they are feeling, primary illness and facts which modify their disease experience
- **Memory Book.** Assisted patients to come up with memory book to record their disease experience. These can assist their families to understand what the deceased under went through their illness.
- **Support group meetings.** 6 support group meetings have been organized with the aim of assisting patients and their families improve their living standards via sustainable economic projects to kill stigma.
- **Administer painkillers and pain management.** Different approaches to pain management have been discussed and implemented by the palliative care team. This encompasses the total pain approach paying attention to physical, social, spiritual, and emotional components of pain. The management of both nociceptive and neuropathic pains has been practiced. All clinical staff have been trained on prescribing and administering opioids.
- **Filling of the African Palliative Care Association Palliative Outcome Scale.** The APCAPOS is an instrument used for continued assessment of symptoms being experienced by the patient. The team has used the APCA POS for the last few months.

- **Follow up and monitoring.** There have been continuous visits to patients at home and assessment of their pain card it has been easy to monitor the severity of their pain over the care time. Meeting with patients and families assist the team to monitor how well they are progressing as they care for the patients.
- **Outreach.** KICOSHEP expanded its relationship with other formal healthcare organizations from one primary referrer (Kenyatta Hospital) to 8 area hospitals."

Stakeholders

KICOSHEP defined stakeholders as including the following categories: affected persons with HIV, cancer and other life threatening illnesses, their caregivers, palliative care providers from around Nairobi, other community-based organizations and healthcare providers around Nairobi, governmental officials, the public and KICOSHEP staff. Stakeholders were convened in focus groups and in individual interviews prior to the intervention to discuss both the development and implementation of the intervention as well as its implications for other service organizations.

KICOSHEP Clinicians

KICOSHEP relies primarily on community health workers, supported by nurses and physicians, to provide services. CHWs were engaged in discussions and contributed to the development of the intervention. Clinicians provided feedback on the intervention prior to and during its implementation and then at the end of the formal project. Clinicians implemented the intervention with caregivers and affected persons, and with the community.

Affected Persons and Caregivers

Affected persons and caregivers were included in the design and evaluation of the interventions. Formal feedback was provided on the elements of the intervention through the baseline and end of intervention survey. Informal feedback on the process of the study was also provided, both directly, through comments on the services, as well as indirectly, through questions about the program. Affected persons and caregivers also provided input as part of the group of stakeholders.



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Methodology

Qualitative Data Collection

Altarum Institute project staff collected qualitative data throughout the grant period. Data collection means included:

- Telephone meetings with grantee staff;
- Review of submitted information; and,
- Site visits.

Telephone Meetings

Altarum DCV evaluators conducted telephone meetings with grantee staff during which they probed for information about the development of the DCV activities. The DCV evaluators had regular contact with the Hospis Malaysia grantee staff and a constant flow of information about the progress of the intervention was maintained. Infrastructure challenges made communication with KICOSHEP less regular; these challenges included power, phone, and internet outages. We compensated for these problems via ongoing email contact and one-on-one phone calls.

Other Communications

Grantees were actively engaged in the development of each intervention and its evaluation, providing project staff a substantial body of information about the grantees and their activities. As with the telephone meetings, Hospis Malaysia was more active in its communication than was KICOSHEP, so more was known about Hospis.

Site Visits – Training and Evaluation

Training Site Vists. Three formal site visits were conducted with KICOSHEP and two with Hospis Malaysia. The first site visit was conducted early in the process to provide training with leadership and providers from the organization, affected people and other stakeholders. Project leaders with expertise in Decent Care Values and palliative care developed and led the trainings.

Day One – Organizational Self-Assessment and

Tour of Facilities: Activities focused on learning more about the grantees' work and infrastructure, and included on-site visits with staff to patient homes. The training team worked with the grantee project team to review its organizational self-assessment and how successfully it was applying Decent Care Values to patient, family, provider, community and systems interactions.

Day Two – Key Stakeholder Training on Decent Care

Values: The training focused on providing information on the Decent Care Values through didactic and interactive discussion groups. Both demonstration projects reached out to affected people and their carers and family, as well as to other key stakeholders on local and governmental levels, to attend the training. The training staff led a Decent Care Values session based on a module developed by Rev. Ted Karpf. The trainings included a facilitation of "narratives" around health care and values. This was followed by training on the background and description of Decent Care Values and how these support palliative care services and goals.

Day Three – Action Planning and Next Steps: The visits were concluded with a planning session with key staff, who developed an action plan for the next steps for the project to gather input from affected people, create an intervention, and develop evaluation tools. The goal of the action plans was to create interventions informed by the needs assessments to address gaps in the Decent Care Values.

These early training sessions proved to be a critical step in the project's development, and accomplished the following objectives: 1) They modeled how to bring together affected people, their families and carers, providers from across the system, NGOs, and government health representatives to share their narratives on their health care experiences and better understand what they **valued** about their health care as compared to what the **health care system valued**. 2) They provided the demonstration project an opportunity to discuss and integrate the definitions of the Decent Care Values and how the definitions and core intent of the values translate meaningfully within their own languages and culture. 3) They allowed the training team time to work with the grantee on creating step-by-step action plans and timelines for the demonstration projects.

Evaluation Site Visits. One site visit to each of the grantees focused specifically on project evaluation, while others addressed the provision of technical assistance. Both types of site visits featured a qualitative data collection element. The two evaluation site visits focused specifically on understanding the following:

How have DCVs been understood and operationalized?

- Where are there gaps in understanding and how are those gaps being addressed?
- How have affected persons/families experienced DCVs?

How have DCVs been incorporated into the intervention?

- By management
- By direct service provision staff
- By carers
- By affected people
- By others

What have been/are the challenges and facilitators to use of DCVs in the demonstration?

- Culture and language
- Context
- Resources
- Commitment

How useful are the evaluation instruments that are being utilized?

Data were collected through a combination of document review and direct observation, as well as through interviews, discussions, and focus groups.

For the three-day evaluation site visit at Hospis Malaysia, the evaluators conducted the following activities:

- Met and spoke to staff in various positions in Hospis Malaysia over the course of the site visit;
- Attended a focus group of nurses utilizing the Carers Manual;
- Met with affected persons and caregivers in the intervention;
- Observed palliative care training of clinicians from across Southeast Asia;
- Observed daycare services and volunteers working with affected people;
- Provided a presentation to stakeholders about DCVs and conducted a question and answer session; and,
- Observed a meeting of stakeholders who were brought together around DCV by Hospis Malaysia.



For the three-day evaluation visit to KICOSHEP, the evaluators conducted the following activities:

- Led a Site visit to KICOSHEP offices and received a briefing on the operation;
- Reviewed the Decent Care Values in Palliative Care Services Project;
- Conducted a focus group with KICOSHEP staff (not leadership) on their perception of the process of the project to date;
- Received a presentation on the data and results, along with an update on progress of intervention and palliative care development;
- Conducted evaluation sites visit (patients' and carers' houses) – 2 patients, plus inpatient visitation;
- Met with community leaders and government representatives;
- Identified needs for further training;
- Discussed plans to continue DCV interventions beyond the research project;
- Made plans for disseminating project results both within KICOSHEP-K locally and at conferences, in publications, and on the Web; and,
- Discussed any additional issues, such as feedback on the evaluation, suggestions for next steps, and so on.



Qualitative Evaluation Process and Outcomes

This section outlines and describes the evaluation process and outcomes for the Decent Care Values in Palliative Care demonstration projects. Each sub-section is organized by the grantee and the six values where appropriate. Some sub-sections have variability between the two grantees because the information presented is from both the on-site evaluation visits and the grantees own final reports. Each sub-section is split up by grantee to help the reader find similarities and dissimilarities easily between the two demonstration projects.

Hospis Malaysia

Limitations. The evaluative site visit to Hospis Malaysia was conducted only a few weeks after the DCV intervention was fielded, making that visit more formative than summative. The outcomes reported below for Hospis are therefore derived from a combination of evaluator data collection and self-reporting by Hospis. As noted above, direct qualitative data collection over the course of the intervention was limited and therefore, conclusions must be viewed with caution. All data from Hospis Malaysia must also be understood as the result of a very rapid intervention. The brevity of the intervention may limit its demonstrated effectiveness.

KICOSHEP

Limitations. The evaluative site visit to KICOSHEP was made three months after initiation of most of the interventions, so this evaluation was formative and summative. Process and outcome data were derived from the site

evaluation visit and included a considerable amount of self-reporting before and after the visit to KICOSHEP, not all of which could be independently verified.

Affected Persons and Carers Process and Outcomes

Hospis Malaysia

As the evaluation visit occurred two weeks after the initiation of the intervention, outcomes were not observed. The initiation of the process of the intervention was observed and discussed in the site visit report:

The Carer's Guide is being used directly with those providing support to affected people, in this case, persons with life limiting conditions. Affected people are generally in Hospis care less than six months and, more often, less than three. Carers are often family members with little experience of caring for an affected person and Hospis provides additional care for the affected person and support for the carer. The purpose of the intervention is to help carers to be more effective at the care they are providing through being better supported and having better tools with which to manage.

The intervention was just being implemented as the visit was conducted and the site visitors were able to go to three affected persons' homes as carers were provided with the pre-test and a copy of the Carer's Guide. Both the affected person and the key carer were involved in the discussion of the Guide and the

intervention. The intervention is going on currently and so an assessment of how affected persons and carers experienced DCVs is premature. However, at the visits with affected persons and their care givers, there were suggestions of ways in which DCVs might have an effect on the relationship between the carer and the affected person and the carer and professional caregivers. In all three observations, it was clear that the act of the intervention resulted in an understanding and an effect. The understanding was that individual affected persons relied on key carers as part of their “affected family” to work with them on decision making on important issues, and to be an intervener with others on their behalf. This concept of the affected family is a natural extension of extended and interdependent family structures.

Carers were supported through the following directed services, according to Hospis:

- Asking them to use a ‘Distress Thermometer’ to indicate their level and source of distress. Their distress levels are to be assessed during each visit and whenever the needs arise. The carers are empowered to use this as a tool to initiate conversation with the nurses and other care providers.
- Providing information about Hospis Malaysia services, such as who to contact during emergencies; how to order equipment; and how to receive daycare services.
- Providing them resources (websites) to deal with: patients’ physical and emotional problems; medications; family and friends; healthcare providers; daily living; finance; and uncertainty about the future.
- Encouraging carers to seek advice from the Hospis Malaysia nurses whenever the need arises.

In the following section, the process and outcomes for affected persons and carers will be discussed.

The Sample – Hospis Malaysia

A total of forty affected persons and their carers were engaged during the time of the evaluation. Study staff administered a baseline questionnaire to all, as well as a follow-up visit 2-4 weeks after initiation of the intervention to administer a follow-up questionnaire. The interval between baseline and follow-up was very brief. This brevity was artificial in that Hospis needed to develop and

field the intervention in the time available for the project. However, the length of engagement that Hospis normally has with an affected person and her or his carer may also be quite brief. In the future, it will be important for Hospis to utilize the intervention in a more natural timeframe.

One of the observed challenges for the evaluation of the Carer’s Guide is that both affected people and carers appeared to have a high degree of confidence and engagement with Hospis staff prior to the intervention, which was noted in observations and at baseline. While this clearly is a positive situation, it also means that the baseline for some of the measures was quite high, and seeing effects, even if they occurred in the brief period of the intervention, may be very difficult. An additional circumstance that may make understanding of both process and outcomes more difficult is that of working with an affected family rather than a single carer and a separate affected person. As noted both through observation and by Hospis Malaysia staff, the idea of the individual being the sole decision-maker was not generally culturally congruent.

Hospis noted that “Affected people already felt that they were respected by Hospis Malaysia and in general by hospital based health care providers. Agency was a difficult concept for affected people to discuss this, may be because they did not expect to be in control of health care decisions as these are commonly taken by the family unit with varying degrees of participation by affected people. The other factor is the health care culture, communication skills and the concept of shared decision-making are relatively new concepts among health care providers in Malaysia and palliative care is a new specialty.”

The quantitative data provide a window into how carers experienced the intervention. Interestingly, the outcomes show that for carers, the Guide and the process of using it were positive. Hospis reported the following qualitative data collected from a sample of carers and affected persons.

Agency & Dignity

Hospis recounted that: “Most patients felt respected by health care providers, although there were some instances particularly relating to breaking bad news in hospital that were very negative. They concurred with the organisational self assessment that they were treated with respect and dignity by Hospis Malaysia staff. However a diagnosis

of cancer is seen as a stigma and some were reluctant to tell friends or had to take time to correct some of the myths around their illness." Experiences in hospitals were variable.

Hospis noted that: "The project identified that families (carers) were experiencing more issues with agency and dignity than affected people. This may be related to the concept of autonomy, which in this culture relates more to the family unit than to the individual. There is also a more patronising culture in health care delivery and this may influence affected people's expectations of agency."

Interdependence and Solidarity

Hospis reported that: "Most affected people and carers drew support only from health care workers and immediate family. Family members supported them both emotionally and practically with financial aid or transport to hospital. There was little involvement of other community resources. However in terms of spiritual care several mentioned religious groups coming to pray for them. There was a sense that the affected people and their carers were quite isolated in the community and that there is a lack of awareness in the community as well as lack of services apart from the community palliative care team. They expressed a need for more financial support and support with transport to and from hospital."

Subsidiarity and Sustainability

Hospis described that when: "Asked about what they needed from health care services in particular Hospis Malaysia, affected people and their carers said they lacked and wanted information about: Hospis Malaysia services, including accessibility; how to care for the patient, including emergencies; and where to source for this information. Most carers lacked and wanted social and emotional support. Most care provision centred around patients rather than their carers. The carers were unsure who and where they can seek help from for their own needs."

From the interviews, it was found that the needs of the patients and carers changed with time. Although patients' needs were assessed by the Hospis Malaysia nurse at the beginning of the care process, there was no system for reassessment subsequently and carer's needs are not part of the routine assessment.

The Sample – KICOSHEP

A total of 122 individuals participated in the research at KICOSHEP. This included 60 patients who completed the African Palliative Care Association (APCA) Palliative Outcome Scale (APCAPOS) on three separate occasions: prior to the introduction of the intervention, during the intervention, and post the intervention. The 60 included 20 persons from each of three different slum communities in Nairobi (Fuata Nyayo, KPA, and Matumba). In addition KICOSHEP engaged another 62 people to participate in a variety of ways including: 1) focus groups for affected people – 24 persons, caregivers – 8 persons, and pediatrics – 24 persons; 2) In-depth interviews with home bound persons – 2, members of the public – 2, and public officials – 2.

The diagnoses of the 60 patient sample included 30 people living with HIV, 18 cancer patients, and 12 with other conditions including diabetes, brain trauma, hypertension, and kidney problems. The sample was stratified by slum community, with equal numbers from the three. Patients were mostly referred from health facilities and were a purposive sample. The focus groups and interviews occurred at the beginning of the project and were used to help inform the development of the interventions used in this study.

KICOSHEP Outcomes

Agency & Dignity

- Shared confidentiality process developed with new informed consent.
 - KICOSHEP changed its consent to make sure that patients know that they are being cared for by an interdisciplinary team, which will share information to improve care.
- Increase in cancer patients admitted (1/3 of cancers in Kenya are HIV related) 25 current cases. One of the changes due to the intervention was this increase in cancer services related to their expansion of palliative care services and increased capability to provide services.
 - KICOSHEP is now seen and known as more of a palliative care organization, as opposed to an HIV/

AIDS organization, it is now routine for people with cancer to enroll in the program.

- Increased urgent access, from 2 days to same or one day.
- Decrease in pain scores, on a 0-10 scale, after using opioids from 7-10 to 0-2. The pain scale is being used with all patients.
 - Since the use of opioids has been introduced, patients with pain have had it relieved. Twenty percent of patients had pain levels between 7-10 on the 0-10 scale on admission. Average pain scores were now lowered to 0-2.

Interdependence and Solidarity

- New KICOSHEP Strategic Plan incorporates DCV's with input from all stakeholders. Easier to accept palliative care from KICOSHEP than hospice.
 - KICOSHEP believes that they have improved the survival of patients referred at the last stage, through respite care, improved pain relief and overall improved health management; this is based on anecdotal evidence.
 - The use of a memory book has been extended to adults and incorporates a component on pain.
- Reductions in return to hospital for inpatients at KICOSHEP and for home care patients.
 - Patients in the inpatient respite/treatment center are returning home more often and not being admitted to hospital as often now that staff have access to opioids and increased skills in palliative care. An analysis will be done to compare re-hospitalization rates during the project with previous rates.

Subsidiarity and Sustainability

- Affected people have increased choice of CHWs and National Changes have occurred.
 - With the implementation of the new CHW strategy, patients now have more choice as to which CHW they will access at home. The CHW concept was developed by KICOSHEP and has now been embraced by the government to expand access to

CHW throughout Nairobi. Each CHW monitors up to 160 families in a cluster. A Community Health Council coordinates the care provided and the community selects the CHWs.

Organizational/Staff Process and Outcomes

Hospis Malaysia

In addition to engagement with carers and affected persons, Hospis Malaysia engaged all of Hospis Malaysia staff and a wide group of community stakeholders in the intervention. Information from staff regarding the intervention was gathered through focus groups. External stakeholders were brought together in two meetings focused on engagement around DCVs and on creating a more seamless system of communication and support.

At Inception of Intervention

Nurses are the primary Hospis caregivers, with engagement by clinicians. In a focus group during the evaluation site visits, Hospis nurses noted that they had had concerns about the intervention as well as hopeful expectations of it. The nurses had been concerned that the intervention would create additional work. In the piloting of the intervention, the nurses had already experienced some positive effects of the use of the intervention materials with carers and affected persons. Rather than more work, the nurses found that the materials that they were providing to carers provided a vehicle for the carer to be more actively engaged with the nurse and to have a better grasp of some of the information and elements of care that might be needed. Physicians were not interviewed during the site visit.

Late in the Intervention

Hospis Malaysia conducted a focus group with Hospis nurses late in the intervention to explore the same topics. Hospis reported that:

- The nurses view the Carer's Guide as saving time—they do not have to write or explain in so much detail about the service.

- Nurses reported varying usage of the Guide, some had not got into a routine of giving it to each family. Some believed that the Guide is under-used by carers, estimating that only 10% use it.
- Nurses noted some concerns regarding the potential for abuse of information in the Guide, such as handing emergency contact numbers to those not registered with the service.
- There were also concerns that too much information may cause anxiety.
- Some nurses observed that the Guide is seen by some carers as a form of support that helps them to understand that they are not alone.
- The nurses reported that the medication and notes pages were particularly useful.
- The nurses said that they enjoyed being part of the research process and, in particular, taking part in discussions.
- One nurse commented that the Guide gave her something to show people to illustrate what she is doing professionally and that this gave her a sense of pride in her work.
- Nurses reported that the Distress Thermometer was not used much, although some found it useful as a basis for discussion but thought carers found it difficult to give a number. Overall, the nurses were not enthusiastic about the Distress Thermometer.
- The nurses observed using the Guide is a new experience, and that health care providers need to get used to using it.
- Most of the nurses said that they would prefer the Guide to be smaller but not too thick, feeling that if it is too thick, carers will not read it.
- Nurses said that they wanted less writing, shorter words, point form, and pointed out some errors in translation.
- Hospis also conducted a focus group with physicians after one month of using the Guide. The following came from that focus group.
- Patients and carers did not really seem to be reading the Guide. Physicians were concerned that the lack of use could be due to issues of literacy and language.
- Physicians were concerned that there is not enough information for non-cancer patients.
- The doctors reported being selective about who they gave the Guide to, based on assessment of potential burden to carer and/or affected person. There was particular concern that the Guide might create anxiety if carers have too much information.
- Limited use of distress thermometer but felt it helped carers identify specific areas of distress.
- They liked the appearance and content and felt the colour coding relating to different topics was useful. They also liked the medication chart. They were split in their views about the size.
- They thought that the content should be simplified. The websites were useful because it was noted that many carers do access the internet without knowing which websites are reliable.
- It was useful in dealing with large families and many carers, they can be asked to refer to information rather than the health care providers repeating it.
- Carers may not be ready to read it immediately and may prefer to wait.
- Carers are pleased to receive the guide even if they do not read.

Clinician Response to Guide

As can be seen from the limited early response from nurses and the later response from nurses and physicians, the response to the Guide was largely positive with some concerns regarding form and use. The information was seen as useful for the carer and may have helped the carer feel more in control while providing the carer with information that they could use with other family members. Nurses and physicians both cited a concern that too much information could create anxiety for carers; physicians reported that they had been selective about providing the Guide to patients. The way in which these concerns were handled suggests that some clinicians are not recognizing issues of agency for affected persons.

Nurses and physicians suggested improvements that they felt could be made to improve utility of the Guide. Both groups saw the Distress Thermometer as being the least useful element, although physicians believed that it could

help to identify specific areas of concern. Issues of literacy of the client population and the language level used in the Guide were also cited.

Other Outcomes

Hospis Malaysia cited additional outcomes of the development and implementation of the Carer's Guide. Hospis noted that: "Within the organization the intervention has been a useful tool, creating a sense of solidarity between affected people and carers and health care providers. This was shown in the focus group discussions held with nurses and doctors after the intervention. Being part of a research process was also reported to be a positive experience by the nurses focus group and highlighted the need for the organization to incorporate decent care values into its working processes."

Finally, Hospis reported that: "...carers expressed interest in contributing to the development of palliative care services, at the time of being interviewed many were too busy with their duties as a carer to become more actively involved in organisations. A follow up study may show us whether their interest is sustained over a longer period of time. Affected people are often too unwell to attend meetings etc but this may change as there is a trend for earlier referrals to the service."

Organizational/Staff Outcomes – KICOSHEP

KICOSHEP

A palliative care physician, Dr John Weru, was engaged to support the clinical team once a week, seeing patients and training the new clinical officer on the palliative care approach. We met with the interdisciplinary clinical staff without leadership present to gauge their understanding of DCV and the project. The staff articulated a clear understanding of the values of agency, dignity, interdependence, solidarity, and sustainability. As is common they did not understand subsidiarity, but were able to grasp the idea of local control as a definition. The staff team also participated in the development of a new strategic plan for KICOSHEP that clearly incorporated the values of Decent Care as an organization. Changes noted include:

- Moving from biweekly to daily team meetings (Interdependence, Solidarity). The team is now more up to date and flexible about who gets seen on a given day.
- Expanding from working/networking with one hospital (Kenyatta) to engaging eight Nairobi hospitals. (Interdependence).
- Creating a community liaison desk, which links the program directly with the community and has a core responsibility of ensuring a healthy relationship between the organization and the community. This desk is manned by a volunteer social worker. (Interdependence, solidarity)
- Reducing staff need to consult with the Executive Director as staff feel more empowered to deal with complex issues.
- Increasing (Interdependence, Solidarity) livelihood skill development by increased family involvement.
- KICOSHEP has an extensive program to teach livelihood skills to affected people. The new thing they've changed is that they are now engaging family members to take over a business when the affected person becomes ill so that family income is maintained.

Community/Systems Outcomes

Hospis Malaysia

In the process of developing and conducting the intervention, Hospis brought together a group of stakeholders to immediately review the intervention, but also to look at gaps in services and places where the systems functioned less than optimally. These individuals represented affected persons, carers, clinicians, and policymakers. Bringing together the stakeholder group opened up new conversations about the process, content, and intersections of care for affected people. These conversations have both immediate and longer term potential for improvement in the quality and continuity of palliative care. The stakeholder's group evolved through the time of the intervention and has begun actively addressing those identified issues. Those policymakers and palliative care providers who have engaged with Hospis around the intervention have learned the values and their utility through this process; their use of them is unknown at this time but warrants study.

Hospis also noted that: “This project was useful in demonstrating the benefits to other palliative care providers of working together across all organisations to pool resources and develop palliative care. Hospis Malaysia now is part of the consultation group for the development of a National Strategy for Palliative Care and will therefore be able to push the agenda of decent care.”

Hospis also found that: “By inviting stakeholders to 2 meetings during the course of this project, ties have been strengthened but this is mainly amongst health care providers. It also gave an opportunity for affected people and carers to exchange views with the wider palliative care community, advocacy workers in other organisations and other health care providers. The challenge is to continue these meetings. The project identified a lack of wider community support for affected people, in the future the Carer’s Guide may help to increase awareness of palliative care. The nurses and doctors focus group observed that the guide was being read by visitors to affected peoples’ homes.”

Hospis has a significant position as a thought leader and provider of palliative care training across Southeast Asia. As Hospis trains palliative care providers from across Southeast Asia, DCVs are being incorporated into their training, resulting in a further diffusion of the values. The fidelity and use of the values is unknown but warrants study.

KICOSHEP

During the evaluation visit the team had an opportunity to discuss KICOSHEP’s impact on the general health care and community based care system in Nairobi. A representative from the Ministry of Health’s community based care office informed us that KICOSHEP was one of the originators of home-based care in Kenya and that their impact has been very significant. They are considered a model for community based home based care. In addition, the Kenyan Association for Hospice and Palliative Care now views KICOSHEP as a potential role model for other community-based organizations (CBOs) in Kenya. It is hoped that they will be able to teach other CBOs about how to graft palliative care into the home-based care system, particularly in communities where there are no hospice services.

Decent Care Values

Organizational Self-Assessments

Both Hospis Malaysia and KICOSHEP were asked to conduct an organizational self-assessment at the beginning of the project and to repeat of the self-assessment at the end of the project. This assessment used a 0-5 point Likert scale for the organization to rate itself (Rating 1= Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always) on the degree to which it met a series of attributes including: core attributes of Decent Care and core attributes of Agency, Dignity, Interdependence, Solidarity, Subsidiarity, and Sustainability separately. Finally each organization was asked to answer in narrative form the following three questions:

1. *What do I/we need now?* Central to each patient assessment is the need to work with the patient and carers to identify what is important to them and what they hope for. With this goals of care are set and together needs are identified in terms of symptom management, psychological/spiritual support, and practical help, e.g., loan of equipment.
2. *How do I/we live in the face of disease?* This question is addressed by looking at meaning and helping to make sense of what has happened. It is also addressed by working with patients and carers, providing services such as practical support, education in nursing care, after-hours emergency care, and access to other health care services, as needed.
3. *How might I/we flourish?* For the patient and carers this question is addressed by looking at goals of care that respond not only to medical needs but also address goals in terms of what patients would like to achieve in their lifetimes. Volunteers help to support some of these goals and daycare offers a more creative approach to care.

In addition, KICOSHEP carried out an additional self-assessment using the *African Palliative Care Association’s Standards for Providing Quality Palliative Care Across Africa*. This additional self-assessment was repeated at the conclusion of the pilot project to determine the degree of improvement in the provision of palliative care by KICOSHEP. The results of these organizational self-assessments are summarized below.

In general terms KICOSHEP and Hospis expressed both improvement and deterioration in their self-assessments, though much more improvement than decline. This may be due to the programs having developed a greater appreciation of the reality of their abilities to meet the core attributes. It may also reflect a much stronger understanding of the meanings of the values and the myriad levels of effort required to affect and live the change that they entail.

Comparison of ratings by category for Hospis Malaysia and KICOSHEP

Differences in self-assessment for Hospis Malaysia and KICOSHEP may not be particularly meaningful in that they are affected by culture, values, and history but are presented here for descriptive purposes. A perfect possible score was 125 (5 x 25 questions). Outlined in Table 1 are how each organization's scores changed.

Overall, Hospis Malaysia improved by a total of 7 rating points. However they showed improvement in Core attributes of Decent Care (2 points), Dignity (1 point), Solidarity (3 points), and Subsidiarity (3 points) but had declining scores in Agency (-1 point) and interdependency (-1 point). Sustainability remained unchanged. Overall KICOSHEP improved by a total of 14 rating points. They showed improvement in all areas with the exception of staying the same but at generally high levels in Decent Care and Solidarity.

KICOSHEP Palliative Care Self-Assessment

In January 2011 we asked KICOSHEP to use the APCA *Standards for Providing Quality Palliative Care in Africa*, which we provided to them. This was done to determine

how well their organization met standards for palliative care that were developed specifically for Africa.

In September 2011 we requested that KICOSHEP re-complete a palliative care self-assessment using the same APCA Standards. In the interim APCA had developed a more formal Standards Self-Assessment Tool, which KICOSHEP used. The APCA Standards are divided into three levels (basic, intermediate, and advanced). The initial self-assessment was done in a more general way by noting for each major section whether KICOSHEP was meeting the standard at a basic, intermediate, or advanced level.

The results of the initial self-assessment found that for the 31 sections measured KICOSHEP was meeting 35.5% of the standards at the basic level, 45.1% of the standards at the intermediate level and 19.4% of the standards at the advanced level. On a three point scale with 1 = basic, 2 = intermediate, and 3 = advanced KICOSHEP self-assessed its level of compliance at 1.84, closer to intermediate than basic.

The more sophisticated Standards Self-Assessment Tool utilized a 5- point rating scale for every individual standard with 1 = never met; 2 = rarely met; 3 = sometimes met; 4 = often met; 5 = always met. The tool measures 554 standards, including 81 basic standards, 309 intermediate standards, and 164 advanced standards. The results of KICOSHEP's self-assessment in the post intervention period are summarized below.

Comparing the results of the palliative care self-assessment done prior and following the beginning of the demonstration project is challenging due to the fact that a different scale of measurement was used. Doing a

Table 1. Decent Care Values Organizational Self Assessment Pre/Post Results

Site	Hospis Malaysia	Hospis Malaysia	Hospis Malaysia	KICOSHEP	KICOSHEP	KICOSHEP
Value/Time	Pre-Intervention	Post-Intervention	Change Score	Pre-Intervention	Post-Intervention	Change Score
Organizational/Governance	11	13	+2	14	14	0
Agency	23	22	-1	21	23	+2
Dignity	11	12	+1	13	15	+2
Interdependence	18	17	-1	21	24	+3
Solidarity	3	6	+3	13	13	0
Subsidiarity	7	10	+3	11	14	+3
Sustainability	14	14	0	8	12	+4
Totals	87	94	+7	101	115	+14

global scoring using average score results can make a very general comparison.

For the pre-intervention self-assessment using the 3-point scale an average score of 1.84 means that there was an overall standards compliance of 61.3%. For the post-intervention self-assessment using the 5-point scale an average score of 4.28 means that there was an overall standards compliance of 85.5%. This then is one way of characterizing the progress made by KICOSHEP on palliative care development in the course of the demonstration project.

Quantitative Data

Grantees also collected a variety of quantitative data through survey interviews with affected persons and their families. Each grantee conducted before and after administrations of a survey instrument Altarum provided them. The survey was reviewed and approved by a U.S. institutional review board, and also by local research ethics committees in Kenya and Malaysia. Informed consent was obtained from all participants. In Malaysia, the survey was administered to a sample of 40 affected persons and carers before the intervention then again approximately 2-4 weeks post-intervention. In Kenya, the survey was administered to 60 individuals pre-intervention in May 2011, then twice again, once in July 2011 and a final time in October 2011.

The survey instrument included two sets of items: the first were drawn from the African Palliative Care Association's Palliative Care Outcomes Scale (APCA POS) (Harding et al. Health and Quality of Life Outcomes 2010, 8:10) and the second included a series of items that assessed whether decent care values had been adopted or internalized by affected persons and carers. The first two supplemental survey items were asked of affected persons while the second two items were asked two times, first with respect to the experience of care as delivered by the grantee and second with respect to the experience of care as delivered by organizations or individuals other than the grantee.

Exhibit 1: Supplemental Survey Questions about Decent Care Values

Question	Response Options
How important is it to you to be able to manage and direct your own care?	0 (no, not at all important) - 5 (very important)
Over the past three months, have you been able to let your main provider/doctor know what you need from them?	0 (no, not at all) - 5 (as much as wanted)
Have you been as involved in decisions about your health care as you wanted to be?	0 (no, not at all) - 5 (as much as wanted)
Have you been treated with respect and dignity by those who are helping with your health care?	0 (no, not at all) - 5 (yes, all the time)

Results of Supplemental Survey Questions about Decent Care Values

To assess whether the interventions had an effect on agency and dignity among affected persons, respondents were asked about the importance of managing one's own care and separately about their ability to let the doctor know about their needs. Managing and directing one's own care was more highly valued among affected persons after the interventions than before the interventions among both grantees, but the difference was statistically significant ($p=0.03$ or better) only in Kenya.

Affected persons in both Kenya and Malaysia were more likely to report being comfortable with telling their doctor what they needed after the intervention than before. In Kenya, the July assessment responses in the final survey wave showed a statistically significant increase (+0.63, $p < 0.001$) over baseline. The increase observed in the data from Malaysia showed no significant increase.

Discussion of Findings

Hospis Malaysia

In the Hospis Malaysia demonstration, we saw an organization take the values of Decent Care and use them to attempt to affect change at three levels. At the organizational level, Hospis wove the values into all aspects of their work. In working with affected persons, they were able to develop

an intervention that appears to have helpful effects for carers, which should, in turn, result in the provision of higher quality care for the affected person. In addition, the successful intervention should bring carers and affected persons into a relationship that is marked by greater interdependence and solidarity, and which should support the agency of the affected person. That agency, however, as noted, is mediated by the cultural context which may focus more on an affected family than an individual.

Hospis reached out to a variety of stakeholders to explore the development of its intervention and to engage in a larger conversation about palliative care and the system of care. The bringing together of these stakeholders has already resulted in useful conversations. The challenge will be to continue the conversations, ensure that affected persons and carers are central to those conversations, and to develop system improvements that serve Decent Care Values.

Hospis noted that: “The unexpected changes were related to the process of the project more than the intervention. Involving stakeholders and all staff of the organization in the project strengthened ties between all involved and helped to focus care to affected people rather than part of routine service delivery.”

Finally, Hospis, which trains palliative care clinicians throughout Southeast Asia, has incorporated DCVs into all of its trainings. This use of DCVs is not a direct result of the intervention, but part of an ongoing incorporation of the values into Hospis’ work. This use of the values to train palliative care clinicians has potential for far-reaching effects on the shape and provision of palliative care in Southeast Asia.

KICOSHEP

In the KICOSHEP demonstration, we were able to see how both Decent Care Values and palliative care services can improve, expand, and enhance the services of a CBO. There are many communities in low and middle income countries where CBO’s provide home based care but are not skilled up to include palliative care services and there are usually no hospices in the community. CBOs are in an excellent position to embrace Decent Care Values; the combination of Decent Care Values and palliative care services helps to complete the continuum of care.

KICOSHEP would like to replicate the Decent Care Values in Palliative Care Services programs in other parts of the

country by training nurses and caregivers in areas like Malaba in W. Kenya, Kisumu in Myanza, and Machakos in Eastern Kenya and by teaching other CBOs in Kenya and elsewhere how to graft Decent Care Values and palliative care services into their existing home-based care programs.

The Way Forward

Lessons learned in this demonstration point to ideas for future activities that might continue to build understanding of how the Decent Care Values bridge human rights principles with the practice of medicine. Overall, we have demonstrated that Decent Care Values are related to palliative care values and that it is feasible to improve palliative care services through inclusion of this values model. We have also demonstrated the following:

- **Cross-cutting cultural resonance.** Applying the Decent Care Values across cultures was feasible, the demonstration projects were in a “middle-class” southeast Asian city of Kuala Lumpur in Malaysia; and in a township of Nairobi in Kenya. These two locations are radically different in populations, religion, economics, and culture – yet both found resonance and applicability of the values.
- **Cross-cutting relevance in differently resourced countries.** Based on the outcomes and changes implemented in Malaysia and Kenya, we have demonstrated that using a values based approach can facilitate change in a resource-poor or a resource-rich environment – it levels the playing field for all.
- **Identifying the significance of role and voice.** Using the Decent Care Values refocuses and increases the importance placed on understanding the separate and different roles and voices in the healthcare system, e.g. affected person/patient, family, physician, nurse and other supports.
- **Using the Decent Care Values can be a model for change.** Providing a way for communities to engage in dialogue about what they need and what they value in the healthcare setting creates paths forward to address needs and gaps on the individual, community and social levels.

Quotes from the Grantees

KICOSHEP

“Palliative care and Decent Care networks strengthened number of organizations and networks for KICOSHEP and through these new networks, KICOSHEP was able to secure morphine and DF118 drugs for pain. Before this demonstration project, palliative care was only done in a hospice but it was made clear [by the Altarum TA team] that we could provide palliative care at home the way KICOSHEP has been doing its other home based services. The Altarum TA team assisted us with knowing what we can do better, what we can change and what can be done at the organization level.”

Hospis Malaysia

“The [Decent Care Values] self assessment was very valuable (going through the responses on-site) and being questioned by someone outside of our organization was really helpful to think through what we’re doing. Having the [Altarum TA team] onsite to provide training gave us a much clearer understanding about Decent Care Values, this provided clarity and a way forward. We felt much was achieved by being able to speak face to face and the visiting team clearly understood Hospis Malaysia. Having their presence at the [community] stakeholders meeting provided Hospis Malaysia with a higher platform for other people to come in and helped to encourage wider interest.”