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DECENT CARE VALUES IN PALLIATIVE CARE SERVICES A FORMATIVE EVALUATION

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ACRONYMS

AFRO	Regional Office for Africa (WHO)
APCA	African Palliative Care Association
COTR	Contracting Officer's Technical Representative (USAID)
DCV	Decent Care value
EMRO	Regional Office for the Eastern Mediterranean (WHO)
ILO	International Labour Organization
NGO	Non-governmental organization
PLHIV	People living with HIV/AIDS
USAID	United States Agency for International Development
WHO	World Health Organization
WPRO	Regional Office for the Western Pacific (WHO)

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EXECUTIVE SUMMARY

Decent Care is an emerging health care-related paradigm that seeks to move past “patient-centered care” and “patient empowerment,” both of which grant a *role* to affected persons in making decisions about their own health care, to placing affected persons at the *center* of health care planning and implementation. The concept of Decent Care was developed in 2006 through a collaborative process sponsored by the World Health Organization (WHO), the Ford Foundation, and the Altarum Institute. A nearly week-long meeting, held in Vevay, Switzerland, brought together a host of stakeholders, including affected individuals, health care providers, policymakers, and others. The central outcome of the meeting was the identification of the six core values that define Decent Care:

- Agency
- Dignity
- Interdependence
- Solidarity
- Subsidiarity
- Sustainability

Implementing these values requires that the health care process be embedded in the larger context of family and community, with the active involvement of those who make decisions about policy and resource allocation. Without this engagement, care will not be decent.

Following the 2006 Decent Care consultation, which resulted in the definition of Decent Care, four additional meetings were held, including a global consultation in Tunisia in 2009 and regional meetings in Jordan, Uganda, and Vietnam in 2010. These four meetings explored the application of Decent Care values specifically in the context of palliative care services in diverse cultures and conditions. This report describes the results of a formative evaluation conducted in late 2010 and early 2011 to assess the effects of four palliative care-focused consultations on the personal and professional lives of the participants, and to understand the experience of utilizing the Decent Care values (DCV) in diverse settings. The following questions guided this evaluation:

- Who has applied Decent Care values?
- How have the concepts and values been applied?
- What has the experience been of those who have applied the concepts and values?
- What facilitators and barriers were encountered?
- What have been the effects and outcomes to date?
- What are the plans, if any, for future use?

A total of 74 meeting participants (from a potential respondent pool of 137 with verified contact information) responded to an online survey, composed primarily of open-ended questions regarding implementation of the six values. Respondents were divided into three general categories: affected persons, including family members and caregivers; activists, health care and service providers, advocates, and employees of non-governmental organizations (NGOs); and policymakers and employees of governmental and donor agencies.

Respondents were strongly positive about the concepts and values of Decent Care, with 97% of respondents finding the meetings relevant and/or useful. Of the 97%, only 16% had not used the information they had gained at the meetings; those who gave specific reasons cited lack of opportunity or other barriers to implementation. A few said they had already applied the values.

Of the 74 respondents, 57 (80%) indicated they had applied the values since attending one or more of the four meetings. The most commonly applied values were agency and dignity, followed by interdependence and solidarity, and then subsidiarity and sustainability. The most frequently cited values to be incorporated into respondents' lives and work are shown in Table I, in order of frequency:

Table I. Decent Care Values Used by Participants (n=74)

Decent Care Value	Percentage Utilizing Value
Dignity	87.5%
Agency	82.5%
Solidarity	75.0%
Interdependence	67.5%
Sustainability	62.5%
Subsidiarity	55.0%

Table 2 displays the specific Decent Care values used by each participant group. While it is not possible to draw strict comparisons, given the different sample sizes of the participating groups, the data suggest that policymakers used the values slightly more uniformly. Of 27 respondents in the activist/service provider/health care provider/advocate/NGO category, 26 used the value dignity. This is not surprising given that it was already a familiar term and an essential value in palliative care. These participants also interpreted interdependence in terms of their relationships with affected persons and with each other in the provision of care.

"Decent Care values were a turning point in my life."
- Tunisia and Uganda, Activist/Provider

Table 2. Values Used by Participant Type (n=40)

Decent Care Values Used	Affected People/Family (n=4)	Activist/Service Provider/Health Care Provider/Advocate/NGO (n=27)	Policymaker/Donor/Government (n=9)	Response Percent	Response Count
Agency	4 (100%)	21 (77.8%)	8 (88.9%)	82.5%	33
Dignity	3 (75.0%)	26 (96.3%)	6 (66.7%)	87.5%	35
Interdependence	0 (0.0%)	23 (85.2%)	4 (44.4%)	67.5%	27
Solidarity	1 (25%)	23 (85.2%)	6 (66.7%)	75.0%	30
Subsidiarity	0 (0.0%)	15 (55.5%)	7 (77.8%)	55.0%	22
Sustainability	1 (25%)	17 (63.0%)	7 (77.8%)	62.5%	25

Analysis revealed that respondents in all three groups embraced the personal-level values of agency and dignity. For those working in palliative care, these values were often seen as already being an important part of the palliative care philosophy. These were also values that participants most often found accessible both conceptually and in terms of their ability to affect a change. While many respondents stated that they had used agency in their work, some appeared to be using the term in a way that is more consistent with a patient-centered care framework than with Decent Care.

Solidarity and interdependence were also seen as accessible and useable values, with interdependence trailing solidarity. Subsidiarity and sustainability were adopted least often, but were in line with the numbers of donors, policymakers, and governmental representatives at the four meetings.

For those engaged in palliative care, the clearest challenge to utilization of Decent Care values was an oft-cited belief that the values were already in use and the perception (by a minority) that they are redundant to palliative care. Given that Decent Care was introduced as a comprehensive concept at the meetings, there was a surprising lack of comments or descriptions of how Decent Care could

“The DCVs have helped me in humanizing the process of providing care for the PLHIV in this part of the world. This kind of experience naturally perpetuates itself.” (Vietnam, activist/provider)

inform efforts to improve, expand, or create the upstream support systems that make quality palliative care at the level of the affected person possible. This may reflect the relatively small number of respondents who identified themselves as policy makers. Practitioners and activists are often focused on more immediate changes while policy makers are required to think in terms of larger systematic change. Alternatively, it is possible that the respondents who identified themselves as policy makers were already familiar with Decent Care.

The practical understanding of Decent Care values is likely limited because Decent Care, as a set of values intended to guide the development and implementation of a system of health care centered on the affected person, is just beginning to spawn demonstrations. Part of the challenge will be to encourage professionals and affected people to step beyond their comfort zones and think about how Decent Care can inform their planning and strategy. Then people may begin to address the systems in which they work. At least three critical conditions must be addressed before Decent Care values can be adopted:

- Additional facilitated and reported opportunities for regional/state/local discussions of the values, implementation opportunities, and implications are needed.
- Case studies of demonstrations undertaken of Decent Care values will be important to providing examples that can be studied for practical lessons and trends in challenges and facilitators.
- The development of linguistically accessible educational materials on Decent Care values, based on the four meetings and on subsequent utilization of the values, will allow for wider dissemination and potentially for utilization of the values.

INTRODUCTION

OVERVIEW OF DECENT CARE

The concept of Decent Care moves past “patient-centered care” and “patient empowerment,” both of which grant a *role* to affected persons in making decisions about their health care, to placing affected persons at the *center* of health care planning and implementation. The Decent Care movement challenges the existing provider-centric norms of (Western) medicine and asserts that individuals must be fully engaged in the health care process rather than simply passive recipients of treatments and/or services. It also reaches beyond the traditional patient-provider dyad to include the community in problem-solving and supporting care.¹ As part of the process, Decent Care adopts a language that shifts the discourse that makes “affected persons” the focal point of the health care process. Ultimately, it is an expansion and elaboration of Principle IV of the 1978 Alma Ata Declaration on Primary Health Care:²

*The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.*³

Decent Care took its inspiration from the global *Decent Work* movement of the International Labour Organization (ILO).⁴ The concept of decent work expands past the idea of work as solely an income-producing endeavor to consider the voices and aspirations of people with respect to their working lives. Work that is decent—that is, respectful of an individual’s humanity, personal dignity, family stability, and community ties—paves the way for broader social and economic advancement by strengthening individuals, their families, and their communities.⁵ The key principles of Decent Work are freedom, equality, security, and dignity. Decent Care echoes these principles by placing the affected individual at the center of all care, responding to her or his particular needs within the context of illness to create a comprehensive system of care that endeavors to meet those needs.⁶

The concept of Decent Care was developed in 2006, when the first Global Consultation on Decent Care was held in Vevay, Switzerland. Sponsored by the World Health Organization (WHO), the meeting brought together 40 individuals, including affected people, health care providers, faith leaders, social scientists, ethicists, and philosophers to define the values inherent in the provision of Decent Care, and to consider its practical implications for care giving and public policy for people living with HIV/AIDS (PLHIV). The fundamental conclusion of this first meeting was that:

¹ Ferguson, J.T., T. Karpf, M. Weait, R.Y. Swift (2006). *Report on the Global Consultation on Decent Care: 26-30 June 2006*. Geneva: World Health Organization, page 4.

² Marshall, K. (2010). *A Discussion with Reverend Canon Ted Karpf*. Downloaded 2-23-11 at <http://berkeleycenter.georgetown.edu/interviews/a-discussion-with-reverend-canon-ted-karpf>.

³ *Declaration of Alma Ata International*. Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. Downloaded 2-24-11 at http://www.paho.org/english/dd/pin/alma-ata_declaration.htm

⁴ Ferguson, J.T., T. Karpf, M. Weait, R.Y. Swift (2009) *Decent Care: Living Values, Health Justice and Human Flourishing*. Report to the Ford Foundation, page 1.

⁵ International Labour Organization (ILO) (2011). *Decent Work Agenda*. Accessed 2-28-2011 at <http://www.ilo.org/global/about-the-ilo/decent-work-agenda/lang-en/index.htm>

⁶ Ferguson, J.T., T. Karpf, M. Weait, R.Y. Swift (2009) *Decent Care: Living Values, Health Justice and Human Flourishing*. Report to the Ford Foundation, page 2.

...each PLHIV should have the most competent care available that responds to the breadth of life and health issues that face her or him, and that the management of that care should be under the individual's direction.⁷

One goal of this meeting was to work toward agreement on a framework for Decent Care that would foster a common understanding of the concept among a diverse set of stakeholders. Because Decent Care calls for a holistic approach to care that addresses not only the individual's physical needs, but also respects her or his dignity and self-worth, a common vocabulary that respects the varied perspectives and common goals of Decent Care advocates is vital for moving the conversation forward.⁸ The Vevay participants were charged with developing *convergence* around the concept of Decent Care, rather than *consensus*. Convergence provides an avenue for participants to develop a perspective on a global understanding while serving as an opportunity to refine concepts in light of local culture, language, and experience. A major outcome of this process was a set of core values that, when fully embraced, make care decent (Table 3).⁹

Table 3. The Values of Decent Care

Individual Values	Agency	Acknowledging the right and responsibility of an affected person to control the resources and methods by which he or she achieves health or responds to illness
	Dignity	Acknowledging the right of the affected person to be treated in a manner that preserves and respects her or his humanity
Social Values	Interdependence	Recognizing that achieving health requires the collaboration of those with different skills and resources
	Solidarity	Recognizing the need of the affected person and her or his family for care and support in achieving health or in living with illness
Systems Values	Subsidiarity	Focusing on the development of systems-level priorities that place the affected person in the center of the health universe and ensuring that available resources are accessible
	Sustainability	Recognizing that a Decent Care system must endure over time, and that this requires system-level support

Source: Vietnam meeting report¹⁰

The three paired sets of values focus first on the affected person, then on the community and the health and services systems, and finally on the systems and policies that support health. The values of agency and dignity are at the heart of Decent Care: without acknowledging, responding to, and respecting the agency of the individual, care is not decent. Also, at its most fundamental, decency requires principled

⁷ Ferguson, J.T., T. Karpf, C.E. Crain, R. Swift, N. Tashima (2006). *Report on the Global Consultation on Decent Care: 26-30 June 2006*. Geneva: World Health Organization, page 3.

⁸ Ferguson, J.T., T. Karpf, C.E. Crain, R. Swift, N. Tashima (2006). *Report on the Global Consultation on Decent Care: 26-30 June 2006*. Geneva: World Health Organization, page 3.

⁹ Crain et al. (2009). *Report on the Global Consultation to Introduce Decent Care Values to Palliative Care Services*. Takoma Park, MD: LTG Associates, page 1.

¹⁰ WHO (2010). *Consultation on HIV Palliative Care and Decent Care Values in the Context of Primary Health Care in Asia, 15-16 March 2010, Hanoi, Vietnam*, page 16.

respect for the dignity of other human beings.¹¹ Examples of the values may be found in the evaluation survey included in the appendix. The movement to incorporate these six values into palliative care services around the world is the focus of this formative evaluation, funded by the United States Agency for International Development (USAID).

THE WHO CONSULTATIONS ON DECENT CARE VALUES IN PALLIATIVE CARE SERVICES

Overview

The initial focus of the originators of the Decent Care concept was mainly in the area of HIV/AIDS prevention and treatment, but the values are applicable to the complete health care spectrum, from prevention to treatment to end-of-life care for those living with life-threatening or life-altering conditions. Building on the momentum of 2006 global consultation in Vevay, the WHO and the Ford Foundation, with support from the Altarum Institute, held a second global consultation in Tunisia in 2009 and three regional consultations in Jordan, Uganda, and Vietnam in 2010. These four meetings were the first opportunity to explore the values of Decent Care in the palliative care context. The purpose of these meetings was to bring together a full range of stakeholders to explore the application of Decent Care values in the context of palliative care services for PLHIV and others living with life-threatening, life-altering conditions.¹² Some of the values underlying Decent Care are already central tenets in some health care contexts, especially in nursing and in caring for individuals in hospitals, hospice, and other assisted care settings.¹³ Thus, palliative care service was seen as a congruent and natural choice for the next setting into which to expand the call for Decent Care.

The intent of the consultations was to bring together stakeholders from across the health care universe, from affected individuals, caretakers, and health care providers to activists, donors, and policymakers. Attendees represented a wide range of organizational affiliations, including national government agencies, international public health organizations, private foundations, faith-based organizations, schools of medicine, professional associations, hospitals and health centers, and charitable services providers. Attendance at the regional meetings was multinational. Many, though not all, of the represented organizations had a mission or vision that focused on palliative care for people living with life-threatening or life-altering conditions. Some attendees did not have a professional involvement, but instead were living with a life-threatening or life-altering condition or were connected to someone who was. In all, 153 participants attended one or more of the global or regional meetings.

The Global Consultation on Decent Care Values in Palliative Care Services: Tunisia

The Global Consultation on Decent Care Values in Palliative Care Services was held in January 2009 in Tunisia. Sponsored by the WHO and the Ford Foundation with support from the Altarum Institute, this meeting continued the process established by the Vevay meeting in that it was a global forum for conversation among affected persons and other stakeholders to identify points of convergence for creating a shared framework for Decent Care in palliative care. The indicators of success for this meeting, which were achieved,¹⁴ included: (1) participants in attendance who represented the spectrum

¹¹ Crain et al. (2009). Report on the Global Consultation to Introduce Decent Care Values to Palliative Care Services. Takoma Park, MD: LTG Associates, page 1.

¹² WHO (2009). Decent Care Values in Palliative Care Services (white paper). Geneva, Switzerland: WHO Office of Partnerships. Accessed 2-24-11 at <http://aidscompetence.ning.com/profiles/blogs/full-concept-paper-decent>

¹³ Ferguson, J.T., T. Karpf, C.E. Crain, R. Swift, N. Tashima (2006). Report on the Global Consultation on Decent Care: 26-30 June 2006. Geneva: World Health Organization, page 33.

¹⁴ Crain et al. (2009). Report on the Global Consultation to Introduce Decent Care Values to Palliative Care Services. Takoma Park, MD: LTG Associates, page 4.

of stakeholders in palliative care services, (2) development of a shared understanding for palliative care delivery that meets the Decent Care standards, (3) encouragement of palliative care projects, and (4) publication of a monograph.¹⁵ Forty-nine participants attended the Tunisia meeting from countries around the world.¹⁶

The Regional Consultations: Jordan, Uganda, and Vietnam

A year after the 2009 Tunisia meeting, the regional consultations were held to provide an opportunity for participation at a more local level, and to tailor the discussion around Decent Care to include greater diversity in local cultural knowledge and experience. While some participants had previously attended the Vevay and/or Tunisia meetings, many were first-time participants in a Decent Care consultation. The first regional meeting was hosted by the WHO's Regional Office for the Eastern Mediterranean (EMRO) in Amman, Jordan, in February 2010. The stated objective of the *WHO Consultation on Decent Care Values in Palliative Care Services* was to explore the potential value of the concept of Decent Care values in palliative care services and the ways in which they resonate across cultures.¹⁷ Discussions revolved around the meaning of and experiences with the various Decent Care values, as well as implementation barriers and potential facilitators. The meeting produced a set of recommendations for expanding the reach of Decent Care values in that region.¹⁸ Twenty-three participants attended the Jordan meeting from Egypt, Lebanon, Pakistan, Palestine, and Sudan.¹⁹

The next regional meeting was coordinated by the African Palliative Care Association (APCA) in collaboration with the WHO and the Regional Office for Africa (AFRO). The *Decent Care Values in Palliative Care Services: An African Regional Consultation Meeting* was held in February 2010 in Kampala, Uganda. This meeting followed the precedent set by the previous meetings by including a range of participant perspectives in a convergence-focused discussion with respect to Decent Care, in this case with an emphasis on African settings.²⁰ The 54 participants at the Uganda meeting represented Cameroon, Ghana, Kenya, Malawi, Namibia, Nigeria, South Africa, Tanzania, Zambia, and Zimbabwe.²¹

The third regional meeting, *Consultation on HIV Palliative Care and Decent Care Values in the Context of Primary Health Care in Asia*, was held in March 2010 in Hanoi, Vietnam, sponsored by the WHO and the Regional Office for the Western Pacific (WPRO). This meeting's objectives focused on sharing experiences and developing annual work plans at the country level for improving access to palliative care while raising awareness of Decent Care values in policy and programming.²² The participant and presenter list included individuals from Cambodia, China, Indonesia, Papua New Guinea and the Philippines, as well as resource persons and observers from India, Thailand, and the United States. A total of 41 persons attended the Vietnam meeting.

15 Lazarus, J.V., T. Karpf, J.T. Ferguson, R. Swift (2008). *Restoring Hope: Decent Care in the Midst of HIV/AIDS*. New York, New York: World Health Organization.

16 WHO (2010). *Consultation on Decent Care Values in Palliative Care Services*, 12-16 January 2009, Tunis, Tunisia, pages 47-52.

17 WHO (2010). *Consultation on Decent Care Values in Palliative Care Services*, 7-9 February 2010, Amman, Jordan, page 1.

18 WHO (2010). *Consultation on Decent Care Values in Palliative Care Services*, 7-9 February 2010, Amman, Jordan, page 8.

19 WHO (2010). *Consultation on Decent Care Values in Palliative Care Services*, 7-9 February 2010, Amman, Jordan, page 15.

20 WHO (2010). *Decent Care Values in Palliative Care Services: An African Regional Consultation Meeting*. 18-19 February 2010, Kampala, Uganda, page 7.

21 WHO (2010). *Decent Care Values in Palliative Care Services: An African Regional Consultation Meeting*. 18-19 February 2010, Kampala, Uganda, page 42-50.

22 WHO (2010). *Consultation on HIV Palliative Care and Decent Care Values in the Context of Primary Health Care in Asia*, 15-16 March 2010, Hanoi, Vietnam, page 5.

Table 4 summarizes the attendance at the four meetings focused on Decent Care values in palliative care. As 14 participants attended more than one meeting, unduplicated total attendance was 153 individuals.

Table 4. Participants at the WHO Consultations on Decent Care Values in Palliative Care Services

Meeting Attended	Participants
Jordan	23
Tunisia	49
Uganda	54
Vietnam	41
Total	167

PURPOSE OF THE FORMATIVE EVALUATION: THE MASTER QUESTIONS

The purpose of this formative evaluation is to assess the effects of the consultation on the personal and professional lives of the consultation participants and to understand the experience of utilizing Decent Care values in diverse settings. The following questions guided survey development, implementation, and analysis.

- Who has applied Decent Care values?
- How have the concepts and values been applied?
- What has the experience been of those who have applied the concepts and values?
- What facilitators and barriers were encountered?
- What have been the effects and outcomes to date?
- What are the plans, if any, for further/future application?

METHODS AND PARTICIPANTS

SURVEY DESIGN AND IMPLEMENTATION

Survey Design

In consultation with the USAID Contracting Officer's Technical Representative (COTR), LTG developed and refined a set of master questions intended to elicit the impact of conference participation on the personal and professional lives of consultation participants and to understand the experience of utilizing Decent Care values in diverse settings. The questions posed were primarily open-ended inquiries regarding participants' experiences with Decent Care values in palliative care after attending one of the meetings. The final set of survey questions was based on the master questions (see above, "Purpose of the Formative Evaluation: The Master Questions").

To streamline the process and reduce the burden on participants who may not have had an opportunity to implement the values, as well as those who did not find the meetings useful or relevant, an initial segmenting question was asked. This segmenting allowed those who did not find the meeting useful or relevant to skip the rest of the questions, and those who found the meeting useful but had not used the values to explain further. Participants in this latter group were asked to explain in detail why they had not used the values, while those who indicated they both found the meetings useful and had implemented at least one value were then asked to identify the values used and provide additional detail for each. Specifically, they were asked to describe their experiences with using the values and any facilitators or barriers encountered, and to provide specific examples or stories if possible. Both groups were asked to note anything about themselves that might provide additional insight into their responses.

Participant Recruitment

Participants from the World Health Organization consultations in Tunisia and the three regional meetings were invited to respond to the survey. Contact information was obtained from each meeting's final report, which produced a list of 153 individuals who had attended one or more meetings. An email contact list was created using the email addresses included in the consultation reports. An initial test message was sent to announce the upcoming survey, which also served as a check on the status of the email addresses. As notices were received of rejected email messages, LTG staff attempted to locate valid alternative addresses by searching the Internet and contacting individuals and organizations that might have up-to-date information. After all avenues for following up on rejected messages were exhausted, the contact list contained a total of 137 addresses that either had not returned rejection notices or had been positively affirmed by the intended recipient. However, while the email system used (Gmail) returns notices for messages rejected outright, it is still possible that some messages to valid addresses or otherwise not returned as rejected may not have reached their intended recipients.

Because the survey was anonymous, participants were asked to self-report only their sex and their *primary* role with respect to Decent Care in palliative care. The three options for primary role were:

- **Affected People/Family:** This category includes those who consider themselves personally (i.e., beyond professionally) affected by life-threatening or life-altering conditions, as well as caretakers, family members, etc.
- **Activists/Service Providers/Health Care Providers/Advocates/NGOs:** This category includes those who provide direct and indirect services to affected persons, and those who consider advocating or acting on behalf of affected people to be their primary role.

- **Policymakers/Donors/Government:** This category includes those whose occupation places them in a position to make decisions regarding health care provision, resources, and policy, but who may not work specifically with or on behalf of affected people.

Survey Implementation

The survey was implemented using SurveyMonkey, a web-based survey service that allows researchers to upload an instrument to the site for completion by invited participants (<http://SurveyMonkey.com>). SurveyMonkey can handle both fixed-response questions and open-ended inquiries of any length. It also has features for response validation and skip patterns to direct participants to different questions depending on earlier responses, and to make sure they answer all relevant questions in the appropriate format. After the questions were developed as described above, they were uploaded to SurveyMonkey and formatted with skip patterns to guide participants to the appropriate sections. The survey was pilot tested by five individuals (not potential participants) who tried the various skip patterns to make sure they functioned as expected, that the questions were understandable, and that the format was clear. The survey was then edited and reformatted to address issues identified during the pilot test.

The 137 meeting participants with email addresses that had not returned rejection notices were invited to respond to the survey via an email invitation that included a link to the SurveyMonkey site. A total of four reminder messages were sent out over increasingly shorter intervals for five weeks. The last message also offered to provide a Microsoft Word version by email for participants who were unable or preferred not to respond to the online survey (See Annex B).

Data Analysis

The data were extracted from SurveyMonkey in Microsoft Excel format and reformatted for use with ATLAS.ti, a qualitative data analysis software package, and with Microsoft Word. The fixed-response questions (sex, participant type, values used/not used) were analyzed using SurveyMonkey's "Crosstab Responses" feature. This information was collected primarily for background and segmenting for analytical purposes.

Analysis of the open-ended responses was conducted using the "Constant Comparative Method."²³ This method takes an inductive approach in which data are examined throughout the data collection period for new meaning and insight. The process is iterative; the data are revisited on multiple occasions and new themes and patterns are identified on an ongoing basis. An initial set of codes based on the survey questions was created, and new codes were added as needed. These codes were assigned to the participants' textual responses using ATLAS.ti software. After coding was completed, text corresponding to a given code was extracted for all participants and by meaningful subsets of the respondents, such as participant type. The output from this last process is essentially a cross-tabulation of the open-ended responses by the selected subset. These segments were inspected for themes and patterns that illuminate the perspectives of the program participants and answer the master questions (Section B.3).

²³ Glaser, B.G., & A.L. Strauss (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.

FINDINGS

RESPONDENT CHARACTERISTICS

Responses were received from 74 of the 137 invited participants for an overall 54% response rate. The largest number of participants attended the Tunisia meeting, followed by Uganda, Vietnam, and Jordan (Table 5).

Table 5. Survey Participants by Meeting Attended (n=74)

Meeting Attended	Response Percent	Response Count
Tunisia	42.5%	31
Uganda	39.7%	29
Vietnam	17.8%	13
Jordan	12.3%	9
Skipped question		1

Of these, 18 surveys may be considered incomplete because the participant did not answer any questions beyond some combination of the basic demographic queries (sex, meeting attended, participant type, values used/not used). Of the 74 participants who initiated the survey, 2 indicated they did not find the meetings relevant or useful and exited the survey at that point (via the automatic survey skip pattern), 3 did not answer the question, 12 found the meetings useful but did not use the values, and 57 found the meetings useful and did use the values (Table 3). Forty-nine of the participants were female and twenty-five were male.

Table 6. Relevance of Meeting to Survey Respondents (n=74)

Did you find the meeting relevant or useful?	Response Percent	Response Count
Yes, and I have used the information I learned	80.3%	57
Yes, but I have not used the information I learned	16.9%	12
No (exited survey)	2.8%	2
Skipped question		3

Of the 12 respondents who stated that they had found the meetings helpful but had not used Decent Care values, 3 did not answer any further questions, 5 selected “Did not have the opportunity,” and 2 selected “other reasons.” Of those who offered additional open-ended responses, three stated that they were already using Decent Care values in their palliative care practice, while two others noted that there were barriers to implementation, and one noted that he or she was no longer in a position to implement them directly.

Affected People/Family was selected as the primary role by 7 participants, while 47 selected *Activists/Service Providers/Health Care Providers/Advocates/NGOs*, and 13 selected *Policymakers/Donors /Government* (the remaining participants did not answer the question). Of those who did not use the values, one was from the *Affected People Family* category, eight were from the *Activists/Service Providers/Health Care Providers/Advocates/NGOs* category, and three were from the *Policymakers/Donors/Government* category (Table 4). While it is recognized that participants may fit into one, two, or all three categories for the purpose of this evaluation, participants were asked to select the category that they felt best fit

them. Note: The findings reported in the tables in the remainder of this report reflect only the responses of participants who answered the specific question, which in all cases is a subset of the original 74 who initiated the online survey.

Table 7. Participant Type by Use of Values (n=67)

Participant Type	Used	Not used	Total
Affected People/Family	6 (85.7%)	1 (14.3%)	7 (100.0%)
Activist/Service Provider/Health Care Provider/Advocate/NGO	40 (85.1%)	7 (14.9%)	47 (100.0%)
Policymaker/Donor/Government	10 (76.9%)	3 (23.1%)	13 (100.0%)
Total	56 (83.6%)	11 (16.4%)	67 (100.0%)

As Table 7 suggests, participant type was not a factor in whether respondents did or did not use the values. Given the selection process and the emphasis on anonymity, it is not possible to determine the characteristics of non-responders or speculate as to their views on Decent Care. It is possible that participants who did not find the conference relevant or helpful had less interest in a follow-up survey, resulting in a selection bias that skewed toward the positive. Nevertheless, those who did respond offered a considerable amount of information about how Decent Care has affected them, changed how they work, and affected those around them.

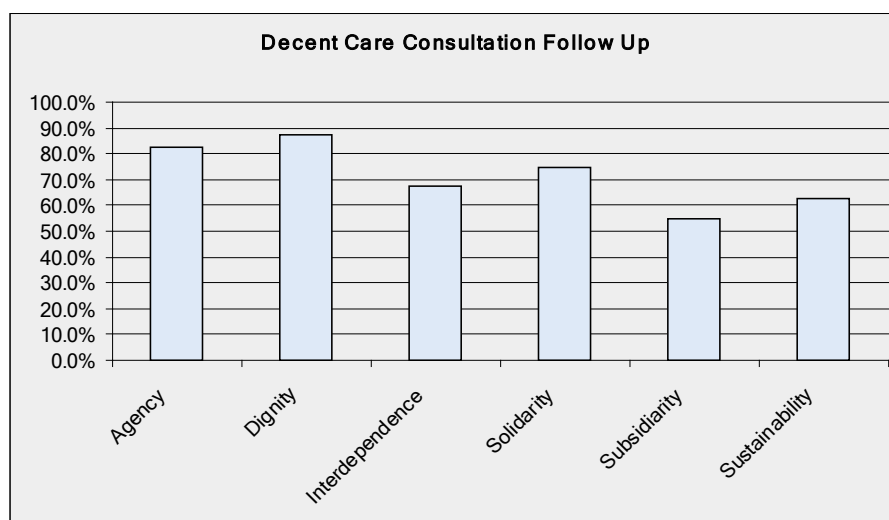
Use of Decent Care Values

Of the 57 participants who indicated they found the meetings relevant or useful *and* that they used the values since the meeting, 40 completed the section of the survey that asked them to indicate which values they had used. Dignity was the most commonly used value, followed by agency, solidarity, interdependence, sustainability, and subsidiarity (Table 8 and Figure 1). Responses to the open-ended questions about the values used are discussed in the relevant sections below.

Table 8. Values Used by Participants Who Found Meetings Relevant or Useful (n=40)

Which Decent Care values have you used? Mark all that apply.	Response Percent	Response Count
Agency	82.5%	33
Dignity	87.5%	35
Interdependence	67.5%	27
Solidarity	75.0%	30
Sustainability	62.5%	25
Subsidiarity	55.0%	22

Figure 1. Values Used by Participants (n=40)



The following table provides further detail regarding which participant group used specific Decent Care values. While it is not possible to draw strict comparisons given the different sample sizes in the participating groups, the data suggest that policymakers used the values in a slightly more balanced manner. Twenty-six respondents in the activist provider category used the value dignity. This is not surprising given that it was already a familiar term and an essential value in palliative care. Activist providers also interpreted interdependence in terms of their relationships with affected persons and with each other in the provision of care (Table 9).

Table 9. Values Used by Participant Type of Those Who Found the Meetings Relevant or Useful (n=40)

Decent Care Values Used	Affected People/ Family (n=4)	Activist/Service Provider/Health Care Provider/ Advocate/NGO (n=27)	Policymaker/ Donor/ Government (n=9)	Response Percent	Response Count
Agency	4 (100%)	21 (77.8%)	8 (88.9%)	82.5%	33
Dignity	3 (75.0%)	26 (96.3%)	6 (66.7%)	87.5%	35
Interdependence	0 (0.0%)	23 (85.2%)	4 (44.4%)	67.5%	27
Solidarity	1 (25%)	23 (85.2%)	6 (66.7%)	75.0%	30
Subsidiarity	0 (0.0%)	15 (55.5%)	7 (77.8%)	55.0%	22
Sustainability	1 (25%)	17 (63.0%)	7 (77.8%)	62.5%	25

The data from Table 9 can be interpreted a number of ways. First, 100% of respondents who identified as affected people stated that they used agency and 75% said they used dignity. This makes sense given that these are the two values that most directly address affected people's concerns regarding their care. Respondents in the second category are a diverse group, but they are all involved in program implementation or direct service provision. This may explain why the respondents stated that they used the values of dignity, interdependence, and solidarity at the highest rates. These three values speak most directly to program implementation and toward the relationships between affected persons and those

providing care. Respondents who identified as policymakers showed balance in their use of values. Open-ended responses from those respondents suggested that they made efforts to incorporate all of the values into policy documents and training efforts.

Of the 12 participants who indicated they found the meetings relevant or useful but had *not* used the values since the meeting, 8 responded to the question regarding their reasons for not using them (Table 7). The most common reason was lack of opportunity. No one indicated uncertainty about how to translate the values into practice.

Table 10. Reasons Values Were Not Used by Participants Who Found Meetings Relevant or Useful (n=8)

Why were you not able to use the Decent Care values? Mark all that apply	Response Percent	Response Count
No opportunity to implement values	62.5%	5
Other reasons	25.0%	2
No power to implement values	12.5%	1
Not sure how to translate values into practice	0.0%	0

Six participants provided responses to the open-ended question regarding not using the values. Three indicated very clearly that they already were using the values of Decent Care, and that attending the meeting had not changed their approach to health care or services. The respondent who cited not having the power to implement the values explained further:

*I did my best to the utmost extent to apply the context of decent care values through training students in hospitals & doing bed side education for oncology patient but still we don't have in my home land a home based care for oncology patients and there is no system (to) adopt these ideas at the national level.
(Jordan, Activists/Service Providers/ Health Care Providers/Advocates/NGO)*

Findings by Participant Type

Affected People/Family

Seven respondents identified themselves as Affected People/Family (Table 8). One did not find the meeting helpful. Three said they found the meeting helpful but did not respond to any of the questions. The three who did respond provided a total of 13 comments. Two of the respondents described how they have promoted the concept of Decent Care to other groups and the third discussed the challenges of providing Decent Care for chronically ill individuals. Based on their responses, it would appear that the respondents could have easily placed themselves in the activist provider category.

Table 11. Meeting Attended by Individuals Self-identifying as Affected People/Family (n=7)

Affected People/Family: Meeting(s) Attended	Response Percent	Response Count*
Tunisia	57.1%	4
Jordan	28.6%	2
Vietnam	42.9%	3
Uganda	0.0%	0

*Some individuals attended multiple meetings.

Activists/Service Providers/Health Care Providers/Advocates/NGOs

The largest number of respondents (47) identified themselves as members of the Activist/Service Provider/Health Care Provider/Advocate/NGO category (Table 12). This category encompasses a wide range of positions and activities, and the descriptions of people's work suggest there is some overlap with the other two categories. Of the 47, 6 stated they had found the meeting helpful but had not used Decent Care values, while 17 stated that they had used the values but did not respond further to questions; this left 27 respondents who responded to the open-ended questions. Within this group of 27, some respondents discussed all six values and provided additional information about their work, while others offered shorter comments on a few of the values.

Table 12. Meetings Attended by Persons Self-identifying as Activists/Service Providers/Health Care Providers/ Advocates/NGOs (n=47)

Activists/Service Providers/Health Care Providers/Advocates/NGO: Meeting(s) Attended	Response Percent	Response Count*
Uganda	48.9%	23
Tunisia	36.2%	17
Vietnam	14.9%	7
Jordan	10.6%	5

*Some individuals attended multiple meetings.

Responses varied significantly depending on the person's job and experience, and there was no discernable pattern with regard to the length of responses. Respondents did follow patterns in responding to the values. All but four responded to both agency and dignity. In addition, only one respondent listed interdependence but not solidarity. The most notable pattern across the 27 respondents who provided answers to the open-ended questions is that people's respective positions affected how they talked about Decent Care values.

Policymakers/Donors/Government

Of the 13 respondents who identified themselves as members of the Policymakers/Donors/Government category (Table 13), 3 said that they found the conference helpful but had "No opportunity to implement values." One respondent stated he had used the values but did not elaborate further. One respondent noted that she worked in palliative care and used the values, but that her English was limited. The remaining eight respondents wrote extensively about how Decent Care values had affected their work. Five respondents described their efforts to introduce Decent Care values into training programs and systems of palliative care. Three respondents described working at the donor level, promoting Decent Care values, and integrating Decent Care into policy documents. These respondents viewed their work as being further upstream in the system of care.

Table 13. Meetings Attended by Persons Self-identifying as Policymakers/Donors/Government (n=13)

Policymakers/Donors/Government: Meeting Attended	Response Percent	Response Count
Tunisia	53.8%	6
Uganda	23.1%	3
Vietnam	23.1%	3
Jordan	7.7%	1

One respondent who worked at the donor level noted that he advocated for Decent Care, but faced challenges in understanding the values. He did, however, note that he used the values to improve his management practices. Another promoted access to controlled substances, an essential component of palliative care, while the third has advocated at the government level that Decent Care values be integrated into policies and into the technical support he provided

The five other respondents described their work as administrators or trainers. Two respondents described their jobs as planning for home-based care and community therapeutic care initiatives. Another described working closely with organizations to develop training materials that integrate Decent Care values into their programs for PLHIV and people in palliative care. Finally, one of the respondents noted being responsible for improving palliative care at a hospital. The respondents were positive toward Decent Care, and emphasized that training and capacity building were essential to its implementation. Two respondents noted that they faced challenges regarding available resources.

In the following discussion, quotations are presented verbatim, and are followed by a note in brackets indicating the meeting(s) attended by the respondent, along with her or his occupation as determined from open-ended responses to the survey.

Themes

Occupation and Perspectives on Decent Care

Although there is no certain way of determining people's occupations or titles, respondents provided enough information to allow them to be divided into two groups. The first group consists of palliative care physicians and practitioners. The second consists of those who work in community health or HIV, or who are involved in policymaking. The respondents stating they were palliative care providers or physicians tended to describe Decent Care values as a matter of improved communication and micro-interaction with "patients." Part of implementation included training new students to be better listeners and to treat clients with dignity. These providers tended to focus more on the values of agency and dignity than on the rest of the values, and did not typically describe their work as part of a larger effort to transform care. Another theme reinforced that view, with several respondents noting they already practiced Decent Care values in their palliative care practices, and as such did not need to change the way they provided care. The following quotations from palliative care providers illustrate this point:

Our work already uses these values expressed slightly differently in our palliative care strategy that includes principles to guide implementation such as dignity, etc. So in many ways these duplicated what is already in place. [Uganda, provider of technical support for palliative care programs]

I am a palliative care physician and we are using these principles even before attending the meeting. [Tunisia, palliative care physician]

Having been involved in palliative care for over 25 years, the Decent Care values reinforced our own core philosophy and practice. [Uganda, patient care coordinator, national-level]

As a palliative care provider, my patients and their family members are given the power to direct the care and chose its course. They are empowered with information and choices and supported to practice self-agency. [Jordan, palliative care provider]

I have implemented these values throughout my career. This has not changed since the Decent Care meeting. [Vietnam, health care provider]

The second group, which looked at Decent Care values as part of a larger strategy for creating and changing systems, was largely comprised of respondents working in community health, HIV, or at a policymaking level. For these respondents, Decent Care presented a new way of looking at health care, rather than reinforcing the perceived values of an existing specialty. One woman noted when discussing the value solidarity that Decent Care extended to all aspects of life:

Parish priests offering support in form of foodstuffs, paying rent to those who cannot get their food, buying medicines, linking them with other support services, microfinance activities where clients were able to be part of support groups that beneficiary with loans and started small businesses and are now self reliant. The church has continued to stand by the beneficiaries to ensure they live a fulfilled life. The program, with support from community/support group members, renovated beneficiary houses that were dilapidated and unfit for human life. This is in solidarity with members of the community in living in habitable houses. Staffs collected foodstuffs from community members, clothes and other items and distributed to Orphans and vulnerable children as well as People living with HIV & AIDS across the year. Caregiver meetings of the OVC and PLHIV are trained on how to support the people they care for. They are mobilized to participate in activities of the project in order to further support each other. When a CHW drops for one reason or another he or she is replaced by an able caregiver or someone living with HIV. Children of those PLHIV are supported through school to reduce the burden of life on them. [Uganda, coordinator, USAID HIV programs]

Another respondent stated:

Decent Care values were a turning point in my life. The values formed a drive that pushed me to mobilize a rural community to establish a hospital and provide Decent Care to those in need with their involvement. These values were adopted by the rural hospital and will continue to drive the culture of that hospital. In the HIV program, I oriented management, program staff, and service providers on these values which were in line with the organization values. Thereafter, they formed basis for the program review meetings in 2009. [Tunisia/Uganda, medical doctor/manager for HIV programs]

One person noted how her organization is incorporating Decent Care values:

The hospice is already implementing a five year strategic plan to ensure development of the organization in all areas like resource mobilization and allocation, human resource development, expansion of service delivery, improvement of quality of service, improvement of communication and networking, development of research and information gathering, strengthening institution capacity, leadership and governance and enhancement of financial sustainability. Lack of enough resources to implement all areas of the strategic plan is a setback. [Uganda, nurse administrator providing palliative care leadership]

A provider who did not have a background in palliative care stated:

The DCVs have helped me in humanizing the process of providing care for the PLHIV in this part of the world. [Vietnam, physician working with PLHIV]

The distinction between the two groups and their perspectives described above is not sharp, and in fact reflects the discussions from the Uganda conference. The Ugandan conference report²⁴ clearly describes how participants with a background in palliative care questioned the novelty of Decent Care, and at least implicitly questioned its utility. Participants at that meeting commented on the language of Decent Care, focusing on word choice in particular, while acknowledging that the underlying values were consistent with palliative care principles. Some quotations from providers are consistent with comments from the Ugandan conference that were critical of the terms Agency and Subsidiarity. Still others suggested that Decent Care is potentially redundant and unnecessary.

Other respondents argued that Decent Care provides a larger framework for community health that goes far beyond provider-affected person interactions. In discussing the value of Sustainability, one respondent stated:

In sustainability, PLHIV, their caregivers, and community health workers have been empowered to sustain themselves through the small businesses. Livelihood efforts and agriculture activities were enhanced to help clients get access to food to improve their food security. The program provided seeds to caregivers and PLHIV to plant. In so doing, beneficiaries are able to feed on some portions as well as sell others to gain profit from them. Clients were linked to existing micro-finance institutions to access larger loans (than were accessing in the savings led micro-credit facility within the program). They are trained on business management and are able to access loans to improve if not start businesses. Business keeps them occupied and (they) are able to earn a living. [Uganda, coordinator, USAID HIV programs]

This response describes a system of care that extends beyond the provider-affected person interactions, institutional responsibilities, and medical definitions of well-being. It envisions a broader range of response in which the idea of Decent Care becomes more comprehensive and encompassing. This usage of Decent Care shares structural similarities to the concept of Decent Work, as described in the introduction. Both are frameworks for guiding change at national, local, organizational, and personal levels, yet neither concept specifies programmatic change. In the absence of a more specific operational plan, some conference participants focused on those values that resonated with their own practice and experience.

Three themes regarding implementation of Decent Care emerged from the analysis. Some related to specific values while others were of a more general nature.

Families versus Individuals

The first theme revolved around challenges related to implementation of the values of agency and dignity. Several respondents noted that they faced difficulties in implementing the values. As one provider described:

I had difficulty in the family members who at times, may over rule the patient's desire to have a quiet exit. At times, I totally became "useless" when the family insisted that a dying patient be intubated and mechanically ventilated. This was not the patient's desire and I believe her dignity was not preserved. [Tunisia, physician]

Another provided a thought-provoking example:

A terminally ill lady who has metastatic cholangiocarcinoma has verbalized that she wanted to go in a quiet way, no intubation at all. She just wanted to see her daughter who was flying in from the U.S.

²⁴ WHO (2010). Decent Care Values In Palliative Care Services: An African Regional Consultation Meeting. 18-19 February 2010, Kampala, Uganda.

before she dies. The patient arrested and much as I know she doesn't want to be intubated, the rest of the family asked that she had full resuscitation, since the daughter was still on her way to Manila. I felt that her wishes were not met and I somehow felt I didn't give her the dignity she wanted. The family has taken over and at this point, the whole concept of dignity and patient's wishes are dissolved in a complicated knot of family relations that seeks to make the patient well, but in fact, brought the opposite. [Tunisia, pain doctor specializing in end-of-life care]

Finally, one provider had a pragmatic attitude toward the problem:

In Indian culture, even though we recognize the need to respect agency, it may not be fully practical as the family members' agency sometimes comes as first. This is because there is a strong family support system and family members want to protect their loved ones from the medical information given by the professionals. [Tunisia, palliative care physician]

Resources

A second theme was the inadequacy of available resources for implementing Decent Care:

It is an African culture for community members to assist each other in time of difficulties, again poverty and distances poses a challenge to solidarity as there are limited resources to assist those who need agent assistance. [Uganda, policymaker]

The greatest challenge in all these has been continuity of funding. Those that are bed ridden require much more support than anyone else. Good nutrition, medication, etc. A CHW may visit a client who is in need of the service but has nothing to offer...it remains a challenge that not many may meet. [Uganda, coordinator, USAID HIV programs]

The difficulty is that as more patients are referred and more resources are needed, it may become an issue of resources. [Tunisia, CEO and medical doctor specializing in palliative care]

Another participant who was not able to implement the values saw the barrier as one of funding focus:

This is because of challenges in funding. Funding is nowadays through Requests For Applications (RFAs) that have to meet the set objectives or basic requirements of such Request. The activities that we carry out are donor funded or driven. Donors' interests are in many cases different from ours and because we still need to exist (as organizations), we have always applied for their funds as long as we meet the given criteria. [Uganda, person living with HIV]

A more complete discussion of the relationship between Decent Care and resources is provided in the next section.

Individual Engagement with Decent Care Values

A final theme emerged that helped explain respondents' other answers about Decent Care. Many of the respondents described their training and work experience, and then noted that Decent Care was either personally transformative in that it helped them integrate their personal values with professional ethical concerns, or described it as a framework for informing policymaking. The following quotations illustrate the perspective of those who thought of Decent Care as personally transformative.

As a physician it helps me keep my focus on more than the biology of disease, to open my eyes constantly to the larger questions of meaning and experience people have when they are ill, suffering or dying, and the importance of community, culture and life history to the way a person has these experiences. [Tunisia, physician]

The DCVs have helped me in humanizing the process of providing care for the PLHIV in this part of the world. This kind of experience naturally perpetuates itself. [Vietnam, physician working with PLHIV]

Decent Care has benefited tremendously as by and by I have learnt to respect people as they are, I have recognized that as a person, I have a lot to learn in order to be a better person so I can serve others (especially suffering terminally/chronically) better. Decent Care stirs responsibility and understanding in you that helps you to be useful to those around you. [Uganda, community health and HIV care and management]

The following quotations illustrate the perspective that while Decent Care values should guide policy that will ultimately change systems, they are not necessarily personally transformative:

All the above have been used in my area of work in health policy and health providers capacity-building tools. The barrier is that the values are not yet mainstream and there is the language has not yet made it to the popular literature. There is also a need to generate the evidence base. [Tunisia, physician and health policymaker]

The ideas from the meeting served as one of the inputs for a policy guidelines document on accessibility and availability of controlled medicines. If implemented by the countries, everybody will benefit from these guidelines. [Tunisia, policy officer for controlled medications]

Finally, a few participants described how Decent Care values were both personally transformative and also guided people's interactions with donors, national and local governments, communities, and affected persons. For those participants, Decent Care provided a comprehensive framework for addressing change at multiple levels, as the following quotations illustrate:

Have been able to educate others to seek care and treatment and their lives have improved. Some clients who had been captives of negative traditional beliefs have been able to turn around, recognise the deception they have suffered from and have sought care and treatment and their lives have changed tremendously. Parents have let go of their stigma and taken their infected children to care and support. Thanks to Decent Care training I attended in Uganda. If you need more information, please send me an email and I will gladly respond so. God bless as you continue to help people through decent care. [Uganda, community health and HIV care and management]

Learning and using values of Decent Care has help me to have better vision and broader perspectives, which helps to guide our implementing partners in a more efficient and effective way. Absolutely, I will continue to do so in the future. [Vietnam, technical assistance provider for programs funded by organization]

My experience is that these values can be scaled up such that all program managers in HIV and other care programs are sensitized. The first two will enhance the provider-client relationships and build foundation for good quality care. Although the 3rd and 4th are also important, the first two and last two are critical in improving health care in developing countries, especially for palliative care. HIV programmes can implement Decent Care. These values can also help in reviving the ever falling medical ethics. The advantage with these values is that they do not follow a legal approach but rather enhance the moral behaviors of individuals who provide care. [Tunisia/Uganda, medical doctor/manager for HIV programs]

These final three quotations suggest that Decent Care is a philosophy or approach that can support efforts of providers, affected persons, advocates, activists and policymakers to address challenges they all encounter in the health care delivery system. In addition to focusing on the values that directly affect one's own personal experiences and medical practice, Decent Care encourages people to step outside their routines and critically examine how their work fits within a larger system.

DISCUSSION

TWO CAMPS

As was stated at the beginning of the findings section, the vast majority of respondents spoke positively of Decent Care values. Nevertheless, the findings suggest that respondents fell into one of two camps. The first camp, made up mostly of palliative care providers, felt that Decent Care was good, but only complemented the existing philosophy and structure of palliative care. Survey responses from this group focused primarily on the values of agency and dignity, and paid less attention to the latter four values that focus more on systemic change. The idea that Decent Care is palliative care simply rebranded comes though clearly from some respondents. However, that finding is likely an artifact of the way in which Decent Care and palliative care were introduced at the different meetings. In the final report from the Uganda conference, for example, it was noted that Decent Care and palliative care were presented in parallel. Participants commented on Decent Care on multiple levels, including its language, and the fact that it was not “new,” by which they appeared to mean that palliative care has already incorporated the values of Decent Care.

The second camp of respondents, made up mostly of community health workers and program administrators who work with affected people, described Decent Care as a set of values that guide their personal interactions and as a framework that gives voice and structure to their desires to change the system and to connect with affected people and with communities in more profound ways. For this camp, Decent Care serves as a holistic framework for systemic change.

The survey responses do not suggest that the division between the two camps is sharp or contentious. This is not surprising, given that Decent Care was introduced at the regional meetings as a parallel framework that could be used to enhance palliative care. The values guiding palliative care were compared side by side with Decent Care. As a result, many of the palliative care respondents focused on the fact that palliative care had already integrated some of the Decent Care values into its standard practice. Respondents in the palliative care camp noted repeatedly, and in some cases defensively, that Agency and Dignity were already central values in their practice.

A second reason why the two camps may have emerged in the data is that respondents tended to comment on those values with which they were familiar, and not comment on others. For example, relatively few respondents discussed the concept of subsidiarity, although it is a crucial value for considering the control over decision-making and resource allocation.

What was missing from the data – which may reflect the small number of policymakers in the survey – were comments or descriptions of how Decent Care could inform efforts to improve, expand, or create the upstream support systems that make quality palliative care possible at the level of the affected person. Decent Care was developed to apply at multiple levels within systems of care. It can provide policymakers, politicians, activists, and providers with the tools to innovate and create a system that is responsive to the needs of affected people.

Addressing Challenges and Barriers

The survey revealed two common sets of anticipated barriers to implementing Decent Care values in palliative care. The first describes the ethical challenge that individual providers in any system of care must face: balancing the rights of the affected person as an individual against the rights of the affected person deeply embedded in familial and social networks where other people, gods, or beliefs hold sway. This is a critical issue, and a subject of considerable debate. However, its importance takes on new meaning when creating a new system of affected person-driven care.

As it was noted above, one goal for the regional meetings was to tailor the perspective on Decent Care to include greater diversity in local cultural knowledge and experience. Providers described struggles to apply Western or modern medical notions of agency and dignity to social and cultural situations in which people define the individual differently. In many cases, providers had to confront ethical and cultural dilemmas that the use of the concepts could not, by themselves, resolve. The physician's relationship to the affected person, as defined in contemporary biomedicine, focuses on a single relationship, structured by a specific code of ethics that emphasizes individual rights and privacy. Families and friends, on the other hand, may have culturally sanctioned, persuasive, and potentially legal claims over an ill person. Those claims may be religious, economic, or familial. Families and friends in such situations may not recognize a Western individualized notion of the relationship between a physician and a "patient."

The conflicts between individual rights and family claims extend far beyond health care. People may ascribe the affected person's condition to underlying social conflicts, to witchcraft, or to the failure to observe rituals or respect ancestors. The patient's condition may also have profound economic consequences. These issues raise important questions about the meaning of agency and how it is translated into practice in real settings. To provide Decent Care, providers may have to incorporate local understandings and cultural practices that they do not understand well or agree with. For example, in community health efforts for PLHIV, the articulation of the values of agency and interdependence can be particularly challenging. On the one hand, affected persons are supposed to have their autonomy; on the other, family members, friends, and the community have claims on them as well.

The second barrier, lack of resources, is also an important challenge. Availability of and access to resources is always an issue in health care, as it is in local, national, and global economic development more generally. As a result, it raises larger questions about fairness in the global order and relationships between rich and poor countries. The authors of Decent Care were aware of this issue:

*It is essential to note that the development of decent care will not necessarily affect the resources available or the priority given to the prevention and treatment of HIV in a particular area. One of the important contextual issues is that each place – nation, province, and locality – will have critical priorities and resources that must be directed to address those priorities. However, if decent care is enacted, it is anticipated that prevention and treatment will be more effective (more appropriate and responsive) thus reducing resource burden. In turn, this may result in the increased availability of resources to enhance services for HIV prevention and treatment, and to increase the resources available to address other issues. An additional potential outcome of decent care is that caregivers will be more satisfied with the results of the relationship and the services and their well-being will be improved.*²⁵

Decent care provides a framework and set of principles for the distribution of resources at a particular time or place. Agency, dignity, interdependence, and solidarity help break down institutional barriers between providers and affected persons, and between organization and community, while subsidiarity and sustainability emphasize the importance of building policy to direct and control necessary resources.

Finally, respondents tended to talk about incorporating Decent Care into their personal lives, or they described it as a method for promoting systems change. Decent Care promotes personal reflection and critical analysis of one's participation in the system. It is not surprising that respondents tended to describe Decent Care in one of those two ways. For most people, life is a series of daily routines that one can more or less control. They can reflect on their routines and change them; if that does not work well enough, someone from the outside can suggest system changes that more substantially alter routines. People are not typically asked to change personally as well as to collaborate on systemic change. Decent Care promotes both.

²⁵ Ferguson, J.T., T. Karpf, C.E. Crain, R. Swift, N. Tashima (2006). *Report on the Global Consultation on Decent Care: 26-30 June 2006*. Geneva: World Health Organization, page 3.

While the vast majority of respondents were positive about Decent Care based on what they learned, it appeared that many of those trained in palliative care treated Decent Care as a tool to be applied within a narrow range. This is not surprising. Experts in a discipline often have a hard time hearing a different view of their work, especially if it is presented in a limited way. It is possible that proponents of Decent Care could face similar challenges when they introduce it to other disciplines within primary care or behavioral health. Providers already believe they are providing good care, and they envision providing better care, especially if, for example, they had the proper resources.

CONCLUSIONS

Respondents all agreed that the values of Decent Care are important, and that more has to be done. Decent Care and palliative care have their strongest affinities in their response to the dynamic between provider and affected person. In both wealthy and poor countries, affected people directly experience personal challenges in addressing health issues. The ethical issues that palliative care providers face regarding an affected person's right to decide versus her or his family's rights are not reserved for poor countries. Palliative care focuses on improving affected people's quality of life in the face of life-threatening, life-altering conditions. Because it focuses on quality of life as opposed to providing a "cure," palliative care has faced some resistance from mainstream biomedicine, and has been a source of extensive ethical debate. In the United States, palliative care has faced challenges related to accessing controlled medicines and concerns regarding euthanasia. From the beginning, palliative care has emphasized the importance of the affected person's agency and dignity, albeit in a language that differs from Decent Care.

As described in detail in the conference reports, the goals of Decent Care are greater than simply making adjustments in how providers interact with affected persons. As noted at the Ugandan conference, Decent Care seeks to "transform health systems around the primacy of persons in health care and build a bridge between human rights principles and the practice of medicine."²⁶ It is an activist perspective, designed to re-energize and transform systems in which stakeholders scramble for resources, grasp onto or increase their positions, and accept the various externalities that prevent them from doing better. However, the survey results suggest that a significant number of participants at the regional conferences ended up thinking about Decent Care as it applied to existing practices in palliative care. Palliative care, as a medical discipline, developed within the dominant institutions of biomedicine in wealthy countries. Palliative care providers reshaped how the medical field addressed chronic pain and suffering by giving patients greater control over their care decisions, and by focusing on improving the affected person's quality of life, rather than focusing more narrowly on cure of a disease state. In many respects, it represented a significant shift in values orientation within mainstream biomedicine.

Decent Care seeks to extend those core principles of agency and dignity, but does so through a different strategy. It is a framework, expressed through six inter-related values, that all stakeholders, including affected people, can and should use to critically analyze health care. Rather than starting with the interaction between affected person and provider, Decent Care centers the affected person and her or his quality of life in a living community. It assumes that when affected persons have agency and dignity, they will have a better quality of life. In turn, affected persons will have agency and dignity when they drive the decision-making process.

Decent Care is a response to health care systems in which care may be depersonalized, episodic, and fragmented. In both wealthy countries and in poor, the forces driving health care are multiple and competitive. The bureaucracies and governments under which people live have considerably more power than affected persons, often making decisions that are not in their best interests. Palliative care also seeks to give patients agency and dignity, but it does so largely within the more general assumptions and realities of the existing health care system. Decent Care encourages people at all levels in the health care system, as well as in institutions responsible for supporting that system, to critically analyze and address the challenges in the system of care so that providers can ultimately collaborate with affected persons to create a world in which care is decent.

²⁶ WHO (2010). Decent Care Values in Palliative Care Services: An African Regional Consultation Meeting. 18-19 February 2010, Kampala, Uganda, page 12.

NEXT STEPS

Decent Care is a set of values that are intended to guide the development and implementation of a system of health and health care centered on the affected person. While it started officially in 2006, Decent Care is still in its early stages. Some activists have eagerly embraced Decent Care, and some early adopters have begun demonstration projects. Nevertheless, the health care field has had relatively limited exposure to Decent Care values. To expand Decent Care, it will be important to expand in three areas.

First, it will be necessary to have more opportunities for facilitated discussions about Decent Care and practical, realistic ways of implementing Decent Care at the regional, state, and local levels. Decent Care places affected persons at the center, and affected persons live in local areas. Local can range from remote rural areas, to high-density urban areas with deteriorating infrastructure, to conflict zones, to high-technology, high-resource areas. It will be vital to explore how different kinds of externalities affect the use of Decent Care values.

Second, Decent Care materials need to be developed that are linguistically and culturally competent to allow affected people, caregivers and other service providers, and policymakers the opportunity to apply or adapt Decent Care values to specific social and cultural contexts.

Third, as more programs implement Decent Care, evaluators and researchers must produce and disseminate case studies that document practical lessons in challenges, barriers, and facilitators. For example, case studies of how Decent Care transformed similar programs that began at different development and resource levels could highlight its potential flexibility. One area with potential is collaboration between palliative care organizations and professionals and the PLHIV community. Both groups are already familiar with some of the key elements of Decent Care, although they have not had opportunities to formally collaborate and implement Decent Care from start to finish.

Decent Care challenges each person to move beyond what has been the way of receiving or providing of care. Decent Care insists that affected persons, as well as all who would engage in their care, recognize and learn to place the affected person at the center of the web of care. Decent Care is a values-based approach. When everyone, from affected persons to high-level government policymakers, embraces Decent Care, they also engage with others to create systemic change. Affected persons are the heart of that engagement. When systems lose sight of that – their centrality – care quickly stops being decent.

APPENDIX A. SCOPE OF WORK

Global Health Technical Assistance Project
GH Tech
Contract No. GHS-I-00-05-00005-00

Scope of Work
(Revised: 10-08-10)

I. TITLE

Activity: GH/OHA: Survey report of participants attending a WHO/PEPFAR sponsored Palliative Care and Decent Care workshop and the effect of workshop participation on subsequent palliative care programming and service delivery.

Contract: Global Health Technical Assistance Project (GH Tech), Task Order No. 01

II. PERFORMANCE PERIOD

On/about late October 2010 – no later than mid February 2011

III. FUNDING SOURCE

OHA/GHCS – State (former GHAI)

IV. OBJECTIVES AND PURPOSE OF ASSIGNMENT

The consultants will develop and conduct survey, and produce a report on a survey of the uptake and utilization of palliative care and Decent Care values by PEPFAR and non-PEPFAR supported palliative care programs, providers, and policy makers represented at one of several WHO-sponsored meetings. This survey would be a short-term, formative exploration of the following issues:

- Who has utilized palliative care and Decent Care values;
- How have concepts and values been utilized;
- What has the experience been of those who have utilized the concepts and values;
- What facilitators and barriers were encountered;
- What has been the effects and outcomes to date; and,
- What are the plans for further/future utilization?

V. BACKGROUND

Decent Care has been called a “concept”, an “action philosophy”, and, a “new paradigm”. Likened to the patient empowerment and patient-centered care movements, Decent Care began as a discussion to focus on engaging in the kind of conversation that generated the Decent Work movement by the International Labor Organization (ILO). The ILO work inspired the World Health Organization (WHO) and the Ford Foundation to convene philosophers, health experts, theologians, social scientists, activists and others in Vevey, Switzerland to undertake the formative discussions of Decent Care. From that convening, the core values of Decent Care were defined. To date, there has been no systematic follow-

up with those participants to understand if and how the values have been incorporated into their work. The defined values are illustrated below.

As a philosophy or as values, the concept of Decent Care was intriguing, but lacking the grounding that would allow its utility to be understood. It was determined that the most fertile area of health care to begin the exploration of Decent Care would be in palliative care. Palliative care has a history of being the most patient- and family-centered of mainstream health care disciplines and so was chosen to attempt to develop the values into implementable concepts of care. In January of 2009, the WHO, again funded by the Ford Foundation, convened a large body of palliative care specialists, international donors, governmental agencies, as well as “affected people”²⁷. Fifty people from Africa, the Americas, the Middle East, South Asia, the Pacific, and Asia attended the five-day meeting in Tunisia. At the end of the Tunisia meeting, many participants said that they were prepared to take what they had learned and look toward ways of implementing the values. No follow-on survey was undertaken to determine what kinds of activities have been undertaken, with what fidelity to the values, what kinds lessons had been learned, and what kinds of outcomes had been experienced.

A year after the Tunisia meeting, three additional regional meetings were funded by the WHO to promote that uptake of Decent Care Values in Palliative Care. With funding from the Office of the Director General of the WHO, three WHO regions were granted funding to host meetings. In the spring of 2010, meetings of palliative care experts, governmental and non-governmental organizational representatives, donors, and affected persons were held in Amman, Jordan; Kampala, Uganda; and, Hanoi, Vietnam. The purpose of the meetings was to explore palliative care in the regional context, and to introduce the values of Decent Care. As with the Tunisia meeting, many left these meetings saying that they were prepared to undertake the application of Decent Care Values in palliative care. Again, no follow-on survey has been planned.

VI. SCOPE OF WORK

Steps to undertaking the survey will include the following:

1. Conduct COTR meeting to ensure clarity of process and products.
2. Develop report outline; COTR review and comment. Finalize report outline.
3. Consolidate all meeting participant lists.
4. Test individual contact information for current accuracy and updating where inaccurate.
5. Send alert message to all participants to inform them of the upcoming survey and invite them to participate.
6. Develop lists of participants who represent the following groups:
 - a. Affected persons;
 - b. NGO/PVO representatives;
 - c. Palliative care organizational representatives (may overlap with b and if so, lists may be consolidated)
 - d. Governmental representatives divided by global, country, regional, and local;
 - e. Donors;
 - f. Others.
7. Develop and refine master questions for each group in collaboration with COTR.

8. Develop instruments for each group utilizing both closed and open-ended responses. COTR review and comment; finalize instruments.
9. Post the instruments on SurveyMonkey or like site.
10. Send invitations to each participant with repeat invitation to participate, particular address for their instrument, and timeframe for response.
11. Monitor responses from each group and send email reminders to encourage responses.
12. Determine with COTR satisfactory response and whether to extend timeframe to encourage higher response rate.
13. Manage and analyze responses; quantitative with SPSS, qualitative with Atlas.ti.
14. Develop draft report according to final outline (i.e. methodology, findings, and potential next steps).
15. Develop USAID briefing outline; COTR review and comment. Finalize briefing outline and develop PowerPoint. Provide briefing for USAID.
16. Review and finalize draft report based on USAID review and feedback.
17. Edit and format final report.
18. Distribute final report.

Timeframe for survey: 4-5 months.

VII. METHODOLOGY

Develop a survey tool to determine the effect of conference participation on post-conference programming in areas of palliative care. The survey should be structured in a manner that ascertains information based on the roles/responsibilities of the participant – government, clinical/facility managers, clients, etc.

The survey tool should be circulated to all participants and information collected in an appropriate manner to assure accuracy and timeliness.

Information from survey should be analyzed to determine the effect of conference participation on any changes to policy, programmatic or clinical practice environment.

Based on findings, a draft report should be submitted to USAID for review and comments.

A USAID debriefing presentation will be made upon completion of the draft report.

Based on feedback from the USAID debriefing presentation, a final report should be submitted to USAID for final review and approval.

VIII. TEAM COMPOSITION, SKILLS, AND LEVEL OF EFFORT

Illustrative LOE by Task

Task	# of Days
Task 1: Meet With GPO and Develop and Finalize Report Outline.	2
Task 2: Consolidation of all Meeting Participation Lists.	1.25
Task 3: Test Individual Contact Information.	0.75
Task 4: Send Alert Message to All Participants.	0.5

Task 5: Development of Participant Lists by Groups.	1.75
Task 6: Develop and Refine Master Questions for Each Group.	5
Task 7: Development of Instruments.	3
Task 8: Posting of Instruments on SurveyMonkey.	1.25
Task 9: Participant Invitations and Follow-up	1
Task 10: Monitoring and Managing Survey Responses.	5
Task 11: Management & Analysis of Responses.	15
Task 12: Development of Report and Revisions.	11.5
Task 13: Prepare for and conduct USAID Briefing.	2
Estimated LOE	50 days

IX. LOGISTICS

The consultants will be responsible for all activities, supplies, materials, equipment and related activities to complete the above mentioned tasks and deliverables. Additional support from either GH Tech or USAID is expected within the scope of the project. Dissemination of information will occur through GH Tech including the formatting and production of a final report.

Any additional support not foreseen will be provided by the USAID Point of Contact (POC)/COTR, John G Palen, HIV Care and Support Advisor, USAID/OHA.

X. DELIVERABLES

Work plan and Methodology

The consultants will propose an implementation schedule and methodology to complete the survey report with target dates for producing each deliverable, including a draft outline for the report. USAID/OHA will review the proposed work plan and submit comments within five working days. The contractor will then revise the work plan, incorporating USAID/OHA comments. The work plan and methodology must be finalized and approved prior to the initiation of the survey.

The consultants will provide bi-weekly status reports on work plan implementation to the COTR and GH Tech.

Draft Survey Report

The consultants will submit the first draft report to the COTR and GH Tech for review. The draft report will be a 20 – 30 page report outlining methods, findings, conclusions, and recommendations from the survey. The report should include appendix with the survey instrument and list of names of survey participants (if authorized by participant). The COTR will review the draft report and provide consolidated USAID feedback within ten working days.

PowerPoint Presentation

The consultants will develop a power point presentation for a USAID/OHA briefing. The outline and presentation will be shared with GH Tech and COTR for review and comment prior to the USAID briefing.

Second Draft Survey Report

The consultants will submit the second draft of the report to the COTR, approximately 10 days after receiving written USAID comments. The COTR will collect comments from the USAID/OHA and submit them within five working days to GH Tech to revise/finalize/complete the report.

Final Survey Report

GH Tech will submit copies of the edited and formatted final document to the COTR Manager approximately 30 days after USAID provides final approval of the report content and sign off. The final report will be approximately 20-30 single-spaced pages in length, excluding the executive summary and Attachments. Procurement sensitive information will be removed from the final report and incorporated into an internal USAID Memo. The remaining report will then be released as a public document on the USAID Development Experience Clearinghouse (DEC) (<http://dec.usaid.gov>) and the GH Tech project web site (www.ghtechproject.com).

XI. RELATIONS AND RESPONSIBILITIES

GH Tech will undertake the following specific responsibilities:

- Recruit, hire, and manage the consultants.
- Provide administrative and technical support for the consultants, as needed.
- Edit, format, and submit the final survey report.

OHA/GHCS will undertake the following responsibilities:

- Documents. Identify and prioritize background materials for the consultants and provide them in advance of the assignment, preferably in electronic form.
- Survey Preparations. Provide a list of meeting participants and contact information. Introduce the consultants to project partners, local government officials, and other stakeholders, where applicable and appropriate.
- USAID Point of Contact (POC). Throughout the assignment, ensure constant availability of the POC person and provide technical leadership and direction for the team's work.
- Meeting Space and Invitations. Provide meeting space for initial discussions and briefing presentation for USAID/OHA.
- Timely Reviews. Provide timely review of draft/final reports and approval of the deliverables.

XII. WASHINGTON CONTACT PERSON

The Consultants will be supervised by John Palen, Palliative Care Advisor, OHA.

John Palen (USAID/HQ)
Phone: 202-684-9931
Email: jpalen@usaid.gov

APPENDIX B. SURVEY INSTRUMENT

INSTRUCTIONS

Thank you for participating in this survey. All of your responses will be confidential and anonymous. This survey contains several open-ended questions. As a result, the length of time necessary to complete it will depend on your responses to those questions. However, we do not expect the survey to take more than 20 minutes.

Below are definitions for the six values of Decent Care, along with some practical examples. Taken together, the six values capture the Decent Care approach. Depending on your individual circumstances, it may not be possible to implement all six values. Please review and keep these definitions in mind when thinking about your responses, and answer each question as completely as possible.

Agency

The power of the individual to assemble and direct one's own care and treatment. Agency is the heart of Decent Care: Without providing space for, acknowledging, responding to and respecting the agency of the individual, care is not decent. Example: An affected person is provided information and access to the resources to design and direct her or his care.

Dignity

Honouring the unique individuality and life world of the individual, her or his needs, desires, relationships and values. Dignity represents the humanity of Decent Care. Example: The affected person's values and sensibilities are accounted for in every care activity.

Interdependence

Reciprocity of caring process; the interconnectedness of individuals and systems. Example: All involved in the care of an affected person recognize that the process of caring accrues benefit and responsibility for each.

Solidarity

Being actively responsible for each other's well-being and advocating for each other's needs. Example: Caregivers, affected persons, members of the community, service providers and others actively promote one another's well-being, and seek to improve it for everyone.

Subsidiarity

Responsive and responsible policy creation and resource allocation. Examples: Members of the local community, local organizations, and local government agencies have decision-making power regarding the allocation of medications and resources. The state government creates policy that supports a local service focus on affected person-centered programs.

Sustainability

Stewardship of resources and planning to ensure continuation of Decent Care processes. Example: Community members, service organizations, and government agencies at all levels collaborate to ensure that affected person-centered programs receive the funding, resources, and support that ensure their continued viability.

Please follow the instructions in bold italics as you proceed through the survey.

1. First, please indicate whether you are:
☐ Male
☐ Female
2. Next, please indicate which Decent Care Consultation meeting(s) you attended:
☐ Tunisia
☐ Jordan
☐ Uganda
☐ Vietnam
3. Did you find the meeting relevant or useful?
☐ Yes, and I used information I learned at the conference.
☐ Yes, but I did not use information I learned.
☐ No: ***You do not need to complete the rest of the survey. We appreciate your time and willingness to participate. Please save and return this document to decentcareltg@gmail.com.***
4. Please select the ONE category that you feel best describes your role regarding Decent Care:
☐ Affected People/ Family
☐ Activists/Service Providers/Health Care Providers/Advocates/NGOs
☐ Policymakers/Donors/Government

INSTRUCTIONS:

If you answered “Yes, and I used the information I learned” to Question 3 above, please complete Questions 5 through 13.

If you answered “Yes, but I did not use the information I learned” to Question 3 above, please complete ONLY Questions 14 and 15.

5. Which values have you used? ***Please mark all that apply.***
☐ Agency
☐ Dignity
☐ Interdependence
☐ Solidarity
☐ Subsidiarity
☐ Sustainability

For the remaining questions, please feel free to write as much as you wish in response to all relevant questions. There is no space limit for your responses.

6. If you responded yes to **Agency**, please describe how you have used the value and include anything that has posed difficulties or provided assistance as you used it.
7. If you responded yes to **Dignity**, please describe how you have used the value and include anything that has posed difficulties or provided assistance as you used it.
8. If you responded yes to **Interdependence**, please describe how you have used the value and include anything that has posed difficulties or provided assistance as you used it.
9. If you responded yes to **Solidarity**, please describe how you have used the value and include anything that has posed difficulties or provided assistance as you used it.
10. If you responded yes to **Subsidiarity**, please describe how you have used the value and include anything that has posed difficulties or provided assistance as you used it.
11. If you responded yes to **Sustainability**, please describe how you have used the value and include anything that has posed difficulties or provided assistance as you used it.
12. In what ways has using the values of Decent Care benefited your life or that of others around you and will it continue to in the future?
13. Please tell us anything about yourself that will help us better understand your responses.

Please respond to the following two questions ONLY if you answered “Yes, but I did not use the information I learned” to Question 3 above.

14. Please tell us why you have not used the values of Decent Care. Below is a list with some possible reason. Please mark and comment on all that apply, and feel free to add additional reasons as appropriate:
- _____ Not sure how to translate values in practice. Comment:
- _____ No opportunity to implement values. Comment:
- _____ No power to implement values. Comment:
- _____ Other reasons I could not use the values (please provide additional details):
15. Please tell us anything about yourself that will help us better understand your responses.

Thank you for participating in this survey. We may be requesting further information from conference participants. This may include conducting another survey or contacting individual participants for interviews. Please feel free to share with us any program

descriptions, case studies, or other sources of information that can help us understand how you have used the values of Decent Care in your work. You can send information to decentcareltg@gmail.com or croeber@ltgassociates.com. We thank you in advance for your continuing participation.

With warm regards,

Carter Roeber
Project Director
LTG Associates, Inc.
Takoma Park, MD
Endnotes

For more information, please visit:
<http://www.ghtechproject.com/resources>

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