

## Methodology

### **PART 1: Current role and educational needs of doctors in South Africa involved in end-of-life palliative care**

*Sample Selection.* Interviews were conducted between February and December of 2007. To be included in the study, health care providers were: a) providing care for patients with life-threatening illnesses, b) able to complete (up to) one hour of interview, and c) able to communicate in English. Family members needed to be: a) caring for a relative with a life-threatening illness (not necessarily the primary caregiver but involved in care-giving tasks on a regular basis), b) 18 years of age or older, c) competent to provide valid informed consent, and d) able to speak English, Afrikaans, or Xhosa. The criteria for a patient participants was that they were: a) dealing with a life-threatening illness, b) able to complete one half hour interview, c) 18 years of age and older, d) willing and able to provide informed consent, and e) able to communicate in either Xhosa, Afrikaans, or English.

There were two different procedures utilized to select the sample for this particular component of the research project: one for the face to face interviews held in the Western Cape Province and another for the telephonic interviews for participants in the remaining 8 South African provinces. Each will be described in turn.

*Western Cape Participants* Following approval by the Research Ethics Boards (REB) at University of Cape Town, University of Manitoba and Hospice and Palliative Care Association of South Africa, a letter containing a brief overview of the research project was sent to the administrators of the 15 HPCA member hospices in the Western Cape province of South Africa. Seven to ten days after the letter of invitation was sent, a follow-up phone call was placed to determine the interest level of the administrator and to

establish a meeting time to discuss the research in more detail. Fourteen hospice managers or CEOs expressed interest in the project; contact with one hospice manager was difficult due to recent staff changes and so after 3 attempts, the hospice was excluded from the study. Once a commitment was made, a date was set to visit the hospice. If a hospice doctor visited the hospice infrequently, the date was set according to the hospice doctor's schedule.

The sample of participants was generated during the hospice visits. The head nursing sister would typically walk through the hospice and ask patients and other nursing sisters if they'd like to be involved. If they agreed, the interview would occur shortly thereafter. Typically there would be between 3-7 interviews per hospice visit. If the visit was off-site, a nursing sister would drive the researcher to the patient or family care provider's home. This was the most efficient way of meeting with patients for both the researcher and the nursing sister; the nursing sister would be able to complete her care tasks (during which time the researcher made observation notes), and the researcher would conduct an interview. The most obvious benefits to this system were twofold: having a familiar face—the nursing sister—introduce the project likely increased the participation rate and the opportunity to observe nursing care in a natural environment was valuable. The drawback to the system was that the nursing sister was physically present, although rarely directly involved in the interview. When questions were asked about the patient or care giver's satisfaction with nursing care, participants never provided a negative rating, which may have been due to the proximity of their care giver. That said, in the few instances where the nursing sister did not accompany the researcher to the interview, satisfaction with care was always rated positively.

When the interview was conducted with the assistance of a Xhosa translator, the questions would be asked by the lead researcher in English and then transcribed (if necessary) into Xhosa. At times participants would reply in English and at others in Xhosa; participants were encouraged to respond in the language they felt most comfortable speaking. When responses were in Xhosa, the translator would provide a brief summary. In this way, the interviewer could process the meaning of the participant's comments and ... adjust questions and comments in response to unanticipated answers" (Twinn, S. 1997; ) (p. 573). Having the Xhosa translator present allowed the lead researcher to continually shape the interview.

At times, information from the interview led to the selection of participants not working or residing in the hospice organization. For example, a key informant in the hospice referral system is an oncology social worker. Thus, based on the contact information for hospital social workers provided at the hospice, additionally interviews were held.

Other provinces in South Africa The proposed methodology indicated that doctor participants would be randomly selected from a list generated through an online list of practitioners working in South Africa. Although such a list was available online, the information on it was incomplete. While three attempts were made to contact doctors by post using this method, the rate of acceptance was too low for it to be considered an effective method; of 186 letters sent, 7 individuals indicated interest in participating. Thus, other sampling approaches needed to be considered to meet the recruitment targets. The next group that was targeted was current or former students and about one third of the sample was made up of students. In several provinces, namely Limpopo,

Mpumalanga and the Northern Cape, it was most challenging to locate participants.

Using contact information provided by the Rural Health Initiative of South Africa and Yellow Pages, the researcher made contact with hospital managers within those provinces. By faxing or emailing project information directly to the medical managers (followed up by a phone call), the full compliment of participants was reached.

***Interview Guides.*** A framework developed by Stewart et al. (1999) acted as a guide for the interview and observation development. Of particular value was that the framework incorporates a range of perspectives including those of patients, families, and health care providers. While the framework was developed in the United States, local South African health care experts confirmed that it had direct relevance to palliative care in South Africa. Thus, Stewart's framework guided the development of the interview and observation schedule for all participant groups.

In particular, three separate interview guidelines and one observation checklist were created. As seen in Stewart's framework, there are five specific categories (personal and social environment, structure of care, process of care with physicians, nurses, and social workers, satisfaction with health care, and quality and length of life) that are related to a more general review of experiences at end of life. Material pertaining to process of care and satisfaction with care were further developed; patients and family care providers were asked to detail the care that they received as well as their satisfaction with care. For example, in the interviews of health care providers, the interview question "How are patients told of a terminal diagnosis and what to expect?" begins to explore this concept.

As interviews progressed and as various issues apparently were more meaningful within the discussion than initially expected, the interview guide was refined and adapted over time. For patients and family care providers, the refinements meant that the questions were asked in a more efficient way than first proposed. While this tended to shorten the length of the interview, it (more importantly) meant less confusion and repetition for the participants.

Interviews questions of health care providers were refined as certain issues became apparent or important. The bulk of the refinements to the questions were made within the first two months of data collection. For example, the initial interview schedule incorporated a number of demographic questions (e.g, Where did you receive your medical training from? Have you taken additional training in palliative care?) which were moved to the Health Care Provider Survey. Removing them from the interview schedule did not eliminate the information but rather allowed other questions to be added.

Secondly, as the face-to-face interviews often contained an observation period where the health care provider was asked supplementary questions—recorded as observation or field notes—and as this was not available during the phone interviews, contextual questions were added to the interview. For example, participants were asked to provide a general description of how and where people were cared for at end-of-life in their particular region of South Africa. Also, participants were asked to describe in general terms the area where they lived: population demographics, available health care resources, employment, and so on.

Over time and with experience, the lead researcher became more attuned to South African issues that respondents typically discussed. By creating questions around those

issues, it gave more of the respondents the opportunity to respond directly to the issue and the researcher the ability to look for common themes or sub-themes around those issues.

To evaluate the educational needs of doctors working in South Africa, a 36-item survey developed by Barnabe and Kirk {{1102 Barnabe,C. 2002; }} was utilized. In 2002, they completed a palliative care education needs assessment for Manitoba physicians using a mail-out survey. Within the survey was a section related to various components of palliative medicine (pain, symptom control, bereavement, psychosocial aspects of death, professional issues, ethics, establishing a palliative care program in the community, principles of palliative care, communication with the patient and family, interdisciplinary communication, and personal ability to cope with a dying patient) with respondents scoring their importance from 3 (very important) to 1 (not important). Both the health care provider survey and the interview questions were vetted by South African health care informants to ensure that the language and relevance were sensitive and appropriate respectively.

***Method of Analysis.*** All interviews were audio-taped, transcribed verbatim (where possible), and analyzed using the NVivo 7 software program. Transcriptions of English interviews were completed within 1-14 days of each interview in order to retain data; the different accents of participants made it necessary to transcribe quickly to retain accuracy. Transcribing of Xhosa interviews was completed in two stages with the assistance of two Xhosa speaking translators. In the first step, one Xhosa translator would verbally translate the participant's interview while the lead researcher would type. To ensure accuracy, the second Xhosa translator would review and edit the transcripts. If

there was a discrepancy, the translators would work together to find the accurate meaning. Following the advice by Twinn {{1608 Twinn,S. 1997; }}, it was more important to produce a meaning-based translation rather than a word-for-word product.

The Interpretive Description methodology, proposed by qualitative nurse researchers Thorne, Reimer Kirkham and MacDonald-Emes {{1611 Thorne,S. 1997; }}, was used to guide the analysis. Interpretative Description, developed as an alternative to other research processes such as grounded theory and ethnography, allows for both a description of and an interpretation about a health or illness phenomena from the perspective of those experiencing it. As the authors of the process describe it, Interpretative Description ~~is~~ a grounded approach to articulating patterns and themes emerging in relation to various clinical phenomena. This method provides direction for qualitative description and allows for its extension into the realm of interpretation and explanation in the context of qualitative credibility criteria" {{1612 Thorne,S. 2004; }} (p. 8). As such it is an appropriate tool to analyze the responses by all participants in the research project. Analyzing data using Interpretative Description is an inductive process whereby the researcher works to understand the overall picture. The framework by Stewart et al {{1538 Stewart,A.L. 1999; }} used in the project fits well with the Interpretative Description methodology in that they both propose examining a health issue through a range of participant samples (e.g. doctors, nurses, patients).

As the analysis aimed to understand an overall picture, phrase coding was used to first generate themes and sub-themes and then to look at bigger questions such as ~~—~~ "what is happening here?" or "what am I learning about this?". Broad questions were used to stimulate a more coherent framework in Interpretative Description methodology. In this

way, a new framework or model was generated based on the qualitative data. Thus, patterns and themes were articulated in relation to existing literature.

To evaluate the survey data, data were analyzed using SPSS 11.0. Descriptive statistics, including means and frequencies of item responses, were calculated. To assess the statistical significance between the scores of doctors and other health care providers, a two-sample t-test was performed.

***Biases & Limitations.*** Although eliminating all biases is not possible, a systematic approach to data collection, interpretation and communication was used to address the influence of bias upon the researcher and research findings. To ensure credibility through reflexivity and in the attempt to sustain objectivity as a researcher, the reflective process of field notes were incorporated into the design{{1613 Pope,C. 2000;1614 Mays,N. 2000; }}. However, as objectivity is highly difficult to achieve in a qualitative setting, the researcher also reflected upon the broader assumptions made in the course of the research{{1614 Mays,N. 2000;1613 Pope,C. 2000; }}; reflecting on the researcher's role as a foreign, English speaking female was critical within this process.

Nvivo 7 was used throughout the project as computer-assisted coding and analysis is seen by some to enhance credibility{{1613 Pope,C. 2000; }}. Additionally, A co-researcher- Dr. Genevieve Thompson- based in Winnipeg, Manitoba, assisted with the analysis by reviewing the data and addressing inconsistencies found in the early analyses of the data. In this way, the co-researcher could examine the influence of bias upon the research findings as much as possible{{1611 Thorne,S. 1997; }}. Discrepancies or negative cases were examined throughout the analysis {{1614 Mays,N. 2000;1613 Pope,C. 2000; }}.



Biases were dealt with in an ongoing manner. As the primary investigator is English speaking, the participants chosen at the start of the study were all able to speak English with some fluency. In doing so, the majority of the sample was either English or Afrikaans. To ensure the sample was generalizable to the population of South Africa, a Xhosa-speaking translator was hired. The researcher conducted the interviews and translation was provided when participants spoke in Xhosa. While the content of the interviews did not seem different in comparison to the ones conducted in English, the overall sample was more robust in that it more accurately reflects the ethno-cultural variation found within South Africa's diverse population.

Due to distance and cost factors, phone interviews were conducted with doctors not living in the Western Cape; face to face interviews were conducted with those living in Western Cape. The reality of the project was that there were fewer face to face interviews (n=8) compared to phone interviews (n=40). The face to face experience may have provided data that was more complex and rich due to the added depth an in-person interview affords. The analysis, therefore, needed to examine possible differences in the content of the interviews.

## **PART 2: Evaluation of the UCT Distance Education Program**

*Sample Selection.* All past and present course registrants were considered eligible. Contact information was provided through the administrative records at the School of Public Health and Family Medicine. However, as current records were not available for nine students, the eligible pool of participants was 125.

*Surveys.* Data was collected using three different measurement tools- General Survey, Graduate Survey and Pre-Post Workshop Survey- which were designed to

evaluate specific aspects of the course. Proven techniques such as using short and simply worded titles and limiting length to four pages {{1544 Lund,E. 1998; }} were used to increase response rates.

General Survey. The General Survey was designed to evaluate student competence in areas such as pain, assessment, changes in treatment, and general palliative care concepts. It was developed from the course objectives.

Graduate Survey. The Graduate Survey was designed to assess graduates' perspectives of the distance education palliative care course. It included survey questions based on the course objectives as well as open-ended questions in order to solicit information about changes in care practice, benefits, limitations, and suggestions.

Pre-post surveys. First and second year students are required to attend a 3-day workshop each year at the University of Cape Town. A pre-post survey was used to measure the efficacy of these workshops. The survey was based on the intended workshop objectives and all workshop attendees were considered eligible participants.

**Procedures.** Field Testing began in late January, 2007. Surveys were sent to five graduates of the distance education course (Dr. Gwyther identified doctors living in the Western Cape to ensure rapid response) for feedback on cultural appropriateness. Four people responded and their comments were used to finalize the surveys.

On February 21, 2007 the Graduate and General Surveys were mailed out to students who were not in the first or second year of the course; 30 packages containing General Surveys and 66 with both the Graduate and General Surveys were mailed. Due to an error in compiling the address list, an additional six graduates were sent surveys on

April 26th. Seven packages were returned due to wrong addresses and accurate postal information was unavailable.

To increase the response rates, a second mailing- containing a letter of introduction, consent forms and survey(s)- was posted to 80 people (22 received General Survey and 58 received both General and Graduate Survey) on May 1, 2007. Another reminder came in the form of a telephone call; from June 18-20<sup>th</sup>, the research assistant phoned participants to introduce the project and encourage participation. Of the 24 calls where the researcher was able to speak directly to the participants, 14 requested to have the project documents sent out via email, 7 stated that they were in the midst of completing the surveys, 2 indicated a different mailing address, and 1 stated that he/she was too busy to complete the survey. 27 additional calls were placed but circumstances were such that direct communication did not occur. Following the phone reminders, 14 people sent in surveys.

The final reminder was sent via email. 48 people were emailed either a General Survey or a General and Graduate Survey; 12 of the emails were returned due to incorrect addresses. Reminder letters were sent to the participants whose email address was not correct (n=19). Based on returned mailings, contact information was incorrect for nine students.

Workshops were held at University of Cape Town in late February and early March for the first and second year students respectively. At the start of those workshops, the research project was introduced and the students were given the Pre-workshop Survey and General Survey. Students who were not in attendance were mailed the General Survey only (n=5, March 22, 2007). The Post-workshop Surveys were

mailed on June 12, 2007, to the 25 participants who had completed the Pre-workshop Survey at the course workshop.

***Analysis.*** All survey data was entered into SPSS 11.0 for analysis. Descriptive statistics, including means and frequencies of item responses were conducted. Additionally, two-tailed paired *t*-tests were used to evaluate perceived changes in knowledge pre- and post workshop. Two-tailed Pearson correlations were used to examine associations between knowledge and background variables.

***Ethical considerations.*** This study was carefully designed and adheres to the Declaration of Helsinki 2000 {{1543 World Medical Association General Assembly 2004;1541 Mamdani,B. 2004; }}. The project did not involve deception and measures were taken to preserve anonymity and confidentiality. While the researcher had access to identifying information when gathering data by survey or interview, the dissemination of the project results do not reflect this.

All participants had the project explained to them prior to signing the consent form and were provided with a copy of the participant information sheet that outlines the purpose of the study and the expected role of the participant. The consent form was treated as only one level of consent and if a participant had asked to withdraw from the project at any time- his or her right- it was made clear to the participant that there were no negative consequences associated with that decision. Family members and patients were considered “vulnerable populations” so additional measures were put in place: if at any time a participant indicated distress, the interview process would be halted and offered social work services. At no point did any patient, family member or other project

participate indicate distress. All participants who signed a consent form completed the entire research protocol.

## Results

### **PART 1: Current role and educational needs of doctors in South Africa involved in end-of-life palliative care**

#### **Participants**

There were a total of 116 participants-- including patients, family care providers, nursing sisters, other health care providers, and doctors-- interviewed for this research project (Table 1).

***Patients.*** There were a total of 22 patients interviewed in the study. The patients' ages ranged from 26 to 79 with an average age of 51.3 (SD 16.2). The majority of the patients, 45%, had either HIV/AIDS (with or without TB) or some form of cancer (41.1%). The average length of the interview was 10 minutes 30 seconds (range 3:49-28:13, SD 5.4).

***Family Care Providers.*** There were 13 (six white, four coloured, two black, and one Indian) family care providers (FCP) interviewed for the study. The ages of the FCPs ranged from 26 to 70, with a mean age of 53.9 years. The vast majority of patients cared for by the FCPs interviewed had cancer (n=10), two had HIV/AIDS and another had MS. The average length of the interviews was 7 minutes (range 3:53-19:29, SD=5.31). All of the interviews were conducted in the homes of the FCP.

***Nursing Sisters.*** There were 18 nursing sisters interviewed for the project. Regarding ethnicity, there were an equal proportion of white and colored nurses interviewed for the project. Three (16.7%) of the participants were black and one  
13 of 30

participant chose not to reveal ethnic background. Half of the participants stated that Afrikaans was their first language. English was spoken by 22.2% of the sample and Xhosa by 11.1%. The average length of the interviews was 22.8 minutes. All of the participants were employed at hospices; 22% (n=4) of the respondents were working in an in-patient unit and 78% (n=14) were employed in home-based care settings.

**Other Health Care Providers.** There were 15 participants that represented other health care professions including social work (n=9, 60.0%), home-based care (n=5, 33.3%) and spiritual care (n=1, 7.7%). The participants' ages ranged from 32-63 (m=44.9, SD= 11.0). The average length of interviews was 20:44 minutes (range= 4:59-38:27, SD= 11.6). Almost three quarters (73%) of those interviewed worked at hospices with the remaining working in public hospitals.

**Table 1: Descriptive Statistics of Participants**

Characteristic	PATIENTS (N=22)		FAMILY CARE PROVIDERS (N= 13)		NURSING SISTERS (N=18)		OTHER HEALTH CARE PROVIDERS (N=15)	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<b>Gender</b>								
male	12	54.5	2	15.4	0	0	1	7.7
female	10	45.5	11	84.6	18	100	14	93.3
<b>Ethnic Background</b>								
Black	11	50.0	2	15.4	3	16.7	3	20.0
White	6	27.0	6	46.1	7	38.9	8	53.3
Coloured	4	18.0	4	30.8	7	38.9	4	26.7
Indian	--	--	1	7.7	--	--	--	--
Not specified	1	5.0	--	--	1	5.5	--	--
<b>Primary Language</b>								
Xhosa	11	50.0	2	15.4	2	11.1	3	20.0
English	3	13.6	4	30.8	4	22.2	1	7.7
Afrikaans	5	22.7	5	38.5	9	50.0	10	66.7
Bilingual	1	.5	--	--	1	5.5	--	--
Not specified	1	.5	2	15.4	1	5.5	1	7.7
Other	0	0	--	--	1	5.5		

**Doctors.** There were a total of 48 interviews conducted with medical doctors. Of these, 40 were telephonic interviews and 8 were face-to-face. Doctors' ages ranged from 30 to 69 years across all provinces. The mean age was 47.9 years (median=47, SD=9.9). 64.6% (n=31) of the doctors were male and 35.4% or 17 of the doctors were female. Three ethnic or racial backgrounds (white, black, and Indian) were represented in the sample with the majority (68.8 %) being white; 22.2% of the participants were black, and 8.3% Indian. A breakdown of participant language is seen in Table 2.

**Table 2: Descriptive Statistics of Doctors (n=48)**

	Western Cape (n=8)		Northern Cape (n=5)		North West (n=5)		Gauteng (n=5)		Eastern Cape (n=5)		Limpopo (n=5)		Mpumalanga (n=5)		Free State (n=5)		KwaZulu Natal (n=5)		TOTAL (N=48)	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
<b>Gender</b>																				
male	4	50	4	80	4	80	2	40	2	40	5	100	3	60	3	60	4	80	31	64.6
female	4	50	1	20	1	20	3	60	3	60	0	0	2	40	2	40	1	20	17	35.4
<b>Ethnic Background</b>																				
white	7	87.5	2	40	1	20	5	100	3	60	2	40	5	100	5	100	3	60	33	68.8
black	1	12.5	1	20	4	80	-	--	2	40	3	60	-	--	-	--	-	--	11	22.9
Indian	-	--	2	40	-	--	-	--	-	--	-	--	-	--	-	--	2	40	4	8.3
<b>Primary Language</b>																				
English	3	37.5	1	20	2	40	4	80	2	40	-	--	1	20	1	20	4	80	18	37.5
Afrikaans	4	50.0	2	40	-	--	1	20	-	--	2	40	3	60	4	80	1	20	17	35.4
Xhosa	1	12.5	-	--	1	20	-	--	2	40	-	--	-	--	-	--	-	--	4	8.3
Sutu	-	--	-	--	1	20	-	--	-	--	1	20	-	--	-	--	-	--	2	4.2
Tswana	-	--	1	20	-	--	-	--	-	--	-	--	-	--	-	--	-	--	1	2.1
Venda	-	--	-	--	-	--	-	--	-	--	1	20	-	--	-	--	-	--	1	2.1
Other	-	--	-	--	-	--	-	--	-	--	1	20	-	--	-	--	-	--	1	2.1
Unspecified	-	--	1	20	1	20	-	--	1	20	-	--	1	20	-	--	-	--	4	8.3

## Results (in progress)

**Health Care Professional Survey.** 75 of the health care professionals who were interviewed also completed the Health Care Professional Survey and the demographics of

the respondents can be seen in Table 3. Respondents' ages ranged from 30-64 (mean- 47.48, SD- 8.97).

Respondents were asked to “consider the educational needs of physicians within the field of palliative medicine. Rank each issue as *very important*, *somewhat important*, or *not important*, according to your personal opinion”. Six sections-- pain, symptom control, bereavement, psychosocial aspects of death, professional issues, and ethics -- were composed of several questions each. Five additional areas-- establishing a palliative care program in the community, principles of palliative care, communication with the patient and family, interdisciplinary communication, and personal ability to cope with a dying patient-- were presented in a single question.

**Table 3: Demographic for Health Care Professional Survey (N=75)**

<b>Variable</b>	<b>Count</b>	<b>Percentage</b>
<b>Sex</b>		
male	31	41.3
female	44	58.7
<b>Province</b>		
Eastern Cape	5	6.7
Free State	5	6.7
Gauteng	6	8.0
KwaZulu Natal	4	5.3
Limpopo	5	6.7
Mpumalanga	3	4.0
Northern Cape	2	2.7
North West	5	6.7
Western Cape	40	53.3
<b>Role</b>		
Nursing Sister	15	20.0
Social Worker	10	13.3
Doctor	44	58.7
Professional Carer	6	8.0

It was apparent that respondents felt that all areas should be considered important fields of study for doctors with only slight variation between issues. 97.2% of the time



respondents selected the ratings “very” or “somewhat” important as compared to 2.8% of the responses in the category “not important”. Of the 49 times that “not important” was selected, euthanasia was selected 18 (36.7%) times. The topic areas selected as having the highest overall importance were pain management (average of 2.97 out of 3), communication with patient and family (2.96), pain assessment (2.96), control of symptoms nausea and vomiting (2.94), and principles of palliative care (2.94). Those that scored the lowest overall were related to pain and neurophysiology (2.53), pain and comprehensive therapies (2.42), research in palliative care (2.41), and euthanasia (2.22). Average scores of doctors and other health care workers are shown in Table 4.

**Table 4: Health Care Professional Scores—Doctors and Other Health Care Workers**

Survey Items (number of questions per area)	Doctors (n=44)		Other health care workers (n=31)	
	Mean	S.D.	Mean	S.D.
Establishing a palliative care program in the community (1)	2.9	0.3	2.8	0.5
Principles of palliative care (1)	2.9	0.2	2.9	>0.1
Communication with the patient and family (1)	2.9	0.3	3.0	0.0
Interdisciplinary communication (1)	2.9	0.4	3.0	0.0
Personal ability to cope with a dying patient (1)	2.9	0.3	3.0	0.0
Professional Issues (2)	5.2	1.0	5.1	1.2
Psychosocial aspects of death (3)	8.3	1.1	7.9	1.5
Bereavement (6)	16.1	2.7	16.1	2.8
Symptom Control (10)	28.0	2.8	26.0	7.5
Pain (5)	13.4	1.2	13.2	3.3
Ethics (5)	12.1	3.4	12.1	2.1
<b>Total Score (36)</b>	<b>97.4*</b>	<b>8.1</b>	<b>92.6</b>	<b>17.8</b>

\* highest possible score=108

A 2-sample *t*-test comparing the mean scores of two groups (other health care providers and doctors) by total score and category total indicates that the only significant difference between scores of the two groups was found in the category of “interdisciplinary communication” (see Table 5). In this instance, other health care providers—a group consisting of nursing sisters, social workers, and home-based carers—placed a significantly greater value on the category. A separate analysis examining scores by sex showed no significant differences between the scores of male or female respondents in any of the categories.

**Table 5: 2-Sample Independent *t*-test (two tailed):**

Survey Items (number of questions per area)	Mean difference	<i>t</i> -value	P-value	95% CI
Establishing a palliative care program in the community (1)	-0.1	-0.6	0.5	-0.3 to 0.1
Principles of palliative care (1)	<0.05	0.6	0.6	-0.1 to 0.1
Communication with the patient and family (1)	0.1	1.4	0.2	<-0.05 to 0.2
<b>Interdisciplinary communication (1)</b>	<b>0.1</b>	<b>2.1</b>	<b>&lt;0.05</b>	<b>&lt;0.05 to 0.3</b>
Personal ability to cope with a dying patient (1)	0.1	1.9	0.06	<-0.05 to 0.2
Professional Issues (2)	-0.1	-0.4	0.7	-0.6 to 0.4
Psychosocial aspects of death (3)	-0.3	-1.1	0.3	-1.0 to 0.3
Bereavement (6)	-0.2	<-0.05	1.0	-1.3 to 1.3
Symptom Control (10)	-2.0	1.6	0.1	-4.5 to 0.5
Pain (5)	-0.2	-0.4	0.7	-1.3 to 0.8
Ethics (5)	0.2	0.3	0.8	-1.1 to 1.5
<b>Total Score (36)</b>	<b>-4.8</b>	<b>-1.6</b>	<b>0.1</b>	<b>-10.9 to 1.3</b>

## **PART 2: Evaluation of the UCT Distance Education Program**

### **Participants**

Of the 125 current or past students invited to participate in the study, 83 (66.4 %) responded to the General Survey. Over half of the respondents were female (47 or 56.6 %) and 53.0% (44) were current students. There have been 71 graduates from the distance education program but accurate contact information was not available for all of them. Of the 67 possible respondents, 41 (or 65.7%) returned a completed Graduate Survey. Of the students that began the course in 2006, there were 16 workshop participants. 15 out of a possible 16 participants completed the pre-survey and six the post-workshop survey. Of the students who began the course in 2007, there were 13 workshop participants. 9 out of a possible 13 participants completed the pre-survey and the post-test was completed by 8 out of a possible 9 respondents (see Table 7).

***Table 7: Pre-Post Survey Workshop Response Rates***

<b>Workshop</b>	<b>Total Participants</b>	<b>Pre-Survey (count)</b>	<b>Response Rate (%)</b>	<b>Post-Survey (count)</b>	<b>Response Rate (%)</b>
2006	16	15	93.4%	6	40%
2007	13	9	69.2%	8	88.9%

The demographic overview of participants (see Table 8) indicates that for both the Graduate and General Survey, there were more male respondents- 65.9% and 56.6% respectively. In addition, the majority of participants were aged 30-44 years (51.2% and 51.8%) or 45 years and older (46.3% and 44.6%).

Table 8: Demographic Overview of Survey Participants

<i>Variable</i>	<b>General Survey (n=83)*</b>		<b>Graduate Survey (n=41)**</b>	
	Count	%	Count	%
<b>Sex</b>				
Male	35	42.2	14	34.1
Female	47	56.6	27	65.9
Data not provided	1	1.2	--	--
<b>Age</b>				
18-29	2	2.4	1	2.4
30-44	43	51.8	21	51.2
45+	37	44.6	19	46.3
Data not provided	1	1.2	--	--

\* response rate: 66.4%

\*\* response rate: 65.5%

## Results

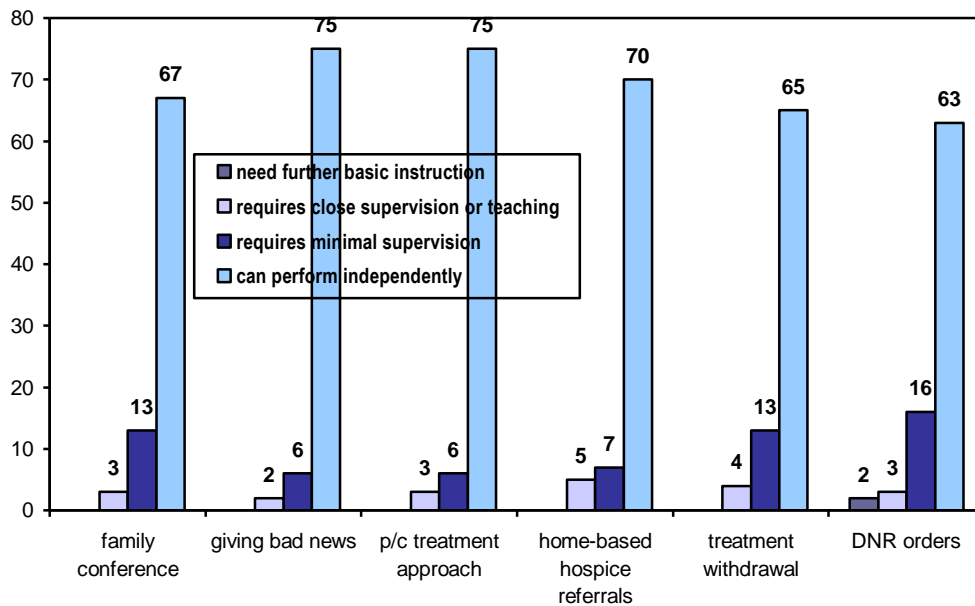
### General Survey

Of the 125 current or past students invited to participate in the study, 83 (66.4 %) responded to the General Survey. Over half of the respondents were female (47 or 56.6 %) and 53.0% (44) were current students. There were five sections to the survey- Palliative Care Activities, Pain Assessment, Changes in Treatment, and General Concepts in Palliative Care- that covered aspects of the course.

**A) Palliative Care Activities.** Students were asked to rate their degree of competence (3- can perform independently to 0- need further basic instruction) in relation to 6 palliative care activities including conducting a family conference, giving bad news to a patient or family member, discussing treatment withdrawal, or discussing home-based hospice referral with patient and family. The responses indicate that the majority of participants (95.8%) felt that they could perform the activities with little or no

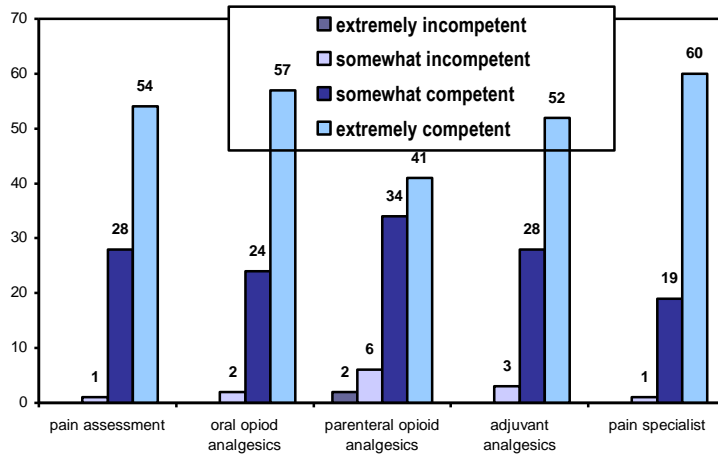
supervision. Two participants stated that further instruction was needed in the area of discussing Do Not Resuscitate (DNR) orders and 21 participants indicated that close supervision or additional teaching was needed.

**Table 9: Participant Responses for Palliative Care Activities**



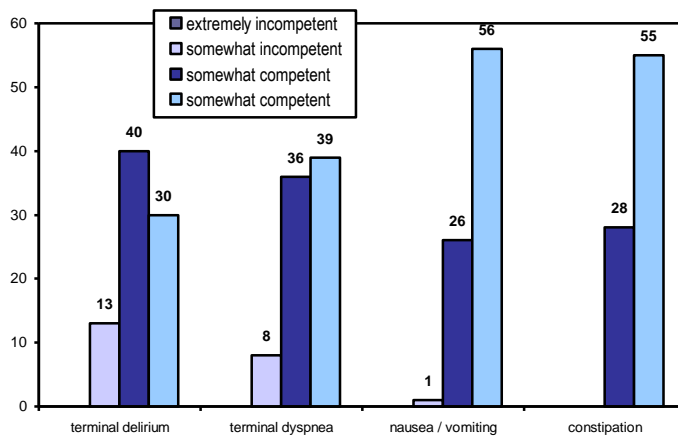
**B) Pain.** Five questions were provided to assess student competency in the field of pain including pain management, assessment of pain, use of adjuvant analgesics, and use of oral and / or parenteral opioid analgesics. 96.4% of the responses were in the categories –extremely” or –somewhat” competent while 15 (3.6%) responses identified perceived incompetence. Student responses were mixed in the area of parenteral opioid analgesics with 41 (49.4%) feeling extremely competent, 34 (41.0%) as somewhat competent, and 8 (9.6%) stating that they were either somewhat or extremely incompetent. It is the area with the highest count of responses in the –somewhat competent”, and –extremely or somewhat incompetent” choices.

**Table 10: Participant Responses for Pain Category**



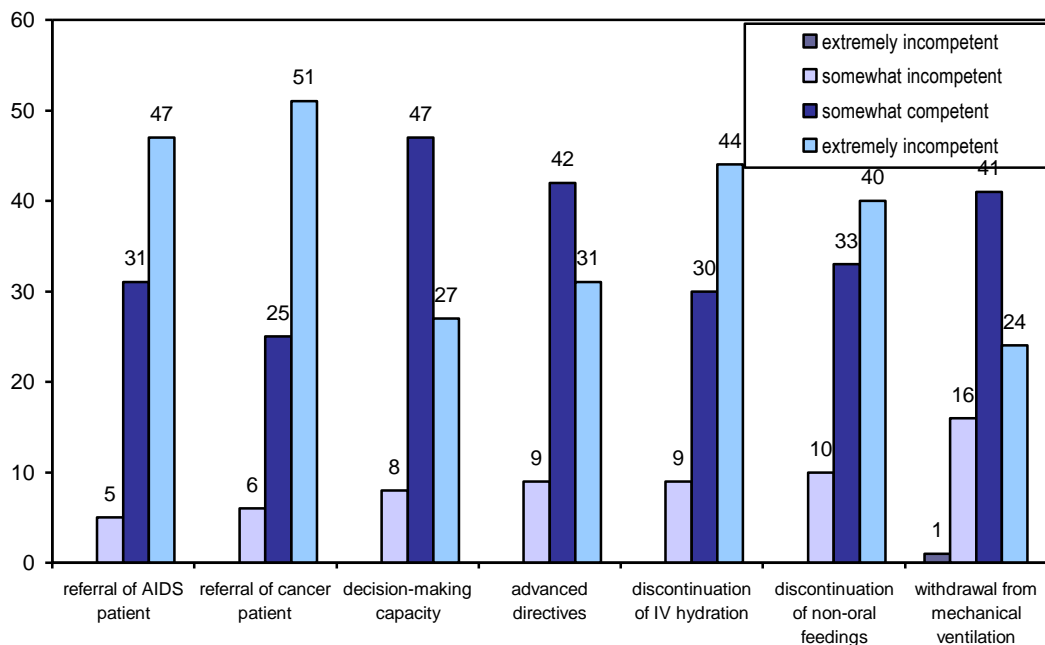
**C) Assessment.** Four questions relating to assessment were used to measure participant competence in assessing terminal delirium, dyspnea, nausea / vomiting, and constipation. The results indicated that in general, the majority of students generally feel competent in all the assessment areas. However, when comparing results to the two previous categories of Pain and Palliative Care Activities, there is a higher proportion overall of participants that have selected “somewhat competent” (39.2 %) as compared to “extremely competent” (54.2%).

**Table 11: Participant Responses for Assessment**



**D) Changes in Treatment.** Students were asked to respond to seven questions in the category “Changes in Treatment”. Topics ranged from knowing when or how to refer patients with AIDS or cancer to home-based hospice programs, determine decision-making capacity of patient or family care providers, discuss advanced directives, and discontinue various types of treatment. There was some variation in the responses; while the majority of responses (88.9%) indicated “somewhat” or “extremely” competent, there were a balanced proportion of “somewhat competent” responses (43.1%) to “extremely competent” (45.8%). In three questions—those referring to determining decision making capacity, discussing advanced directives, and withdrawal from mechanical ventilation—more students chose “somewhat competent” than “extremely competent”.

**Table 12: Participant Responses for Changes in Treatment**

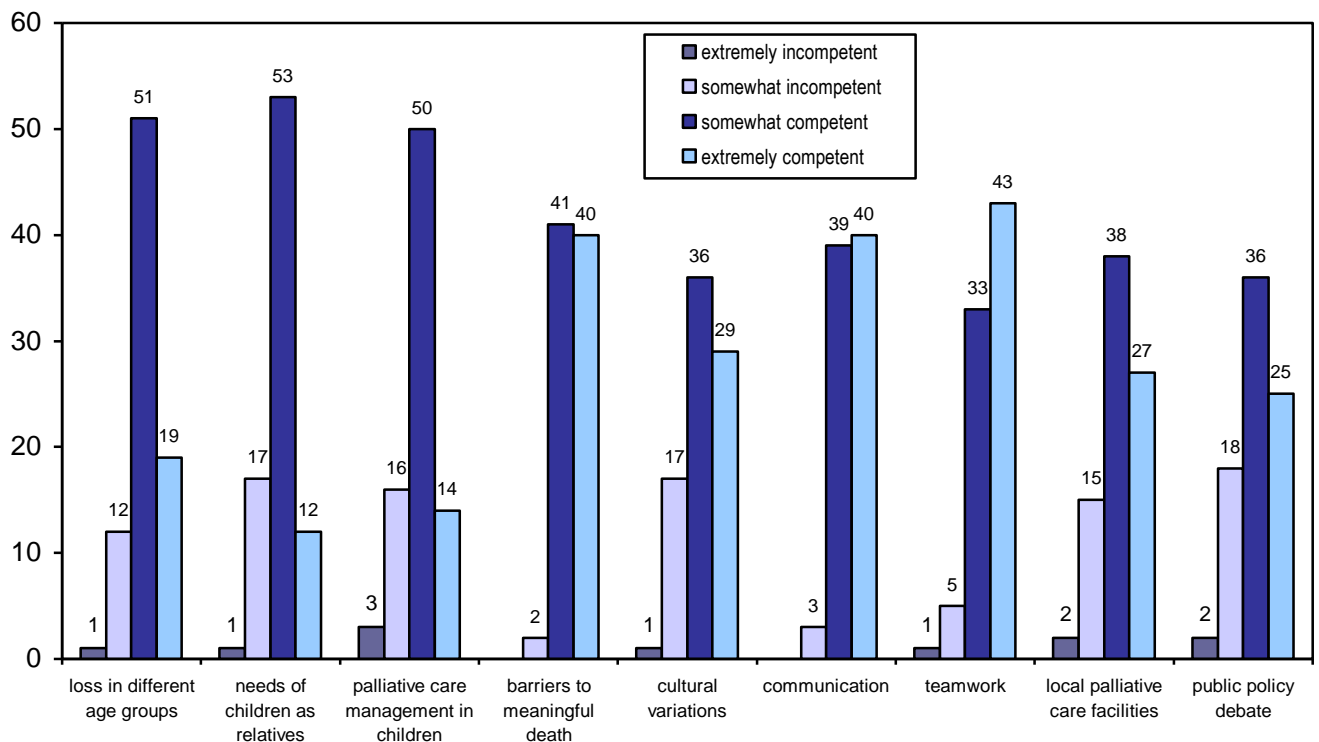


**E) General Palliative Care Concepts.** The final section of the survey was composed of nine questions. The first three related to different aspects of pediatrics and palliative care and examined loss in different age groups, the needs of children as family

members, and palliative care management in children. The remaining six questions looked at broad palliative care concepts including cultural variations in dealing with death and dying, patient and staff communication, team work, knowing how to access local palliative care resources, and finally understanding the elements of the broader public policy debate around palliative care in South Africa.

Out of 742 responses, 249 (33.6%) were “extremely competent”, 377 (50.8%) were “somewhat competent”, 105 (14.1%) were in the category “somewhat incompetent”, and 11 (1.5%) as “extremely incompetent”. If examining the 249 responses to the three pediatric questions, a higher proportion (154 or 61.8%) of the responses indicate “somewhat competent” as opposed to “extremely competent” (45 or 18.1%) which may be an indication that this is a subject area that needs additional focus.

**Table 13: Participant Responses for General Palliative Care Concepts**





The mean score for the General Survey was 75.0 (SD 12.9) with scores ranging from 34.0 to 93.0. A higher score indicated greater perceived competence in the area being evaluated. Palliative Care Activity scores averaged 16.7 (range: 6.0 – 18.0, SD 2.6), Pain scores averaged 12.9 (range: 5.0 to 15.0, SD 2.3), and Pain Assessment averaged 9.9 (range: 6.0 to 12.0, SD 2.0). Scores for the category General Concepts in Palliative Care averaged 19.2 (range: 5.0 to 27.0, SD 4.5) and Changes in Treatment were 16.3 (range: 7.0 to 21.0).

In all survey sections, males (n=35) had higher scores than did females (n=47). However, a two-tailed two-sample independent *t*-test found that there were no significant differences between the total scores of male and female respondents [ $t(80)= 1.5, p=0.1, CI -1.4 to 10.0$ ]. In the five areas evaluated in the survey, no significant differences in scores were found: Palliative Care Activities [ $t(80)=1.3, p= 0.2, CI -0.4 to 1.9$ ], Pain [ $t(80)=1.4, p=0.2, CI=-0.3 to 1.7$ ], Assessment and Management [ $t(80)=0.7, p=0.5, CI=-0.6 to 1.2$ ], General Concepts in Palliative Care [ $t(80)=1.5, p=0.1, CI=-0.5 to 3.5$ ], and Changes in Treatment [ $t(80)=1.2, p=0.2, CI=-0.6 to 2.5$ ].

An analysis comparing scores of graduates to current students determined that in both total score and category scores, the graduates scored higher (current students- mean 71.4, SD 14.2, graduates- mean 79.0, SD 9.9). The 2-sample independent *t*-test expanded further on these findings and it became apparent that graduates have significantly higher scores than current students in all categories with the exception of “Assessment and Management”. These results may suggest greater confidence in palliative care principles in particular those taught in the distance education palliative care course at the University of Cape Town.

**Table 14: 2-Sample Independent *t*-test (two tailed)**

	Activity	Pain	Assessment & Management	General PC Concepts	Changes in Treatment	Total Score
<i>t score</i>	-2.5	-2.7	-1.9	-2.2	-2.6	-2.8
P (level of significance)	0.02	0.01	0.07	0.03	0.01	<0.01
Mean difference	-1.4	-1.3	-0.8	-2.1	-1.9	-7.5
Standard error	0.5	0.5	0.4	1.0	0.7	2.7
Confidence Intervals	-2.5 to -0.3	-2.3 to -0.3	-1.7 to 0.1	-4.1 to -0.2	-3.4 to -0.5	-13. to -2.1

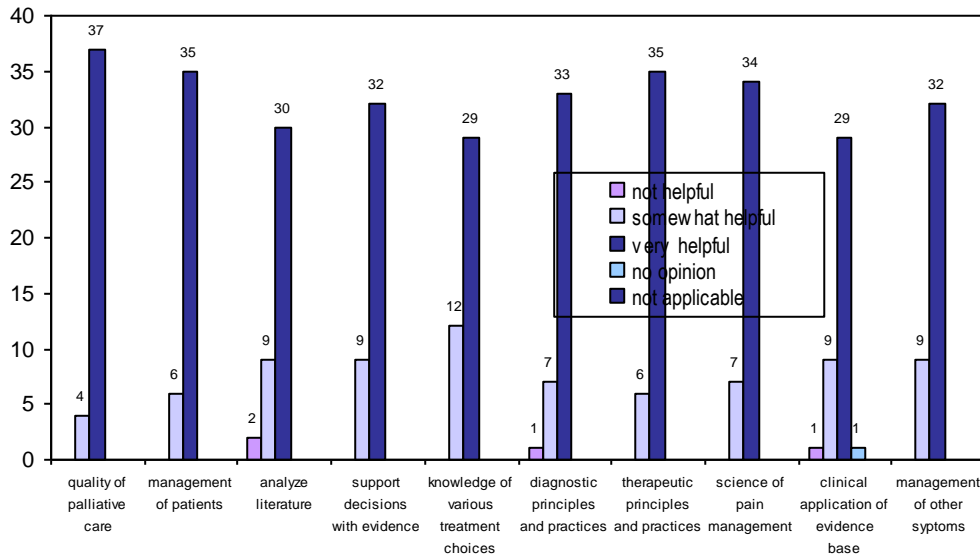
df=81, 95% confidence interval

### Graduate Survey.

67 graduates were invited to participate in the study and 41 (65.5%) completed the Graduate Survey. The survey consists of 33 questions; 25 are in a multiple-choice format and 8 are open-ended. The questions were grouped in four categories: general aspects of the course, clinical assessment in palliative care, team approach, and end-of-life care in South Africa.

**A) General Aspects.** Students were asked to rate how helpful the course was in relation to 10 general components of the course. The scale ranged from “not helpful”, “somewhat helpful”, “very helpful”, “no opinion”, to “not applicable”. For example, students were asked to determine the usefulness of the course in helping them to examine the quality of palliative care in a number of patients with different conditions, to critically analyze the literature concerning the principles of palliative medicine, to evaluate the scientific basis of pain management, and to discuss clinical application of evidence based palliative care.

An analysis of the total scores for this section shows that the overwhelming majority of responses were in the categories “very helpful” (79.7%) or “somewhat helpful” (19.1%).



When posed with the question “Can you describe why you enrolled in the palliative care distance education program?”, a variety of themes were apparent in the responses. Ten of the responses were related to specific aspects of the course like the reputation of the lecturers, the approach used fit personal principles, or the format fit with work schedule. In addition, five general themes arose in the analysis of the responses.

**A) Lack of Knowledge in Palliative Care.** Approximately half (22 of 48) of the responses identified that the main driver for enrolling in the course was that they lacked skill or knowledge in the field of palliative care. Three specified that they had not received any training in palliative medicine in their undergraduate medical degree while others described a personal sense of inadequacy in dealing with patients with chronic or life threatening conditions. In the words of one respondent,

***“I needed knowledge in palliative care to care for our many terminal HIV/AIDS patients and to educate our undergraduate students. We receive NO training in the undergraduate years (1972-78) and post-graduate years (M.Fam.Med: 1982-83).” (6249)***

B) ***Patient Need.*** Ten of the responses identified the needs of patients as being critical; a desire to provide better care for patients with in life-threatening situations was stated. Within their workplace, they were seeing patients- often dying- in distress and they felt a lack in ability to care for them. As one respondent wrote,

***“I was working in a large provincial hospital and we were seeing a large number of indigent HIV patients. At the stage the government was not providing ARVs. I felt totally ill-equipped to deal with this group of mainly young patients who were staring death in the face”. (6242)***

In addition, respondents were witness to inadequate care provision by other health care providers and felt a need to better meet the needs of patients.

C) ***Lack of Palliative Care Management Plans in the Workplace.*** Five of the responses identified that a reason for enrolling was that they wanted to have a more structured approach to end-of-life care within the workplace. Whether it be to assist a hospice organization, a palliative care unit, or public hospital, students wanted to learn how to manage the increasing need for palliative care within the community.

D) ***Palliative Care Qualification.*** The issue of “qualification” was identified in seven of the responses. Being able to receive a university diploma, a type of specialization, was a key sentiment expressed here. Often times, students had learned “on the job” and now wanted to formalize that training. The words of one participant express the need to extend the on-site job experiences to an academic setting:

***“I was working in palliative medicine and felt the need for comprehensive, formalized training” (6239)***

E) *Personal Interest*. Four of the respondents identified that the key reason they enrolled in the course was simply out of a deep personal interest in the subject area.

### **Dissemination of findings**

The results of this evaluation will be of use to several different audiences and so dissemination of the findings will be completed in several different ways. First, a general summary (1-2 pages) of the results will be made available to the project participants upon completion of the research. Second, the thesis results will be sent to Professor R. Ehrlich (Head of School of Public Health and Family Medicine) and Dr. Gwyther (Convener postgraduate programmes in palliative medicine at University of Cape Town; Education and Research Co-ordinator for Hospice Palliative Care Association of South Africa). The

extensive documentation found in the dissertation will provide them with an overview of the program and could lead to program modifications. Finally, the research will be written up with the purpose of publishing in a variety of academic journals.