



NEW HAMPSHIRE PALLIATIVE CARE SURVEY
FOR
THE PALLIATION WORKGROUP OF NEW HAMPSHIRE

Conducted By:
New Hampshire Comprehensive Cancer Collaboration
New Hampshire Hospice and Palliative Care Organization

MAY 2013

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EXECUTIVE SUMMARY

The Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) in conjunction with NH Hospice and Palliative Care Organization conducted a survey in May of 2013. The specific area of interest is how patients are informed about palliative care in New Hampshire. This effort is the second circulation of this survey and serves to monitor progress made since the initial survey conducted in August 2010. One hundred twenty-two (122) surveys were emailed to various NH healthcare provider organizations including in-patient, out-patient, nursing, skilled, and long term health care facilities. On May 8, 2013 all facilities were sent an email inviting them to participate in an internet survey. A reminder was sent on May 15 and May 22, 2013. Eighty five (85) telephone interviews were conducted from June 3 thru June 7, 2013 for respondents who did not respond via the online survey. Ultimately, sixty three (63) surveys were completed yielding a response rate of 52 percent. Although lower than 63 percent participation rate achieved in 2010; this is still high for a survey of this type.

The following bulleted points summarize the major findings of the survey. Figures at the end of this section depict these findings. Section A contains the open-ended responses, the 2010 survey results can be found in Appendix B, and Appendix C includes the survey instrument.

** In cases where there are fewer than 20 respondents, caution should be used when looking at differences since one organization's response may have a large impact on percentages.*

Organizations

- Over half of the organizations (60%) that responded are nursing, skilled or long-term care facilities, 24 percent are in-patient care facilities and 16 percent were out-patient care facilities.
- Each of the types of facilities had high response rates within their type;
 - In-patient care (hospitals) had a 65 percent response rate, 15 out of 23 hospitals responded. The population decreased slightly for this facility type by .08% from the initial survey conducted in 2010.
 - Out-patient care facilities had a 67 percent response rate, 10 out of 15 cancer centers and oncology practices responded. There was no change in the population for this facility type from the initial survey conducted in 2010.
 - Nursing, skilled or long-term care facilities had a 45 percent response rate, 38 out of 84 facilities responded. The population increased for this facility type by 33% from the initial survey conducted in 2010.

Monitoring Observation: Survey participation for Cancer Centers/Oncology Practices increased by 43% since the survey conducted in 2010.

- The majority of organizations (92%) responding to the survey report identifying patients in need of Palliative care.

Monitoring Observation: This is a 5 percent increase from the survey conducted in 2010.

- The majority of organizations (58%) reported either 100 or less beds available or patients in the practice, 36 percent reported between 100 and 200 beds or patients, and 7 percent report organizations larger than 200 beds or patients.

Palliative Care Services

- The majority of organizations (83%) report having staff responsible for coordinating palliative care for cancer patients; 10% have dedicated staff and 73% have staff that coordinate in addition to other duties. **Figure 1**
 - Nearly three-quarters of in-patient or out-patient organizations (72%) report having staff responsible for coordinating palliative care for cancer patients; 12% have dedicated staff and 60% have staff that coordinate in addition to other duties.
 - 89 percent of nursing, skilled or long-term facilities report having staff responsible for coordinating palliative care for cancer patients; 8% have dedicated staff and 82% have staff that coordinate in addition to other duties.

Monitoring Observation: From the initial survey performed in 2010, there has not been a significant change in the overall percent of organizations that report having staff responsible for coordinating palliative care for cancer patients. There has however been a slight shift among Nursing, Skilled, Long-Term care facilities where a staff person's role is dedicated solely to coordinating palliative care; increasing from 2% in 2010 to 8% in 2013.

- More than a third (39%) of organizations provide palliative care services after a cancer patient is referred for palliative care through their own staff, 13 percent use a contracted agency to provide services, nearly half (47%) use a combination of staff and contracted agency services, and 2 percent report some other means of providing services. **Figure 2**
 - More than half (58%) of in-patient or out-patient organizations provide palliative care services through their own staff, 17 percent use a contracted agency to provide services, 21 percent use a combination of staff and contracted agency services, and 4 percent report some other means of providing services.
 - Just over a quarter (26%) of nursing, skilled or long-term care facilities provide palliative care services after a cancer patient is referred for palliative care through their own staff, 11 percent use a contracted agency to provide services, more than half (63%) use a combination of staff and contracted agency services, and none report utilizing some other means of providing services.

Monitoring Observation: Among Nursing, Skilled, Long-Term Care facilities there has been a 64 percent change noted in the use of staff to provide palliative care services; increasing from 16 percent in 2010 to 26 percent in 2012. A shift can also be seen for In-Patient or Outpatient organizations toward contracted agencies; increasing from 8 percent in 2010 to 17 percent in 2013.

- Fewer than half (37%) of organizations have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (25%), nurse practitioners (18%), social workers (15%), or some other provider (5%). **Figure 3**
 - Nearly half (44%) of in-patient or out-patient organizations have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (23%), social workers (14%), nurse practitioners (10%), or some other provider (9%).
 - A third (33%) of nursing, skilled or long-term care facilities have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (26%), nurse practitioners (23%), social workers (16%), or some other provider (3%).

Monitoring Observation: A significant shift can be seen among In-Patient or Out-Patient organizations away from physicians toward social workers providing the initial assessment of cancer patients who are referred for palliative care. A similar shift can be seen among Nursing/Skilled/Long-Term Care facilities away from physicians toward nurse practitioners and registered nurses.

- Most palliative care teams include social workers (91%), physicians (75%), registered nurses (75%), pastoral/spiritual care providers (52%), and nurse practitioners (39%). Fewer organizations report having board certified palliative care physicians (32%), complementary/alternative medicine practitioners (14%), board certified nurse practitioners (20%), and board certified registered nurses (16%). **Figure 4**
 - Within in-patient or out-patient organizations, most palliative care teams include social workers (86%), board certified palliative care physicians (57%), physicians (48%), pastoral/spiritual care providers (48%), and registered nurses (43%). Fewer organizations report having board certified palliative care registered nurses (29%), board certified nurse practitioners (29%), complementary/alternative medicine practitioners (19%), and nurse practitioners (14%).
 - Within nursing, skilled or long-term care facilities, most palliative care teams include social workers (94%), registered nurses (94%), physicians (91%), pastoral/spiritual care providers (54%), and nurse practitioners (54%). Fewer organizations report having board certified nurse practitioners (20%), board certified palliative care physicians (17%), complementary/alternative medicine practitioners (23%), and board certified palliative care registered nurses (9%).

Monitoring Observation: The combination of staff that comprises the palliative care staff has not seen significant change between surveys. The most notable change has been the overall increased involvement of board certified palliative care nurse practitioners; increasing from 11% in 2010 to 20% in 2013.

Informative Practices

- The majority of organizations provide palliative care information when curative care is no longer available (56%), at hospice referral (56%), or when there is a change in condition (51%). Fewer organizations provide information when there are uncontrollable symptoms (42%), at the time of terminal diagnosis (37%), at first contact (22%), at time of first cancer diagnosis (22%) or at the beginning of treatment (19%). None of the survey participants reported giving no information. **Figure 5**
 - The majority of in-patient or out-patient organizations provide palliative care information when curative care is no longer available (68%). Fewer organizations provide information when there is a change in condition (48%), at hospice referral (44%), when there are uncontrollable symptoms (44%), at the time of terminal diagnosis (40%), at first contact (16%), at the beginning of treatment (8%), or at time of first cancer diagnosis (4%). Four percent say no information is given.
 - The majority of nursing, skilled or long-term care facilities provide palliative care information when curative care is no longer available (65%), at hospice referral (61%), or when there is a change in condition (54%). Fewer organizations provide information at the time of terminal diagnosis (47%), when there are uncontrollable symptoms (37%), at first contact (35%), at the beginning of treatment (28%), or at time of first cancer diagnosis (28%). Two percent say no information is given.

Monitoring Observation: Improvements in informative practices have been identified since the initial survey conducted in 2010. None of the survey respondents reported providing no information to patients, as opposed to the overall 2% in 2010.

- Palliative care information is directed toward the following groups at the following rates: cancer patients (79%) non-cancer patients (68%), family members (53%), children (3%), clinical staff (74%), and non-clinical staff (40%). **Figure 6**

- Palliative care information is directed toward the following groups at the following rates at in-patient or out-patient organizations: cancer patients (76%) non-cancer patients (52%), family members (56%), children (8%), clinical staff (64%), and non-clinical staff (20%).
- Palliative care information is directed toward the following groups at the following rates at nursing, skilled or long-term care facilities: cancer patients (81%) non-cancer patients (78%), family members (51%), children (0%), clinical staff (81%), and non-clinical staff (54%).

Monitoring Observation: Little change was observed with regard to information directed toward these groups. Growth opportunities exist throughout, mainly among non-clinical staff.

- Patients are most often provided information verbally for all topics on palliative care followed closely by printed information, internet links, audio/visual methods, or some other method. For more detailed descriptions see figures: **Figures 7 to 11**
 - This pattern holds for both in-patient/out-patient organizations as well as nursing, skilled or long-term care facilities.

Monitoring Observation: While verbal information has continued to be the most predominant way of disseminating information, printed and internet resources are quickly on the rise.

The area of Pain and Symptom Management has shown the greatest improvement since 2010, with no survey respondents reporting a lack of information. The greatest opportunity for continued improvement exists with regard to Spiritual Aspects of cancer, as several respondents continue to report having no information resources available.

Organizational Awareness

- Forty two percent (42%) of surveyed organizations had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 37 percent had not and 21 percent did not know if they had or had not heard of the project.
Figure 12
 - More than half (63%) of in-patient or out-patient organizations had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 21 percent had not and 17 percent did not know if they had or had not heard of the project.
 - Over one quarter (29%) of nursing, skilled, or long-term care facilities had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 47 percent had not and 24 percent did not know if they had or had not heard of the project.

Monitoring Observation: Awareness of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative Care has grown since the initial survey conducted in 2010, from 34% of those surveyed to 42%. In-Patient or Out-Patient facilities solely contributed to this increase, where no notable increases were seen in Nursing, Skilled or Long-Term facilities.

- Twenty one percent (21%) of surveyed organizations offered in-service programs to increase staff education about palliative care at least twice a year, 42 percent offered programs at least once a year, 13 percent offered programs at least once every other year, and 24 percent offered programs less than every two years. **Figure 13**
 - Nearly one quarter (21%) of in-patient or out-patient organizations offered in-service programs to increase staff education about palliative care at least twice a year, 29 percent offered programs at least once a year, 13 percent offered programs at least once every other year, and 38 percent offered programs less than every two years.

- One-third (21%) of nursing, skilled, or long-term care facilities offered in-service programs to increase staff education about palliative care at least twice a year, 50 percent offered programs at least once a year, 13 percent offered programs at least once every other year, and 16 percent offered programs less than every two years.

Monitoring Observation: In-service palliative care education programs have decreased by 34% since the 2010 survey was performed. In-Patient or Out-Patient facilities have shown the most dramatic decreases and contribute to the majority of this decrease.

Cancer and Palliative Care

- Forty percent (40%) of surveyed organizations report that 1 to 10 percent of their patients have cancer, a third of organizations (36%) report that 11 to 30 percent of their patients have cancer, 10 percent of organizations report that a third to half of their patients have cancer, and 14 percent of organizations report that half or more of their patients have cancer. There were no organizations that reported having no volume of cancer patients. **Figure 14**
 - Less than one-quarter (23%) of in-patient or out-patient organizations report that a tenth of their patients have cancer, 27 percent report that 11 to 30 percent of their patients have cancer, 18 percent report that a third to half of their patients have cancer, while a third (32%) report that half or more of their patients have cancer.
 - Half (50%) of nursing, skilled, or long-term care facilities report that a tenth of their patients have cancer, 42 percent report that 11 to 30 percent of their patients have cancer, 6 percent report that a third to half of their patients have cancer, and 3 percent report that half or more of their patients have cancer.

Monitoring Observation: All respondents reported having some volume of cancer patients as opposed to the 2010 results which showed 4% of those surveyed having no cancer patients.

- A third of organizations (33%) report that 1 to 10 percent of those referred to palliative care have cancer, another third (34%) report that 11 to 50 percent of those referred to palliative care for are cancer patients. Nearly a quarter (21%) report that over 50 percent of those referred to palliative care have cancer and 12 percent report that none of the patients referred for palliative care have cancer. **Figure 15**
 - Five percent (5%) of in-patient or out-patient organizations report that 1 to 10 percent of those referred to palliative care have cancer, one-quarter (24%) report that 11 to 50 percent of those referred to palliative care have cancer, while nearly half (48%) report that over 50 percent of those referred to palliative care have cancer. Twenty four percent (24%) report that none of those referred to palliative care have cancer.
 - Nearly half (49%) of nursing, skilled, or long-term care facilities report that 1 to 10 percent of those referred to palliative care have cancer, 41 percent report that 11 to 50 percent of those referred to palliative care for are cancer patients. While 5 percent report that over 50 percent of those referred to palliative care have cancer and 5 percent report that none of the patients referred for palliative care have cancer.

Monitoring Observation: The most significant shift can be seen in In-Patient or Out-Patient organizations. While these organizations reported that 0 percent of patients referred for palliative care had cancer in 2010, 24 percent were reported in 2013. Since it can be seen when referencing **Figure 14** that the percentage of cancer patients in these organizations has been relatively unchanged, one can ascertain that these organizations have begun to more broadly offer their palliative care services beyond those with cancer specifically.

Communication

- The majority (75%) of respondents selected email brochures as the best way to inform them of the best practices of palliative care, followed by mailed brochures (16%), newsletters (5%), and a website (5%). **Figure 16**
 - This pattern holds for both in-patient/out-patient organizations as well as nursing, skilled or long-term care facilities.

FIGURES

Figure 1 – Q10: Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

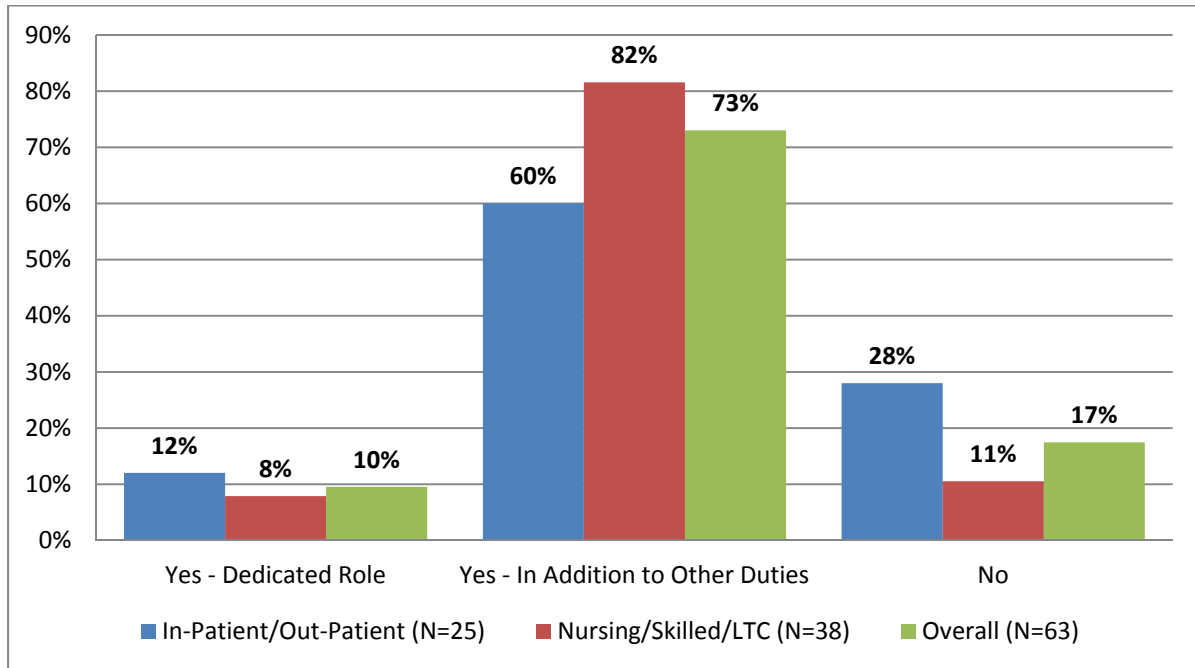


Figure 2 – Q11: Who provides palliative care services after a cancer patient is referred for palliative care?

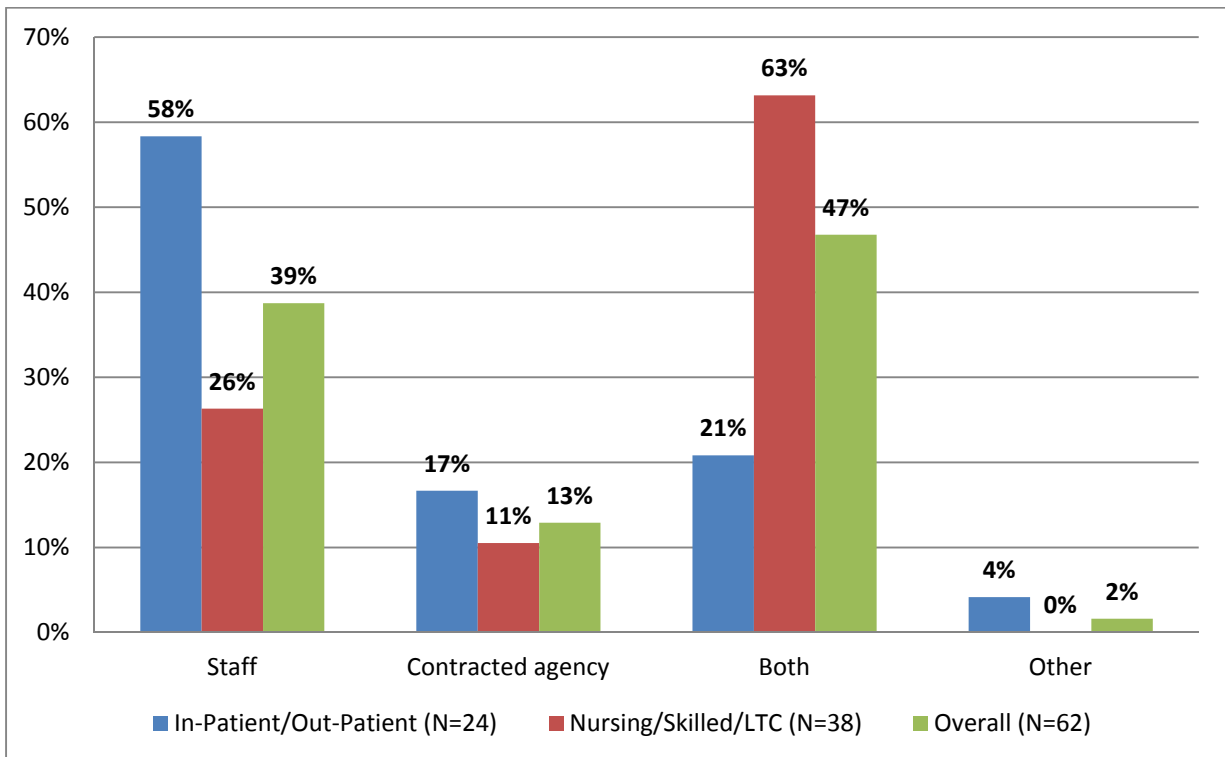


Figure 3 – Q12: Who provides the initial assessment of cancer patients referred for palliative care?

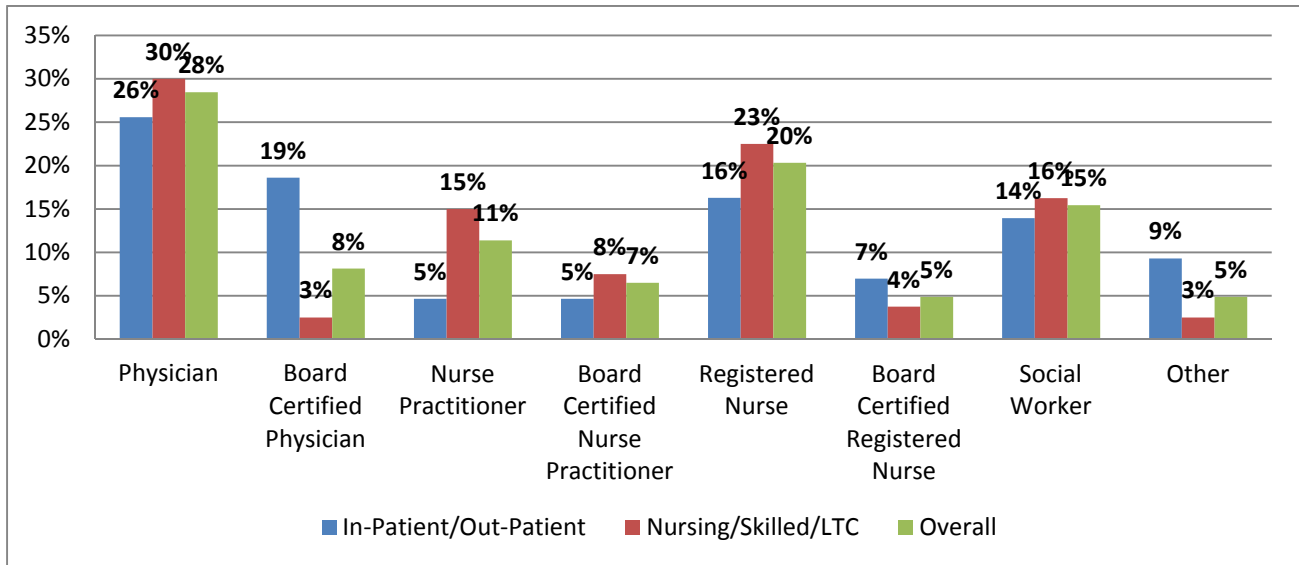


Figure 4 – Q13: Who makes up the palliative care team / program available to your cancer patients?
(Check all that apply. Percentages may add to more than 100 percent.)

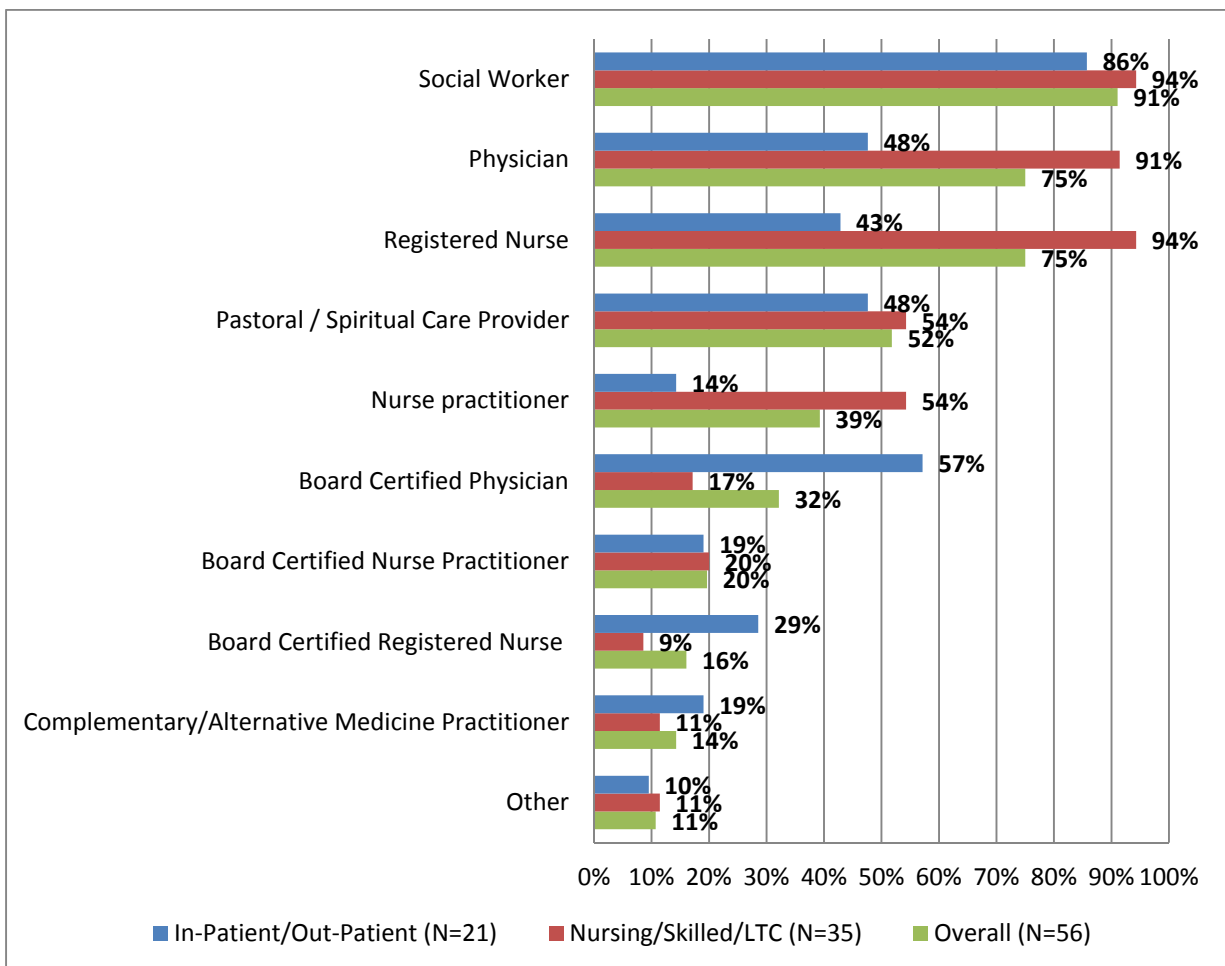


Figure 5 - Q14: When is palliative care information given to cancer patients?
(Check all that apply. Percentages may add to more than 100 percent.)

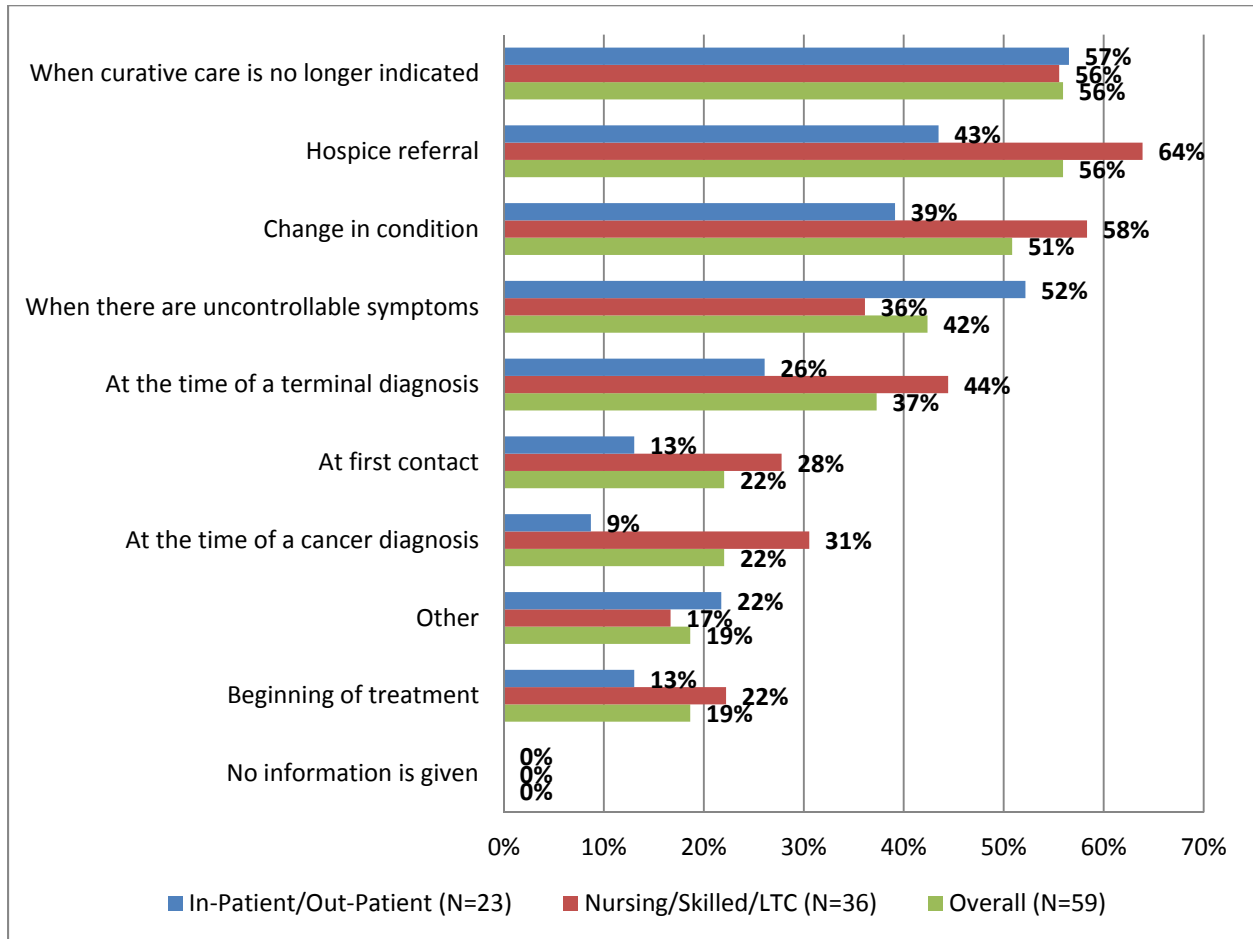
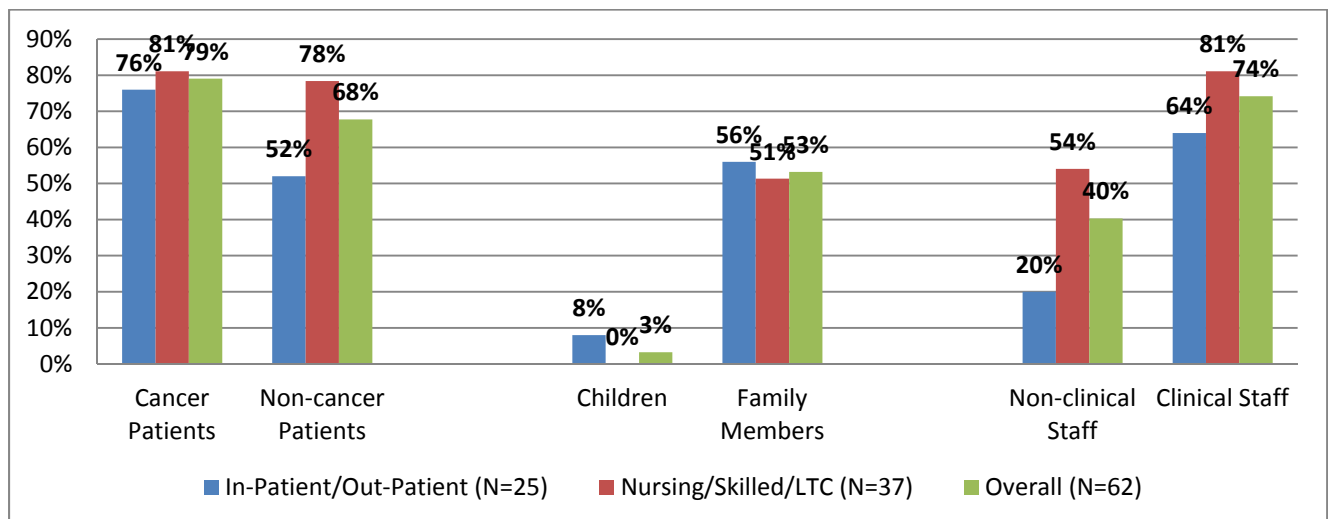


Figure 6 - Q15: Does your organization provide information about palliative care services directed toward educating each of the following groups: % YES (See detailed tables for N's of individual questions)



Figures 7 to 11 - Q16: How does your organization offer information to cancer patients on the following issues?

Figure 7 - Pain and symptom management.

(Check all that apply. Percentages may add to more than 100 percent.)

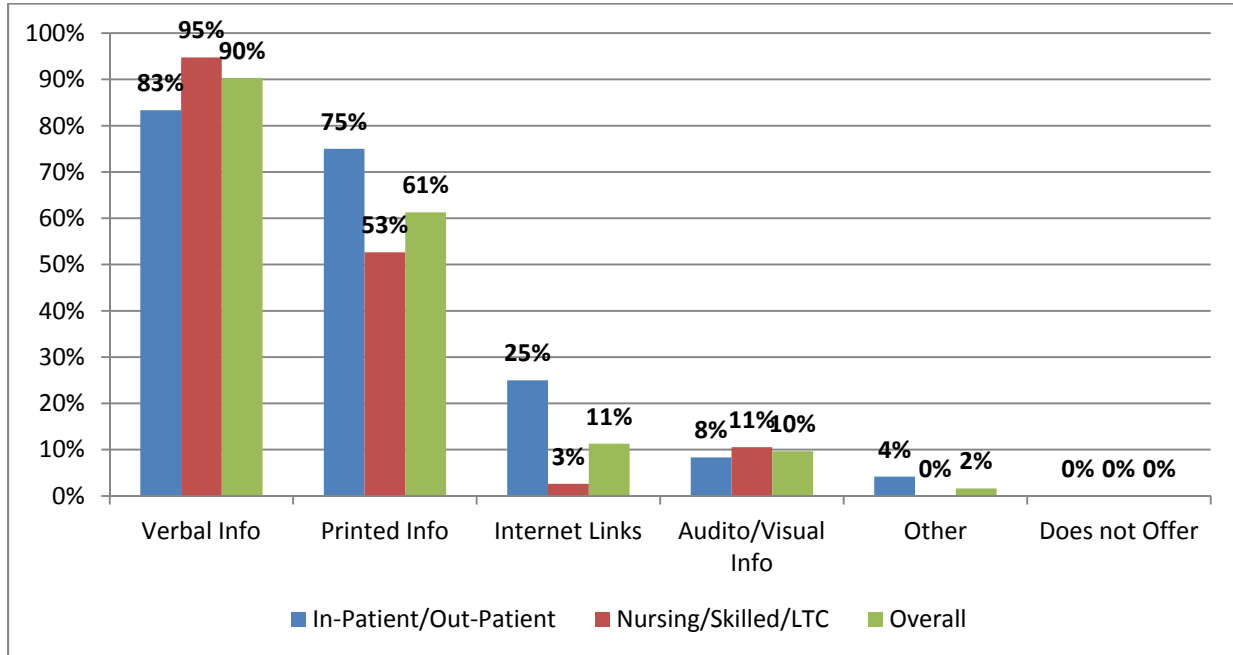


Figure 8 - Psychosocial and emotional aspects of cancer.

(Check all that apply. Percentages may add to more than 100 percent.)

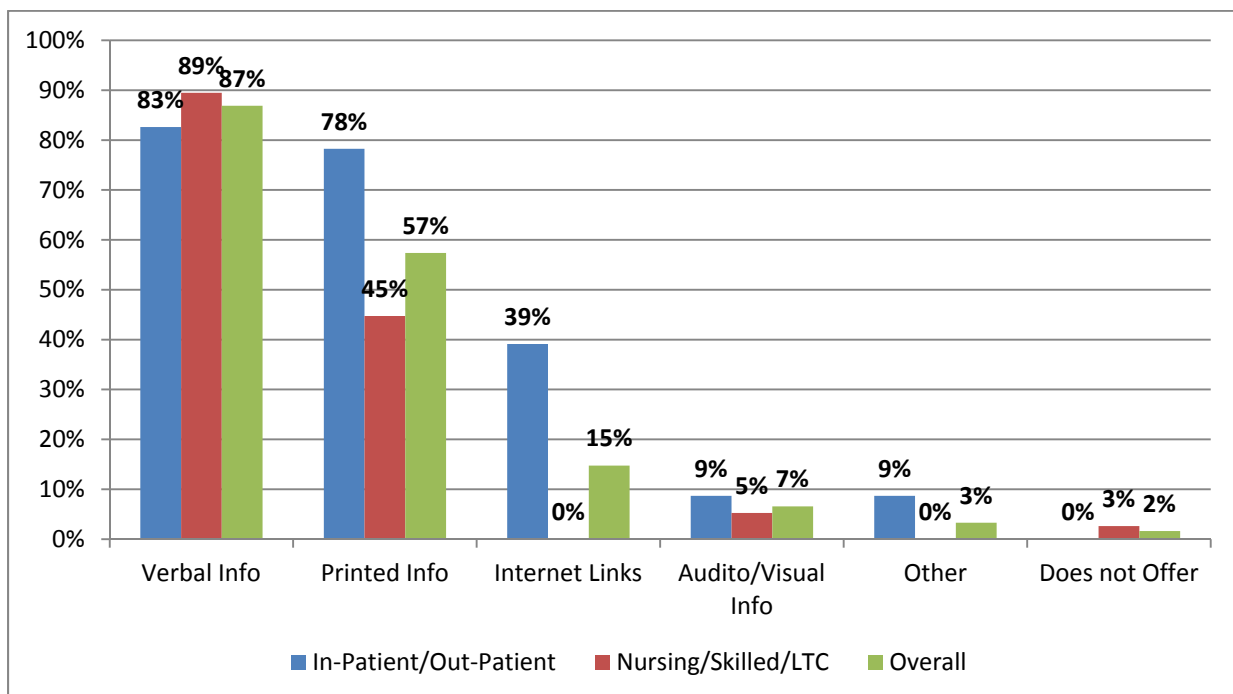


Figure 9 - Advance care planning.
(Check all that apply. Percentages may add to more than 100 percent.)

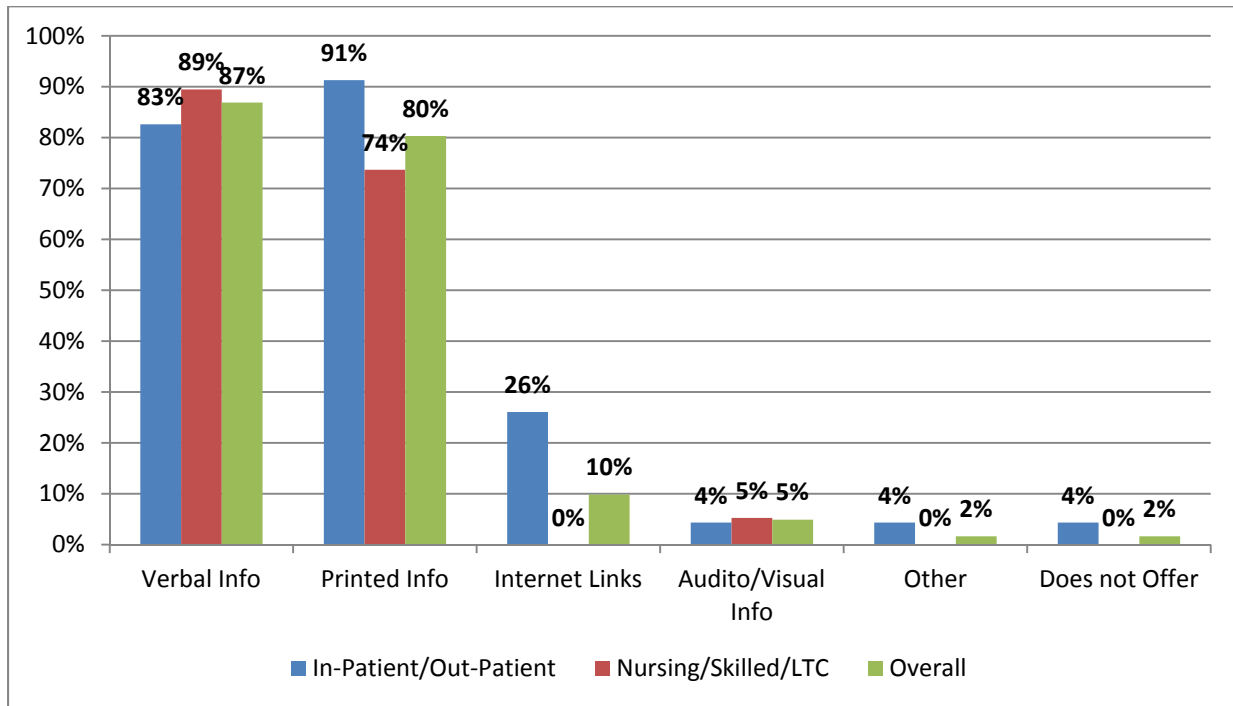


Figure 10 - General information about palliative care (as described in introduction).
(Check all that apply. Percentages may add to more than 100 percent.)

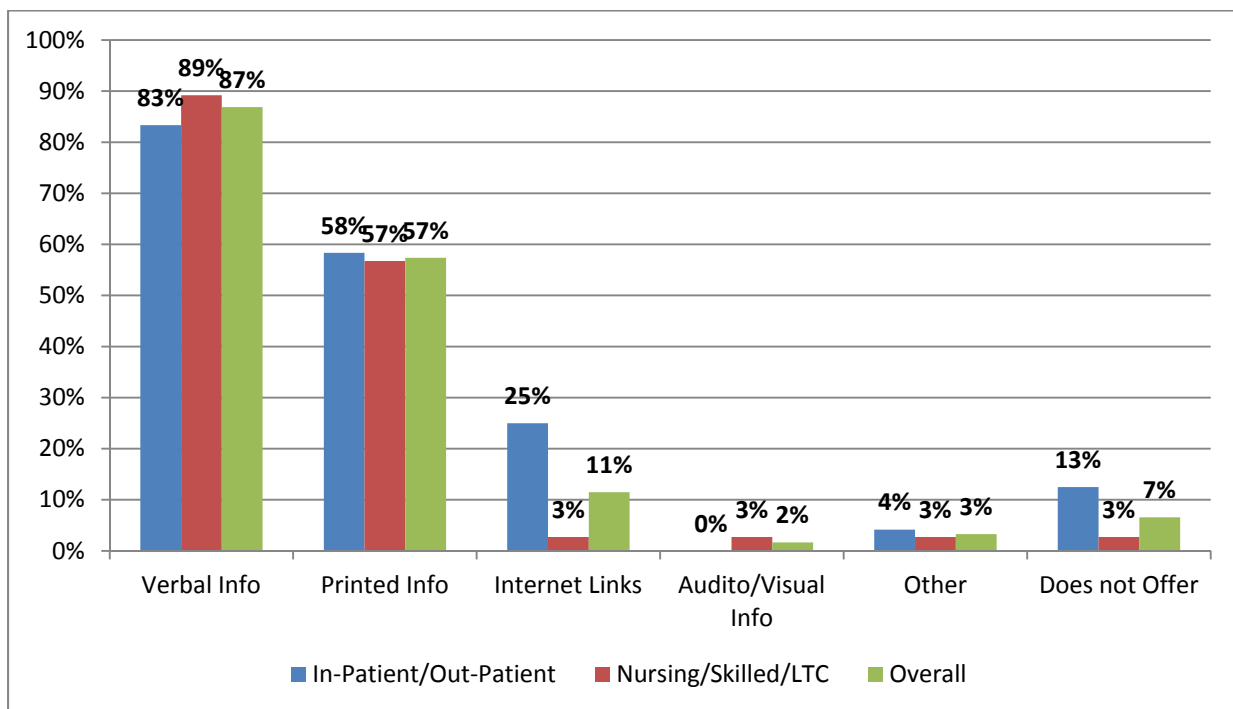


Figure 11 - Spiritual aspects of cancer.
(Check all that apply. Percentages may add to more than 100 percent.)

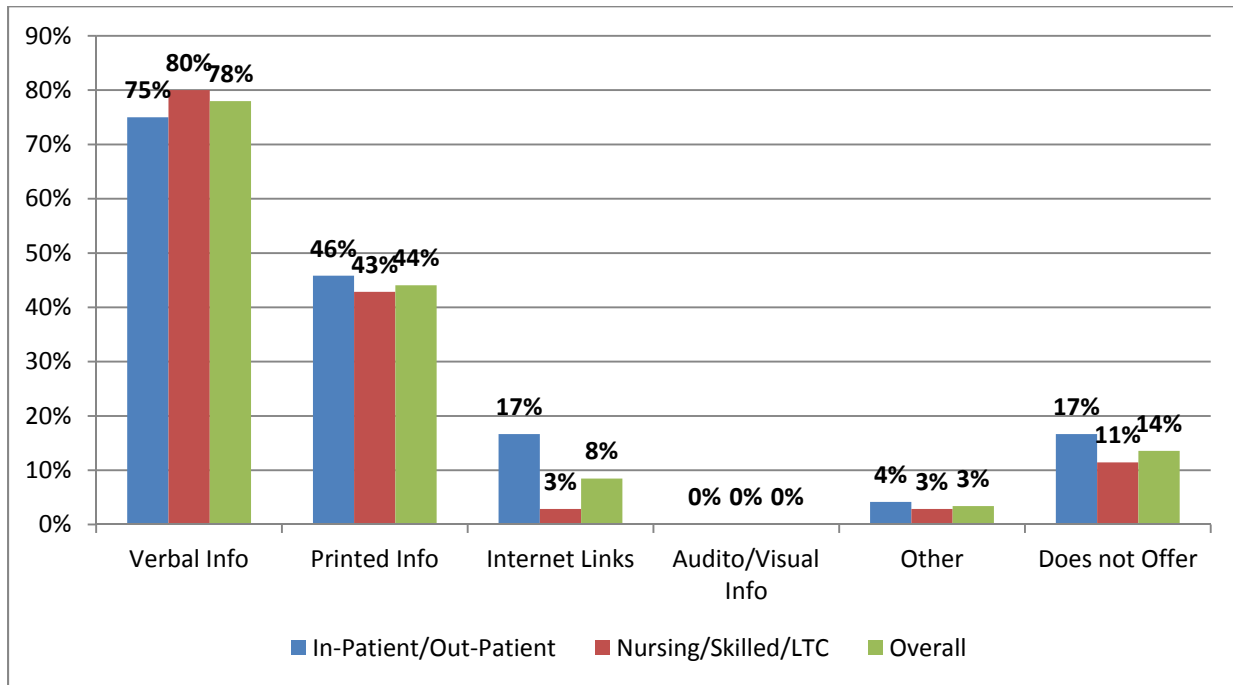


Figure 12 - Q17: Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care?

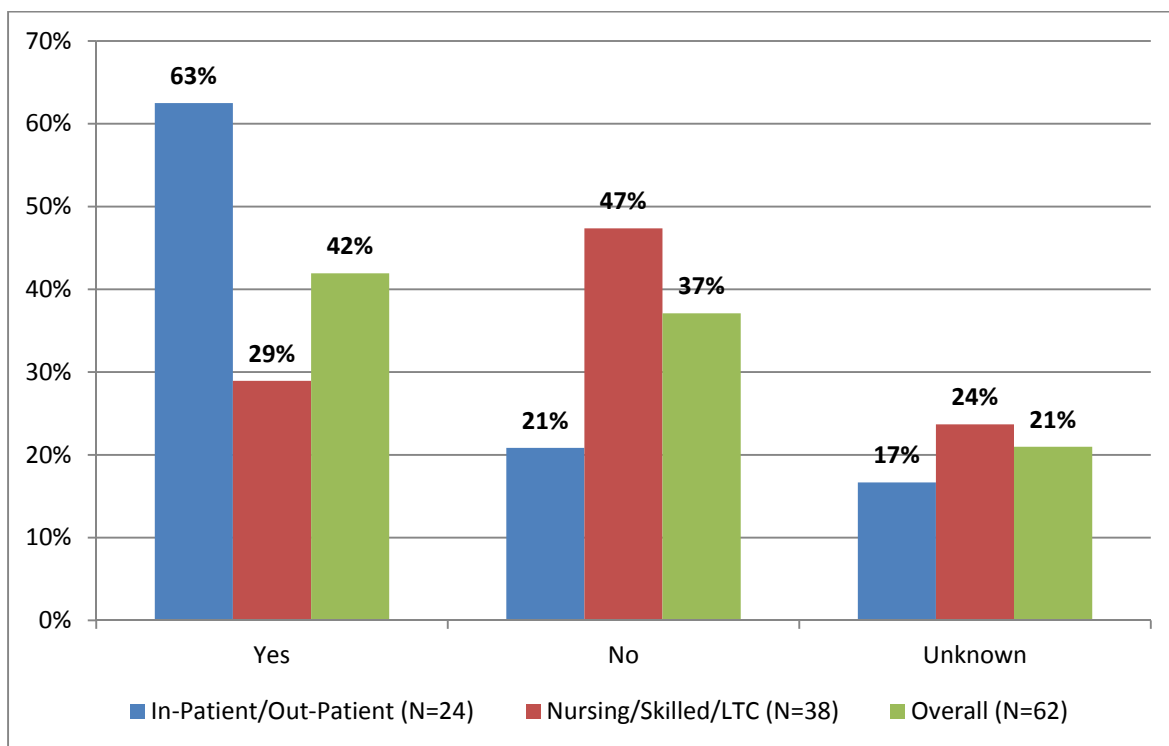


Figure 13 - Q19: How often does your organization offer in-service programs to increase staff awareness or education about palliative care?

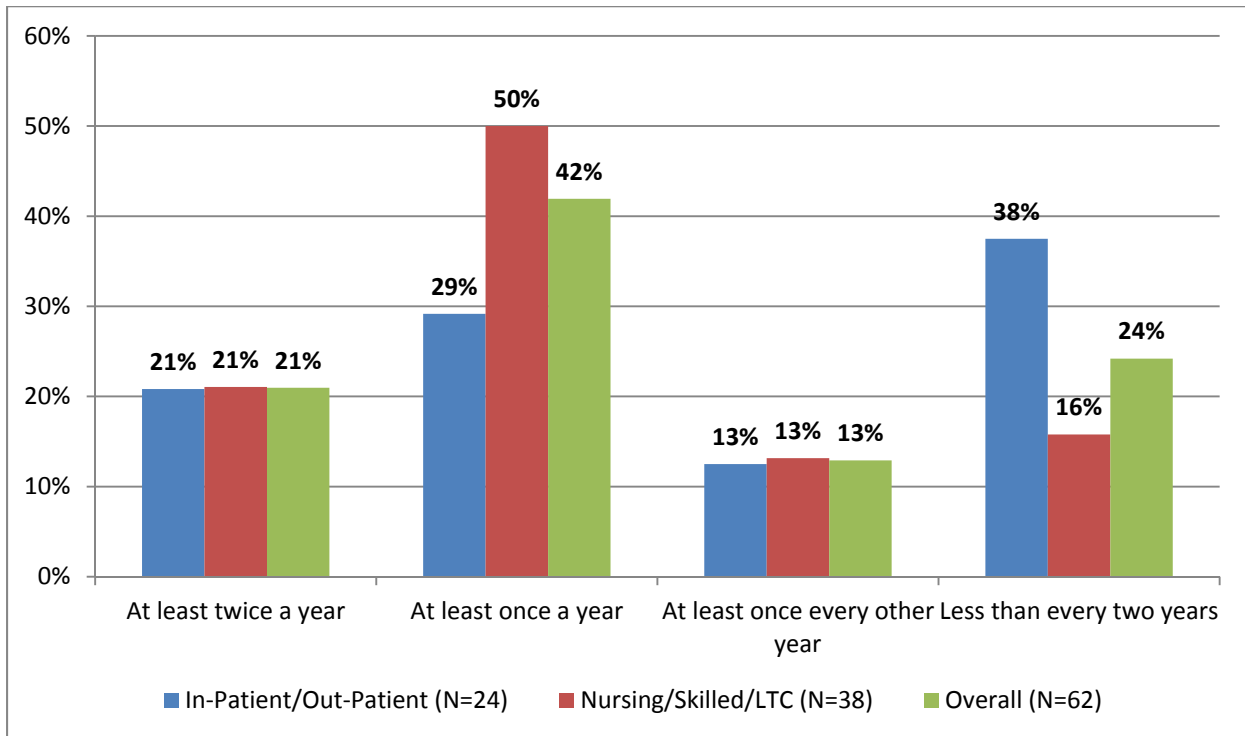


Figure 14 – Q6: Approximately what percentage of patients admitted to your organization annually, have cancer?

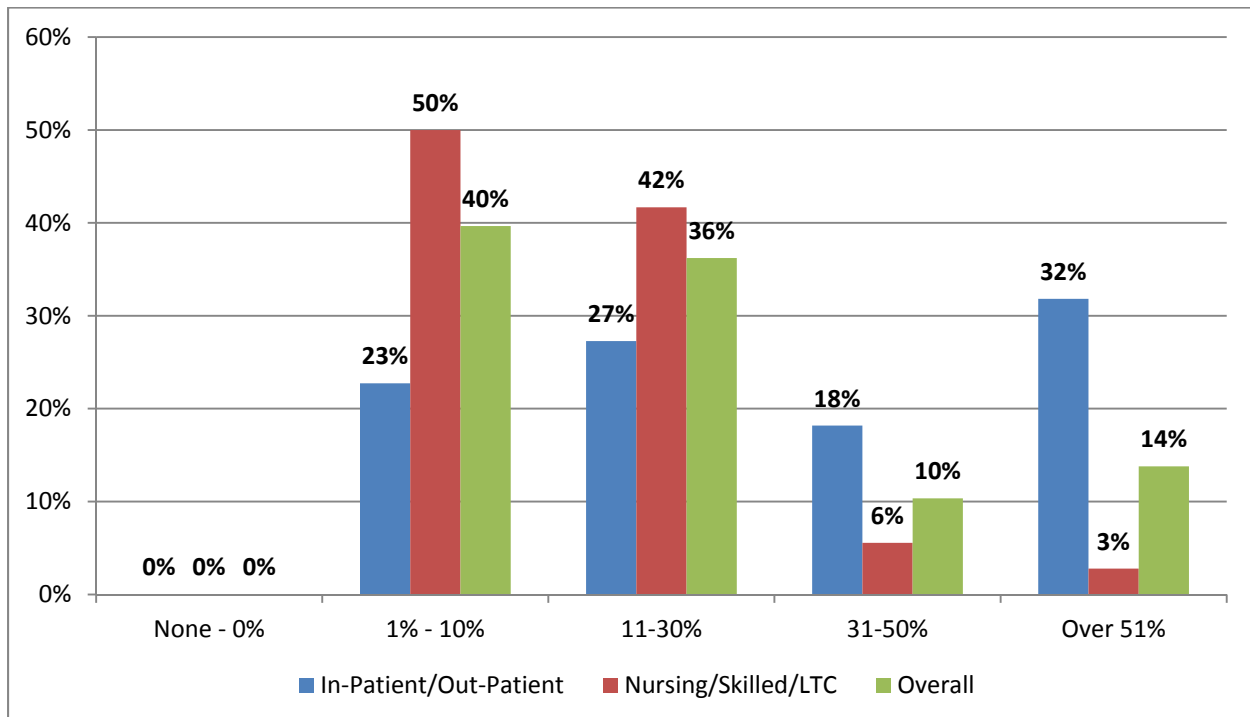


Figure 15 – Q9: Approximately what percentage of patients who are referred to palliative care have cancer?

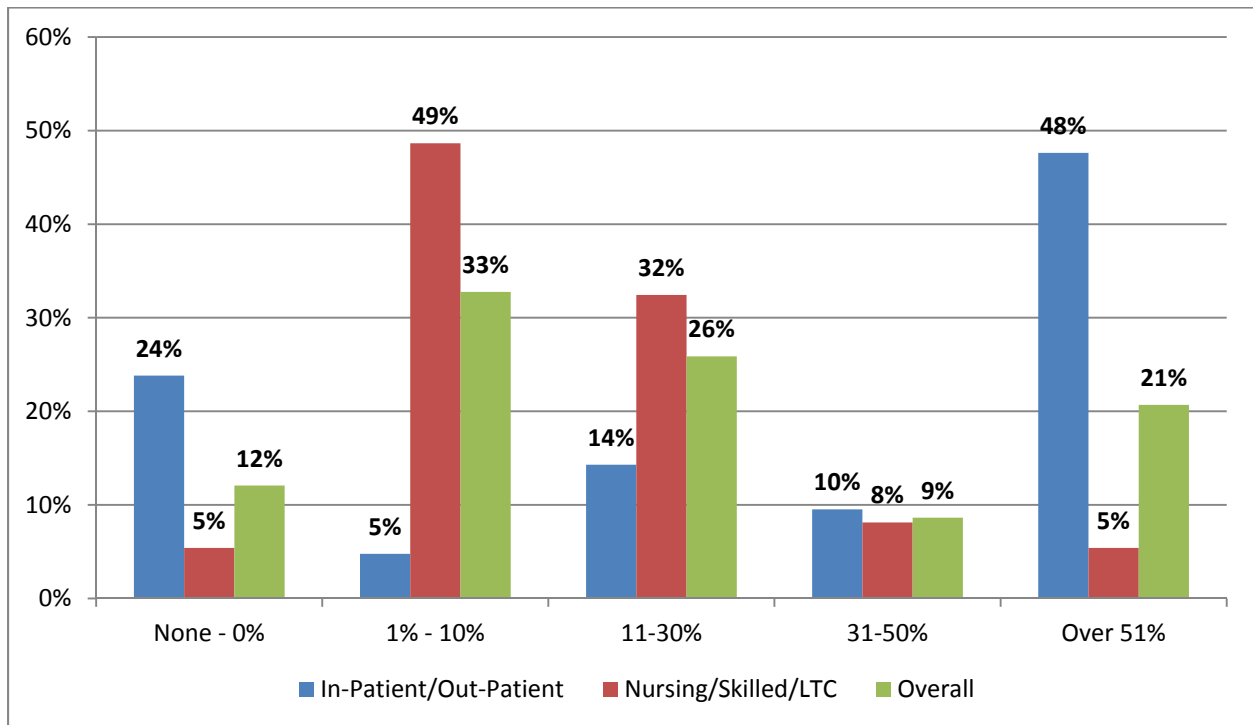
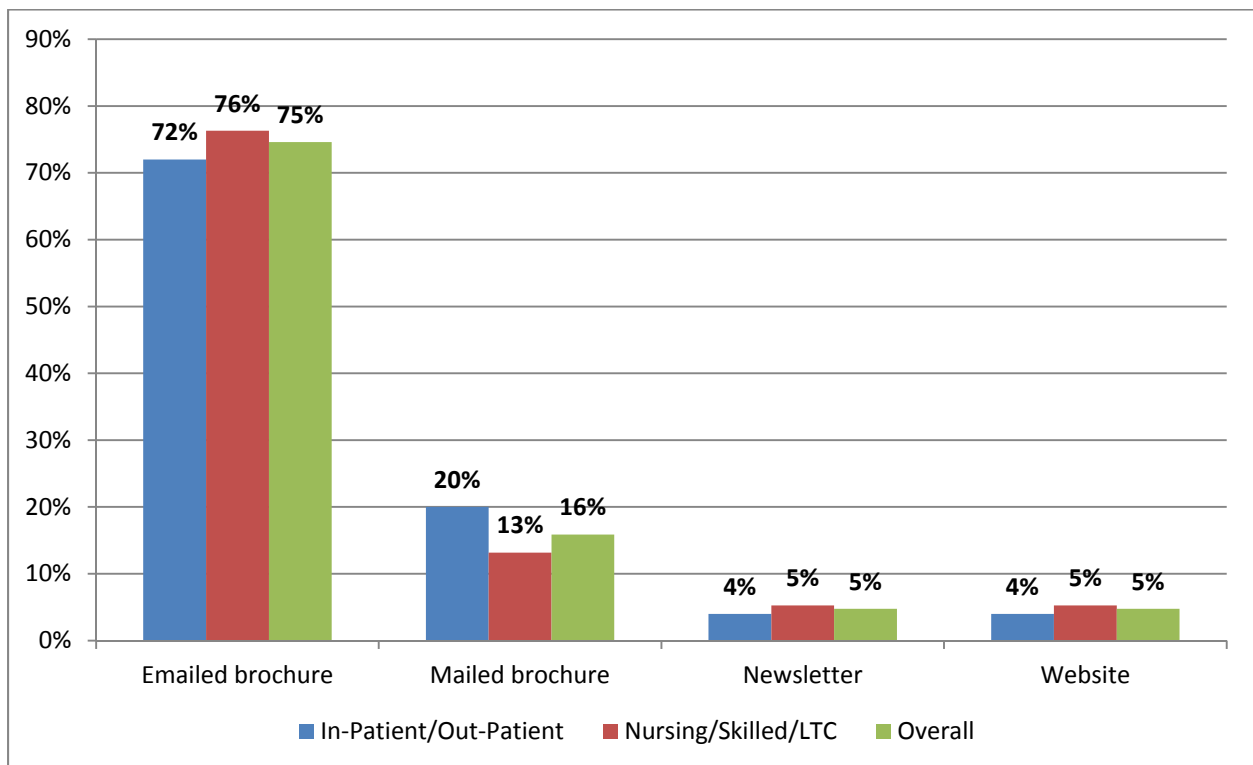


Figure 16 – Q2: What is the best way to inform you of updates for best practices of palliative care?
(Check all that apply. Percentages may add to more than 100 percent.)



APPENDIX A
OPEN ENDED RESPONSES

Q8: Do you perceive any barriers to providing palliative care to cancer patients in your organization? (Yes – Please Describe)

- Providers
- Cultural & Professional - Some providers see this as part of their job even if it is not being done.
- Lack of understanding of palliative care needs
- Perception that palliative care is the same as hospice care
- Not funded - Hospice is but not palliative care
- Occasionally difficult for residents and families to choose between their Medicare A Benefit and accessing a Hospice Benefit.
- Oncologists are quite hesitant to order Palliative Care consults
- It is sometimes difficult to get the patient what they need because of how our Hospice works. It seems sometimes repetitive for our nurses to call palliative care to ask for a tx, they have to call their doctor, and then get back to us.
- Staff education is always ongoing to help our staff care for the specific needs of our palliative care patients. Other issues include communication with outside hospice providers (at times). Helping families understand is always a challenge as well.
- Education barriers
- Families not understanding
- Sometimes the Cancer MDs are telling patient their disease won't kill them, however their treatment is and it is hard to get those patients to address palliative issues.
- Resources, educational level of providers, lack of education in the public, bias about palliative care
- Wide range of understanding or mis-understanding of end of life care issues by patients, families and at times, health care workers. Lack of patient, family and, primary care discussions and decisions about end of life care. Often leaving emergency department or inpatient staff in a rough situation when planning and decisions should have been made well in advance of an acute or emergent situation.
- We do not have trained practitioners for this service.
- We do not currently have a formal program.
- Sometimes staff and even patients think palliative care is strictly for end of life or imminent situations.
- Support structure
- More staff/provider education may be helpful
- Negative patient and provider perception of the term
- Education and resource access
- Oncologists do own palliative care, individualized; don't meet with a palliative care consult, positions for palliative care not refilled or only working part time.
- Time helping the patients to understand what palliative care is and how it can be helpful.
- We are a specialty- need to have primary provider approval in order to refer.

Q11: Who provides the initial assessment of cancer patients referred for palliative care? (Other – Describe)

- Through Home Health Palliative Care Services
- Contracted agency's staff

Q13: Who makes up the palliative care team that provides services to your cancer patients? (Other – Describe)

- Pharmacy
- LPN, LNA
- Dietary, Activities, Rehab (comfort measures)
- MD/RN,MSW
- We do not currently have any residents on palliative care
- LPNs, LNAs, Hospice Organization
- No true team

Q14: When is palliative care information given to cancer patients? (Other – Describe)

- At first contact because information is included in new patient packet
- Consult
- Depends on situation
- In hospital prior to admit to our SNF
- Nothing formal
- Time of cancer diagnosis is yes or no
- Unclear as our facility does not have palliative care, we refer to local VNA Hospice
- Usually from hospital prior to admit
- Usually have a plan in place already
- We do not have any residents that have been referred for palliative care services. Mostly the referral is generated via our nursing staff
- When felt appropriate, can be any time
- When identified by the IDT
- When IDT assesses that the option should be offered to the patient

Q20: Do you have any additional comments for the Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NHCCC) about your palliative care information needs?

- Additional educational programs. We are not a palliative care facility however it is our core philosophy and our approach to caring for the elderly.
- All medical and nursing staff can benefit from more education and information.
- Fact sheet or brochure, would add to patient care books. Good talking point to bring up to their physician.
- Small rural communities have hybrid programs and communicate across institutions to care for patients.

- There is a real need for more information in rural communities. More must be done to educate patients and families by the Primary Care Providers, Oncology Groups and other Specialist. Patient need to plan for end of life and communicate those plans to care team, family and significant other.
- We are in need of any guidance to get this started for our community.
- Would love to have additional information distributed to use via mailed brochure or other.

APPENDIX B
2013 SURVEY QUESTIONNAIRE

Palliative Care Survey

Palliative Care Survey Objective

The Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) in conjunction with NH Hospice and Palliative Care Organization invite you to participate in this brief survey about information related to palliative care services in New Hampshire. This survey should take between 5 - 10 minutes to complete. The Palliation Workgroup is working toward the following objective: Increase the participation of health care organizations providing palliative care services to cancer survivors.

The National Consensus Project for Quality Palliative Care states:

"The goal of palliative care is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for the patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care."

Responses to this survey will be kept confidential within the Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) and all results will be reported in the aggregate. Thank you for taking the time to complete this important survey. Our work could not be done without the continued support of institutions like yours.

About your Organization

***1. Who is the best person to contact within your organization with information about palliative care for patients and staff?**

Contact Name	<input type="text"/>
Organization Name	<input type="text"/>
Mailing Address 1	<input type="text"/>
Mailing Address 2	<input type="text"/>
City/Town	<input type="text"/>
State	<input type="text"/>
Zip Code	<input type="text"/>
E-mail Address	<input type="text"/>
Phone Number	<input type="text"/>
Fax Number	<input type="text"/>

Palliative Care Survey

2. What is the best way to inform you of updates for best practices of palliative care?

- Mailed brochure
- Emailed brochure
- Newsletter
- Meeting / Conference
- Website
- Other (please specify)

3. Which of the following best describes your organization?

- In-Patient Care
- Out-Patient Ambulatory Care
- Nursing/Skilled/Long Term Care Facility
- Other (please specify)

4. How many beds do you have at your organization? (In-Patient or Nursing/Skilled/LTC)

5. How many patients do you currently have in your practice? (Outpatient ambulatory or other)

Palliative Care Survey

6. Approximately what annual percentage of patients admitted to your organization have cancer?

- None - 0%
- 1% - 10%
- 11% - 20%
- 21% - 30%
- 31% - 40%
- 41% - 50%
- 51% - 60%
- 61% - 70%
- 71% - 80%
- 81% - 90%
- 91% - 99%
- All - 100%

About your Organization's Palliative Care Program

7. Does your organization identify cancer patients in need of palliative care?

- No
- Yes (please describe)

Palliative Care Survey

8. Do you perceive any barriers to providing palliative care to cancer patients in your organization?

- No
- Yes (please specify)

9. Approximately what percentage of patients who are referred to your palliative care program have cancer?

- None - 0%
- 1% - 10%
- 11% - 20%
- 21% - 30%
- 31% - 40%
- 41% - 50%
- 51% - 60%
- 61% - 70%
- 71% - 80%
- 81% - 90%
- 91% - 99%
- All - 100%

10. Does your organization have staff that are responsible for coordinating palliative care services for your cancer patients?

- Yes - That is the staff member(s) dedicated role
- Yes - They coordinate palliative services in addition to other duties
- No
- Other (please specify)

Palliative Care Survey

11. Who provides palliative care services after a cancer patient has been referred for palliative care?

- Staff
- Contracted agency
- Both
- Other (please specify)

12. Who provides the initial assessment of cancer patients referred for palliative care?

- Physician
- Board Certified Palliative Care Physician
- Nurse practitioner
- Board Certified Palliative Care Nurse Practitioner
- Registered nurse (RN)
- Board Certified Palliative Care Registered Nurse
- Social worker
- Pastoral / Spiritual care provider
- Complementary/Alternative Medicine (CAM) practitioner
- Other (please specify)

Palliative Care Survey

13. Who makes up the palliative care team that provides services to your cancer patients? (Check all that apply)

- Physician
- Board Certified Palliative Care Physician
- Nurse practitioner
- Board Certified Palliative Care Nurse Practitioner
- Registered nurse (RN)
- Board Certified Palliative Care Registered Nurse
- Social worker
- Pastoral / Spiritual care provider
- Complementary/Alternative Medicine (CAM) practitioner
- Other (please specify)

14. When is palliative care information given to cancer patients? (Check all that apply)

- At first contact
- At the time of a cancer diagnosis
- At the time of a terminal diagnosis
- Beginning of treatment
- When curative care is no longer indicated
- Hospice referral
- Change in condition
- When there are uncontrollable symptoms
- No information is given
- Other (please specify)

Palliative Care Survey

15. Does your organization provide information about palliative care services directed toward educating each of the following groups:

	Yes	No	Don't Know
Cancer patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-cancer patients in need of palliative care services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Children in need of palliative care services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family members in need of palliative care services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-clinical staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. How does your organization offer information to cancer patients on the following issues? (Check all that apply)

	Does Not offer	Patients are given printed Information (brochures, handouts, info sheets, etc.)	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information (video/DVD/CD-Rom)	Other
Pain and symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosocial and emotional aspects of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advance care planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General information about palliative care (as described in introduction)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual aspects of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative Care, also known as the 8 domains of palliative care?

- Yes
- No
- Don't know / Not sure

Palliative Care Survey

18. Does your organization provide training to staff members on how to discuss palliative care with patients and families?

- Yes
- No

19. How often does your organization offer in-service programs to increase staff awareness / education about palliative care?

- Less than every two years
- At least once every other year
- At least once a year
- At least twice a year

20. Do you have any additional comments for the Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NHCCC) about your palliative care information needs?

APPENDIX C
2010 SURVEY RESULTS

**NH PALLIATIVE CARE SURVEY
FOR
THE PALLIATION WORKGROUP OF THE NEW HAMPSHIRE
COMPREHENSIVE CANCER COLLABORATION (NH CCC)**

Tracy A. Fowler, M.A.
Richard Barney

University of New Hampshire
Survey Center

August, 2010

**The University of New Hampshire
Survey Center**

The UNH Survey Center is an independent, non-partisan academic survey research organization and a division of the UNH College of Liberal Arts.

The Survey Center conducts telephone, mail, e-mail, Internet, and intercept surveys, as well as focus groups and other qualitative research for university researchers, government agencies, public non-profit organizations, private businesses, and media clients.

Our senior staff has over 40 years experience in designing and conducting custom research on a broad range of political, social, health care, and other public policy issues.

Dr. Andrew E. Smith, Director
UNH Survey Center
Thompson Hall
Durham, New Hampshire 03824
603/862-2226 (voice)
603/862-1488 (FAX)
Andrew.Smith@unh.edu

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Executive Summary

The University of New Hampshire Survey Center conducted a survey for The Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) in conjunction with NH Hospice and Palliative Care Organization. The specific area of interest is how patients are informed about palliative care in New Hampshire. One hundred twenty-nine (129) surveys were emailed to various NH healthcare provider organizations including in-patient, out-patient, nursing, skilled, and long term health care facilities. On June 16, 2010 those with unique email addresses (105) were sent an email inviting them to participate in an internet survey, those without an email address were mailed a paper survey (24). A reminder was sent on June 21, 2010. Telephone interviews were conducted between June 16, 2010 and July 9, 2010 for respondents who did not respond by email or mail. Ultimately, eighty-two surveys were completed (38 by mail or email and 44 by telephone) yielding a response rate of 64 percent which is high for a survey of this type.

The following bulleted points summarize the major findings of the survey. Figures at the end of this section depict these findings. Section A contains the open-ended responses, detailed tabular results can be found in Appendix B, and Appendix C includes the survey instrument.

** In cases where there are fewer than 20 respondents, caution should be used when looking at differences since one organization's response may have a large impact on percentages.*

Organizations

- Over two-thirds of the organizations (69%) that responded are nursing, skilled or long-term care facilities, 22 percent are in-patient care facilities and 9 percent were out-patient care facilities.
- Each of the types of facilities had high response rates within their type;
 - In-patient care (hospitals) had a 72 percent response rate, 18 out of 25 hospitals responded.
 - Out-patient care facilities had a 47 percent response rate, 7 out of 15 cancer centers and oncology practices responded.
 - Nursing, skilled or long-term care facilities had a 90 percent response rate, 57 out of 63 facilities responded.
- The majority of organizations (88%) responding to the survey report identifying patients in need of Palliative care.
- The majority of organizations (56%) reported either 100 or less beds available or patients in the practice, 32 percent reported between 100 and 200 beds or patients, and 12 percent report organizations larger than 200 beds or patients.

Palliative Care Services

- The majority of organizations (85%) report having staff responsible for coordinating palliative care for cancer patients; 9% have dedicated staff and 76% have staff that coordinate in addition to other duties. **Figure 1**
 - Three-quarters of in-patient/out-patient organizations (76%) report having staff responsible for coordinating palliative care for cancer patients; 24% have dedicated staff and 52% have staff that coordinate in addition to other duties.
 - Nearly 9 out of 10 nursing, skilled or long-term facilities (88%) report having staff responsible for coordinating palliative care for cancer patients; 2% have dedicated staff and 86% have staff that coordinate in addition to other duties.

- More than a quarter (27%) of organizations provide palliative care services after a cancer patient is referred for palliative care through their own staff, 10 percent use a contracted agency to provide services, more than half (60%) use a combination of staff and contracted agency services, and 4 percent report some other means of providing services. **Figure 2**
 - More than half (52%) of in-patient or out-patient organizations provide palliative care services through their own staff, 8 percent use a contracted agency to provide services, one third (32%) use a combination of staff and contracted agency services, and 8 percent report some other means of providing services.
 - Less than one-fifth (16%) of nursing, skilled or long-term care facilities provide palliative care services after a cancer patient is referred for palliative care through their own staff, 11 percent use a contracted agency to provide services, nearly three-quarters (71%) use a combination of staff and contracted agency services, and 2 percent report some other means of providing services.

- Over half (54%) of organizations have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (19%), nurse practitioners (12%), social workers (9%), or some other provider (8%). **Figure 3**
 - Nearly half (46%) of in-patient/out-patient organizations have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (33%), nurse practitioners (16%), social workers (1%), or some other provider (4%).
 - Over half (58%) of nursing, skilled or long-term care facilities have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (13%), social workers (13%), nurse practitioners (9%), or some other provider (9%).

- Most palliative care teams include social workers (85%), registered nurses (80%), physicians (75%), pastoral/spiritual care providers (64%), nurse practitioners (49%). Fewer organizations report having board certified palliative care physicians (28%), complementary/alternative medicine practitioners (25%), and board certified nurse practitioners (11%). **Figure 4**
 - Within in-patient or out-patient organizations, most palliative care teams include social workers (71%), registered nurses (63%), pastoral/spiritual care providers (58%), and physicians (46%). Fewer organizations report having board certified palliative care physicians (42%), complementary/alternative medicine practitioners (29%), nurse practitioners (17%), and board certified nurse practitioners (13%).
 - Within nursing, skilled or long-term care facilities, most palliative care teams include social workers (91%), registered nurses (88%), physicians (88%), pastoral/spiritual care providers (66%), and nurse practitioners (63%). Fewer organizations report having complementary/alternative medicine practitioners (23%), board certified palliative care physicians (21%), and board certified nurse practitioners (11%).

Informative Practices

- The majority of organizations provide palliative care information when curative care is no longer available (66%), at hospice referral (56%), or when there is a change in condition (52%). Fewer organizations provide information at the time of terminal diagnosis (45%), when there are uncontrollable symptoms (39%), at first contact (29%), at the beginning of treatment (22%), or at time of first cancer diagnosis (21%). Two percent say no information is given. **Figure 5.**
 - The majority of in-patient or out-patient organizations provide palliative care information when curative care is no longer available (68%). Fewer organizations provide information when there is a change in condition (48%), at hospice referral (44%), when there are uncontrollable symptoms (44%), at the time of terminal diagnosis (40%), at first contact (16%), at the beginning of treatment (8%), or at time of first cancer diagnosis (4%). Four percent say no information is given.
 - The majority of nursing, skilled or long-term care facilities provide palliative care information when curative care is no longer available (65%), at hospice referral (61%), or when there is a change in condition (54%). Fewer organizations provide information at the time of terminal diagnosis (47%), when there are uncontrollable symptoms (37%), at first contact (35%), at the beginning of treatment (28%), or at time of first cancer diagnosis (28%). Two percent say no information is given.
- Palliative care information is directed toward the following groups at the following rates: cancer patients (84%) non-cancer patients (74%), family members (69%), children (5%), clinical staff (83%), and non-clinical staff (58%). **Figure 6**
 - Palliative care information is directed toward the following groups at the following rates at in-patient or out-patient organizations: cancer patients (72%) non-cancer patients (52%), family members (64%), children (13%), clinical staff (84%), and non-clinical staff (44%).
 - Palliative care information is directed toward the following groups at the following rates at nursing, skilled or long-term care facilities: cancer patients (89%) non-cancer patients (84%), family members (71%), children (0%), clinical staff (82%), and non-clinical staff (64%).
- Patients are most often provided information verbally for all topics on palliative care followed by printed information, internet links, audio/visual methods, or some other method. For more detailed descriptions see figures: **Figures 7 to 11.**
 - This pattern holds for both in-patient/out-patient organizations as well as nursing, skilled or long-term care facilities.

Organizational Awareness

- Thirty-four percent (34%) of surveyed organizations had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 45 percent had not and 21 percent did not know if they had or had not heard of the project. **Figure 1**
 - Nearly half (48%) of in-patient or out-patient organizations had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 36 percent had not and 16 percent did not know if they had or had not heard of the project.
 - Over one quarter (28%) of nursing, skilled, or long-term care facilities had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 49 percent had not and 23 percent did not know if they had or had not heard of the project.

- Thirty-two percent (32%) of surveyed organizations offered in-service programs to increase staff education about palliative care at least twice a year, 44 percent offered programs at least once a year, 9 percent offered programs at least once every other year, and 14 percent offered programs less than every two years. **Figure 13**
 - One-quarter (26%) of in-patient or out-patient organizations offered in-service programs to increase staff education about palliative care at least twice a year, 35 percent offered programs at least once a year, 9 percent offered programs at least once every other year, and 30 percent offered programs less than every two years.
 - One-third (35%) of nursing, skilled, or long-term care facilities offered in-service programs to increase staff education about palliative care at least twice a year, 48 percent offered programs at least once a year, 9 percent offered programs at least once every other year, and 7 percent offered programs less than every two years.

Cancer and Palliative Care

- A plurality of organizations (46%) report that a tenth of their patients have cancer, a quarter of organizations (24%) report that 11 to 30 percent of their patients have cancer, 13 percent of organizations report that a third to half of their patients have cancer, one in ten (11%) organizations report that half or more of their patients have cancer. Four percent of organizations (4%) reported to have no cancer patients annually. **Figure 14**
 - Less than one-quarter (21%) of in-patient or out-patient organizations report that a tenth of their patients have cancer, one-fifth (16%) report that 11 to 30 percent of their patients have cancer, a third (31%) report that a third to half of their patients have cancer, while another third (31%) report that half or more of their patients have cancer.
 - A majority (56%) of nursing, skilled, or long-term care facilities report that a tenth of their patients have cancer, a quarter (28%) report that 11 to 30 percent of their patients have cancer, 6 percent report that a third to half of their patients have cancer, and 4 percent report that half or more of their patients have cancer. Six percent (6%) reported to have no cancer patients annually.
- A third of organizations (34%) report that 1 to 10 percent of those referred to palliative care have cancer, another third report (30%) report that 11 to 50 percent of those referred to palliative care for are cancer patients. A third (32%) report that over 50 percent of those referred to palliative care have cancer and 5 percent report that none of the patients referred for palliative care have cancer. **Figure 15**
 - Over one-quarter (28%) of in-patient or out-patient organizations report that 11 to 50 percent of those referred to palliative care have cancer, while nearly three-quarters (72%) report that over 50 percent of those referred to palliative care have cancer.
 - Nearly half (47%) of nursing, skilled, or long-term care facilities report that 1 to 10 percent of those referred to palliative care have cancer, another third report (32%) report that 11 to 50 percent of those referred to palliative care for are cancer patients. Nearly one-fifth (15%) report that over 50 percent of those referred to palliative care have cancer and 7 percent report that none of the patients referred for palliative care have cancer.

Communication

- Over half of respondents selected email brochures (57%) as the best way to inform them of the best practices of palliative care, followed by mailed brochures (45%), newsletters (31%), meetings/conferences (24%), a website (21%), and/or some other method (2%). **Figure 16**
 - This pattern holds for both in-patient/out-patient organizations as well as nursing, skilled or long-term care facilities.

Figure 1 - Q6: Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

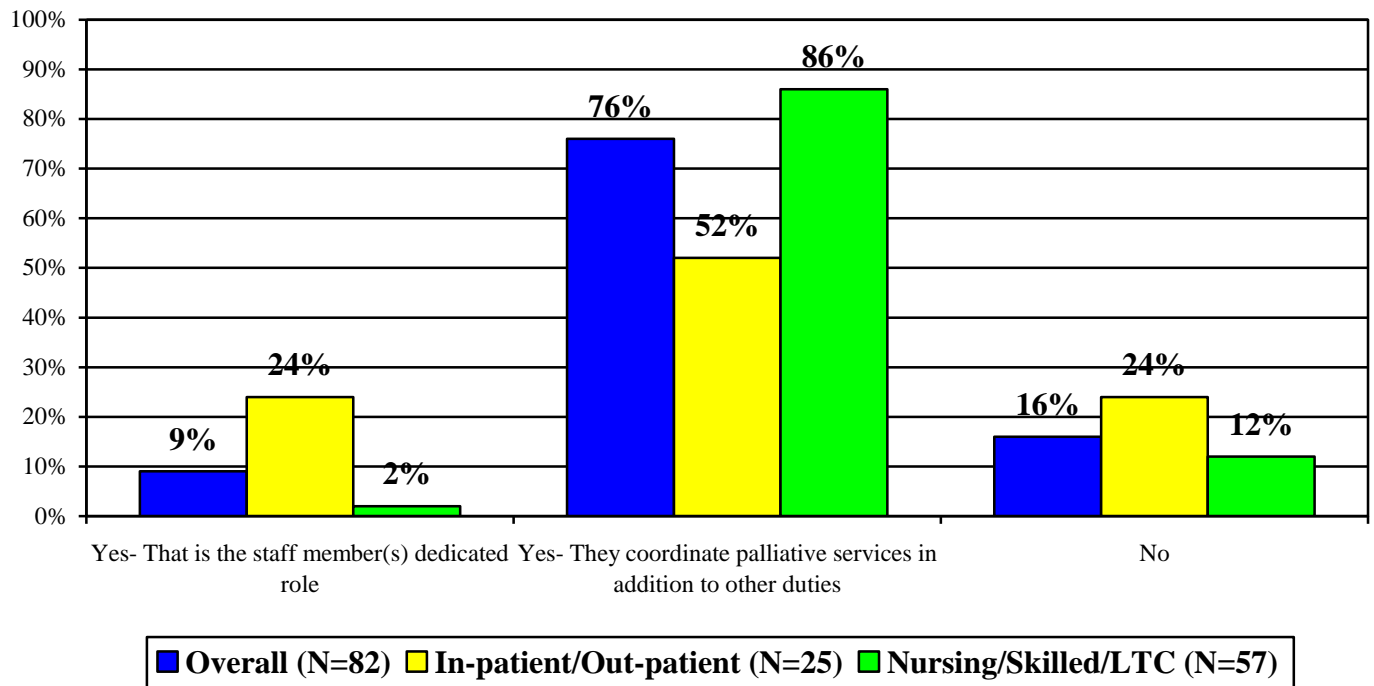


Figure 2 - Q7: Who provides palliative care services after a cancer patient is referred for palliative care?

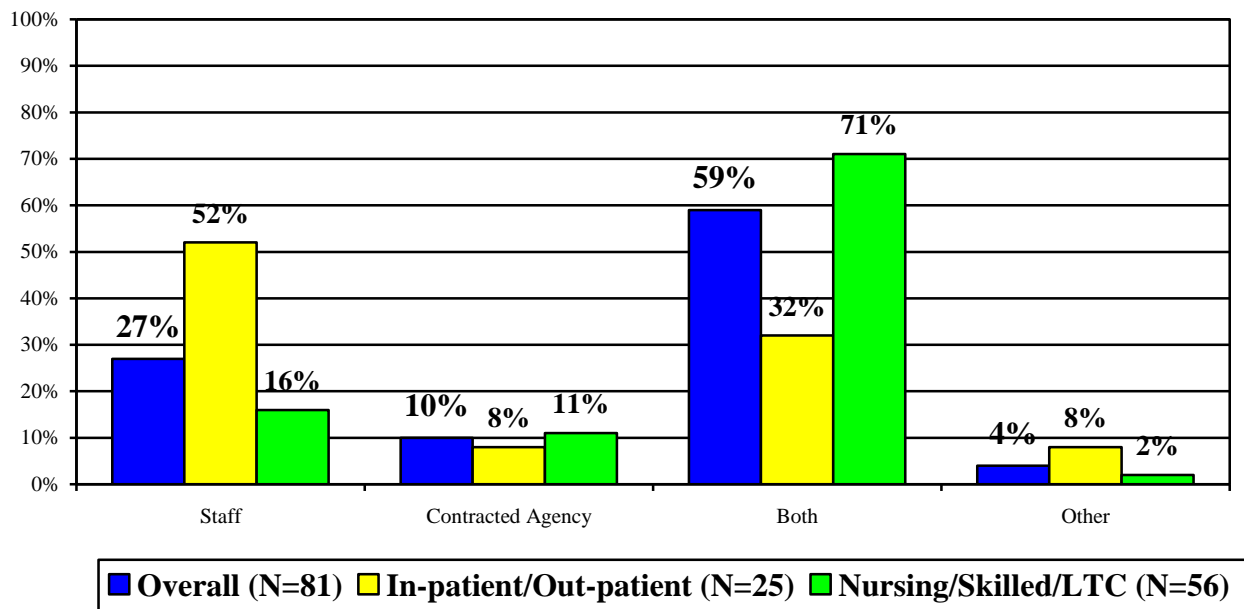


Figure 3 - Q8: Who provides the initial assessment of cancer patients referred for palliative care?

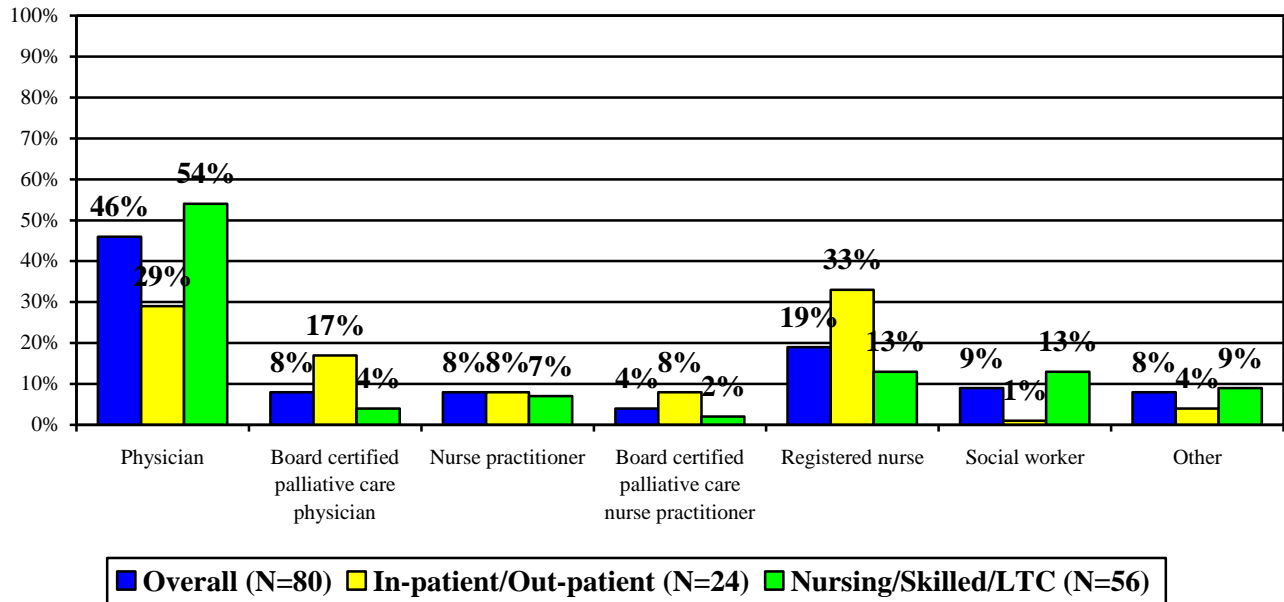


Figure 4 - Q9: Who makes up the palliative care team / program available to your cancer patients?
(Check all that apply. Percentages may add to more than 100 percent.)

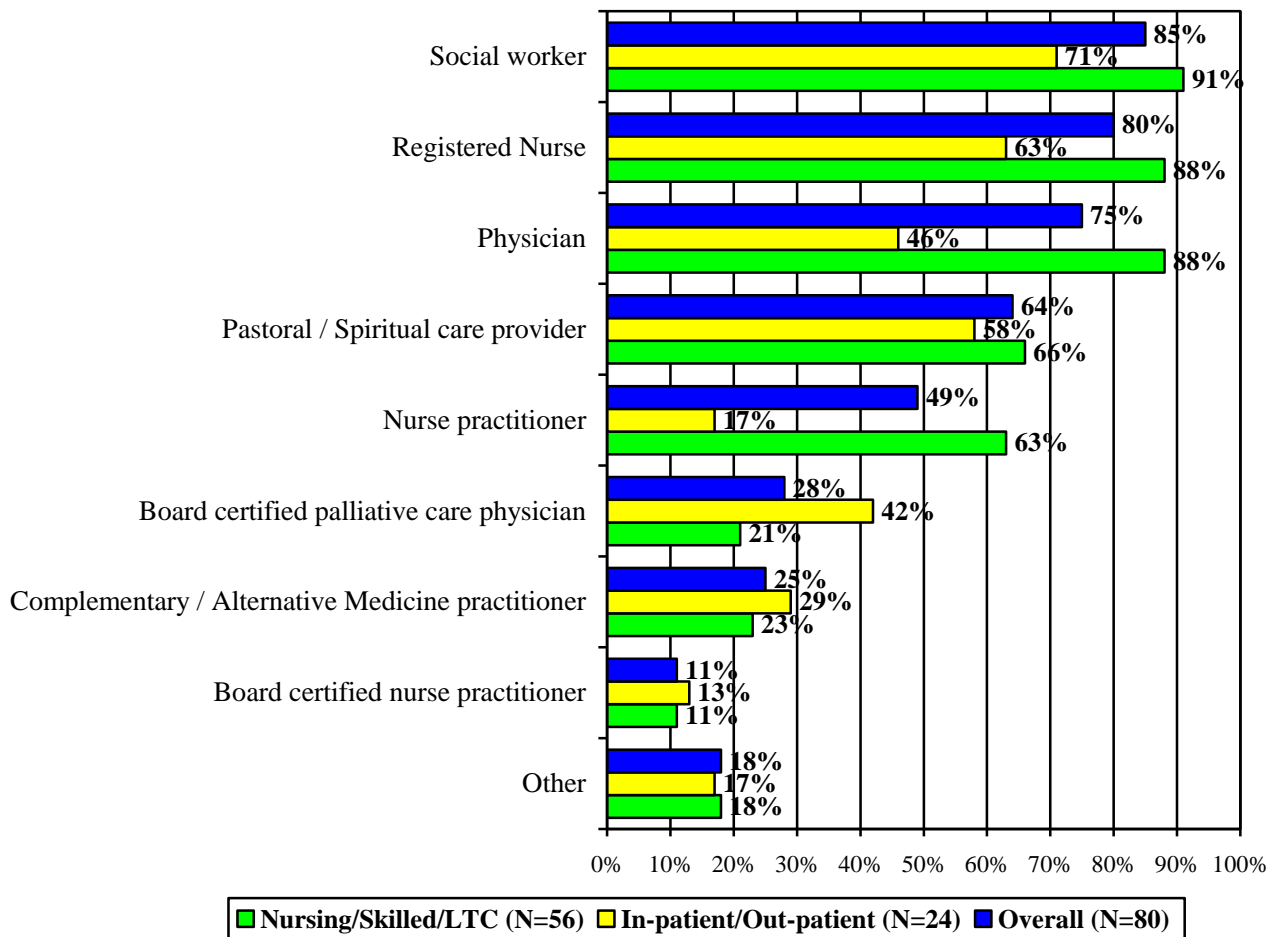


Figure 5 - Q10: When is palliative care information given to cancer patients?
(Check all that apply. Percentages may add to more than 100 percent.)

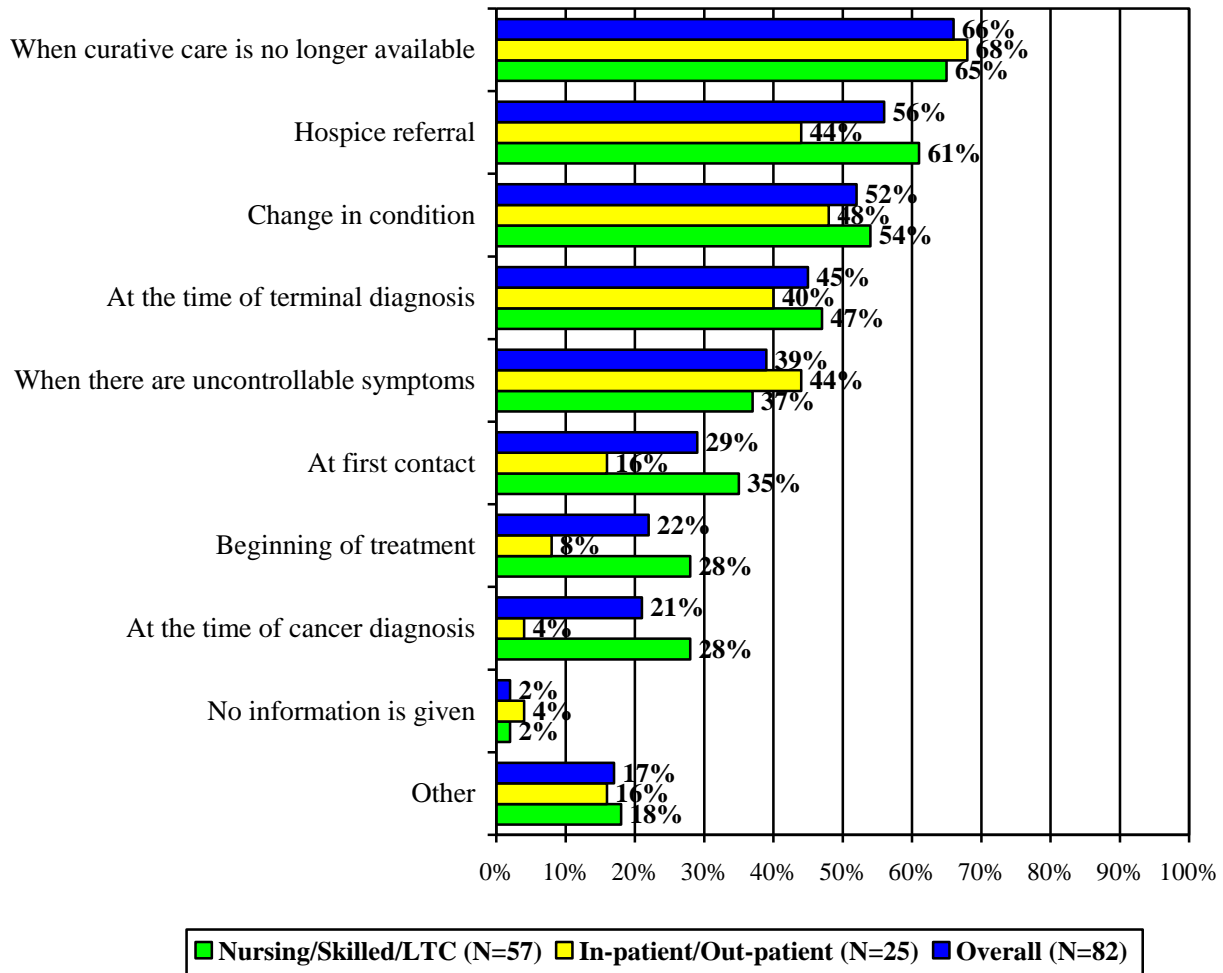
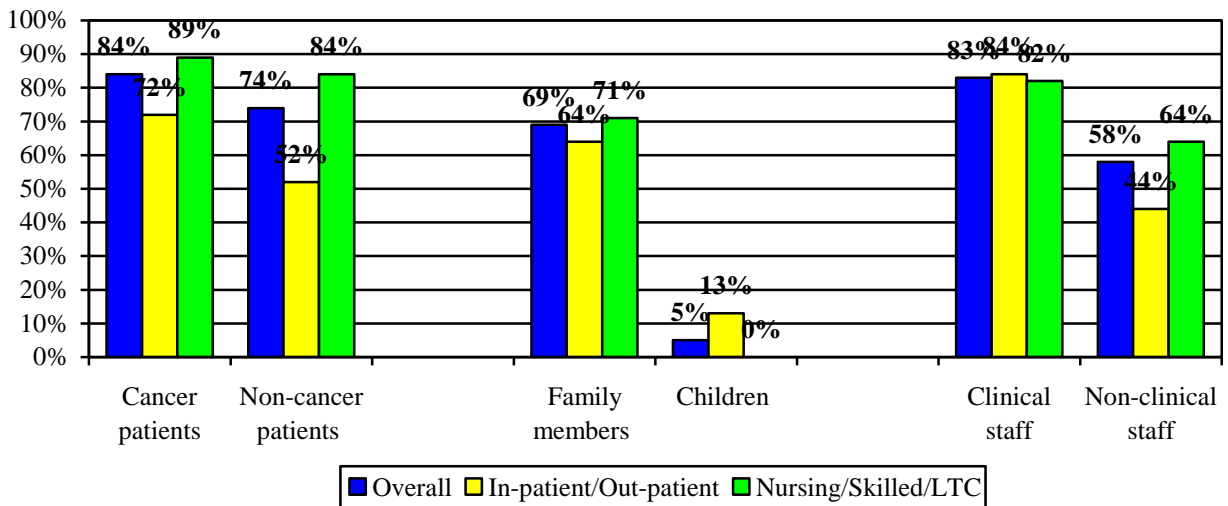


Figure 6 - Q11: Does your organization provide information about palliative care services directed toward educating each of the following groups: % YES (See detailed tables for N's of individual questions)



Figures 7 to 12 - Q12: How does your organization offer information to cancer patients on the following issues?

Figure 7 - Pain and symptom management.

(Check all that apply. Percentages may add to more than 100 percent.)

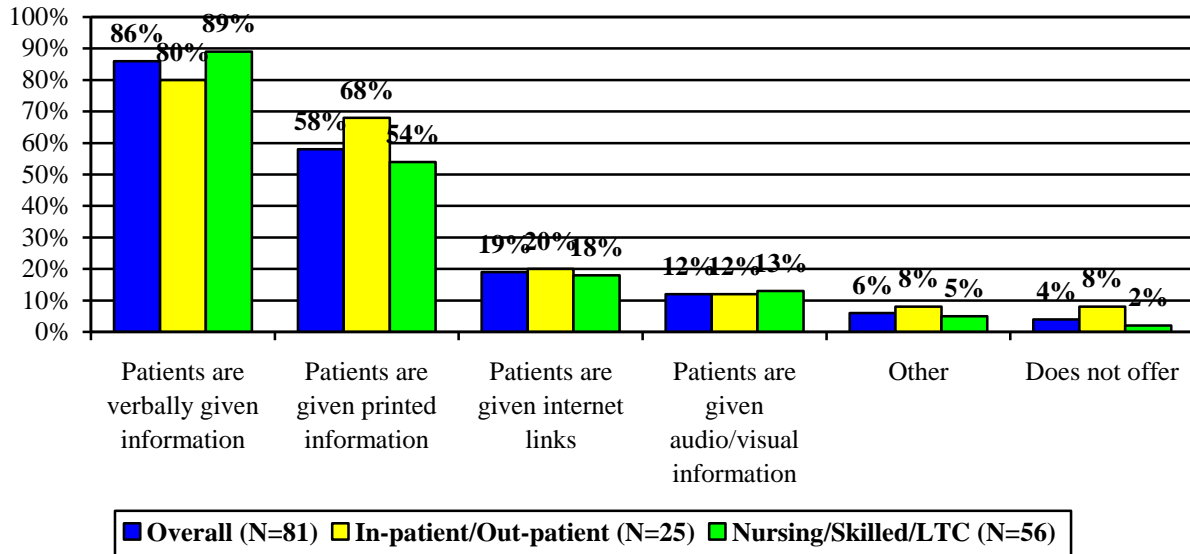


Figure 8 - Psychosocial and emotional aspects of cancer.

(Check all that apply. Percentages may add to more than 100 percent.)

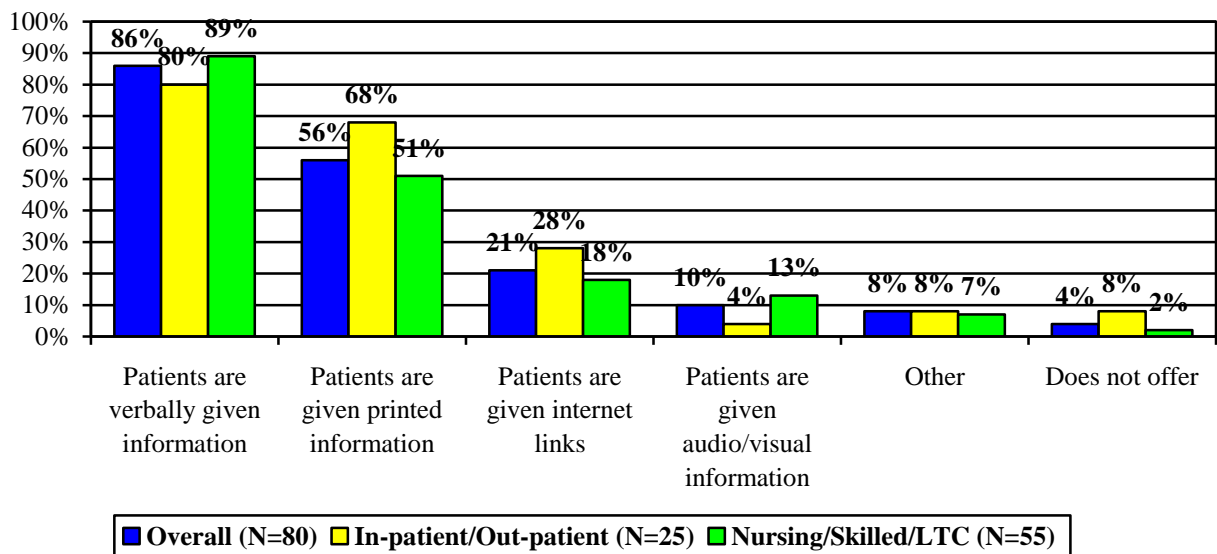


Figure 9 - Advance care planning.

(Check all that apply. Percentages may add to more than 100 percent.)

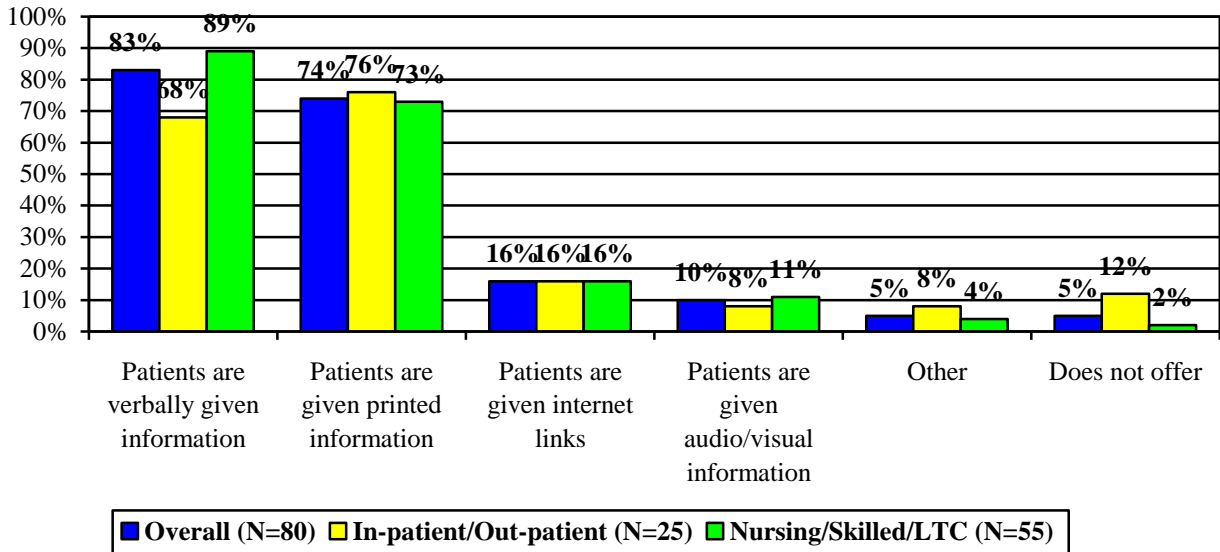


Figure 10 - General information about palliative care (as described in introduction).

(Check all that apply. Percentages may add to more than 100 percent.)

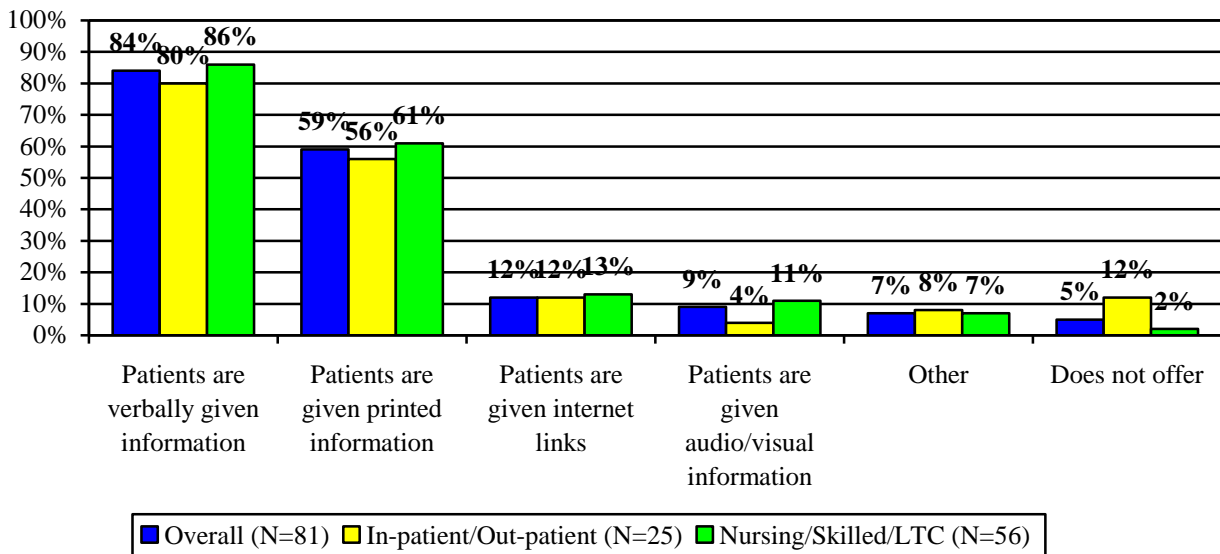


Figure 11 - Spiritual aspects of cancer.

(Check all that apply. Percentages may add to more than 100 percent.)

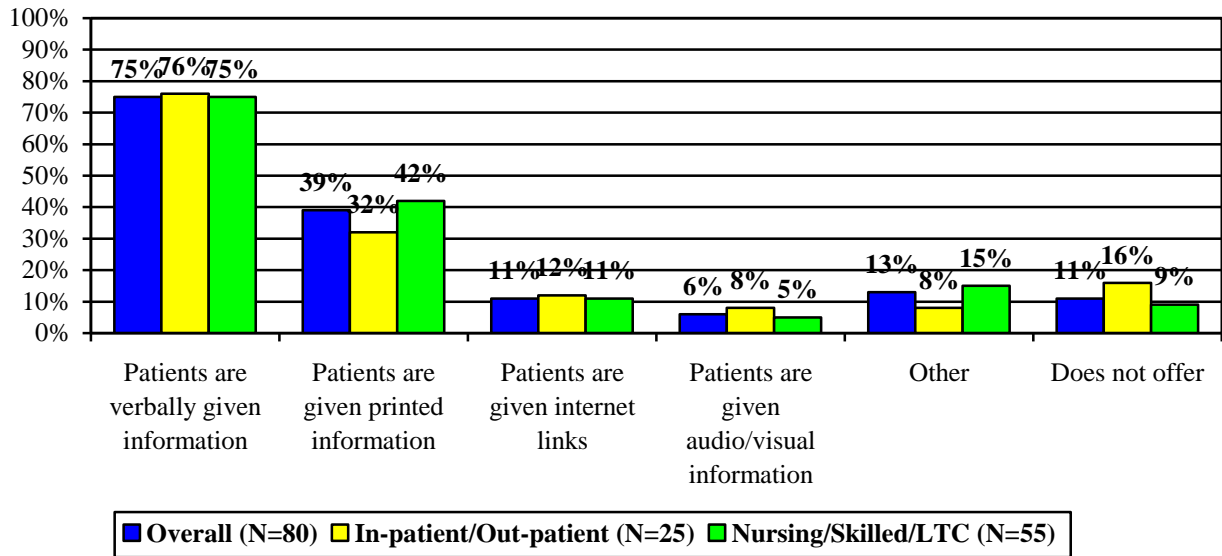


Figure 12 - Q13: Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care?

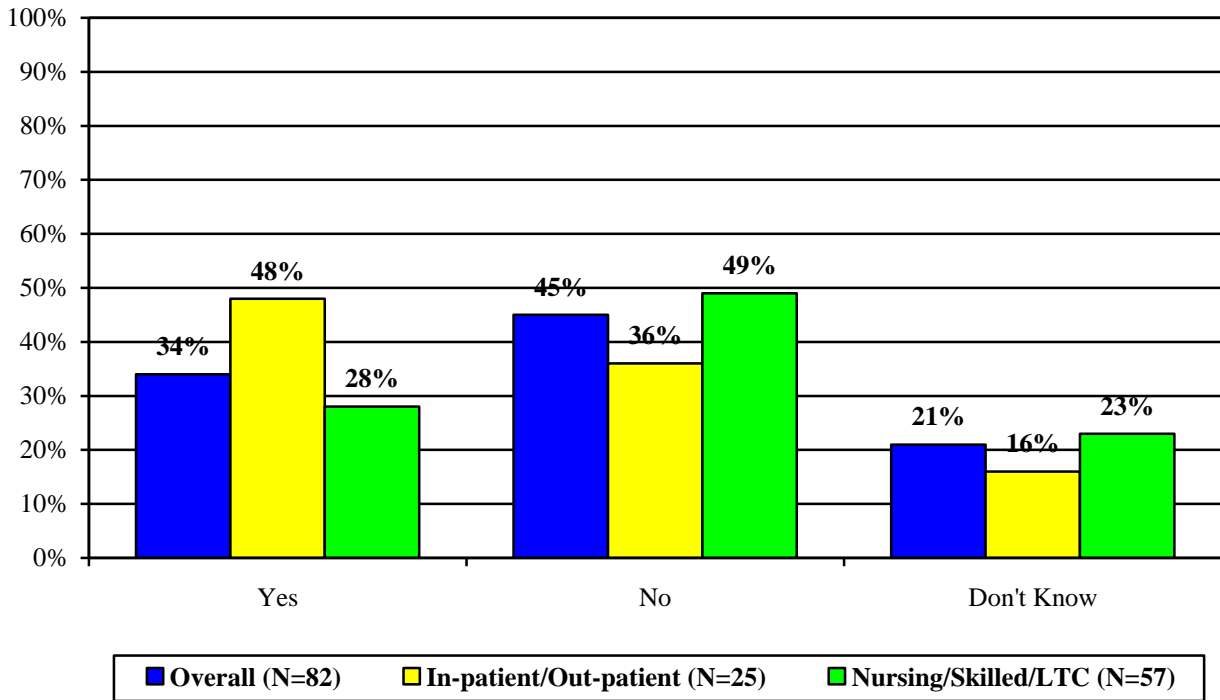


Figure 13 - Q14: How often does your organization offer in-service programs to increase staff awareness or education about palliative care?

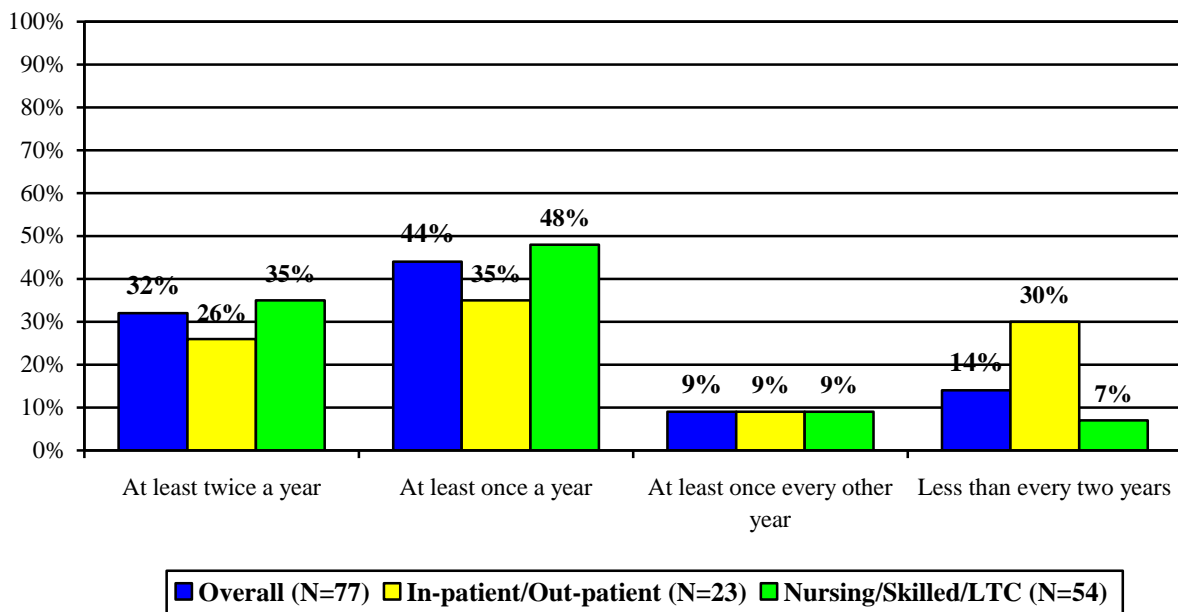


Figure 14 - Q15: Approximately what percentage of patients admitted to your organization annually, have cancer?

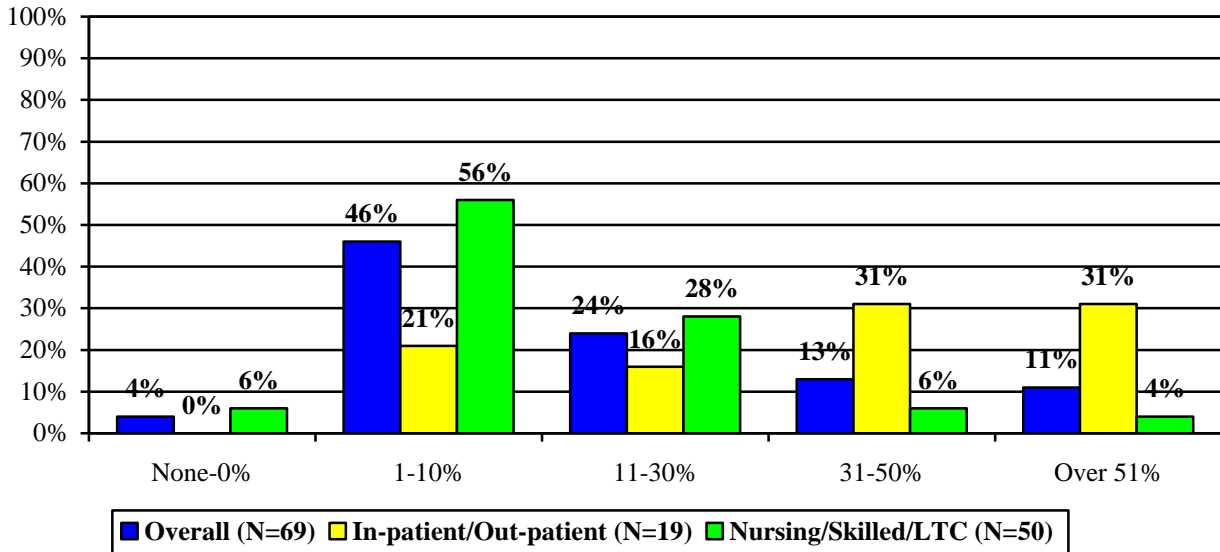


Figure 15 - Q16: Approximately what percentage of patients who are referred to palliative care have cancer?

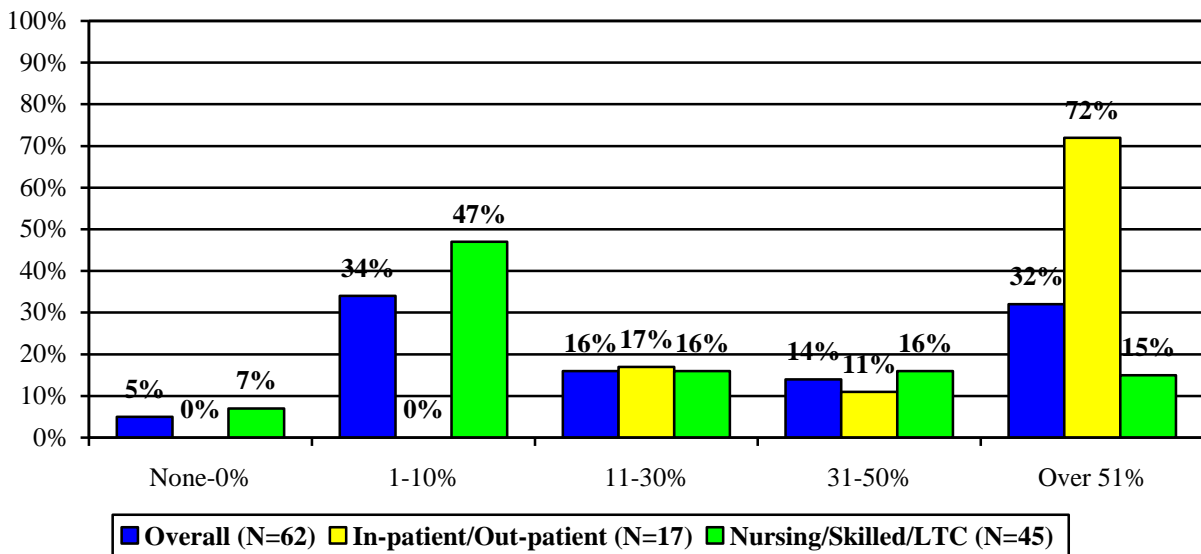
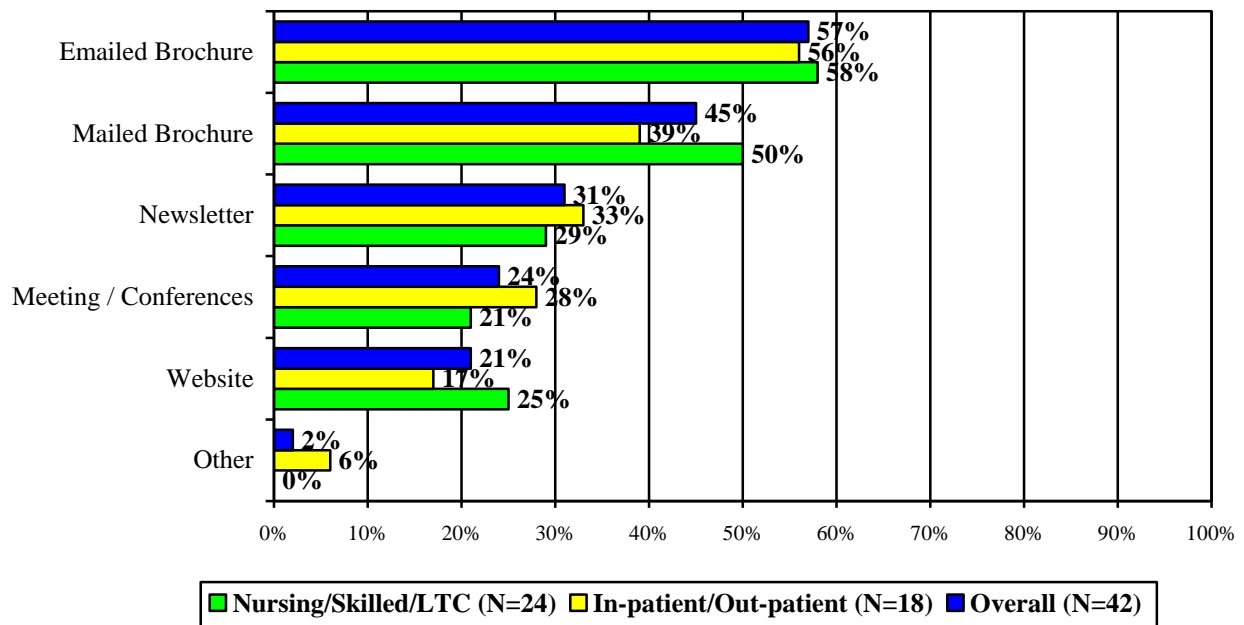


Figure 16 - Q17: What is the best way to inform you of updates for best practices of palliative care?
(Check all that apply. Percentages may add to more than 100 percent.)



APPENDIX A

OPEN ENDED RESPONSES

Q2: Which of the following best describes your organization?

- Continuing Care Retirement Community
- we provide services in all 3 locations
- Inpatient hospital, outpatient physicians/services, VNA homecare/hospice services
- Outpatient Radiation Oncology
- critical access hospital
- all 3
- Both In-patient and Out-patient ambulatory care
- retirement facility
- long term and rehab
- rural hospital
- homecare
- nursing home and skilled

Q6: Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

- We work with Home Health and Hospice
- We have a hospice care unit that can hold 13 residents, and others live throughout the building
- TRYING TO BUILD PALLIATIVE CARE PROGRAM,,, ONLY MYSELF RN, CHPN AND CLERGY
- I make the referral through a contract with the vna.

Q7: Who provides palliative care services after a cancer patient is referred for palliative care?

- Staff and sometimes hospice staff
- Our staff and we have contracts with 3 area hospice agencies.
- Palliative Care staff
- home health or hospice
- does not apply
- I think its an outpatient service, we are in the process of setting up our palliative care services.
- we dont have a palliative group here we do work with them. we have one dr. who has worked with palliative care.

Q8: Who provides the initial assessment of cancer patients referred for palliative care?

- Physician, NP , & RN
- Physician and NP
- IDT
- Nursing staff
- A nurse practitioner assists the board certified palliative care physician in the initial assessment.
- Team approach; Nurse practitioner, social worker, physician (at times)
- Usually it is either our Nurse Navigator, RN or our Board Certified Palliative Care Physician
- All staff working with the particular resident
- Physician and or Nurse Practitioner
- team effort nurses and social workers

- attending physician or nurse practitioner
- we dont really deal with that too much and when they get here they already have it thru hospice.
- no formal referral.
- social worker, rn, or the dr
- physician, nurse practitioner, social worker, or registered nurse, could be any or all of these.

Q9: Who makes up the palliative care team / program available to your cancer patients? (Check all that apply)

- Hospice
- Hospice services
- Social Worker
- Resp Therapist, Nutritionist
- IDT
- on-site hospice evaluations are done at MCNH upon request
- Nursing staff
- HOSPICE
- LNA, activities
- Program Manager, is also the Social Worker.
- Dieticien
- we do not have an established palliative care program
- palliative care team has been disbanded due to lack of interest
- All staff
- In process of development
- Team of specially trained In-patient Palliative Care Volunteers; Music, Art and Expressive therapist
- dietition
- and rehab
- hospice, dietition
- we have a angle care program here for extra support.
- clinical nurse specialist for palliative care.
- we are in the process of forming the services right now.

Q10: When is palliative care information given to cancer patients? (Check all that apply)

- Depends on resident and situation
- Individualized
- Varies widely
- Depends on each physician, and stage of illness. Goal is to referrals much earlier.
- Every new NCCC pt receives an Orientation Booklet with info re PC services offered.
- they would know about before they get here
- they already know about it before they get here
- they are already diagnosed when they get here.
- they already have palliative care when they get here.
- I not sure since they are referred to us
- no formal referral
- the info would be given to them before they get here
- we do care and comfort

Q17: What is the best way to inform you of updates for best practices of palliative care?

- postings for meetings and conferences and mail
- through palliative care member or email.
- mail and email
- any and all of the above
- all of the above

APPENDIX B
TABULAR RESULTS

Q6: Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

	Yes - That is the staff member(s) dedicated role	Yes - They coordinate palliative services in addition to other duties	No	Number Responding
NH Health Providers	9%	76%	16%	82
Organization Type				
In-patient/Outpatient	24%	52%	24%	25
Nursing / Skilled / Long Term	2%	86%	12%	57
Organization Size				
100 or less	9%	79%	12%	43
101 or more	3%	79%	18%	33
Identify Pts Needing PC				
Yes	8%	78%	14%	72
No	10%	60%	30%	10

Q7: Who provides palliative care services after a cancer patient is referred for palliative care?

	Staff	Contracted agency	Both	Other - specify	Number Responding
NH Health Providers	27%	10%	59%	4%	81
Organization Type					
In-patient/Outpatient	52%	8%	32%	8%	25
Nursing / Skilled / Long Term	16%	11%	71%	2%	56
Organization Size					
100 or less	30%	12%	53%	5%	43
101 or more	16%	9%	72%	3%	32
Identify Pts Needing PC					
Yes	28%	10%	61%	1%	72
No	22%	11%	44%	22%	9

Q8: Who provides the initial assessment of cancer patients referred for palliative care?

	Physician	Board Certified Palliative Care Physician	Nurse Practitioner	Board Certified Palliative Care Nurse Practitioner	Social Worker	Registered Nurse (RN)	Other Specify	Number Responding
NH Health Providers	46%	8%	8%	4%	9%	19%	8%	80
Organization Type								
In-patient/Outpatient	29%	17%	8%	8%	0%	33%	4%	24
Nursing / Skilled / Long Term	54%	4%	7%	2%	13%	13%	9%	56
Organization Size								
100 or less	40%	7%	12%	5%	16%	19%	2%	43
101 or more	59%	6%	3%	0%	0%	16%	16%	32
Identify Pts Needing PC								
Yes	49%	8%	7%	3%	10%	17%	6%	71
No	22%	0%	11%	11%	0%	33%	22%	9

Q9: Who makes up the palliative care team / program available to your cancer patients? (Check all that apply. Percentages may add to more than 100 percent.)

	Physician	Board Certified Palliative Care Physician	Nurse Practitioner	Board Certified Palliative Care Nurse Practitioner	Social Worker	Pastoral/ Spiritual Care Provider	Complementary/ Alternative Medicine (CAM)	Registered Nurse (RN)	Other - Specify	Number Responding
NH Health Providers	75%	28%	49%	11%	85%	64%	25%	80%	18%	80
Organization Type										
In-patient/Outpatient	46%	42%	17%	13%	71%	58%	29%	63%	17%	24
Nursing / Skilled / Long Term	88%	21%	63%	11%	91%	66%	23%	88%	18%	56
Organization Size										
100 or less	77%	28%	53%	14%	81%	70%	28%	77%	12%	43
101 or more	78%	22%	50%	6%	91%	56%	25%	88%	25%	32
Identify Pts Needing PC										
Yes	76%	30%	52%	11%	89%	66%	25%	85%	14%	71
No	67%	11%	22%	11%	56%	44%	22%	44%	44%	9

Q10: When is palliative care information given to cancer patients? (Check all that apply. Percentages may add to more than 100 percent.)

	At first contact	At the time of cancer diagnosis	At the time of a terminal diagnosis	Beginning of treatment	When curative care is no longer indicated	Hospice referral
NH Health Providers	29%	21%	45%	22%	66%	56%
Organization Type						
In-patient/Outpatient	16%	4%	40%	8%	68%	44%
Nursing / Skilled / Long Term	35%	28%	47%	28%	65%	61%
Organization Size						
100 or less	40%	26%	49%	28%	60%	63%
101 or more	21%	18%	45%	18%	73%	58%
Identify Pts Needing PC						
Yes	32%	22%	49%	24%	71%	58%
No	10%	10%	20%	10%	30%	40%

	Change in condition	When there are uncontrollable symptoms	No information is given	Other - Specify	Number Responding
NH Health Providers	52%	39%	2%	17%	82
Organization Type					
In-patient/Outpatient	48%	44%	4%	16%	25
Nursing / Skilled / Long Term	54%	37%	2%	18%	57
Organization Size					
100 or less	51%	47%	2%	16%	43
101 or more	55%	33%	3%	15%	33
Identify Pts Needing PC					
Yes	58%	44%	1%	13%	72
No	10%	0%	10%	50%	10

Q11.a: Does your organization provide information about palliative care services directed toward educating each of the following groups: Cancer patients.

	Yes	No	Don't Know	Number Responding
NH Health Providers	84%	13%	2%	82
Organization Type				
In-patient/Outpatient	72%	20%	8%	25
Nursing / Skilled / Long Term	89%	11%	0%	57
Organization Size				
100 or less	84%	14%	2%	43
101 or more	85%	15%	0%	33
Identify Pts Needing PC				
Yes	88%	11%	1%	72
No	60%	30%	10%	10

Q11.b: Does your organization provide information about palliative care services directed toward educating each of the following groups: Non-cancer patients in need of palliative care services.

	Yes	No	Don't Know	Number Responding
NH Health Providers	74%	23%	2%	82
Organization Type				
In-patient/Outpatient	52%	40%	8%	25
Nursing / Skilled / Long Term	84%	16%	0%	57
Organization Size				
100 or less	74%	26%	0%	43
101 or more	79%	18%	3%	33
Identify Pts Needing PC				
Yes	76%	22%	1%	72
No	60%	30%	10%	10

Q11.c: Does your organization provide information about palliative care services directed toward educating each of the following groups: Children in need of palliative care service.

	Yes	No	Don't Know	Number Responding
NH Health Providers	5%	90%	5%	62
Organization Type				
In-patient/Outpatient	13%	78%	9%	23
Nursing / Skilled / Long Term	0%	97%	3%	39
Organization Size				
100 or less	3%	97%	0%	30
101 or more	4%	85%	12%	26
Identify Pts Needing PC				
Yes	6%	92%	2%	52
No	0%	80%	20%	10

Q11.d: Does your organization provide information about palliative care services directed toward educating each of the following groups: Family members in need of palliative care services.

	Yes	No	Don't Know	Number Responding
NH Health Providers	69%	28%	2%	81
Organization Type				
In-patient/Outpatient	64%	28%	8%	25
Nursing / Skilled / Long Term	71%	29%	0%	56
Organization Size				
100 or less	70%	30%	0%	43
101 or more	72%	28%	0%	32
Identify Pts Needing PC				
Yes	72%	27%	1%	71
No	50%	40%	10%	10

Q11.e: Does your organization provide information about palliative care services directed toward educating each of the following groups: Non-clinical staff.

	Yes	No	Don't Know	Number Responding
NH Health Providers	58%	33%	9%	81
Organization Type				
In-patient/Outpatient	44%	44%	12%	25
Nursing / Skilled / Long Term	64%	29%	7%	56
Organization Size				
100 or less	63%	33%	5%	43
101 or more	53%	34%	13%	32
Identify Pts Needing PC				
Yes	59%	31%	10%	71
No	50%	50%	0%	10

Q11.f: Does your organization provide information about palliative care services directed toward educating each of the following groups: Clinical staff.

	Yes	No	Don't Know	Number Responding
NH Health Providers	83%	15%	2%	82
Organization Type				
In-patient/Outpatient	84%	16%	0%	25
Nursing / Skilled / Long Term	82%	14%	4%	57
Organization Size				
100 or less	81%	16%	2%	43
101 or more	85%	12%	3%	33
Identify Pts Needing PC				
Yes	83%	14%	3%	72
No	80%	20%	0%	10

Q12.a: How does your organization offer information to cancer patients on the following issues? - Pain and symptom management.
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
NH Health Providers	4%	58%	86%	19%	12%	6%	81
Organization Type							
In-patient/Outpatient	8%	68%	80%	20%	12%	8%	25
Nursing / Skilled / Long Term	2%	54%	89%	18%	13%	5%	56
Organization Size							
100 or less	5%	56%	81%	16%	9%	7%	43
101 or more	3%	56%	91%	19%	16%	6%	32
Identify Pts Needing PC							
Yes	1%	59%	87%	20%	13%	7%	71
No	20%	50%	80%	10%	10%	0%	10

Q12.b: How does your organization offer information to cancer patients on the following issues? - Psychosocial and emotional aspects of cancer.
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
NH Health Providers	4%	56%	86%	21%	10%	8%	80
Organization Type							
In-patient/Outpatient	8%	68%	80%	28%	4%	8%	25
Nursing / Skilled / Long Term	2%	51%	89%	18%	13%	7%	55
Organization Size							
100 or less	5%	51%	84%	16%	12%	9%	43
101 or more	3%	58%	90%	23%	10%	6%	31
Identify Pts Needing PC							
Yes	1%	57%	87%	23%	11%	9%	70
No	20%	50%	80%	10%	0%	0%	10

Q12.c: How does your organization offer information to cancer patients on the following issues? - Advance care planning.
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
NH Health Providers	5%	74%	83%	16%	10%	5%	80
Organization Type							
In-patient/Outpatient	12%	76%	68%	16%	8%	8%	25
Nursing / Skilled / Long Term	2%	73%	89%	16%	11%	4%	55
Organization Size							
100 or less	7%	63%	79%	12%	9%	5%	43
101 or more	3%	84%	87%	19%	10%	6%	31
Identify Pts Needing PC							
Yes	3%	76%	83%	17%	10%	6%	70
No	20%	60%	80%	10%	10%	0%	10

Q12.d: How does your organization offer information to cancer patients on the following issues? - General information about palliative care (as described in introduction).
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
NH Health Providers	5%	59%	84%	12%	9%	7%	81
Organization Type							
In-patient/Outpatient	12%	56%	80%	12%	4%	8%	25
Nursing / Skilled / Long Term	2%	61%	86%	13%	11%	7%	56
Organization Size							
100 or less	5%	60%	81%	12%	9%	7%	43
101 or more	6%	59%	84%	16%	9%	9%	32
Identify Pts Needing PC							
Yes	1%	62%	86%	14%	10%	8%	71
No	30%	40%	70%	0%	0%	0%	10

Q12.e: How does your organization offer information to cancer patients on the following issues? Spiritual aspects of cancer.
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
NH Health Providers	11%	39%	75%	11%	6%	13%	80
Organization Type							
In-patient/Outpatient	16%	32%	76%	12%	8%	8%	25
Nursing / Skilled / Long Term	9%	42%	75%	11%	5%	15%	55
Organization Size							
100 or less	9%	37%	74%	12%	7%	16%	43
101 or more	16%	42%	74%	10%	3%	10%	31
Identify Pts Needing PC							
Yes	9%	40%	76%	11%	6%	14%	70
No	30%	30%	70%	10%	10%	0%	10

Q13: Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care?

	Yes	No	Don't know / Not sure	Number Responding
NH Health Providers	34%	45%	21%	82
Organization Type				
In-patient/Outpatient	48%	36%	16%	25
Nursing / Skilled / Long Term	28%	49%	23%	57
Organization Size				
100 or less	30%	58%	12%	43
101 or more	36%	33%	30%	33
Identify Pts Needing PC				
Yes	33%	44%	22%	72
No	40%	50%	10%	10

Q14: How often does your organization offer in-service programs to increase staff awareness / education about palliative care?

	Less than every two years	At least once every other year	At least once a year	At least twice a year	Number Responding
NH Health Providers	14%	9%	44%	32%	77
Organization Type					
In-patient/Outpatient	30%	9%	35%	26%	23
Nursing / Skilled / Long Term	7%	9%	48%	35%	54
Organization Size					
100 or less	17%	10%	46%	27%	41
101 or more	7%	10%	40%	43%	30
Identify Pts Needing PC					
Yes	16%	10%	42%	32%	69
No	0%	0%	63%	38%	8

Q15: Approximately what percentage of patients admitted to your organization annually have cancer?

	None - 0%	1% - 10%	11% - 20%	21% - 30%	31% - 40%	41% - 50%	51% - 60%
NH Health Providers	4%	46%	14%	10%	9%	4%	1%
Organization Type							
In-patient/Outpatient	0%	21%	11%	5%	26%	5%	5%
Nursing / Skilled / Long Term	6%	56%	16%	12%	2%	4%	0%
Organization Size							
100 or less	9%	69%	3%	3%	6%	6%	0%
101 or more	0%	23%	30%	20%	10%	3%	3%
Identify Pts Needing PC							
Yes	3%	46%	16%	10%	10%	5%	2%
No	17%	50%	0%	17%	0%	0%	0%

	61% - 70%	81% - 90%	91% - 99%	All - 100%	Number Responding
NH Health Providers	3%	3%	1%	3%	69
Organization Type					
In-patient/Outpatient	5%	11%	5%	5%	19
Nursing / Skilled / Long Term	2%	0%	0%	2%	50
Organization Size					
100 or less	0%	0%	3%	3%	35
101 or more	7%	3%	0%	0%	30
Identify Pts Needing PC					
Yes	3%	2%	2%	3%	63
No	0%	17%	0%	0%	6

Q16: Approximately what percentage of patients who are referred to palliative care have cancer?

	None - 0%	1% - 10%	11% - 20%	21% - 30%	31% - 40%	41% - 50%	51% - 60%
NH Health Providers	5%	34%	10%	6%	6%	8%	10%
Organization Type							
In-patient/Outpatient	0%	0%	12%	6%	6%	6%	18%
Nursing / Skilled / Long Term	7%	47%	9%	7%	7%	9%	7%
Organization Size							
100 or less	10%	45%	7%	7%	7%	3%	7%
101 or more	0%	28%	10%	7%	7%	14%	10%
Identify Pts Needing PC							
Yes	5%	32%	11%	7%	7%	9%	11%
No	0%	60%	0%	0%	0%	0%	0%

	61% - 70%	71% - 80%	81% - 90%	91% - 99%	All - 100%	Number Responding
NH Health Providers	5%	2%	5%	2%	8%	62
Organization Type						
In-patient/Outpatient	18%	0%	12%	0%	24%	17
Nursing / Skilled / Long Term	0%	2%	2%	2%	2%	45
Organization Size						
100 or less	3%	3%	0%	0%	7%	29
101 or more	3%	0%	7%	3%	10%	29
Identify Pts Needing PC						
Yes	4%	2%	5%	2%	7%	57
No	20%	0%	0%	0%	20%	5

Q17: What is the best way to inform you of updates for best practices of palliative care?

	Mailed Brochure	Emailed Brochure	Newsletter	Meeting / Conference	Website	Other-Specify	Number Responding
NH Health Providers	45%	57%	31%	24%	21%	2%	42
Organization Type							
In-patient/Outpatient	39%	56%	33%	28%	17%	6%	18
Nursing / Skilled / Long Term	50%	58%	29%	21%	25%	0%	24
Organization Size							
100 or less	47%	47%	0%	20%	13%	7%	15
101 or more	41%	64%	50%	27%	32%	0%	22
Identify Pts Needing PC							
Yes	44%	53%	33%	25%	22%	3%	36
No	50%	83%	17%	17%	17%	0%	6

APPENDIX C
QUESTIONNAIRE



New Hampshire
COMPREHENSIVE
CANCER
COLLABORATION

Access to Information on Palliative Care Survey



The Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) in conjunction with NH Hospice and Palliative Care Organization invite you to participate in this brief survey about information related to palliative care in New Hampshire. This survey should take between 5 - 10 minutes to complete. The Palliation Workgroup is working toward the following objective: Establish a baseline of how cancer survivors access information about palliative care.

The National Consensus Project for Quality Palliative Care states:

"The goal of palliative care is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for the patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care."

Responses to this survey will be kept confidential within the Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) and all results will be reported in the aggregate. Thank you for taking the time to complete this important survey. Our work could not be done without the continued support of institutions like yours.

About your Organization

1. Who is the best person to contact within your organization with information about palliative care for patients and staff?

Contact Name _____
Organization Name _____
Mailing Address 1 _____
Mailing Address 2 _____
City / Town _____
Zip Code _____
Email Address _____
Phone Number _____

2. Which of the following best describes your organization?

- In-patient care*
- Out-patient ambulatory care*
- Nursing / Skilled / Long Term Care Facility*
- Other - Specify _____*

3. How many beds do you have at your organization? _____
(In-Patient or Nursing/Skilled/LTC)

4. How many patients do you currently have in your practice? _____
(Outpatient ambulatory or other)

About your Organization's Palliative Care Services

5. Does your organization identify cancer patients in need of palliative care?

- Yes
- No

6. Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

- Yes - That is the staff member(s) dedicated role
- Yes - They coordinate palliative services in addition to other duties
- No
- Other – specify _____

7.

Who provides palliative care services after a cancer patient is referred for palliative care?

- Staff
- Contracted agency
- Both
- Other - specify _____

8.

Who provides the initial assessment of cancer patients referred for palliative care?

- Physician
- Board certified palliative care physician
- Nurse practitioner
- Board certified palliative care nurse practitioner
- Social worker
- Pastoral / Spiritual care provider
- Complementary / Alternative Medicine (CAM) practitioner
- Registered nurse (RN)
- Other - Specify _____

9.

Who makes up the palliative care team / program available to your cancer patients? (Check all that apply)

- Physician
- Board certified palliative care physician
- Nurse practitioner
- Board certified palliative care nurse practitioner
- Social worker
- Pastoral / Spiritual care provider
- Complementary / Alternative Medicine (CAM) practitioner
- Registered nurse (RN)
- Other - Specify _____

Palliative Care Information

10. When is palliative care information given to cancer patients? (Check all that apply)

- At first contact
- At the time of a cancer diagnosis
- At the time of a terminal diagnosis
- Beginning of treatment
- When curative care is no longer indicated
- Hospice referral
- Change in condition
- When there are uncontrollable symptoms
- No information is given
- Other - Specify _____

11. Does your organization provide information about palliative care services directed toward educating each of the following groups:

	Yes	No	Don't Know
Cancer patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-cancer patients in need of palliative care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children in need of palliative care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members in need of palliative care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-clinical staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. How does your organization offer information to cancer patients on the following issues? (Check all that apply)

	Does Not offer	Patients are given printed Information (brochures, handouts, info sheets, etc.)	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information (video/DVD/CD-Rom)	Other
Pain and symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosocial and emotional aspects of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advance care planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General information about palliative care (as described in introduction)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual aspects of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care?

- Yes
- No
- Don't know / Not sure

14. How often does your organization offer in-service programs to increase staff awareness / education about palliative care?

- Less than every two years
- At least once every other year
- At least once a year
- At least twice a year

- 15.** Approximately what percentage of patients admitted to your organization annually have cancer?
- | | |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> None - 0% | <input type="checkbox"/> 51% - 60% |
| <input type="checkbox"/> 1% - 10% | <input type="checkbox"/> 61% - 70% |
| <input type="checkbox"/> 11% - 20% | <input type="checkbox"/> 71% - 80% |
| <input type="checkbox"/> 21% - 30% | <input type="checkbox"/> 81% - 90% |
| <input type="checkbox"/> 31% - 40% | <input type="checkbox"/> 91% - 99% |
| <input type="checkbox"/> 41% - 50% | <input type="checkbox"/> All - 100% |

- 16.** Approximately what percentage of patients who are referred to palliative care have cancer?
- | | |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> None - 0% | <input type="checkbox"/> 51% - 60% |
| <input type="checkbox"/> 1% - 10% | <input type="checkbox"/> 61% - 70% |
| <input type="checkbox"/> 11% - 20% | <input type="checkbox"/> 71% - 80% |
| <input type="checkbox"/> 21% - 30% | <input type="checkbox"/> 81% - 90% |
| <input type="checkbox"/> 31% - 40% | <input type="checkbox"/> 91% - 99% |
| <input type="checkbox"/> 41% - 50% | <input type="checkbox"/> All - 100% |

- 17.** What is the best way to inform you of updates for best practices of palliative care?
- Mailed brochure
 - Emailed brochure
 - Newsletter
 - Meeting / Conference
 - Website
 - Other - Specify _____

- 18.** Do you have any additional comments for the Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) about your palliative care information needs?

Thank you for taking the time to complete the survey.

If you would like information about palliative care for your patients:

www.getpalliativecare.org or www.ninr.nih.gov

If you would like information about setting up a palliative care program at your institution: www.capc.org

If you would like general information about palliative care:

www.NHCancerPlan.org or www.NHHPCO.org