

Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

The Way Forward – Moving Towards an Integrated Palliative Approach to Care: Survey of Oncologists and Oncology Nurses





Final Report August 11, 2014



Research Objectives

- The Way Forward, under the direction of CHPCA/QELCCC commissioned Ipsos Reid to conduct a research program with the main objectives of exploring and defining how family/general physicians, nurses and other health professionals:
 - ⇒ currently handle approaching palliative care with their patients
 - ⇒ currently assess/manage patients who may be considered palliative; and,
 - ⇒ identify potential barriers to discussing palliative care earlier in the illness trajectory.
- Following a survey of GP/FPs and nurses working in primary care settings across Canada, a similar survey was conducted among Ontario and Quebec Oncologists, and nurses working in oncology in Ontario and Quebec who belong to the Canadian Association of Nurses in Oncology (CANO). These surveys were done in partnership with Cancer Care Ontario.



Methodology

- Online survey of n=52 Oncologists (medical and radiation oncologists) in Ontario (n=36) and Quebec (n=16) was conducted between May 19 and June 19, 2014. A sample size of n=52 yields a credibility interval of +/- 15.5%, 19 times out of 20.
 - The overall data has been weighted to reflect the proportionate distribution of Oncologists each region.
- Online survey of n=100 oncology nurses in Ontario (n=61) and Quebec (n=38) was conducted between May 19 and June 20, 2014. A sample size of n=100 yields a credibility interval of +/-11.2%, 19 times out of 20.
 - All Ontario and Quebec nurses from the Canadian Association of Nurses in Oncology database were invited to completed the survey.
 - The overall data has been weighted to reflect the proportionate distribution of Oncology nurses each region.
- Reporting note: the small sample sizes in this survey do not allow for statistical significance testing between Ontario and Quebec. Differences should be noted as directional only.
 - **Call out boxes with comparable data for Ontario and Quebec GP/FPs and PC Nurses (not specific to oncology, PC = primary care) have been provided for comparison purposes.



Executive Summary





Executive Summary: Palliative Care

- Oncologists and Onc. nurses believe palliative care has a positive impact for both the patients/family
 members and the health-care system. On the latter, there appears to be an opportunity to better inform
 both Oncologists and Onc. nurses that palliative care has a positive impact on the number of unnecessary
 treatments and deaths in hospital.
- Most Oncologists and Onc. nurses agree that palliative care is not only for end of life, but also feel it can benefit patients once deemed with a progressive, life-limiting disease. Most (77% Oncologists, 85% Onc. nurses) strongly agree that palliative care can be provided alongside treatments to control the disease and three-quarters of Oncologists and seven in ten Onc. Nurses disagree that this care can only be provided by 'palliative care specialists'.
- Most Oncologists believe they have a good sense of when to have a conversation about palliative care, feel they are aware of the supports that are available in the community, and report that they have had good experiences with these conversations.
 - Onc. nurses report feeling less likely to have a good sense of when to have a conversation and are less aware of supports available in the community.
- Among Oncologists in Ontario, there is an opportunity to increase familiarity with CCO symptom management guides, EDITH protocol and CCO Psychosocial and Palliative Pathway for Oncologists.
 - Onc. nurses are more aware of the CCO symptom management guides (nearly all surveyed are familiar with it), but like Oncologists, could be more familiarized with the EDITH protocol and CCO Psychosocial and Palliative Pathway.
- This research reveals a request for a palliative care consultation service to provide support for Oncologists,
 while Onc. nurses prefer education sessions and online toolkits for support/conversation starters.



Executive Summary: Palliative Care/Palliative Approach (2)

- The greatest opportunity for The Way Forward in terms of palliative care specifically delivered by Oncologists, may be to help increase their comfort providing palliative care – with the results suggesting giving them the tools to increase confidence in providing pain control, managing dyspnea and managing patients with limited decision-making capacity and terminal delirium.
- For Onc. nurses, there is similar feedback. There also appears to be a need among some Onc. nurses to clarify and formalize their role, so they feel confident managing dyspnea and managing patients with limited decision-making capacity and terminal delirium is within their scope of work.

Palliative Approach

- Oncologists report feeling fairly comfortable initiating a discussion about a palliative approach to care with patients/family members—54% of Oncologists are very comfortable doing this and the remaining 46% are at least somewhat comfortable.
 - Onc. nurses report feeling relatively less comfortable initiating these discussions than
 Oncologists, with only 32% very comfortable, and 46% somewhat comfortable.
- Nearly all of the Oncologists surveyed have had this type of discussion with their patients/family members. Fewer, but still a large majority of Onc nurses have had these discussions.



Executive Summary: Advance Care Plans (3)

Advance Care Plans

- While Oncologists report feeling less comfortable and less experienced having Advance Care Planning discussions with patients, they are still reporting more comfort and experience (and more knowledgeable about ACPs) than GP/FPs.
 - Onc. nurses report less comfort and less experience having ACP discussions with their patients, compared to Oncologists. Onc. nurses report they have less knowledgeable about ACPs, with most saying they only have enough information to get by; whereas most Oncologists report having more advanced, but not expert knowledge of ACPs.
- Half of Oncologists say they would benefit from more information and tools to help them with ACP discussions, namely, a list of up-to-date resources, and guidelines/checklists. Few Oncologists have heard of the 'surprise question' (28%) but most say it is at least somewhat useful.
- Six in ten Onc. nurses say they would benefit from more information and tools, most would prefer handouts/pamphlets/booklets. More Onc. nurses than Oncologists have heard of the surprise question, and are more likely to think it is useful.
- Among Oncologists, opinions about when people should start ACPs is mixed -- four in ten physicians (42%) believe that people should start ACP when they are diagnosed with a life-threatening illness, while three in ten (30%) believe people should start ACP when they are healthy. On the other hand, Onc. nurses are much more decided in their opinion in that ACPs should start when people are healthy (69%).
 - Oncologists in Quebec are more likely to say ACPs should start when people are diagnosed with a life-threatening illness than Ontario Oncologists who are more likely to say ACPs should start when people are healthy.

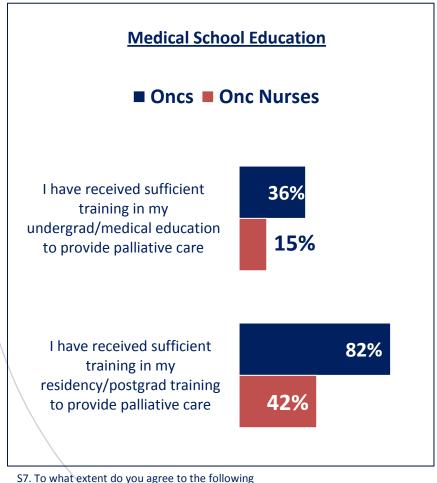


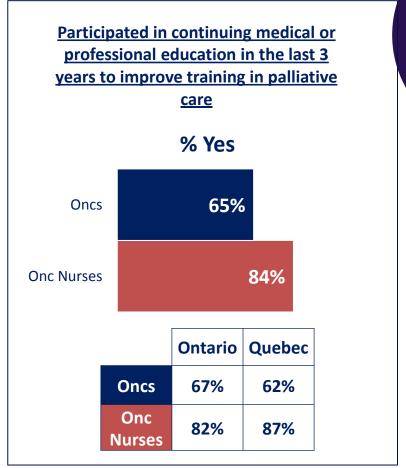
Awareness of Palliative Care



Palliative Care Training

- Most Oncologists (82%) say they have received sufficient training in palliative care in residency/post-grad. Less
 than four in ten (36%) have received training in undergrad. Onc. nurses have received considerably less training
 in undergrad in residency/post grad education in palliative care.
- Two thirds (65%) of Oncologists say they have participated in continuing education in the past three years; while over eight in ten (84%) Onc. nurses have participated in continuing education.





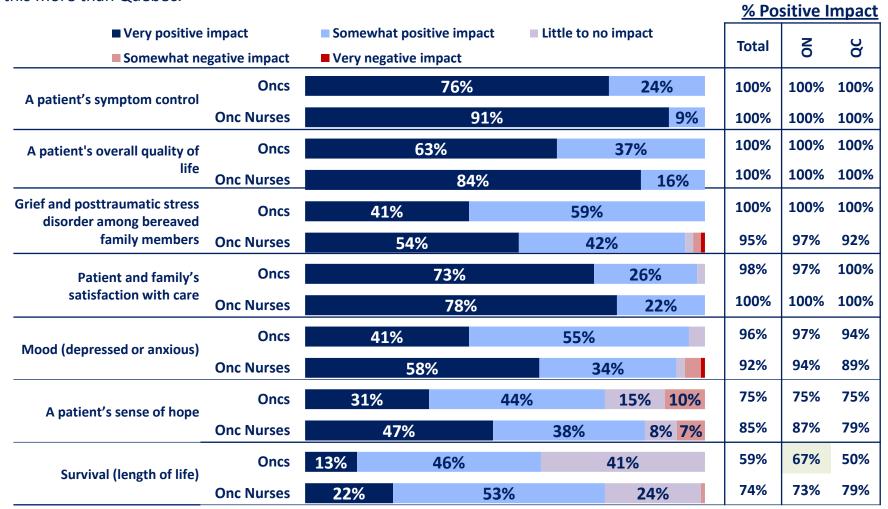
rses n=106

(Oncologists n=52); (Op/



Perceived Benefits of Palliative Care to Patients

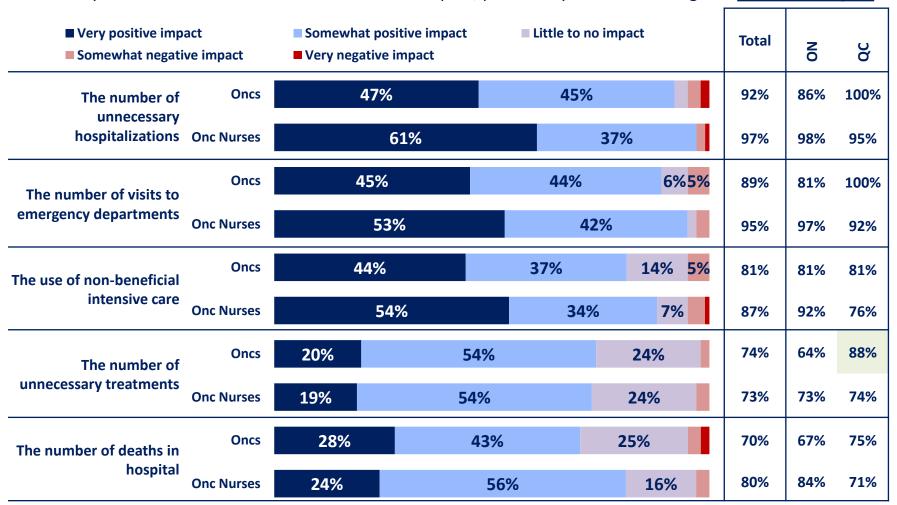
• Oncologists, and to a greater extent Onc nurses, see the positive impacts of palliative care on their patients and their family members, with the exception of impact on survival. Only six in ten (59%) Oncologists and three quarters of (74%) Onc nurses believe there is a positive impact of palliative care on survival, with Ontario Oncologists tending to believe this more than Quebec.





Perceived System Benefits of Palliative Care

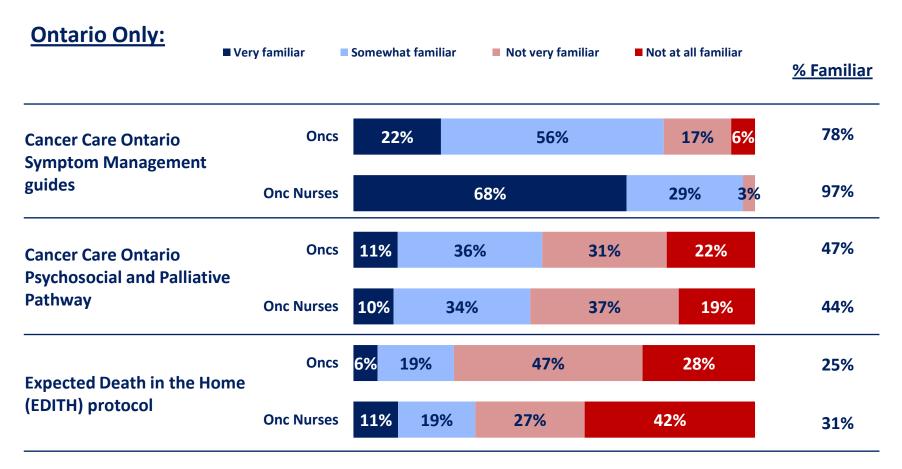
- Majority of Oncologists and Onc nurses believe that palliative care has a positive impact on the healthcare system, however they are slightly less convinced than the positive impact of palliative care on patients.
- Oncologists and Onc nurses could be more convinced of the positive impacts of palliative care on the number of unnecessary treatments and the number of deaths in hospital, particularly Ontario Oncologists. <u>% Positive Impact</u>





Familiarity with Palliative Guides in Ontario

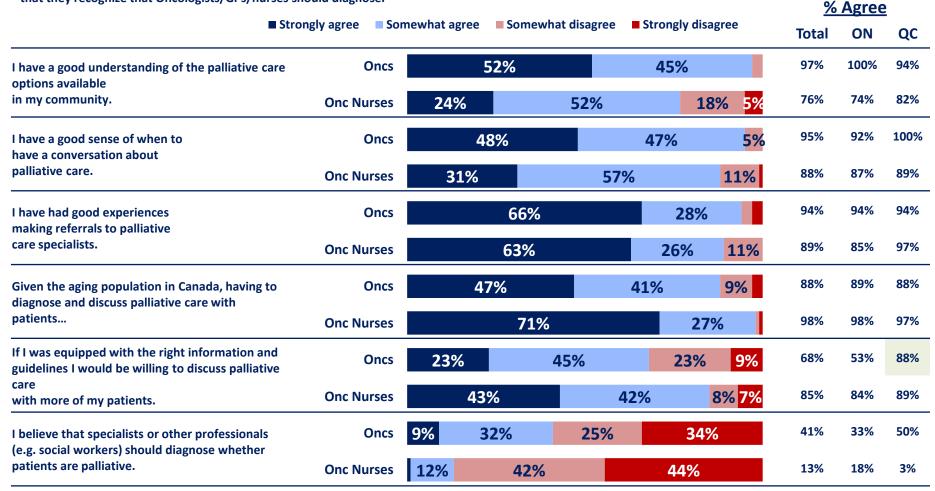
- There is an opportunity to familiarize Oncologists and Onc nurses with the three palliative guides below, especially with the CCO Psychosocial and Palliative Pathway, and the EDITH protocol.
- Only two in ten (22%) Oncologists are very familiar with CCO Symptom Management guides, one in ten (11%) are very familiar with CCO Psychosocial and Palliative Pathway, and only 6% are very familiar with the EDITH protocol.
- Onc nurses are guite familiar with the CCO Symptom Management guides, but much less so with the CCO Psychosocial and Palliative Pathway and the EDITH protocol.





Knowledge About Palliative Care

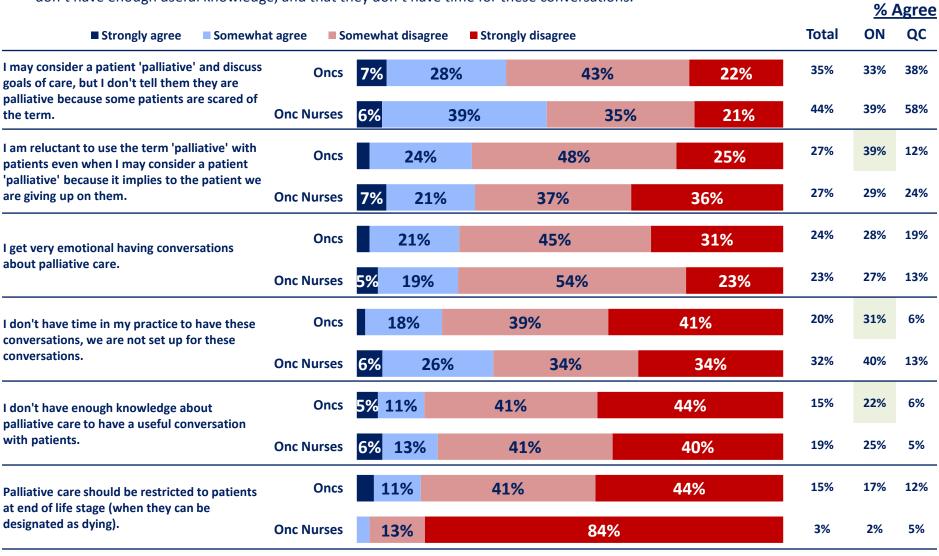
- Oncologists have a good understanding of the palliative care options available, when to have these conversations and have had good experiences; however, Onc nurses are much less likely to agree this is the case. On the other hand, Oncologists are less likely to agree that they would be more willing to discuss palliative care with more of their patients given the right guidelines (as noted later, most Oncologists are already comfortable/have the knowledge to have these discussions), but Onc nurses are more likely to have these conversations given the right information.
- Of note, a majority of Oncologists and Onc nurses disagree that specialists or other professionals should diagnose whether patients are palliative. It is unclear whether they believe the question was referring to themselves as specialists (this statement was written primarily for GPs) or palliative care specialists. However, based on the data on slides 21 and 22 it is likely that this question was interpreted as those other than themselves, and by disagreeing they are saying that they recognize that Oncologists/GPs/nurses should diagnose.





Attitudes Toward Palliative Care (2)

Very few Oncologists and Onc nurses believe that palliative care should be restricted to patients at the end of life, and are not reluctant to use the term 'palliative' when having a discussion with patients. In fact, Oncologists and Onc nurses disagree that they don't have enough useful knowledge, and that they don't have time for these conversations.





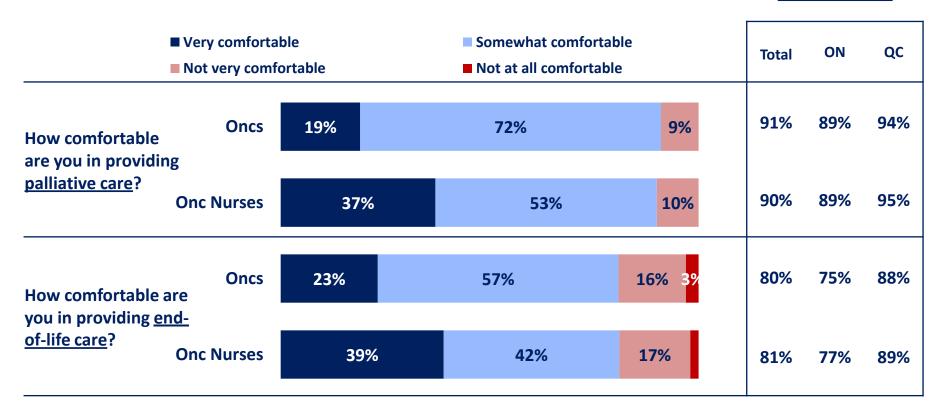
Comfort and Experience with Palliative Care



Comfort in Providing Palliative and End-of-Life Care

- Oncologists are only somewhat comfortable providing palliative and end of life care, while Onc nurses are more comfortable providing palliative and end of life care.
- Only two in ten (19%) Oncologists, compared to four in ten Onc nurses (37%) are very comfortable providing palliative care, and slightly more than two in ten Oncologists (23%), compared to four in ten Onc nurses (39%) are very comfortable providing end of life care.
- Oncologists and Onc nurses in Quebec tend to be more comfortable than those in Ontario.

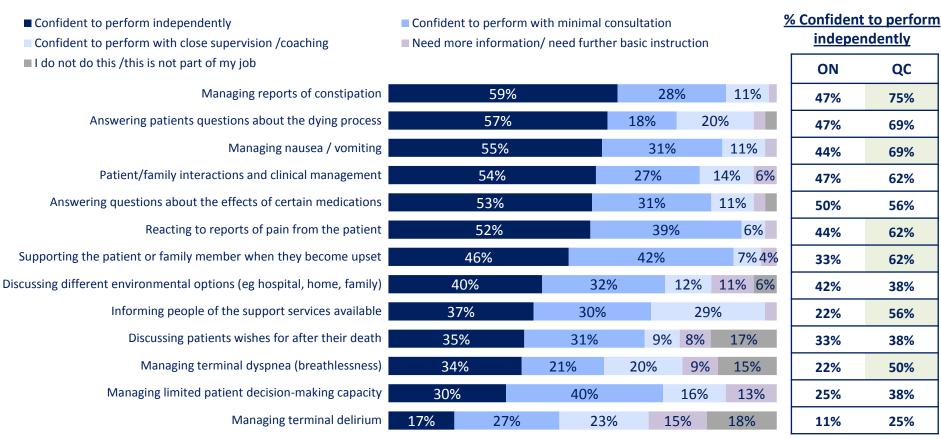
% Comfortable





Confidence with Patient/Family Interactions – Oncologists

- Six in ten or fewer Oncologists are confident to perform the following interactions independently, and while not significant, Ontario Oncologists are generally less confident than Quebec Oncologists.
- Oncologists are least confident with managing terminal dyspnea, managing limited patient decision-making capacity, and managing terminal delirium.



Values 3% and below not labeled

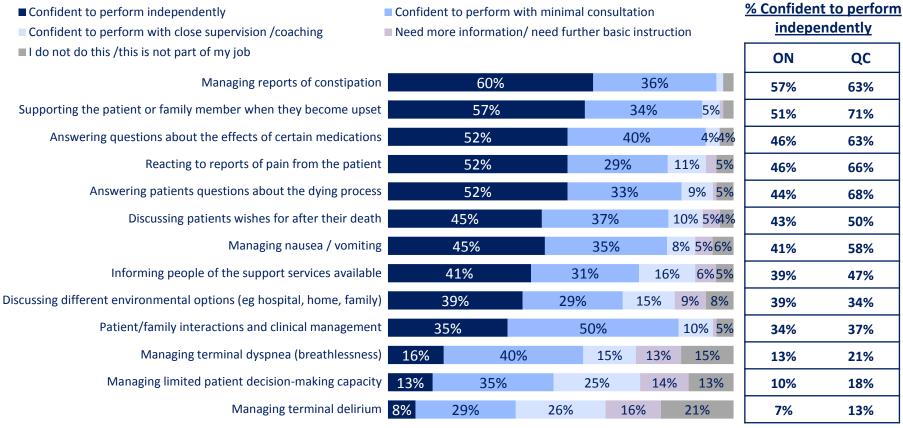
^{22.} Please rate your degree of confidence with the following patient / family interactions and patient management topics, by checking off the relevant box below

Base: All respondents (Oncologists n=52)



Confidence with Patient/Family Interactions – Oncology Nurses

- Similarly, six in ten or fewer Onc nurses are confident to perform the following interactions independently, with Ontario Onc nurses generally less confident than Quebec nurses.
- Onc nurses are also least confident with managing terminal dyspnea, managing limited patient decision-making capacity, and managing terminal delirium.



Values 3% and below not labeled

Ipsos Reid

^{22.} Please rate your degree of confidence with the following patient / family interactions and patient management topics, by checking off the relevant box below



Challenges in Caring for a Patient with Chronic or Life-Threatening Illness

• The most challenging issue in caring for patients with chronic or life-limiting illnesses is control of pain, with half of Oncologists ranking this as the most challenging issue. Oncologists in Quebec tend to rank control of pain at the most challenging issue more often than Ontario.



Values 4% and below not labeled

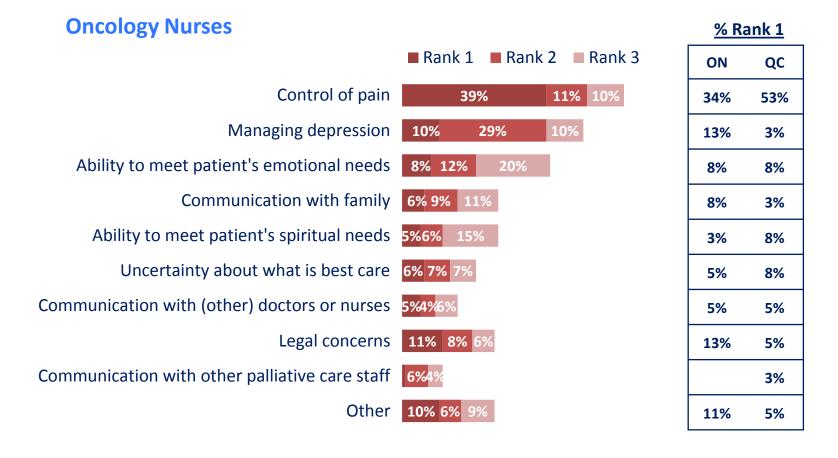
Base: All respondents (Oncologists n=52)

^{4.} Please rank the following in order from 1 to 10, where **1** is **the most challenging** issue you as a physician or nurse face in caring for a patient who has a chronic or life-limiting illness and **10** is **the least challenging** issue. If you have no other issue to add, please check 10 for 'other'.



Challenges in Caring for a Patient with Chronic or Life-Threatening Illness

• Similarly, Onc nurses also rank the control of pain as the most challenging issue, with those in Quebec more likely to rank this as the biggest challenge, compared to those in Ontario.



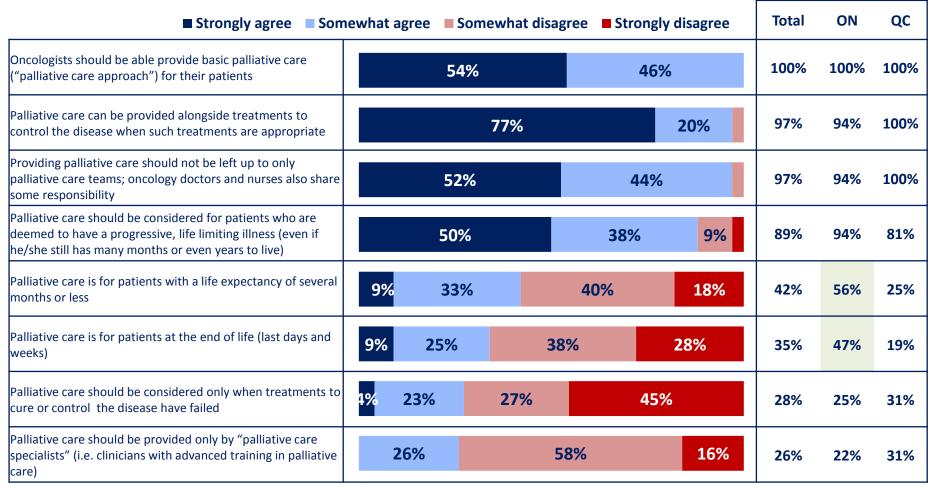
^{4.} Please rank the following in order from 1 to 10, where **1** is **the most challenging** issue you as a physician or nurse face in caring for a patient who has a chronic or life-limiting illness and **10** is **the least challenging** issue. If you have no other issue to add, please check 10 for 'other'.



When Should Palliative Be Considered - Oncologists

- Oncologists are very receptive to providing palliative care and recognize that they have a responsibility to provide this type of care. Almost all Oncologists agree that they should be able to provide basic palliative care (100%), that it can be provided alongside treatments to control the disease (97%), and that it should not be left to only palliative care teams (97%).
- Nine out of ten Oncologists agree (including 50% strongly) that palliative care should be considered for patients who are deemed to
 have a progressive, life limiting illness and not only end of life. Three-quarters strongly agree that palliative care can be provided
 alongside treatments to control the disease.

 <u>% Agree</u>

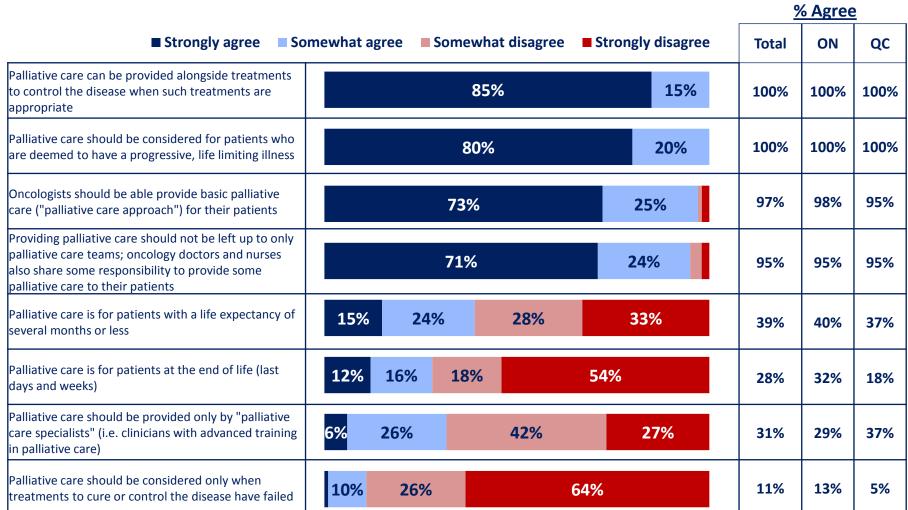


1. To what extent do you agree or disagree... Base: All respondents (Oncologists n=52)



When Should Palliative Be Considered – Oncology Nurses

- Onc nurses strongly agree that palliative care should be considered for patients who are deemed to have a progressive, life limiting illness and that palliative care can be provided along slide treatments to control the disease.
- Onc nurses are also in strong agreement that Oncologists should be able to provide basic palliative care (73%), and it should not be left up to palliative care teams (71%).



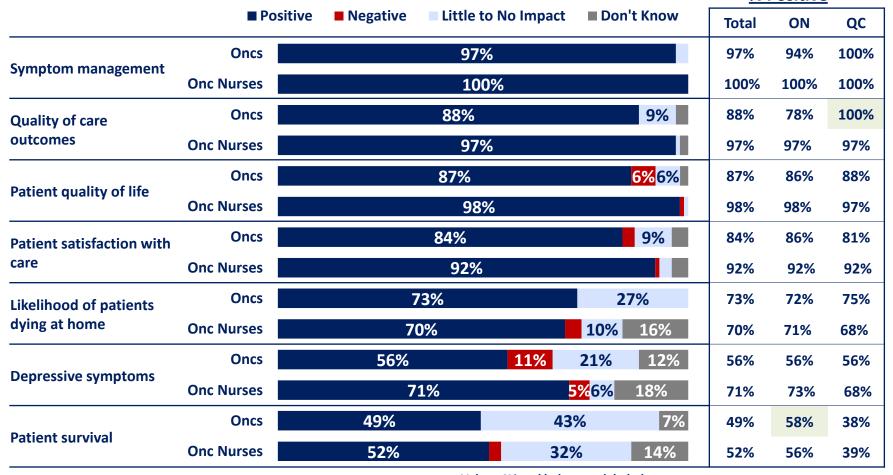


Palliative Approach to Care & Advance Care Planning



Perceived Early Introduction of Palliative Approach to Care

Oncologists and Onc nurses overwhelmingly see the positive impacts of early introduction of the palliative approach to care in symptom management, quality of life, quality of care outcomes, and satisfaction with care. Relatively fewer Oncologists and Onc nurses recognize the positive impacts in likelihood of patients dying at home, depressive symptoms, and patient survival.
 Positive



Values 4% and below not labeled

^{10.} Do you believe that initiating a palliative approach earlier in the illness trajectory (ie. Before someone is designated as "dying" or within the last weeks/months of life) has a positive impact, negative impact or little to no impact on the following:

Base: All respondents (Oncologists n=52); (Onc Nurses n=100)

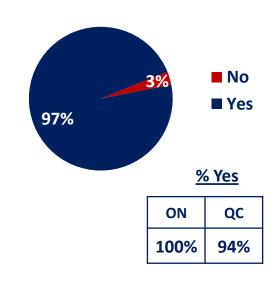


Comfort and Experience with Palliative Approach <u>Discussions</u> – <u>Oncologists</u>

- More than half of oncologists are very comfortable initiating a discussion about a palliative approach to care. All Oncologists are at least somewhat comfortable, however comfort could be increased so that oncologists are very comfortable.
- Almost all Oncologists (97%) in our sample have initiated this conversation at some point.

Comfort Discussing Palliative Approach to Care ■ Not at all comfortable 46% Not very comfortable Somewhat 54% comfortable **■** Very comfortable % Very Comfortable ON 53%

Ever Initiate Discussion on Palliative Approach to Care?



QC

56%

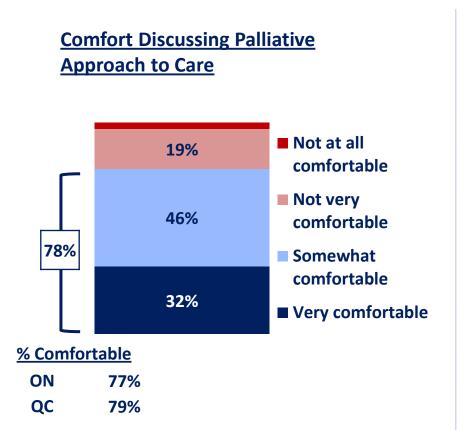
^{8.} How comfortable are you initiating a discussion about a palliative approach to care with patients and/or their family?

9. Have you ever personally initiated a discussion about a palliative approach to care with a patient and/or their family?

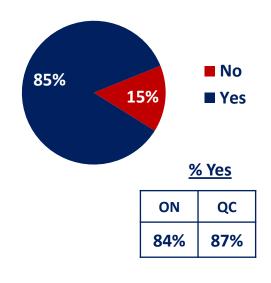


Comfort and Experience with Palliative Approach <u>Discussions</u> – Oncology Nurses

- Onc nurses are less comfortable discussing a palliative approach with their patients, and are less experienced with these conversations.
- Only three in ten (32%) Onc nurses are very comfortable discussing the palliative approach, and less than half (46%) are somewhat comfortable. Over eight in ten (85%) have initiated a discussion with a patient in the past.



Ever Initiate Discussion on Palliative Approach to Care?



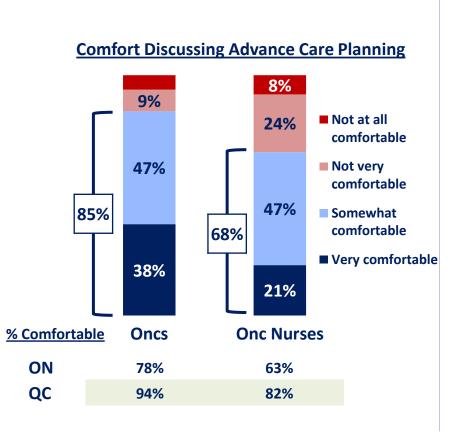
^{8.} How comfortable are you initiating a discussion about a palliative approach to care with patients and/or their family?

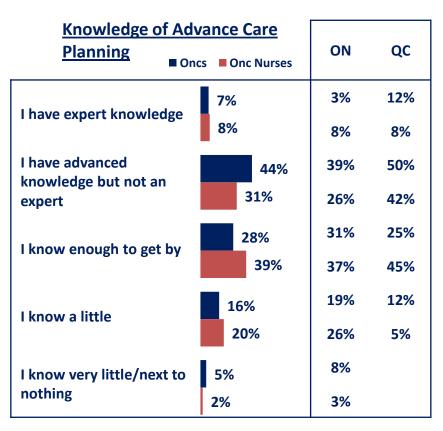
^{9.} Have you ever personally initiated a discussion about a palliative approach to care with a patient and/or their family? Base: All respondents (Onc Nurses n=100)



Advance Care Planning Comfort and Knowledge

- Oncologists and Onc nurses are less comfortable initiating a discussion about <u>ACP</u>s specifically, with only four in ten (38%) Oncologists and two in ten (21%) Onc nurses saying they are very comfortable. Oncologists and Onc nurses in Quebec tend to be more comfortable than those in Ontario.
- While only 7% of Oncologists (8% of Onc nurses) admit to having expert knowledge about ACPs, over four in ten (44%) have advanced knowledge and 28% know enough to get by. Onc nurses are less likely to have advanced knowledge, and more likely to know enough to get by.
- Quebec Oncologists and Onc nurses tend to be more knowledgeable than those in Ontario.





^{12.} Before today, which of the following best describes your level of knowledge of Advance Care Planning?

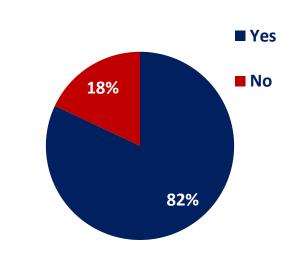
^{13.} How comfortable are you initiating a discussion about Advance Care Planning with patients and/or their family? Base: All respondents (Oncologists n=52); (Onc Nurses n=100)



Experience with Advance Care Planning Discussions – Oncologists

- Eight in ten (82%) Oncologists have discussed an ACP with a patient (the frequency or number of patients is unknown).
- Half of Oncologists say they would benefit from some tools or information to help have ACPs discussions with patients.
 An up-to-date list of resources and access to guidelines/checklists are of greatest interest.

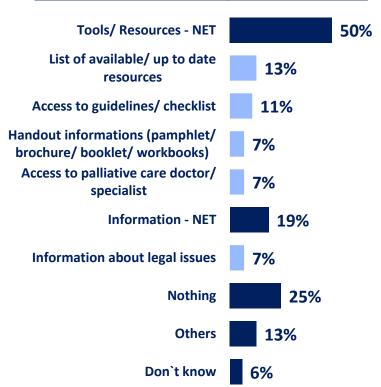
Ever Discussed Advance Care Planning



% Yes

ON	QC
83%	81%

Tools/Information to Help with Discussions



Mentions less than 5% not displayed

^{14.} Have you ever personally initiated a discussion about Advance Care Planning with a patient and/or their family?

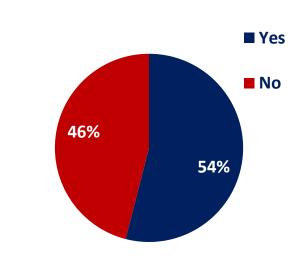
^{15.} What, if any, tools or information would you like to help you have Advanced Care Planning discussion with patients? Base: All respondents (Oncologists n=52)



Experience with Advance Care Planning Discussions – Oncology Nurses

- Just over half (54%) of Onc nurses have ever discussed ACP with their patients.
- Six in ten Onc nurses are interested in tools or information to help with ACP discussions, with handouts (pamphlets/brochures/booklets) and information about how to communication/initiate the discussion of interest.

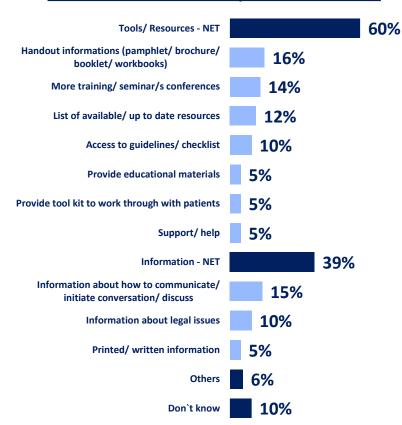
Ever Discussed Advance Care Planning



% Yes

ON	QC
52%	61%

Tools/Information to Help with Discussions



Mentions less than 5% not displayed

^{14.} Have you ever personally initiated a discussion about Advance Care Planning with a patient and/or their family?

^{15.} What, if any, tools or information would you like to help you have Advanced Care Planning discussion with patients? Base: All respondents (Onc Nurses n=100)



"Jane" Scenario

- Almost nine in ten Oncologists (87%) and almost all Onc nurses (95%) would classify Jane as 'palliative'.
- Nine in ten (91%) Oncologists and more than eight in ten (84%) Onc nurses would likely discuss an ACP with her; however only 37% and 39%, respectively, would very likely discuss an ACP.

Jane is a 67 yr old lady with stage IV breast cancer with metastatic disease – to bone, brain and lung. She also has hypertension.

Her cancer is presently controlled on Tamoxifen and she has received radiotherapy to the brain with good response. Her prognosis might be a few months or a couple of years... impossible to know for sure.

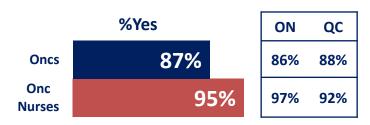
Jane lives at home with her husband and her daughter, both of whom are very supportive. She also has a son who lives nearby.

Overall Jane's performance status allows her to carry out her routine daily activities, but she does require assistance with shopping and cleaning as recently she has been tiring more quickly and has begun to experience some pain in her back which she is managing effectively with Tylenol #3. (ECOG: 2, PPS: 70%)

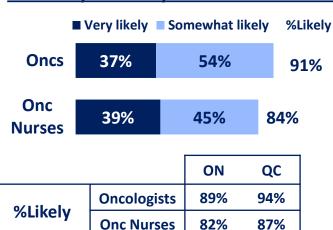
Jane is optimistic about her prognosis and sees herself as a "fighter" but knows her future is uncertain and things could change quickly.



Should Jane be considered palliative?

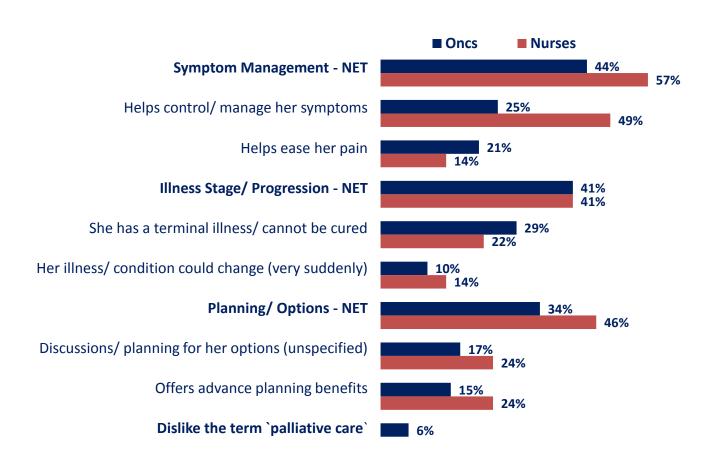


How likely is it that you would discuss an ACP?



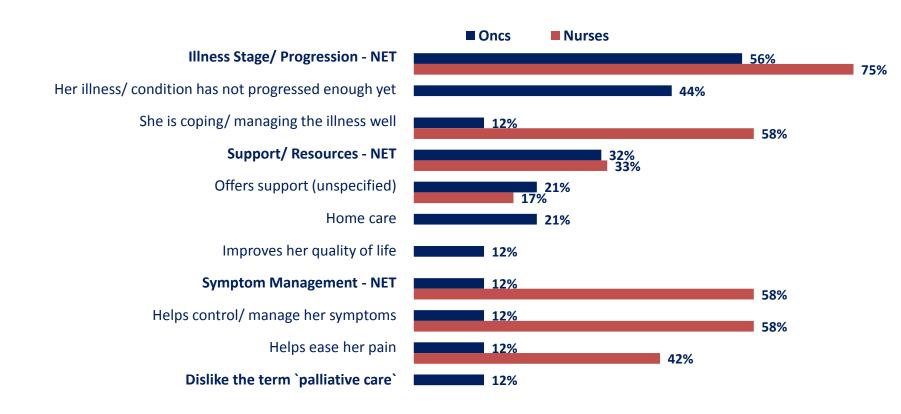


Rationale for **Considering** "Jane" Palliative





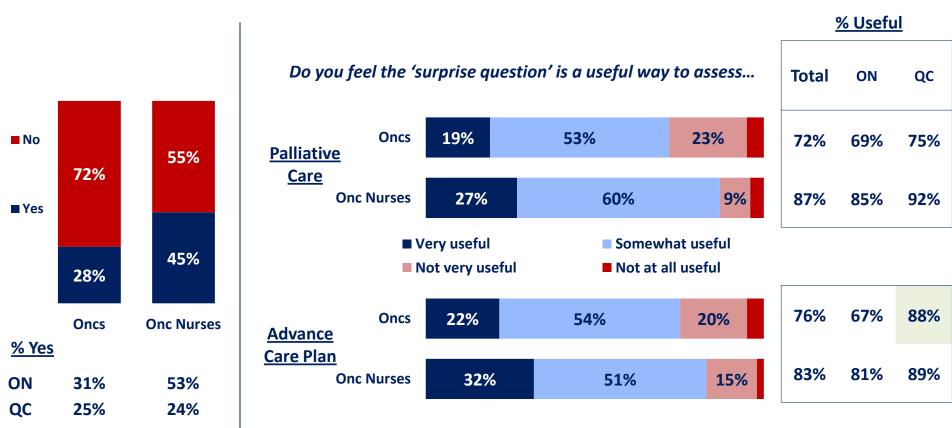
Rationale for **Not Considering** "Jane" Palliative





Surprise Question

- Most Oncologists (72%), and to a lesser extent Onc nurses (55%), have not heard of the surprise question. Three-quarters of Oncologists say the surprise question would be at least somewhat useful to assess whether palliative care (72%) or ACP (76%) is relevant for patients. Oncologists in Quebec are less likely to have heard of the surprise question, but more likely to say it is useful.
- Onc nurses are more receptive to the usefulness of the surprise question, with over eight in ten saying it would be useful to assess palliative care (87%) and ACPs (83%).



To help you assess whether palliative care or an Advance Care Plan is relevant for patients, it is suggested that they consider the following prognostication question: "Would you be surprised if this patient died in the next six to twelve months?"

^{21.} Have you heard of this 'surprise question' before today?

^{22.} Do you feel the surprise question is a useful way to assess whether palliative care is relevant for patients?

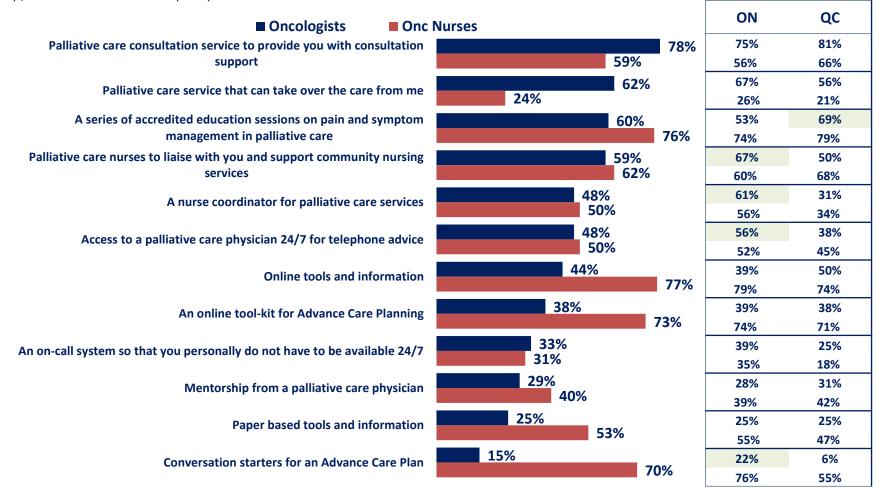
^{23.} Do you feel the surprise question is a useful way to assess whether an <u>Advance Care Plan</u> is relevant for patients? Base: All respondents (Oncologists n=52); (Onc Nurses n=100)



Useful Resources

Oncologists would find a palliative care consultation service (78%) most useful to increase their capacity to have these
discussions, followed by a palliative care service to take over (62%), education sessions (60%), and palliative care nurses (59%).

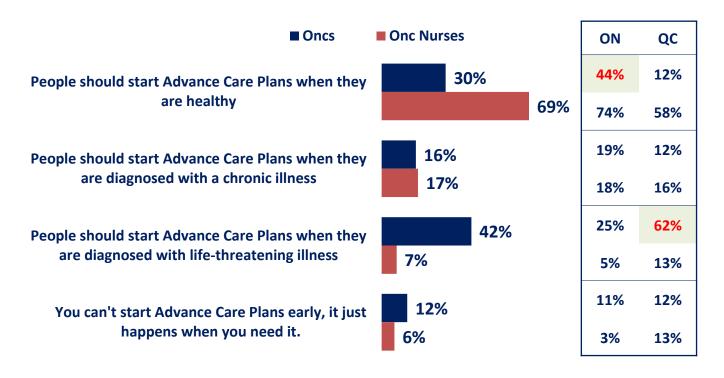
• Onc nurses would find a series of accredited education sessions (76%), online tools/information (77%), and an online tool-kit for ACP (73%) / conversation starters (70%) most useful.





Perceptions of When People Should Start ACPs

- The majority of Onc nurses (69%) believe people should start ACPs when they are healthy.
- Among Oncologists, opinion about when people should start ACPs is more mixed -- four in ten physicians (42%) believe that people should start ACP when they are diagnosed with a life-threatening illness, while three in ten (30%) believe people should start ACP when they are healthy.
- Oncologists in Quebec more likely to say ACPs should start when people are diagnosed with a life-threatening illness than Ontario Oncologists who are more likely to say ACPs should start when people are healthy.



^{24.} According to a Canadian general population study conducted in 2013, 52% of the public thought that people should start planning for end-of-life care when they are healthy.



Demographics



Demographics – Oncologists

Years in Practice	
0 to 2 years	2%
3 to 5 years	14%
6 to 10 years	19%
Over 10 years	65%

Gender	
Male	80%
Female	20%

Region	
Ontario	56%
Quebec	44%

Age	
Under 35	10%
35-55	75%
Over 55	15%

Sub-Specialty	
Medical oncology # (2013 – Ontario only)	358
Radiation oncology # (2013 – Ontario only)	189



Demographic – Oncology Nurses

Years in Practice	
0 to 2 years	3%
3 to 5 years	10%
6 to 10 years	18%
Over 10 years	70%

Gender	
Male	4%
Female	96%

Region	
Ontario	71%
Quebec	29%
Age	

Age	
Under 35	14%
35-55	58%
Over 55	27%