

The Supportive Care Oncology Network- NE Region: Screening for Distress in Northeastern Ontario – Implications for Practice in Rural Health Care

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Regional Cancer
Program

HÔPITAL RÉGIONAL DE
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Acknowledgements

Research Team

Principal Investigator

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Co-Investigators

- Sheila Damore-Petingola, MSW, RSW, Supportive Care Oncology Network, NE
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Partners

- Canadian Partnership Against Cancer-Cancer Journey Action Group
- Northern Cancer Research Foundation

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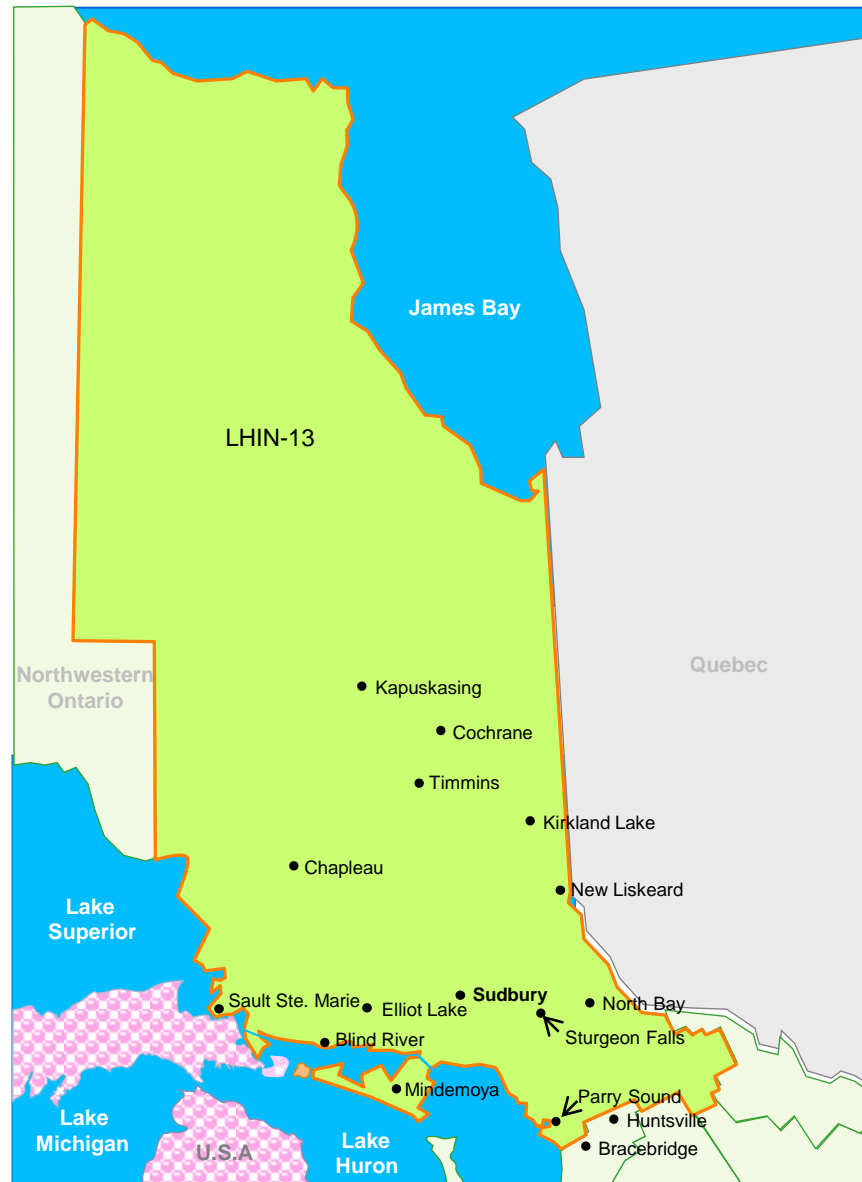
This project is supported by:

The Canadian Partnership Against Cancer –
Cancer Journey Action Group and

The Northern Cancer Research Foundation

Presentation Outline

- Project Outline
- Preliminary Results
- Implications for Practice



**Community
Oncology Clinic
Network (COCN)**

**NE Local Health
Integration
Network (LHIN-13)**

Expanding Screening for Distress in NEO Quality Improvement Project

- Educating health care professionals at the Community Oncology Clinic sites in NEO
 - Identifying patient distress
 - Quantifying the distress with validated instruments – screening
 - Responding to distress by initiating appropriate referrals for assessment and intervention

Definition of Distress

- An unpleasant experience of an emotional, psychological, social, and/or spiritual nature that interferes with the ability to cope with cancer
- Extends along a continuum from common, normal feelings of vulnerability, sadness and fears to problems that are disabling such as depression, anxiety, social isolation, spiritual crisis

National Comprehensive Cancer Network

- Prevalence of distress in cancer patients is consistently reported between 35% and 45% - experience significant levels of distress

Carlson et al 2004; Zabora et al 1997

Project Outline

- Who to Screen: All patients receiving chemotherapy at a COCN site (14 sites)
- When to Screen: Once per cycle of chemotherapy
- How to Screen: Using computerized method when possible; other option paper copy
- Screening domains: Psychosocial, practical and physical
- Tool selection: ESAS and Canadian Problem Checklist

Respecting Cultural Diversity

- Demographic and Health Profile for NE - LHIN
 - Higher proportion of Aboriginals/First Nations/Métis than Ontario as a whole, 10% and 2% respectively
 - Higher proportion of Francophones compared to Ontario as a whole, 24% and 4% respectively

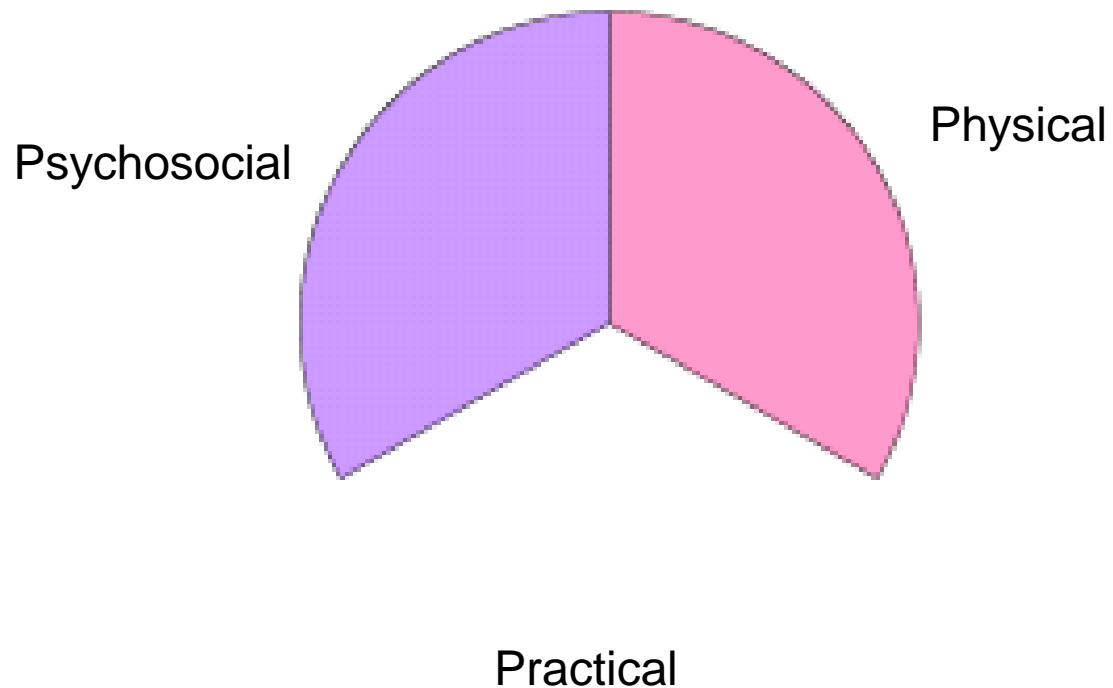
(Population Profile at a Glance – NE LHIN <http://www.nelhin.on.ca>)
- All forms available in English and French

Evaluation

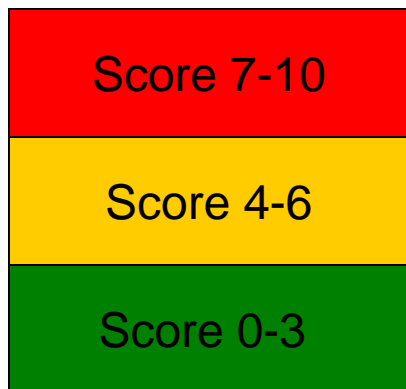
- Edmonton Symptom Assessment System (ESAS)
- Canadian Problem Checklist
- Nursing Outcome Form
- Cultural Demographic Form
- General Demographic Information

ESAS

Screening Domains



Severity of Scores



Edmonton Symptom Assessment System: Numeric Scale

Please circle the number that best describes:

| | | | | | | | | | | | | |
|---------------------------|---|---|---|---|---|---|---|---|---|---|----|-------------------------------------|
| No pain | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible pain |
| <hr/> | | | | | | | | | | | | |
| Not tired | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible tiredness |
| <hr/> | | | | | | | | | | | | |
| Not nauseated | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible nausea |
| <hr/> | | | | | | | | | | | | |
| Not depressed | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible depression |
| <hr/> | | | | | | | | | | | | |
| Not anxious | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible anxiety |
| <hr/> | | | | | | | | | | | | |
| Not drowsy | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible drowsiness |
| <hr/> | | | | | | | | | | | | |
| Best appetite | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible appetite |
| <hr/> | | | | | | | | | | | | |
| Best feeling of wellbeing | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible feeling of wellbeing |
| <hr/> | | | | | | | | | | | | |
| No shortness of breath | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible shortness of breath |
| <hr/> | | | | | | | | | | | | |
| Other problem | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |

Problem Checklist (minimal data set)

Please check all of the following items that have been a concern or problem for you in the past week including today:

| | | |
|---|--|--|
| <p>Practical</p> <ul style="list-style-type: none"> <input type="checkbox"/> Work/School <input type="checkbox"/> Finances <input type="checkbox"/> Getting to and from appointments <input type="checkbox"/> Accommodation <input type="checkbox"/> Legal <input type="checkbox"/> Childcare | <p>Emotional</p> <ul style="list-style-type: none"> <input type="checkbox"/> Fears/Worries <input type="checkbox"/> Sadness <input type="checkbox"/> Frustration/Anger <input type="checkbox"/> Changes in Appearance <input type="checkbox"/> Intimacy/Sexuality | <p>Informational</p> <ul style="list-style-type: none"> <input type="checkbox"/> Understanding my illness and/or treatment <input type="checkbox"/> Talking with the health care team <input type="checkbox"/> Making treatment decisions <input type="checkbox"/> Knowing about available resources <input type="checkbox"/> Awareness of traditional healing practices |
| <p>Social/Family</p> <ul style="list-style-type: none"> <input type="checkbox"/> Feeling a burden to others <input type="checkbox"/> Worry about friends/family <input type="checkbox"/> Feeling alone | <p>Spiritual</p> <ul style="list-style-type: none"> <input type="checkbox"/> Meaning/Purpose of life <input type="checkbox"/> Faith | <p>Physical</p> <ul style="list-style-type: none"> <input type="checkbox"/> Concentration/memory <input type="checkbox"/> Sleep <input type="checkbox"/> Weight |

Principals of Participatory Action Research (PAR)

- Equalizing power imbalances in the project—seeking participants' input
- Research process involves taking notice of the findings at different stages of the research which informs actions to be taken throughout the process (Nelson et al., 1998).

What We Are Studying

1. # of sites screening for distress
2. # of patients screened for distress once per cycle
3. # of patients with scores ≥ 4 reduced during cycle of chemotherapy
4. # of patients with scores ≥ 7 reduced to 4 or lower by next cycle
5. # of patients with score ≥ 4 referred to another professional

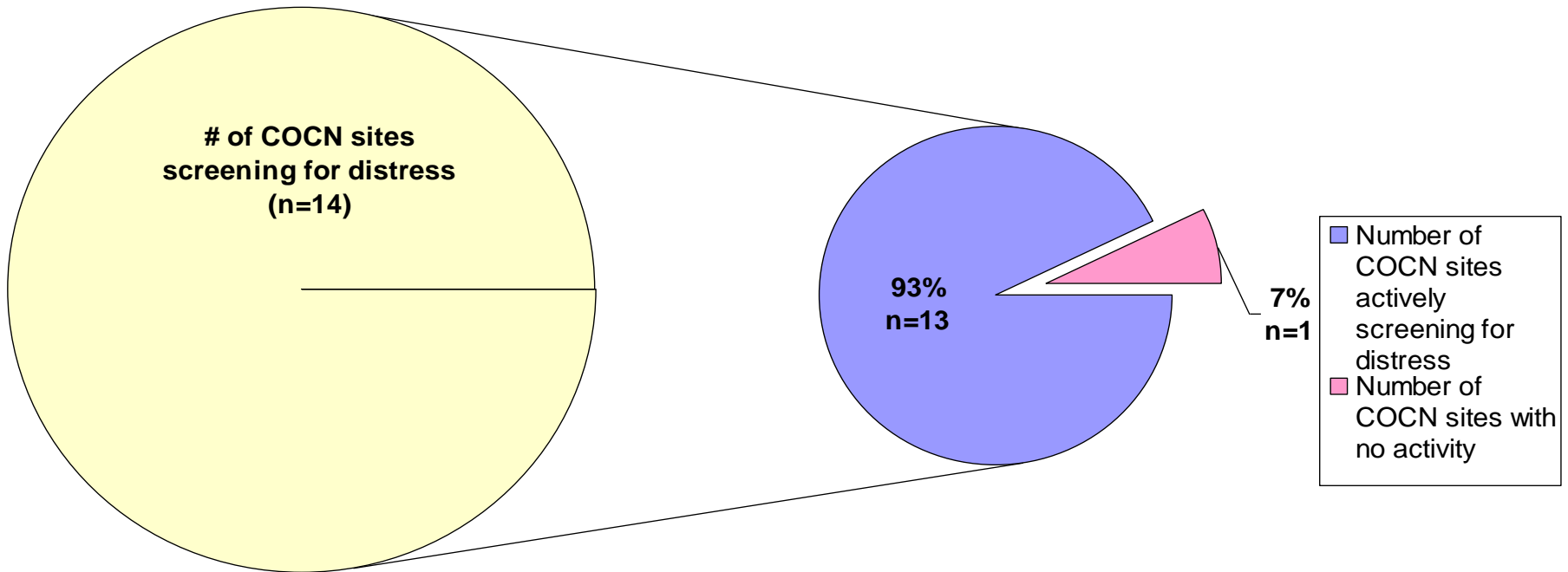
What We Are Studying (continued)

6. # of patients who accept referral
7. # of patients who received services (broken down by discipline)
8. # of patients who received services in community
9. # of patients who received services via telemedicine
10. # of patients who had a decreased score on subsequent visits

Indicator 1

of COCN sites actively screening for distress (n=14)

of COCN Sites (n=14)



Patient's Recruited

| COCN Site | # of eligible pts ^a | # of eligible pts screened ^b | # of pts receiving chemo not screened ^c | % of pts screened | % pts missed |
|---------------|--------------------------------|---|--|-------------------|--------------|
| 1 | 166 | 157 | 9 | 94.6 | 5.4 |
| 2 | 123 | 72 | 51 | 58.5 | 41.5 |
| 3 | 61 | 59 | 2 | 96.7 | 3.3 |
| 4 | 35 | 31 | 4 | 88.6 | 11.8 |
| 5 | 34 | 34 | 0 | 100 | none |
| 6 | 33 | 31 | 2 | 93.9 | 6.1 |
| 7 | 29 | 26 | 3 | 89.7 | 10.3 |
| 8 | 27 | 25 | 2 | 92.6 | 7.4 |
| 9 | 21 | 20 | 1 | 95.2 | 4.8 |
| 10 | 18 | 13 | 5 | 72.2 | 27.8 |
| 11 | 14 | 14 | 0 | 100 | none |
| 12 | 1 | 1 | 0 | 100 | none |
| 13 | 1 | 1 | 0 | 100 | none |
| 14 | 0 | 0 | 0 | n/a | none |
| Totals | 563 | 484 | 79 | 86 | 14 |

Note. Reporting Period from November 2009-March 31st, 2011

^a Total number of pts who received chemo at a COCN site at least once. ^bNumber of pts who received at least one chemo cycle at a COCN site and who completed one or more ESAS. ^cNumber of pts who received chemo at a COCN site and who did not complete an ESAS

ESAS Screens Collected

| COCN Site | Expected # of ESAS Screens ^a | # of ESAS Screens Received ^b | Total # of ESAS Screens Missing | Rate of Screening (%) | % screens missed |
|---------------|---|---|---------------------------------|-----------------------|------------------|
| 1 | 658 | 579 | 79 | 88 | 12 |
| 2 | 443 | 144 | 299 | 32.5 | 67.5 |
| 3 | 274 | 176 | 98 | 64.2 | 35.8 |
| 4 | 186 | 186 | 0 | 100 | none |
| 5 | 142 | 90 | 52 | 63.4 | 36.6 |
| 6 | 114 | 114 | 0 | 100 | none |
| 7 | 112 | 89 | 23 | 79.5 | 20.5 |
| 8 | 104 | 91 | 13 | 87.5 | 12.5 |
| 9 | 71 | 63 | 8 | 88.7 | 11.3 |
| 10 | 58 | 40 | 18 | 69 | 31 |
| 11 | 50 | 50 | 0 | 100 | none |
| 12 | 3 | 3 | 0 | 100 | none |
| 13 | 3 | 3 | 0 | 100 | none |
| 14 | 0 | 0 | 0 | n/a | none |
| Totals | 2218 | 1628 | 590 | 73.4 | 26.6 |

Note. Reporting Period from November 2009-March 31st, 2011

^a Total number of ESAS screens expected if patients were screened only 1 time at every cycle. ^b Total number of ESAS screens received from patients who were screened 1 time at every cycle.

Patients Screened According to Protocol

| COCN sites Enrolled | # of eligible pts ^a | # of eligible pts screened ^b | # of eligible pts not screened ^c | # of eligible pts screened according to protocol ^d | #of eligible pts screened out of protocol ^e |
|---------------------|--------------------------------|---|---|---|--|
| 1 | 166 | 157 | 9 | 105 | 52 |
| 2 | 123 | 72 | 51 | 14 | 65 |
| 3 | 61 | 59 | 2 | 22 | 37 |
| 4 | 35 | 31 | 4 | 14 | 16 |
| 5 | 34 | 34 | 0 | 27 | 7 |
| 6 | 33 | 31 | 2 | 14 | 17 |
| 7 | 29 | 26 | 3 | 12 | 14 |
| 8 | 27 | 25 | 2 | 15 | 10 |
| 9 | 21 | 20 | 1 | 11 | 10 |
| 10 | 18 | 13 | 5 | 6 | 7 |
| 11 | 14 | 14 | 0 | 10 | 4 |
| 12 | 1 | 1 | 0 | 1 | 0 |
| 13 | 1 | 1 | 0 | 1 | 0 |
| 14 | 0 | 0 | 0 | 0 | 0 |
| Totals | 563 | 484 | 79 | 252 | 232 |

Note. Reporting Period from November 2009-March 31st, 2011

^aTotal number of pts who received chemo at a COCN site at least once. ^bNumber of pts who received at least one chemo cycle at a COCN site and who completed one or more ESAS. ^cNumber of pts who received chemo at a COCN site and who did not complete an ESAS. ^dNumber of pts who received chemo at a COCN site and who completed one ESAS at every cycle. ^eNumber of pts who received chemo at a COCN site and who did not completed one ESAS at every cycle.

Gender

| | Frequency | Percent (%) |
|--------------|------------------|--------------------|
| Male | 112 | 44.5 |
| Female | 140 | 55.5 |
| Total | 252 | 100.0 |

Age distribution from 23 – 84 years of age.

Cultural Demographics

| | Frequency | Percent (%) |
|--------------|------------------|--------------------|
| Anglophone | 153 | 60.7 |
| Francophone | 31 | 12.3 |
| Aboriginal | 12 | 4.8 |
| Missing | 56 | 22.2 |
| total | 252 | 100.0 |

Preliminary data – not to be reproduced

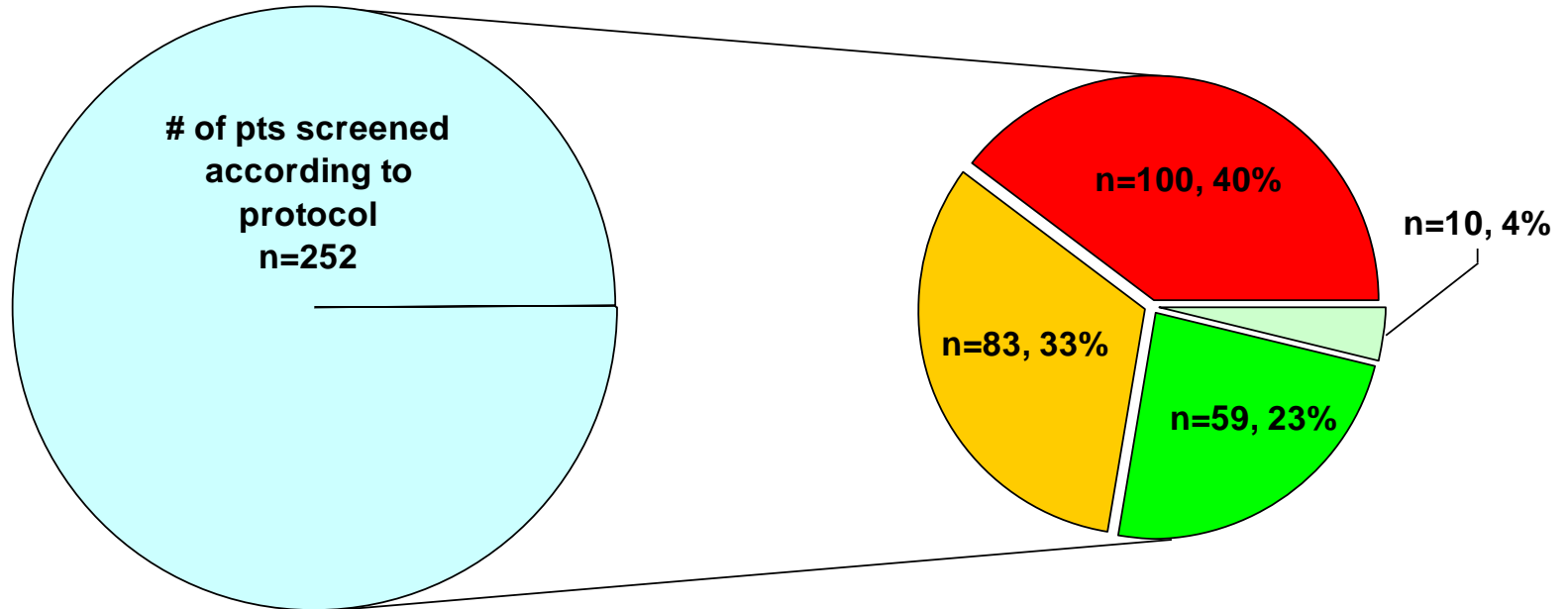
Cancer Site

| | Frequency | Percent (%) |
|---------------|------------------|--------------------|
| G.I. | 87 | 34.5 |
| BREAST | 46 | 18.3 |
| HAEMATOLOGY | 41 | 16.3 |
| LUNG | 35 | 13.9 |
| GYNE | 21 | 8.3 |
| G.U. | 9 | 3.6 |
| HEAD AND NECK | 5 | 2.0 |
| SKIN | 3 | 1.2 |
| CNS | 3 | 1.2 |
| OTHER | 2 | 0.8 |
| Total | 252 | 100 |

Staging

| | Frequency | Percent (%) |
|--------------|------------------|--------------------|
| Stage I | 26 | 18.3 |
| Stage II | 30 | 21.1 |
| Stage III | 79 | 55.6 |
| Stage IV | 7 | 4.9 |
| Total | 142 | 100.0 |

ESAS Symptom Score Distribution



- # of pts with no symptoms indicated
- # of pts with index scores between 1 and 3
- # of pts with index scores between 4 and 6
- # of pts with index scores between 7 or 10

Five Most Frequent Symptoms Identified

| ESAS | CPCL |
|-------------|-------------------------------|
| Tired | Physical Sleep |
| Appetite | Emotional Fear/Worries |
| Wellbeing | Social/Family Worry |
| Drowsy | Physical Memory/Concentration |
| Pain | Physical Weight |

Implications for Practice

- Program development
 - Fatigue
- Referral pathways – resource inventories
 - Community hospital (COCN site)
 - Community (mental health, home care, etc.)
 - Supportive Care Program, Regional Cancer Program (telemedicine)

Implications for Practice

- Professional education
 - Supportive Care Oncology Network-NE Region
 - » Cultural awareness
 - » Symptom Management Guides
 - » Sustainability
- Screening targets
 - Patient status
 - What is realistic
 - Frequency of screening

Conclusion

- The outcomes being tracked may help determine the frequency that patients should be screened for distress while undergoing chemotherapy
- Reduction of ESAS and CPCL scores will be evaluated in the context of nursing interventions and referral patterns to other health care professionals
- Implementing Screening for Distress requires a knowledge translation plan that incorporates evidence, policy, a working plan to engage stakeholders for implementation and sustainability and a strong evaluation plan to track progress and final outcomes

“The vision and initiative of oncology practices across Ontario in simply implementing a patient reporting system represents a major advancement toward bringing the patient perspective into the longitudinal management of cancer. As technology, electronic record systems, and patient questionnaires become more sophisticated, we expect that the Ontario vision will transition to being considered ‘just good care’”.

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