“Road Blocks” in Non-Cancer Palliative Care

Obstacles observed from outpatient non-cancer palliative practice.

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Amanda J Brisebois MSc MD FRCPC
General Internal Medicine and Palliative Care
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Presenter: Dr. Amanda Brisebois
Department of Medicine, Division of Internal Medicine
Department of Oncology, Division of Palliative Care

There are no relationships that pose a conflict of interest to declare AND this program has been developed without support from commercial entities.
OBJECTIVES

- Review Outpatient Non-Cancer Clinic operations, resources, and preliminary data
- Discuss patient cases that emphasize barriers to outpatient non-cancer symptom care, and review these barriers.
- Discuss next steps in non-cancer palliative care
Outpatient Clinic, three half days weekly.
Focus group to support referrals from: Cardiology, Hepatology, Pulmonary, and Renal patient populations.
Referrals mostly from specialists (80%), others from family physicians or nurse practitioners.
Referral criteria based on clinical judgement, and direct discussion with me.
Aim to see patients in last 1-2 years of life.
OUTPATIENT NON-CANCER

REFERRAL REQUEST

DATE:
Requesting Physician:

Non-Cancer Disease:

[ ] GI
[ ] CV
[ ] RESP
[ ] NEURO

[Other non-cancer diagnosis not accepted, call to consider exceptions]

Reason for Referral: (circle all that apply)
A. Symptom Management
   (Specify details below)
B. Poor Performance Status
C. Psychosocial Issues
   (Specify details below)

[Attach referral letter if more explanation required]

Goals of Care Discussed
   YES/NO

If known, goals of care designation

On Transplant List/Transplant Patient
   YES/NO

Comments:

________________________________________________________________________
________________________________________________________________________

Please contact
amandab@ualberta.ca

to expedite urgent referrals

Please attach medication list
HELPING YOU TO:

RELIEVE Symptoms
Talk about your FUTURE
Live without Fear
Attain your GOALS
Build support
Maintain HOPE

DR. AMANDA BRISEBOIS
Palliative Care & Internal Medicine
Edmonton Clinic 3rd Floor (3D): Thurs
Edmonton Clinic 2nd Floor (2A): Friday

Mailing Address: 2D4.48 WCM Centre
University of Alberta Hospital
Edmonton, AB T6G2B7

Office: 780-497-6632
Fax: 780-439-5009

pprismclinic@gmail.com
PPRISM: Progressive Palliative Relationships and Integrated Symptom Management

- 84 patients seen, over 12 months
- Mixture of cardiac, hepatic, pulmonary, and renal diseases
- Neurology, and Hematology patients recently added
- ESAS-r scores, PPS, number of physicians involved, Advance Care Planning and Goals of Care designation, and hospitalizations were assessed at each visit.
- Deaths were recorded, ER visits assessed.
- Patients were seen in initial consultation in the outpatient clinic, and followed either in the outpatient clinic, or in hospital during subsequent admissions.
Symptom Burden Significant

- **ESAS-r Average Scores**
  - Pain 5
  - Fatigue 7
  - Tiredness 3
  - Nausea 2
  - Lack of Appetite 5
  - Depression 5
  - Anxiety 4
  - Well being 5
  - Constipation 5
Patient Data Points

- PPS Average 70%
- Majority (80%) living at home
- Remainder in assisted living
- Goals of Care: Majority M1 (medical management 70%/57 patients)
- Goals of Care: R1 (full resuscitation 25%/20 patients)
- Goals of Care: C1 (comfort care 5%/5 patients)
- Average of 4 physicians involved for each patient (not including hospitalizations)
Health Care Resources Utilized

- Hospitalizations
  - 64% hospitalized. 34% multiple hospitalizations.
- ER visits:
  - 72% of patients had ER visits. 55% multiple visits.
- Deaths 34%
Recurrent Themes in Health Care: Barriers common to outpatient care

- 24 hour physician support (for patients) not available
- Limits to outpatient resources (PT/OT, spiritual support, interdisciplinary resources, social work, home care, respite ....).
- Multiple physicians involved in care.
- Inconsistent communication with primary care, specialists, lack of continuity and transitions complicated.
- Financial limitations for patients (eg. For physiotherapy, alternative therapies, some medications, housing, etc.)
- Multiple other system limitations
Recurrent Themes: Barriers to Outpatient Non-Cancer Palliative Care

- Lack of awareness of the non-cancer palliative care service
- Uncertainty of when to refer patients
- Difficulty in Prognostication
- Recurrent hospitalizations, changes in care plans (includes medication adjustments, goals of care)
- Difficulty adjusting and choosing medications due to medical complexity
- Negative outcomes.
- Difficulties with clinic bookings (long visits, cancellations)
- Difficulties following patients until end of life
- Barriers in assisting patients dying at home.
Lack of awareness of the initiative and non-cancer service

- Inconsistency regarding the definition of palliative care vs end of life care
- Questions regarding how the service fits into existing palliative services
- Uncertainty regarding how to refer, and what services are offered
- Educational Seminars, and word of mouth. Lots of time commitment needed.
Uncertainty regarding when to refer

- Time spent educating about the clinic, my availability, patient selection.
- Goal of seeing patients in the last 1-2 years of life
- Patient population has been much closer to death than initial goals.
- PPS average is high (PPS 70 average), but can be variable (“snapshot”)
- When on Internal Medicine Inpatient service, multiple patients meet criteria for referral, with high ESAS scores, but referrals not being made.
- Several young renal patients referred for chronic pain (with interesting outcomes)
Difficulty in Prognostication

- Patient: 46 year old patient with cirrhosis secondary to NASH
- MELD 24, on transplant list. Prognosis favorable (up to 80% 10 yr survival), but complicated prognostication.
- Severe symptoms, but MELD not high enough to be a priority on the transplant list
- Pain 10/10, Depression 10/10, Anxiety 10/10, Fatigue 9/10, Anorexia 8/10
- Severe emotional burden due to extent of disease, and body transformation
- Multiple re-admissions, pain consultations, medication changes, minimal psychosocial support.
- GI Attending questions the utility of Palliative Care
- Patient ends up dying, 6 months after initial consult, in hospital.
**Recurrent hospitalizations, changes in care plans**

- 48 year old patient with MS, severely disabled. PPS 30%
- Recurrent admissions for decreased level of consciousness, secondary to urinary tract infections, deteriorating renal function, decreased intake. Changes in cognition blamed on opioid, and adjusted every hospitalization.
- Patient in severe pain (both neuropathic and nociceptive)
- MEDD 37mg. LTC initially unable to follow instructions not to continue to send patient to hospital, despite patient request.
- Patient not consistent with goals of care designation (medical management, unwilling to change to comfort measures).
- Now agreement is for attending teams to call me when she is admitted, but it isn’t always done.
- Patient is frustrated with care, and becoming distrustful of physicians
- Just formulated orders to keep the patient in her facility, with multiple supports, despite changes in cognition.
Difficulty adjusting and choosing medications due to medical complexity

- Classic medication dosing can cause significant side effects
- Have to titrate as an outpatient, instructions complex
- Many patients cannot tolerate medication, but outpatient clinic has minimal access to non-pharmacologic support measures
- Many patients have financial limitations (eg. Prefill syringes)
Difficulty adjusting and choosing medications due to medical complexity

- 76 year old lady on hemodialysis
- EF 30%, atherosclerosis. Previous strokes.
- Still mobile, very slow.
- Unable to sleep more than several hours.
- Remeron, imovane too potent even at liquid titrations
- Chronic pain from arthritis. Unable to tolerate 0.1mg Hydromorphone, 7.5mg codeine. Multiple medications tried.
- Multifactorial pain. Family in USA, pushing her to continue dialysis.
Difficulty maintaining medication regimens

- 65 yo referred from the Heart Function Clinic
- EF 23%. Severe dyspnea. Recurrent hospitalizations.
- Received a phone call from nursing staff on ward, patient admitted
- “Your narcotic has caused this patient to be admitted due to confusion”
- Opioid is not always the culprit for symptoms on presentation
- Recurrent admissions, with similar path (opioid stopped, needed to restart as outpatient)
- Admitted to hospital, listed for LTC, despite Palliative Consult
- Died 3 weeks later, in hospital
Negative outcomes

- 85 year old patient. Admitted to cardiology service.
- Unable to alter medications to improve symptoms, maximal support.
- PPRISM consulted for inpatient assessment.
- Patient severely dyspneic, and anxious
- Small doses of Hydromorphone initiated starting at 0.1mg qhs subcutaneous
- Phone numbers left on chart, and informed patient and family that I was available
- Received a call the next week, that the patient died, and suffered dramatically. Dyspneic, anxious. Attending MD did not contact me, despite family requests.
Negative Outcomes

- Patient with renal failure on dialysis. 47 years old. Living independently
- Admitted to hospital, due to recurrent infection and gangrenous foot.
- Long consultation revealed that her trigger to discontinue dialysis would be if she had to be placed in Long Term Care.
- Her pain was well managed on opioid ATC, and prn dosing. Scores had decreased.
- Without including me in conversations, it was determined that she would need to go to LTC.
- She made the decision to withdraw dialysis. Attending MD, did not escalate pain, anxiety medication management. I found out an hour after her death, and arrived in her room to an upset family who felt that she suffered enormously.
Difficulties with clinic bookings

- New Consult = 1.5 hours
- Follow Up = 60 minutes
- Mobility issues, and fatigue = increase hours spent post consultation to manage issues
- Cancellations short notice: Feeling unwell, hospitalizations, multiple physician visits
Difficulties following patients until end of life

- 85 year old. Heart failure.
- Lack of ability to stay involved, multiple reasons (lack of resources to follow up regularly, lack of primary service awareness due to weekly change over).
- Possible perception of abandonment (both by patient and referring MD)
- “Uncontrolled symptoms”, who defines this?
Barriers in assisting patients dying at home

- 93 year old lung disease, severe. FEV1 10%
- PPS 60% at initial consultation
- Excellent family support, but clear that patient was having quick deterioration in performance status
- Plan put in place for hospice (Regional Palliative Care Referral) if family and patient noted deterioration
- Seen in home, but determined too functional, and signed off.
- Palliative Home Care in place, but 2 weeks later, rapid deterioration.
- Re-consult Palliative Care. My support provided outpatient subcutaneous education, prescriptions, numerous hours of family support.
- Family stressed, patient finally made it to hospice the day before his death.
Next Step: Current Gaps

- Currently the non-cancer clinic is running without secretarial support.
- Solutions needed to bridge gaps in continuity of care, especially when patients are admitted to hospital, and subsequently discharged.
- Unable to follow up patients, at the frequency requested
- Continued referrals, need continued clinic exposure.
- Time constraints prevent continued discussions with referring NPs, and physicians.
Next Steps

- Meetings ongoing to create more clinic support
- Patient support group, and Pain Clinic support upcoming
- Trainees interested in becoming involved in non-cancer palliative care.
- Continue to recruit interested health professionals.
- Closer integration with current programs
- Alberta wide care protocols, PEOLC work
Conclusions

- Symptom burden and resource utilization in non-cancer patients is high, and palliative care consultation may aid in addressing these needs.

- Common barrier themes:
  - Communication
  - Uncertainty of needs (clinical and supportive)
  - Consistency of care
  - Added support needed for clinic, patients/families, and other caregivers.

- Continued discussions can help further the initiative, and continue to progress non-cancer palliative care!
QUESTIONS?

pprismclinic@gmail.com

Amanda Brisebois