

Early integration of palliative care - possibilities and challenges

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Established Benefit of Palliative Care

- Patient
 - Improved symptom relief
 - Improved psychological status
 - Improved Quality of Life
 - Improved survival
- Carer:
 - Improved carer psychological status
 - Improved well being and survival of spouses.

Higginson 2009, Temel 2010, Hudson 2011, Christakis 1998, Philip 2013, Temel 2013, Rosenwax 2006



Established benefits of Palliative Care

The system:

- Reduced hospital LOS
- Less ICU, pharmacy, laboratory
- Fewer ED presentations
- Greater likelihood death at home
- Inpatient palliative care consultations resulted in net savings >\$2500 per patient

Morrison 2008, Parikh 2013, Sundararajan 2014



Timeliness of engagement with PC

Timing of referral important

In patients with HGG >120 days required to realise benefit of increased home death

In Singapore, referrals ≥ 30 days before death associated with higher likelihood of home death

Poulose 2013, Sundararajan 2014

So how are we doing?

Overall?

147,678 deaths in Australia in 2013

Just over 2 in 5 patients who died as an admitted patient received palliative care.

31,512 patients accessed palliative care services in 2013, an increase of 3.6% from 2012

AIHW 2013

Poor prognostic cancers ?

Metastatic NSCLC: median survival 4-5 months

High Grade Glioma: median survival 15 months

Mapping patient care using hospital
administrative data sets of admitted episodes all
patients in Victoria

- Diagnosis until death

- Met NSCLC:
 - 62% overall referred to palliative care services,
 - but 26% in final admission.
- HGG: 63% referred to palliative care of those who survived 120 days from diagnosis
- HGG: just 12% survived diagnostic admission but died within 120 days referred to PC

Philip 2015, Sundararajan 2014, Collins 2014

Series of challenges & opportunities: qualitative data

- 2 separate studies exploring the perceptions and views of:
 - a. Patients with HGG, carers (current and bereaved) and HCPs
 - b. HCPs who treat lung cancer
- Exploratory interviews (a), semi-structured focus groups (a & b)
- Thematic analysis within grounded theory framework.

Quantitative survey of lung cancer clinicians

- Survey developed based upon Johnson 2008
- 76% Response rate (42/55)
- Median 6 years experience
- 33% (14/42) Medical Oncology
- 26% (11/42) Respiratory Medicine
- 19% (8/42) Radiation Oncology
- 12% (5/42) Surgical Oncology
- 4 other

- Broad congruence across the 2 cancers
- Ideas that raise issues for palliative care service delivery

Challenges to engagement of palliative care



patients and family caregivers

- Optimism
- Nurturing hope
- Live in the moment, focus on immediate
- *“I’m taking it step by step, because I feel well...I can’t imagine that it would be such a sudden onset that I would just go down really quickly. I can’t imagine that*
- *“it’s all good until it’s not”*

patients and family caregivers

- Patient lacks insight
- Lack of comprehension of carer's challenges.

➤ *“So you try and bring them [the patient] into hospital and the patient will be saying, “No, but I’m actually doing alright. My wife can manage. I’m doing alright,” because of that lack of insight, and the wife’s just sitting there going, “I’m exhausted, and I can’t do this anymore.”*
radiotherapy nurse

patients and family caregivers

- Perception of palliative care
- “I’m not there yet” – pt with HGG (2nd relapse)
- *“Steer people towards palliative care. That’s a must.. even though they’re scared of the meaning, they will get the assistance they need.” P4*

Health care professionals

- HCP perception of palliative care
- Refer for symptom management only
- *“I don’t know if a lot of the barriers are our perceived barriers rather than actually what happens when you speak to a patient about it.” (medical oncologist)*

- Avoid the big picture – focus on another round of treatment
- Focus on other aspects of care
- Focus upon patient solely, not family needs

People care about it but it often drops down because they're focusing on other interventions, Other priorities.” (respiratory physician)

- Confidence in palliative care service
- Trusting relationships

*“Not all Palliative Care Services are the same!”
(radiation oncologist)*

Service factors

- Disjointed fragmented care
 - Silo's of care / bureaucratic blocks to creative options
 - Palliative care unit admissions:
 - prognosis bound,
 - patient's unrealistic expectations.

“Often you’re looking at 8 months of a lingering illness, where the patient is increasingly bed-bound and has behavioural disturbance. That’s too long for an acute pal care service, but doesn’t fit with a nursing home.”

Psychiatrist

Doctors consider referral to palliative care if:

- Uncontrolled symptoms 90%
- Future symptoms 86%
- Terminal illness 64%
- Complex needs 62%
- Need for physical care 60%
- Need for psychosocial support 50%
- Family not coping emotionally 40%

Lung cancer clinicians did not refer last patient because:

- No symptoms 60%
- Not at that stage yet 40%
- Could manage the symptoms themselves 60%

Opportunities
highlighted by needs
which are addressed
by core palliative care
practices



Patient and family caregiver: medical model of care

- Medical model of care
 - Focus on tumour
- Reactive (not proactive) services

- ***“The doctor kept talking about how the tumour was stable... My problem is not just the tumour; it’s what the tumours then cause her to do” C6***
- ***And no mention about length of time of seizures, you know, at what point is too long? When should you call an ambulance? ” C18***

Patient and family caregiver: medical model of care

- Acute system of care not meeting needs
 - Esp. psychosocial needs
- Recognition of need for holistic care
- *“I was just so weak that they couldn’t do anything for me... they haven’t got the palliative skills.”*
- *“Our OT.. said, ‘She’s not safe to be at home.’ And she wasn’t... The medical staff said, ‘Well, why are you admitting her?’ ‘Well she’s not safe.’ ‘Well, that’s not a medical reason.’”*
Cancer Support Nurse

Patient and family caregiver: psychosocial concerns

- Validation of psychosocial concerns, not “dismissive”
- Legitimate family caregiver needs
- Assistance with behavioural changes/ particular disease

*“I wish somebody had
have sat down and said to
me, ‘Do you want to know
why your husband’s acting
like that, or why he
doesn’t want to have a
wash?’ C7*

Patient and family caregiver: information needs

- Need for information both patients and carers
- Staged, anticipatory information
- Recognition of bereavement prior to death.
- Opportunities to talk in bereavement phase

“There were some things I needed to know” C8

“Well when you’re given that kind of news... you don’t know what you need to know, and it’s a case of if you don’t ask the right questions, you don’t get the information.” C1

Patient and family caregiver: care coordination

- Need to navigate fragmented care
- Someone to oversee whole thing e.g. A “go-to” person for each bump/crisis

➤ *We were just being handballed from one to the other. No one...to take responsibility and tell us, you know, what we had to do.”*

Patient and family caregiver: timing

- Timing of palliative care referral - early enough for relationships to be formed
- Routine
 - At diagnosis - but focus on treatment and developing a plan
 - At disease specific times when changed focus eg. HGG: after radiotherapy poignancy as psychosocial issues emerge.

- *Just to be in the system much earlier than when you land in the system..."*
C6
- *'I think if what you do is standard for everybody, it's slightly easier to sell than intermittent. And I think it's rare that you actually bring it up with someone and they say it's a dreadful idea.'*
(medical oncologist)

Patient and family caregiver: creative option

Optimism, an optimistic
option

***“You just get caught up in
appointments, blood
tests, urine tests...
Sometimes you just need
someone to say, ‘OK,
we’re doing really good...
but what’s your bucket
list? P10***

Health care professional

- Possibility of change in focus of priority
- Need to be willing to be responsive, part of the team.
- *“It will mean changing the mind-set so that supportive care—*
- *palliative care—is prioritized at the highest level as is chemotherapy”*
oncologist.
- *I think being at the coalface is essential if you want to see the patients.” (thoracic surgeon)*

Summary: challenges and opportunities

- Patients
- Needs, Optimism
- Information and decision making
- Psychosocial concerns
- Care coordination
- Family Caregivers
- Psychosocial support
- Legitimacy
- Broad holistic focus of care
- Bereavement care

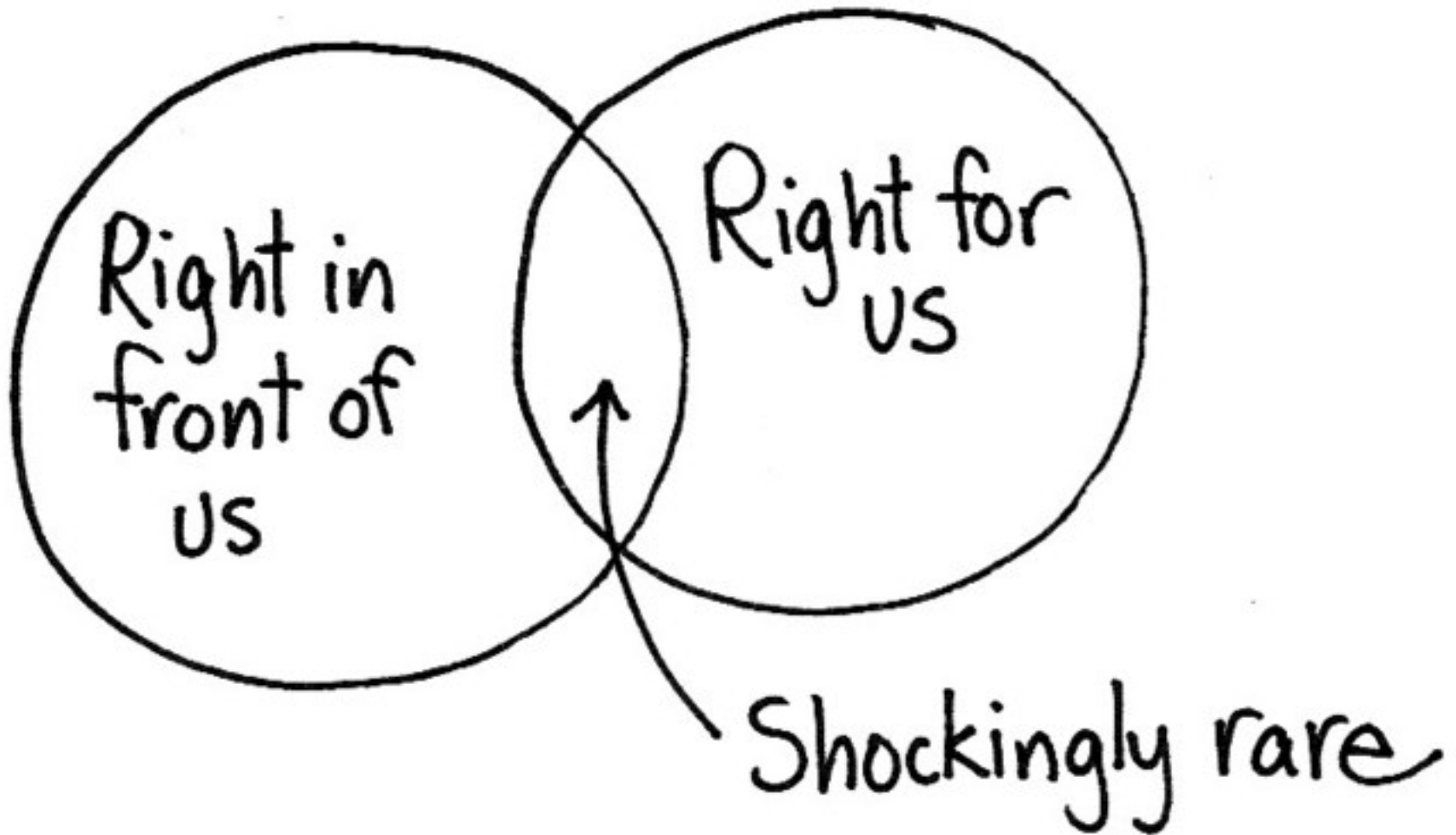
Summary: challenges and opportunities

- Health care professional
- Responsiveness
- Notion of routine helpful
- Prioritisation required



Recommendations

- Practices of palliative care are highly relevant
- Introduce as set of practices - can negotiate the space of hope and fear.
- Routine approach – facilitates conversation, normalises
- Attention to relationship to referrers, responsiveness, communication
- Being creative, different models, different ways of navigating the system



Thoughts for discussion.....

- PC victim of our own marketing – symptom control...
 - Frequently other skills are required
 - Challenge is language of acute hospital vs holistic .
- Victim of our success – our capacity
- Communication: for referring clinicians and for ourselves in liaising back to our referrers.
- Creative responses required: models, marketing, lobbying