Primary Palliative Care Research – challenges and opportunities

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Primary Palliative Care Research Group Members

[Map of the world with stars indicating the locations of group members]

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International Primary Palliative Care Research Group
Cape Town 2010:
Role of the group

Advocacy for pall care in the community
  – Within specialist palliative care
  – Within primary care and secondary care

• Support and networking
• Encouragement of palliative care research and development in the community

• Web resource
  http://www.uq.edu.au/primarypallcare
Caring for all in the last year of life: making a difference

1. Any life-threatening illnesses
2. Any time
3. Any dimension
4. Any nation
5. Any clinician or setting
More best met in primary care  3Cs

Children

Carers

HPPC
1 promoting discourse
2 realising individual & community assets
Public Health and Primary Care Strategy for Palliative Care

Policy
- Palliative care part of national health plan, policies, related regulations
- Funding/service delivery models support palliative care delivery
- Essential medicines
  (Policy makers, regulators, WHO, NGOs)

Drug Availability
- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration
  (Pharmacists, drug regulators, law enforcement agents)

Implementation
- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures
  (Community & clinical leaders, administrators)

Education
- Media & public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Family caregiver training & support
  (Media & public, healthcare providers & trainees, palliative care experts, family caregivers)
TOOLKIT FOR THE DEVELOPMENT OF PALLIATIVE CARE IN THE COMMUNITY

PURPOSE OF THIS DOCUMENT

This resource is being developed to help support and guide individuals and organisations in Europe seeking to further develop palliative care services in primary care settings. The principles outlined in the EAPC Prague Charter and particularly the notion of recognising access to palliative care as a human right underpins this work.

WHY IS DEVELOPING PALLIATIVE CARE IN THE COMMUNITY IMPORTANT?

More patients can benefit from palliative and end-of-life care if it is delivered in the community by Primary Healthcare Teams. For this to happen GPs and nurses working in the community will require training and support by specialist palliative care teams. They will also need adequate time, financial and practical resources, and the ability to prescribe morphine when appropriate.
Primary Palliative Care

Developing research themes
Appropriate care near the end of life.

Cancer Trajectory

Disease modifying treatment

All patients

25% not on Palliative Care Register (PCR)
75% on PCR
69% Specialist PC

Formal Palliative Care

No. of weeks before death

27
Diagnosis

7 5

Death
Organ Failure

100%

Disease modifying treatment

All patients

0% 100%

317 Diagnosis of condition

Time

No. of weeks before death

Palliative Care

13 5wks Death

19% on PCR

81% not on Palliative Care Register (PCR)

10% Specialist PC
Frailty Dementia

Disease modifying treatment

100%

All patients

159wk
Diagnosis of Frailty/Dementia

Time

Palliative Care

80% not on Palliative Care Register (PCR)

20% on PCR

5% Specialist PC

2wks
Death

No. of weeks before death (median)
Avoiding futile treatment

"Off hand, I'd say you're suffering from an arrow through your head, but just to play it safe, I'm ordering a bunch of tests."
Your research ideas

• Explain why that is the most important question for you
• Could it be improved?
Primary Palliative care research – two challenges

Challenge 1: Working with GPs

Challenge 2: Recruiting subjects
Working with GPs

Understand the environment in which GPs work

General practice – whole person care. Caring for dying patients is a tiny fraction of their work.

Meeting patient need is the fundamental driver of a GP

High throughput.

In Australia General Practices are private businesses
Economic imperatives- time is money
Approaching GPs to cooperate with Palliative Care research

Palliative care competes in a very crowded GP research market

Approach GPs and practices personally- personal letters, phone calls, site visits
AVOID – cold calling, email, fax

Care in what you ask GPs to do – keep their involvement minimal and interesting to them.

Do as much as possible for them and GP office staff.
Predicting death study - pilot

Can GPs predict death in 6 and 12 months using either intuition or a predictor tool?

Recruit 40 GPs

Generate patient lists
- all patients over 70 seen by that GP in last 2 years

Randomise

Intuition

Predictor tool

Six months follow up – who died?

12 months followup - who died?
What are the problems?
Predicting death study – GP recruitment

Personal letter/ personal email to GP principal (copy to practice manager)

Then personal phone call from study leader 5 mins

Then RA visits to go through study with GP and practice manager 10-15 mins

RA generates patient lists for GP

GP goes through list 1-2 hours depending on list size

RA returns in a week (or negotiated time) to pick up completed lists Ensures task is not put off
Patient Recruitment-Principles

Go to where the patients are commonly found

Work backwards from the patient to the GP

GPs will nearly always agree to something that will help a named patient
Carer needs study

Recruit patients (n=520)

Randomise

Baseline phone interview

Normal care

GP consultation using NAT-C

1 month phone interview

GP consultation using NAT-C

3 months phone interview

6 months phone interview
What are the problems?
## Principles

<table>
<thead>
<tr>
<th>Principle</th>
<th>Solution</th>
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<tr>
<td>Don’t recruit through GPs</td>
<td>Recruit through oncology clinics (waiting rooms)</td>
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<tr>
<td>GPs will do anything for patients</td>
<td>Intervention – personal approach WITH THEIR PATIENT’S NAME</td>
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<tr>
<td>Make it easy for GPs</td>
<td>Control – no contact</td>
</tr>
<tr>
<td>Make intervention easy for GPs</td>
<td>Intervention was two booked long consultations i.e. FITTED INTO GP’s NORMAL ROUTINE</td>
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Outcomes

392 patients recruited (ran out of money!)

155 of 158 GPs agreed to participate.
Discussion