Developing a working model of Best Supportive Care for people with HPB cancer

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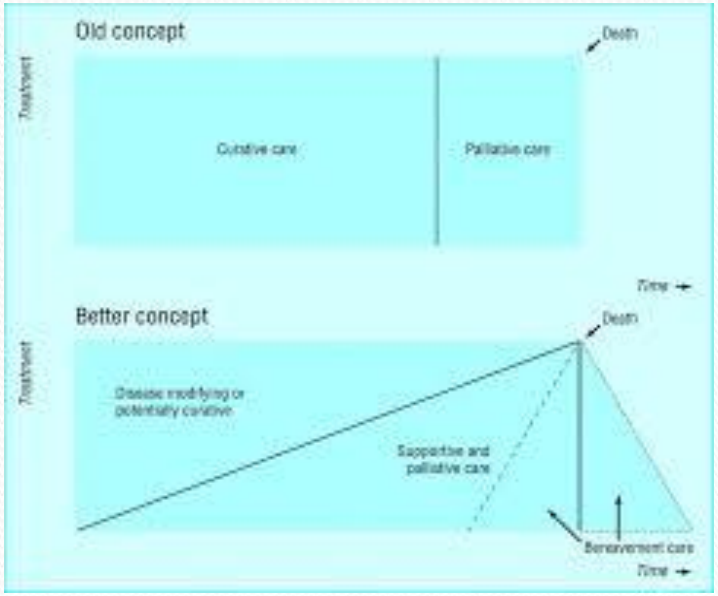
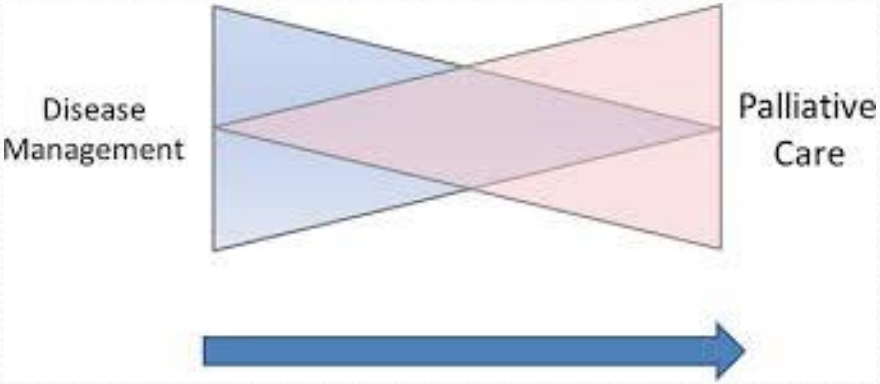
Integrated oncology and palliative care





Key messages

- Best Supportive Care in cancer is ill-defined and this is a barrier to people getting the care they need
- BSC matters just as much as the plan for oncological treatment or surgery and should be ‘something’ rather than ‘nothing’
- BSC warrants care quality standards, a systematic and reliable approach to delivery

Best Supportive Care is BIG

"I want to know why when I'm in a room people ignore me."

Best Supportive Care is vague

- Simply ‘no anti-cancer treatment’?
- An aspiration?

It is not the road map that the frailest people with cancer need it to be

‘Best supportive care is poorly defined in clinical trials, and a standard framework for delivery of such care is needed’

The Lancet Oncology (2012)13;2: e77-e82

ESMO – biliary tract cancer clinical practice guidelines 2016: advanced disease

- *"Patients should have full access to palliative care and symptom management (including pain control)"*
  - Of course
- *"Patients should have a designated point of contact within the multidisciplinary team for advice and support (e.g. nurse specialist)"*
  - Absolutely
- No guidance on how this should happen
- Who is accountable?
- What about out of hours?

Big, vague, variable BSC

- No agreed pathway/s
- No standards of care
- No QPI/s

= no accountability

- Cancer teams secondary care-based
- Primary care offer variable
- Specialist Palliative Care cannot support everyone with advanced cancer

The BSC population with HPB cancers in Fife 2017 n=59

- Median age 73 (range 46-91)
  - 29 pancreatic ca
  - 22 cholangiocarcinoma
  - 6 hepatocellular ca
  - 2 'other'
- MDTM 11 days post-CT
  - 41% had biopsy
- Over half were hospital inpatients at diagnosis
  - 5 died during that admission
- Median survival **56 days** from MDTM
- BSC = **URGENT CARE**

The BSC population with HPB cancers in Fife 2017 n=59

- Evidence of some good care and support, but highly variable
- Variation not accounted for by difference in need

  = unwarranted variation

- Many patients did not have a single consultation or review that focused on honest conversations about what lay ahead, their current/future anticipated needs

What that feels like...

(Fife lung cancer BSC project)

"If somebody had explained to us, not necessarily what was going to happen, but what was available to us. ***You just felt... into the abyss****"*

Carer

"There was nothing more the oncologist could do so we were referred back to the GP... but then they found that he had 'slipped under the radar', because we had no other support. ***Somehow we just disappeared"***

Carer

Our vision in 2013: **BSC as a management plan**

A patient is presented at a cancer MDTM who is too frail for anti-cancer treatment or who chooses BSC. BSC is the agreed ***management plan*** *and the patient/those close to them receive prompt palliative care, wherever they are, with immediate and future needs reliably addressed…*

- Good palliative care, earlier and more consistently
- Care that is multidisciplinary, integrated and coordinated

Macmillan – Transforming Care After Treatment (TCAT) programme funding

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Specialist Palliative Care – led BSC

BMJ 2018 Dec 27;363:k5017

1. Robust identification of *all* BSC patients

- MDT meeting *or before*

2. Proactive comprehensive specialist palliative care assessment and planning

- Palliative care doctor or nurse led, replaced oncology appointment for most
- Assessment location according to needs and preferences
- Inter-professional and multi-professional working

3. Care coordination and follow-up

- Detailed letters available quickly, **written to patients**
- Acute hospital e-alerts
- Follow-up appropriate to needs and preferences

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Lung project outcomes and experiences

- >95% opted for palliative care assessment
- Majority identified at MDTM
- Outpatient care for a quarter
- Shorter hospital admissions
  - Significant cost minimisation
- Less likely to die in hospital
- 700+ patients received enhanced model of care

"Everything they said they would put in place happened, with my GP, District Nurse, Palliative Care"

Patient

"We got ourselves together.. and got all the support we needed."

Carer

No-one likes a self-congratulatory speaker

So why was this not a success story?

- Because a Specialist Palliative Care-led model wasn't sustainable and so no longer exists
  - No funding despite demonstrated value
- Lung cancer team acknowledged value and importance, but unable to prioritise in face of other demands
- Integrated, cancer team-initiated and led model ideologically right..

Integrated, systematic supportive care
- a new way forward in Scotland

- National SHPBN:
  - Best Supportive Care Collaboration
  - Cancer Recovery funding: reducing unwarranted variation through streamlined pathways for diagnosis and treatment. Includes: Early Holistic Care (CNS contact pre-MDT, generic template with local adaptations, a process - not one-off, pancreatic cancer and hepatocellular cancer versions)
- Fife HPB/UGI/lung cancer teams
  - Cancer specialist nurse-initiated and coordinated
  - Close liaison with DNs and GPs: anchoring care in the community
  - Close support of Specialist Palliative Care
    - Advice around any situation, prioritising clinical reviews based on complexity, weekly MDT meeting open

What does this look like?

Bringing accountability to basics of good care...

1. Robust identification:
   - By the cancer team
   - Shared with primary care

2. Comprehensive holistic assessment
   - Wherever the person is
   - Often CNS led, may not be possible
   - May need to focus on diagnosis..

3. Plan for care coordination and follow-up
   - Agreed with patient/family based on need and preference
   - Commonly needs to evolve
   - Letters to patients and professionals, systems updated

Patient and carer information – a simple, but important intervention

- Leaflet for people with HPB cancers/ those they are close to
- Nationally supported, locally developed
  - Scottish HepatoPancreatoBiliary Network – BSC collaborative
  - HPB charities and user groups

- What is Best Supportive Care?
  - BSC aims
  - Who provides it, contact details
  - Specific sections on occupational therapy and dietetics
  - Introduction to charities including how to contact
  - Validating BSC – you matter, your care matters, we are accountable

The *reality* of HPB CNS-led BSC in Fife

- Continuity/relationship pre- and post-MDT helpful, especially when urgent ACP is needed
  - But sense of this role not always being valued by colleagues
  - Patients and families not always ready for ACP
  - Some still keen to see the oncologist
  - It is rewarding work
- Heavy and emotional conversations
  - Confidence takes training and time
  - Peer support critical, where time allows
  - Supervision for CNS around this would be helpful
- Workload is high, at times unmanageable
  - Trying to do as much as possible for all (radical to BSC and all in between)
  - Where does clinical cover (planned/unplanned) come from for a specialist role?
  - If BSC is valued, it needs resourcing

Hopes for BSC

- Robust identification: people for BSC aren't lost
- Reliable offer of honest conversations: wherever they are
- Care planning for all: informed by expressed priorities
- Reliable basic level of written information
- Care anchored in the community for most
- Reliable information sharing: patients and families empowered, systems better set up for urgent care response if needed

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- BSC warrants care quality standards, a systematic and reliable approach to delivery… and it needs resourcing

Thank you

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BRITISH LIVER TRUST

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