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Better Care and Lower Costs?

A Service Development for People with Advanced Lung Cancer in Fife

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TRANSFORMING
YOUR
CANCER CARE

WE ARE
MACMILLAN.
CANCER SUPPORT

Better Care

- Clinicians and leaders
  - What's our vision for the care that we provide?
  - How able are we to articulate what we deliver?

    (never mind for whom, with what impact and at what cost..)
  - How do we know that what we offer is better than an alternative?
  - How to capture 'better' when the ground is shifting?
    - Challenge in research and practice

Better Care

- Better might =
  - **better quality** care
  - care that **adds more value**
  - **better access** to care
  - **more timely** care
  - **more consistent** care
- Number of proxies in common use
- Do we know what we’re aiming for?
- What about Best Supportive Care?

At Lower Costs

- Salaries independent of our clinical decisions
- *Quality* care is our game
- But…
    - We are accountable to taxpayers and people rattling tins at funerals
    - Efficiency should enable us to do more good
- Who knows what their service's budget sheet looks like?
- Not as simple as acute care = expensive
- Costs to families and informal carers

Cost-effectiveness

- Hugely unfamiliar to most of us
  - Health economics not on the Palliative Medicine syllabus
- Increasing interest and may be our friend
- Analysis of relationship between £ in and outcomes
- Can only make a judgement when also measure value
  - Health economist-developed tool to measure wellbeing in an end-of-life population (the ICECAP-SCM)

There is good evidence for palliative care being effective

- Palliative care approaches and specialist interventions
  - *Improved symptom control, mood, wellbeing, quality of life, satisfaction with care, reduction in carer burden, inappropriate acute hospital admissions and interventions, better deaths etc etc*
- Issues of measures used and translation into practice
- There's nothing quite like descriptions of what quality care feels like by service users *in their own words*
  - The practice of palliative care from the perspective of patients and carers (BMJ Supportive & Palliative Care 2014)

Evidence for palliative care as cost-effective

Cost-effective commissioning of end of life care: Understanding the health economics of palliative and end of life care (Public Health England 2017)

- Comprehensive review of reviews and individual studies
- Range of settings and interventions, UK and abroad
- Evidence of palliative care interventions being cost-effective/cost saving
  - Typically by shifting care away from acute hospitals
  - But rarely factoring in additional community costs/informal cost to carers

Best Supportive Care (BSC) – the problem

- Term used across cancer services. Recorded, not defined
- An approach? No-one knows what it means *in practice*
- Culture in cancer – standards all relate to diagnosis anti-cancer treatment, resources follow these
- Specialist palliative care access not needs-based, often relying on people to ask.

Scale/severity of the problem visible to me only when I realised that tiny numbers of people for BSC presented at lung MDM were fit to attend hospital

The vision, 2013

A patient presented at the lung cancer MDM, clearly too frail for anti-cancer treatment. BSC is the agreed management plan and the patient/those close to them receive prompt specialist palliative care, wherever they are, with immediate and future needs reliably addressed..

- Good palliative care, earlier and more consistently
- Care that is integrated and coordinated
- Macmillan – Transforming Care After Treatment (TCAT) programme launched around this time

Do all patients with lung cancer for BSC really need specialist palliative care?

- Already heavy users of specialist palliative care service, though often too late
- High risk of hospital admission and users of acute services
- High symptom burden
- Rapidly changing health and care needs
- High prevalence of socioeconomic deprivation and psychosocial complexity

- Always with idea of learning for other patient groups..

Baseline evaluation findings

103 patients for BSC from diagnosis in 2012

- Median survival from MDM diagnosis **73 days** (IQR 20-133)

- Elderly, poor performance status
- Over half in hospital at time of diagnosis
- 66% didn’t attend clinics following diagnosis
- 83% had hospital admissions between diagnosis/death
- 41% died in acute hospital
- 57% supported by Specialist Palliative Care before they died (76% were referred). Often late..

Baseline evaluation - experiences

The consultant does 'nae want to see me again, there's nothing else they can do. It's just another run to [clinic] for a five minute chat and that's it. ***So there's not much point****.*

Patient

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

The extra resource – 330K over two years

- Project Lead – consultant 4 hours/week
- Specialty doctor – 24 hours/week
- Specialist nurse – 16 hours/week
- Administrator – 32 hours/week
- Evaluation – 2 hours/week later in project

- No AHP input at start
- Separate Social Care project funded but some overlap
- Napier University supported some evaluation activity

The New Model of Care

- Robust identification of patients
- Comprehensive palliative care assessment and care planning
- Care coordination and follow-up

Identification	Specialist Palliative Care Clinician is member of Lung Cancer MDT. Other referrals from Oncology, Respiratory, GP etc
Referral to Specialist Palliative Care	Within 24 hours of MDT
Comprehensive Specialist Palliative Care Assessment	Home, Hospital or Clinic depending on patient frailty or choice
Personalised Care Planning	Patient Action Plan, signposting, anticipatory care planning
Care Co-ordination	Information sharing, referral to other health, social and third sector services, e-alert, eKIS, DNACPR
Follow-up	Individualised regular monitoring and re-assessment of needs and family/carer support

Some of the refinements we made

- Opened up the service to people who had finished anti-cancer treatment but who had active disease
- Weekend helpline unsuccessful
- Clinic resource needed to be mobile
- Follow-up initially for all patients until death, but moved to needs-based reviews, with self-referral back at any stage

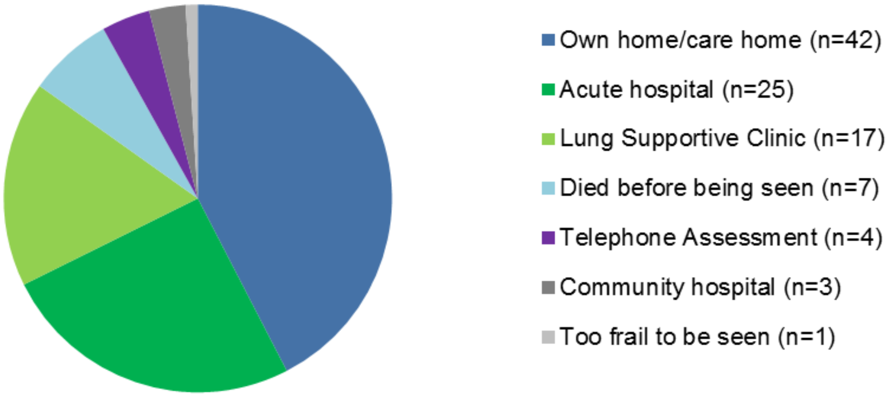
Achievements

- 600+ patients and those close to them have been supported in Fife since January 2015
  - Half BSC from point of diagnosis
- Now a clear model of BSC for anyone with incurable lung cancer
  - A new standard of care locally for a very frail patient group
  - The dog that didn’t bark in the night.. ‘where’s the assessment letter?’
- Secured additional 6 sessions middle grade medical resource to sustain what we can

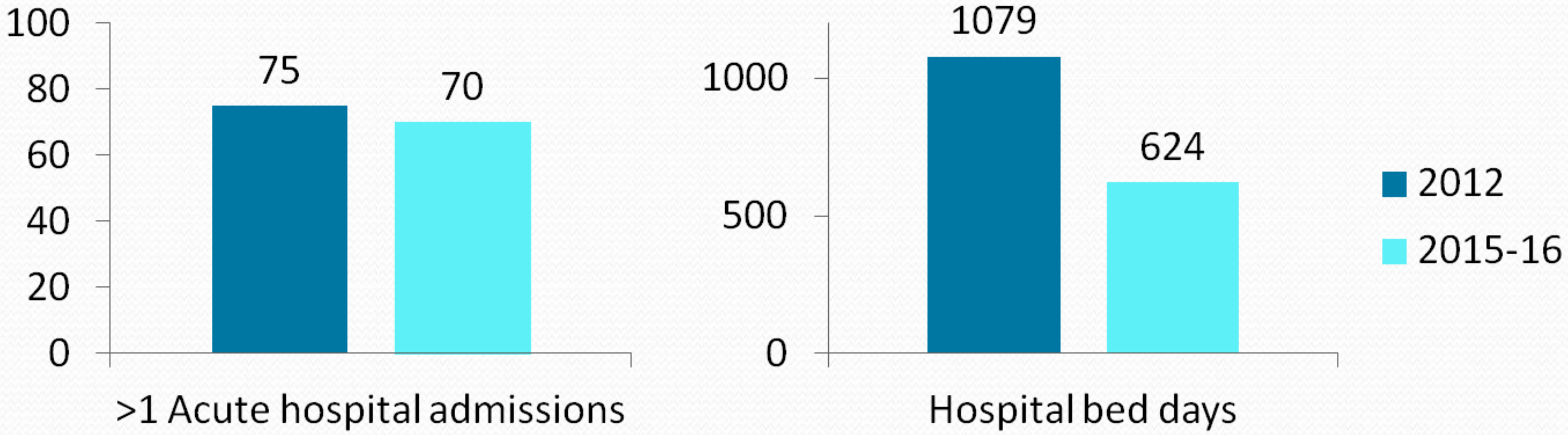
More patients, earlier and receiving care wherever they are

- A 12 month sample of BSC from diagnosis (n=99)
  - 91% received comprehensive specialist palliative care assessments
  - Most referred on day of diagnosis, some before
- Most first assessments conducted at home or when in-patient in hospital

Fig 2. Location of first palliative care assessment for 99 'BSC at diagnosis' patients under the new model of care

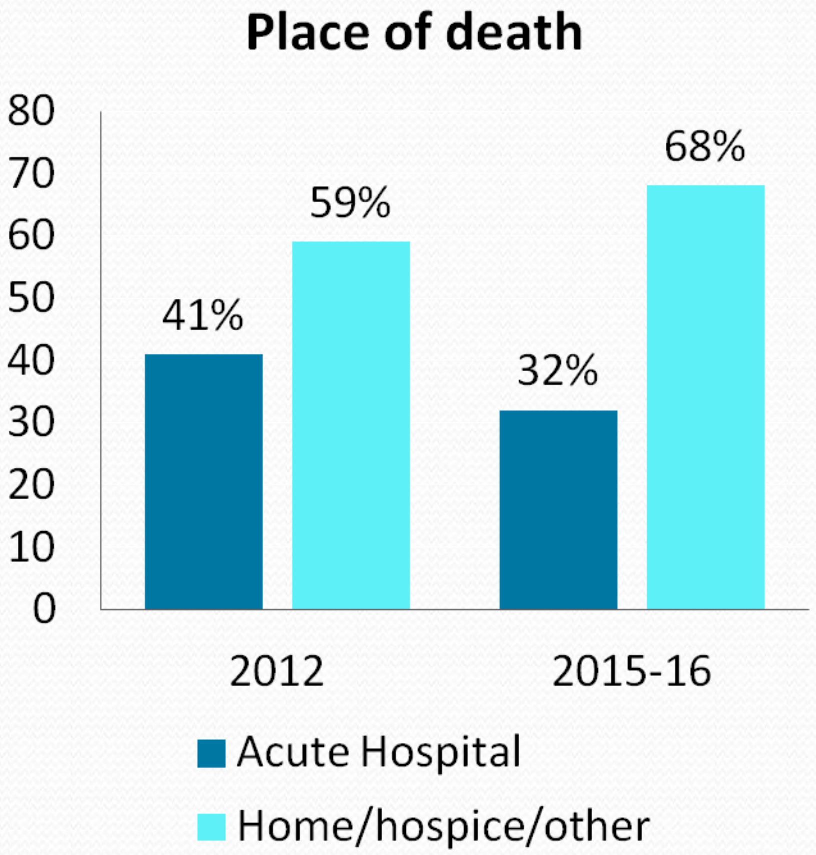


Healthcare resource use: proxies for quality and efficiency



- **67%** of patients had 1 or more secondary care clinic appointments cancelled

Healthcare resource use: proxies for quality and efficiency



Independent Health Economic Analysis

- Conservative cost minimisation for 99 patient subgroup: **£417,261**
- For an estimated investment of £53,650

What has this meant for service users?

Everybody kind of went into a panic with what was going on at the time… but when my dad settled down, it kinda gave us all a bit of a jolt ***we got ourselves together and we were able to speak to the different people and get the support that we all needed****, so it was really good. Name of GP, name of community palliative care nurse, the district nurses and the Marie Curie nurses have all been really, really good*

(Carer)

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

(Patient)

What has this meant for Oncology?

.. it’s been a real bonus to me and my practice because I know that those patients who are not coming my way, or have been my way are going to get rapid, or fairly rapid intervention, and I know that that intervention from the .. team is going to be pretty comprehensive and I know that the communication after that is excellent. So the information that is dispersed following the clinic, to me and to everybody else, is very good, so I think everyone is aware of what’s going on and it makes it very clear.

(Lung Oncologist)

Alignment with current national strategy

- *Strategic Framework for Action for Palliative and End of Life Care* (2016) - identification and care coordination, timely and focused conversations
- *Realistic Medicine* (2014/15) - reducing unwarranted variation in practice, delivering person-centred care, reducing waste
- *National Clinical Strategy* (2016) – improved quality of care, evidence-based practice, person-centredness
- *Beating Cancer: Ambition and Action* (2016) – person-centred, high quality, equitable care

Where did we struggle?

- Clinical workload pressures already high
  - Asking community specialist nurses to do more and to learn new skills
  - E-alerts generated more work in the acute hospital
  - Natural progression to embed new ways of working for other patient groups..

- Evaluation
  - Lack of experience and time
  - Too broad to start and data collection onerous
  - Report writing/producing

Barriers to realising full potential of the project

- No AHP funding in main grant
- Specialist Palliative Care unable to complete/update eKIS following patient assessments
- Detailed letters available on Clinical Portal but not always accessed and not available to roaming OOH GPs
- Communication with social care
- Limited contribution to development from primary care colleagues because of workload

Enablers

- Maintaining focus on quality of care and access to it – shared vision
  - Power of local data
  - Carer representative kept us focused
- Enthusiasm from all stakeholders and active collaboration
  - Clinically
  - Steering group members’ diversity of experience
- Good will

Wider gains

- More cohesive Specialist Palliative Care Service
- Development of shared vision (and language) for service - in particular thinking about whose needs we aren’t meeting
  - Improved understanding of/interest in health economics
- Links with other clinical specialities/social care colleagues
- New ways of working clinically/new skills and confidence
- Up-skilling generalists in acute/community
- Raised profile of the Specialist Palliative Care Service in Fife
  - Also of wider palliative care agenda

What next? Beyond lung cancer in Fife

- Resource for other regions to develop local models of BSC
- Campaigning for a national standard of BSC in lung cancer
- Further Macmillan funding (100K) to use over 12 months
  - Hepatobiliary cancers
  - Cancers of Unknown Primary
  - End-Stage Renal Failure
- Areas to develop:
  - Carer support and assessment – intervention and evaluation
  - Patient-held records?
  - Out of hours information/care ‘rapid stay at home’

We don’t always get it right – there is still work to be done

- Frail elderly man with a new diagnosis of presumed lung cancer, for BSC due to frailty and comorbidity. Diagnosis not communicated with family. Information came in post about living with cancer. 3 in-hospital transfers and later move to community hospital, also delirium and incapacity. *Too many cooks and slipped through the net.*

- Frail elderly woman for BSC with probable colon cancer. Complaint to NHS Fife from daughter about lack of information/care/support at diagnosis - ’Where’s my mother’s palliative care plan?’ and ‘Who’s her consultant?’ *Fair points.*

Key messages

- Palliative care’s ‘active total care’ is treatment. But we need the concepts and language to articulate this and meaningful measures to demonstrate impact

- In Specialist Palliative Care we should be seeking to understand whose needs we are not currently meeting, and making plans to address this

- Improvements in access to care and quality of palliative care are compatible with improved efficiency and efficiency is our business

Conclusions

- People with lung cancer who are for BSC can benefit from proactive Specialist Palliative Care as their primary treatment
- We have demonstrated, with investment:
  - **More equitable access** to specialist palliative care
  - **Earlier** specialist palliative care
  - **More consistent** specialist palliative care
  - **Care that** service users and professionals tells us **works**
  - **Cost reductions**
    - Unclear impact on community costs including to carers

Conclusions

- Many other patient groups (cancer and non-cancer) could benefit from a proactive BSC approach
  - Different models needed – specialist versus generalist-led
  - Framework likely to be transferable
    - Robust identification of patients
    - Comprehensive palliative care assessment and care planning
    - Care coordination and follow-up
  - Might BSC become a legitimate treatment option?
- A shared vision and collaboration with cohesive MDT working have been key
- We are still learning and refining what we do