Breathlessness and the Family

International Breathlessness Conference: Developing treatments for breathlessness

Copenhagen - 7th May 2015

Dr Morag Farquhar (edited version of slides for web)
Impact of breathlessness

• **On patients:**
  • high symptom burden
  • physical disability - houseboundness
  • co-morbidities common
  • anxiety & depression
  • loss of independence & dignity

• **On families:**
  • suffer isolation (restricted lives), role change, anxiety & anger
  • considerable care burden – largely unsupported
Family carers & breathlessness

- terrifying [...] ...you just don’t know what to do, you can’t do anything any way... you’re just helpless aren’t you...

  [wife of patient with emphysema: BIS PreClin c1]

- I usually sleep with half an ear open... I put my life on hold... can’t talk about free time...

  [husband of patient with lung cancer: BIS PreClin c12]

Family carers & breathlessness

**Outline:**

1) Role of family carers in breathlessness
2) Impact on family carers
3) Family carer support needs
4) Supporting family carers
5) Research implications
Family carers & breathlessness

• **Key literature – carers & breathlessness:**

• **Three key sources:**
  - Living with Breathlessness study (LwB: COPD)
  - Learning about Breathlessness study (LaB: cancer & non-cancer)
  - Breathlessness Intervention Service studies (BIS: cancer & non-cancer)
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1) Role of family carers in breathlessness

- Enable patients to be cared for (and often to die) in their place of choice
- Reduce formal care costs
- Role in breathlessness:
  - complex personal care e.g. washing, dressing, managing symptoms, administering medication & oxygen
  - practical & emotional support
  - overnight vigilance
- Often remain unnoticed or invisible
• Cohort of n=115 carers of patients with advanced COPD

• [slide presented data on carer role in advanced COPD from LWB study – in preparation for publication]

• LwB study publications will be listed here:
  • http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/
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2) Impact on family carers

- Caring role comes at a cost:
  - physical & psychological health
  - mortality

- Family carers usually spousal, usually older

- Ambivalence & reality of caring means putting own health second

- Experience:
  - anxiety & emotional distress
  - isolation & restrictions

- Burden of responsibility can be intolerable
Living with Breathlessness study (COPD)

• [slides presented data on carer health, quality of life, and anxiety & depression from LWB study – in preparation for publication]

• LwB study publications will be listed here:

  • http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/
Impact of COPD on families


- www.snrs.org
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3) Family carer support needs

- helpless & powerless
- lack knowledge & strategies
- uncertainty in caring tasks & situations:
  - HCPs receive appropriate training - but carers feel ill-prepared to care
- lack support & assistance
  - some need the relief & support of respite
  - LwB study: 64% could not identify a health care professional for their caring role
What did carers want more support with in advanced COPD? (% at baseline: n=112: LwB)

• [slide presented data on carer support needs from LWB study – in preparation for publication]

• LwB study publications will be listed here:
  • http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/
What are carers unprepared for in advanced COPD? (% at baseline: n=112: LwB)

• [slide presented data on carer preparedness to care from LWB study – in preparation for publication]

• LwB study publications will be listed here:
  • http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/
Learning about Breathlessness study

• Qualitative interviews with 25 patient-carer dyads (cancer & COPD)

• [data & supporting quotes on topics carers of patients with breathlessness want to learn about from LaB study – in preparation for publication]

• LaB study publications will be listed here:
  • http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/other-projects/lab/
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- Effective management of patient’s breathlessness likely to impact on (ameliorate) carer need
- Direct carer support
- Rhetoric of policy - carers should be supported:
  - but little guidance on how

- Rarely acknowledged or supported by healthcare systems:
  - facilitate recognition of patient changes
  - enable creative adaptive responses for carers
Living with Breathlessness study (COPD)

- [slide presented data on limited clinician support for carer role in advanced COPD from LWB study – in preparation for publication]

- LwB study publications will be listed here:
  - http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/
Supporting family carers

- We need to be dramatically better at supporting carers:
  - 1) Identify carer(s)
  - 2) Acknowledge their role & reassure them
  - 3) Assess their psychological health
  - 4) Identify need for (more) support (and desire for more support)
  - 5) Prioritise needs (with carer – greatest need may not be their highest priority)
  - 6) Address priority need (or signpost/ refer-on) & re-assess
Carer Support Needs Assessment Tool (CSNAT)

• Evidence-based screening tool
  • key carer support needs (for EoLC at home) requiring further assessment

• Self-completed; 14 support domains:
  • 7 direct support domains = support for self
  • 7 enabling support domains = support to care

• “Do you need more support with…”
  • e.g. “Do you need more support with looking after your own health?” (D)

• Four response categories:
  • No
  • A little more
  • Quite a bit more
  • Very much more

http://csnat.org

Examples of further support

- Physical – carer’s physical health needs, equipment & aids, respite (sitters, out of hours & night support, admissions), emergency plan
- Emotional / psychological – carer’s mental health, patient anxiety management, hospice day care, cancer support & peer support groups
- Social – social services, peer support groups, online forums, referral to activities (co-provision of respite)
- Financial – social services, Citizens’ Advice Bureau, state welfare provision, charitable funds, supporting ability to carry on working
- Spiritual – faith groups
- Education & information
- Bereavement support
Carer education & information

• Learning about Breathlessness 6 interrelated topics + generic caring skills including:
  • practical caring skills to minimise burden e.g. lifting
  • new life skills - e.g. cooking
  • how to access health & social services - both for patient & themselves
  • communication & negotiation skills - to interact with range of people (clinicians & family), to obtain/retain help, to act as advocate for patient, & to share bad news

• Self-directed, clinician-directed/delivered, or via peer support groups
Example of a carer-targeted intervention

- Carla Reigada – palliative care programme carer intervention

- EAPC poster: P2-319
  - Reigada C, Pais-Ribeiro JL, Novellas A, Gonçalves E
  - Self-care Practice Ability Program: Practical Program for Caregivers in Palliative Care

- https://www.youtube.com/watch?v=0ubstjKI6XY&feature=youtu.be
Breathlessness Intervention Service (RCT)

- Carers liked:
  - Time to talk about breathlessness
  - Multi-disciplinary staff:
    - experts in breathlessness & strategies to manage breathlessness
    - understood life with breathlessness
  - Legitimised breathlessness - symptom acknowledged by experts
  - Gained knowledge about breathlessness - enhanced understanding of symptom & confidence in living with it
  - No longer felt alone
  - Unexpected attention given to carers
  - Additional indirect help to carers – fewer phone calls from their patient

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- **We know**: carers are important & that caring can be difficult (burden)
- **We are learning**: what factors we might be able to support (needs) & influence (preparedness to care) to alleviate difficulty
- **We need to know now**: how needs change with disease progression
  - Living with Breathlessness study programme - longitudinal element
- **What we need next**: further development & testing of carer interventions
  - Learning about Breathlessness study - educational intervention for carers on breathlessness in advanced malignant and non-malignant disease
  - Developing and piloting a Carer Specialist Nurse role for advanced non-malignant disease
Conclusions

- Families play a central role in palliative and end of life care for patients with breathlessness – carers enable care (& death) in place of choice

- Caring comes at a cost: psychosocial distress, impact on health, pressure on finances, (increased carer mortality)

- Ensuring carer support can ameliorate these effects, so we need to:
  - respond to the policy rhetoric of supporting family carers
  - identify family carers
  - identify their support & education needs
  - respond to those needs

- Need to robustly develop & evaluate interventions to better support families & carers living with breathlessness – carers are patients too
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• **Learning about Breathlessness study:**
  • Dimbleby Cancer Care