

# Breathlessness and the Family

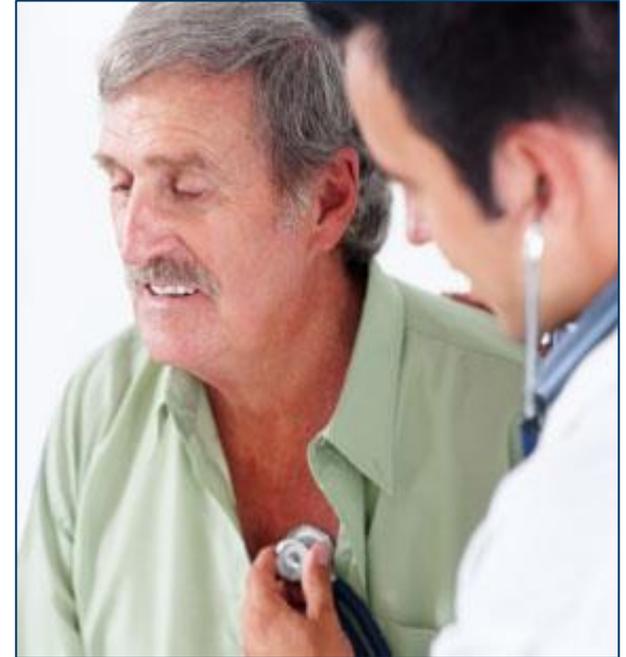
International Breathlessness Conference: Developing treatments for  
breathlessness

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]

Booth S, Silvester S, Todd C. *Journal of Palliative and Supportive Care* 2003;1(4):337-44

# 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:
  - Parnell 2001; Bergs 2002; Booth et al 2003; Seamark et al 2004; Bailey 2004; Goodridge et al 2008; Spence et al 2008; Currow et al 2008; Hasson et al 2009; Gysels & Higginson 2009; Caress et al 2009; Simpson et al 2010; Hynes et al 2010; Currow et al 2012; Grant et al 2012; Malik et al 2013; Philip et al 2014; Farquhar et al 2014; Vincent & Scullion 2014
- 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



# Living with Breathlessness study (COPD)

- 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

- Boyle A. An Integrative Review of the Impact of COPD on Families. Southern Online Journal of Nursing Research 2009:9(3)
- [www.snrs.org](http://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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## 4) Supporting family carers

- 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>

Ewing G & Grande G. Palliat Med 2013; 27: 244-56 / Ewing G et al. Jnl Pain Symp Manage 2013; 46(3): 395-405

# 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=0ubstjKl6XY&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

Farquhar M, Prevost AT, McCrone P, Brafman-Price B, Bentley A, Higginson IJ, Todd C, Booth S. Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed method randomised controlled trial. *BMC Medicine* 2014 12:194.

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# 5) Research implications

- 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

# Acknowledgements

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  - Literature
  - Dr Sara Booth - Breathlessness Intervention Service studies
  - Clarissa Penfold - Learning about Breathlessness study
  - Living with Breathlessness study team
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**WE ARE  
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**NHS**  
*National Institute for  
Health Research*



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- Learning about Breathlessness study:
  - Dimpleby Cancer Care