PRELIMINARY INTERVIEW GUIDE
LOW DOSE MORPHINE STUDY

Patients

1. What was life like for you before you began taking the morphine?
    - Tell me about a typical day…. What effects did COPD have on your life?
    - What changed over the course of your illness? (ie: ADLs, social, emotional, spiritual)
    - What was most difficult for you about this? What was your breathing like? Were there things you could not do? Why/what stopped you?
    - What about relationships, e.g., with spouse, family members, friends—do you think your illness has affected any of these; how?
    - What about formal care—how satisfactory has it been for you? (doctors, nurses, respiratory therapists, clinic visits, hospitals, home support)
    - Other effects?
    - Greatest fears? (exacerbations; getting help; burden to loved ones)
    - Hopes?

2. Since you started the morphine has anything changed? If yes, what and how?
    - Quality of life (factors mentioned in #1), breathing
    - Relationships (as above)
    - Formal care (as above)
    - Other things
    - Fears (as above)
    - Hopes

3. What were your thoughts when your doctor first talked to you about starting morphine? (fears, concerns, hopes, understandings)
    - Did you talk about any of these things with your doctor, then or since?
    - How did your doctor explain it to you? (what did s/he say)
    - Have your thoughts changed since being on the morphine?

4. Is there anything else you want to share with me or other COPD patients, doctors, or families about this morphine experience?

Appendix to: Rocker G, Young J, Donahue M, et al. Perspectives of patients, family caregivers and physicians about the use of opioids for refractory dyspnea in advanced chronic obstructive pulmonary disease.
CMAJ 2012.
DOI:10.1503/cmaj.111758

Informal Caregivers (1)

5. What was life like for you before [patient] began taking the morphine?
    - How would you describe a typical day in your life—how did COPD affect this?
    - Have things changed over the course of the illness? (ie: social, emotional, spiritual)
    - What was most difficult for you about this? Were there things you could not do? Why/what stopped you?
    - What about relationships, e.g., with spouse, family members, friends—do you think the illness affected any of these; how?
    - What about formal care—how satisfactory has it been for you? (doctors, nurses, respiratory therapists, clinic visits, hospitals, home support)
    - Other effects?
    - Greatest fears? (exacerbations; getting help; burden)
    - Hopes?

6. Since [patient] started the morphine has any of this changed? If yes, what and how?
    - Quality of life (factors mentioned in #1), breathing
    - Relationships (as above)
    - Formal care (as above)
    - Other things
    - Fears (as above)
    - Hopes

7. What were your thoughts when the doctor first talked to [patient] about starting morphine? (fears, concerns, hopes, understandings)
    - Were you included in these discussions? If so, how was it explained to you?
    - Were you able to talk about your concerns/questions with the doctor?
    - Have your thoughts/concerns changed since [patient] has been on the morphine?

8. Is there anything else you want to tell me or other COPD patients, doctors, or families about this experience?

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Informal Caregivers (2 – bereavement)

9. What was life like for you before [patient] began taking the morphine?
    - How would you describe a typical day in your life—how did COPD affect this?
    - Had things changed over the course of the illness? (ie: social, emotional, spiritual)
    - What was most difficult for you about this? Were there things you could not do? Why/what stopped you?
    - What about relationships, e.g., with spouse, family members, friends—do you think the illness affected any of these; how?
    - What about formal care—how satisfactory was it for you? (doctors, nurses, respiratory therapists, clinic visits, hospitals, home support)
    - Other effects?
    - Greatest fears? (exacerbations; getting help; burden)
    - Hopes?

10. When [patient] started the morphine, did any of this change?
    - Quality of life (factors mentioned in #1), breathing
    - Relationships (as above)
    - Formal care (as above)
    - Other things
    - Fears (as above)
    - Hopes

11. What were your thoughts when the doctor first talked about starting morphine? (fears, concerns, hopes, understandings)
    - Who was included in these discussions? If you took part, how was it explained to you?
    - Were you able to talk about your concerns/questions with the doctor?
    - Did your thoughts/concerns changed after [patient] had been on the morphine?

12. Is there anything else you want to tell me or other COPD patients, doctors, or families about this experience?

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Summary

The interview guide is designed to elicit patients' and informal caregivers' stories about their life experiences before and after low dose morphine was initiated to help control dyspnea and related symptoms in advanced COPD. The semi-structured open-ended questions will be the basis of a conversation (≈45 minutes with the patient alone and his/her informal caregiver alone) concerning changes patients and informal caregivers have/had noticed in their quality of life, dyspnea/other symptoms, significant relationships, satisfaction with and type of formal care (has being on morphine enabled conversations with formal caregivers that might not otherwise have taken place—or at least had not taken place prior to beginning the morphine intervention?), fears/concerns, and hope(s). Part of the focus of the analysis of this data will be on the balance of benefits: harms (positives, negatives, neutrals) as assessed by the patients themselves and their informal caregivers, and role this plays in how satisfied they are with the formal care they have experienced. As well, it should provide some insight into how particular patients and their informal caregivers interpret this option and how that may or may not affect their experience with it (and/or their compliance), i.e., what beginning a morphine intervention signals to them, how they fit it into their understanding of the illness, its severity (worsening, ?dying), cultural, familial, and historical views of morphine (and/or narcotics use more generally, i.e., addiction risk, association with cancer pain, etc.).

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