Appendix 2

# Pt STATUS AND DEMOGRAPHICS Form

Study PID Number: __ __ -- __ __ __
Site # Sequence#

Post-Opioid Experience Study ……………………………………………………

Patient Initials: ______ -- _______ -- ______
First Middle Last

Date of Birth: ________ -- _______ -- _______
Year Month Day

Gender (circle one): F *or* M

| | Marital status of Patient: | (√) one |
|---|---|---|
| 1 | Married or living as married | |
| 2 | Widowed | |
| 3 | Never married | |
| 4 | Divorced or separated | |
| 5 | Other (specify): | |

Oxygen therapy: No ______ Yes ______ Flowrate _______ Saturation ________% FEV1 _______

| | Ethnic/ Racial Group – *self assessed* | (√) one |
|---|---|---|
| 1 | Asian/ Pacific Islander | |
| 2 | African/ Black North American | |
| 3 | Caucasian | |
| 4 | East Indian | |
| 5 | Native Canadian | |
| 6 | Other (specify); | |

| | Education -- *highest level achieved* | (√) one |
|---|---|---|
| 1 | Elementary school or less | |
| 2 | Some high school | |
| 3 | High school graduate | |
| 4 | Some college (including CEGEP)/ trade school | |
| 5 | College diploma (including DEC)/ trade school | |
| 6 | Attended university | |
| 7 | University degree | |
| 8 | Post graduate degree | |
| 9 | Other (specify): | |

Employment Status

Has your employment status changed as a result of your illness?
❑ No *or* ❑ Yes – *complete below*:

| | Current Employment Status | (√) one |
|---|---|---|
| 1 | Employed full time | |
| 2 | Employed part time | |
| 3 | On paid leave | |
| 4 | On unpaid leave | |
| 5 | Self-employed | |
| 6 | Retired | |
| 7 | Not employed | |
| 8 | Other (specify): | |

| | If YES: What was your previous employment status? | (√) one |
|---|---|---|
| 1 | Employed full time | |
| 2 | Employed part time | |
| 3 | On paid leave | |
| 4 | On unpaid leave | |
| 5 | Self-employed | |
| 6 | Retired | |
| 7 | Not employed | |
| 8 | Other (specify): | |

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.
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| 0 | None | Comorbid Illnesses – *circle all number codes that apply* | | | |
|---|---|---|---|---|---|
| | Myocardial | | | | Cancer/ Immune |
| 1 | Angina | | Endocrine | 25 | Any tumour |
| 2 | Arrhythmia | 15 | Diabetes Type 1 or II | 26 | Lymphoma |
| 3 | Valvular disease | 16 | Diabetes with end organ damage | 27 | Leukemia |
| 4 | Myocardial infarction | | | 28 | AIDS |
| 5 | CHF or heart disease | 17 | Obesity and/ or BMI >30 (weight in kg/ ht in metres)$^2$ | 29 | Metastatic solid tumour |
| | Vascular | | | | Psychological |
| 6 | Hypertension | | Renal | 30 | Anxiety or panic disorder |
| 7 | Peripheral vascular disease or claudication | 18 | Moderate or severe renal disease | 31 | Depression |
| 8 | Cerebrovascular disease | | Gastrointestinal | | Muskoskeletal |
| | Pulmonary | 19 | Mild liver disease | 32 | Arthritis (rheumatoid or osteo-) |
| 9 | COPD, emphysema | | | 33 | Denegerative disc disease (back, spinal stenosis, severe chronic back pain) |
| 10 | Asthma | 20 | Moderate/ severe liver disease | 34 | Osteoporosis |
| | Neurologic | | | 35 | Connective tissue disease |
| 11 | Dementia | 21 | GI bleeding | | Miscellaneous |
| 12 | Hemiplegia (paraplegia) | 22 | Inflammatory bowel disease | 36 | Visual impairment (cataracts, glaucoma, macular degeneration) |
| 13 | Stroke or TIA | 23 | Peptic ulcer disease | 37 | Hearing impairment (very hard of hearing even with hearing aid) |
| 14 | Neurologic illnesses (e.g. MS or Parkinsons) | 24 | GI disease (hernia, reflux) | | |

Palliative Performance Scale (PPS) – *Please circle the applicable % level in the far left column*

| % | Ambulation | Activity and Evidence of Disease | Self Care | Intake | Consciousness Level |
|---|---|---|---|---|---|
| 100 | Full | Normal Activity No Evidence of Disease | Full | Normal | Full |
| 90 | Full | Normal Activity Some Evidence of Disease | Full | Normal | Full |
| 80 | Full | Normal Activity with Effort Some Evidence of Disease | Full | Normal or Reduced | Full |
| 70 | Reduced | Unable Normal Job/Work Some Evidence of Disease | Full | Normal or Reduced | Full |
| 60 | Reduced | Unable Hobby/House Work Significant Disease | Occasional Assistance Necessary | Normal or Reduced | Full or Confusion |
| 50 | Mainly Sit/Lie | Unable to Do Any Work Extensive Disease | Considerable Assistance Required | Normal or Reduced | Full or Confusion |
| 40 | Mainly in Bed | As Above | Mainly Assistance | Normal or Reduced | Full or Drowsy or Confusion |
| 30 | Totally Bed Bound | As Above | Total Care | Reduced | Full or Drowsy or Confusion |

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| | | | | | |
|---|---|---|---|---|---|
| 20 | As above | As Above | Total Care | Minimal Sips | Full or Drowsy or Confusion |
| 10 | As above | As Above | Total Care | Mouth Care Only | Drowsy or Coma |
| 0 | Death | - | - | - | - |

*Please continue on page 2* ------------------------->

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**Opioid details:**

How long has the patient been taking opioids? ___________________________________________
Compliance (patient self-reported)?____________________________________________________
Opiod type (long vs. short-acting) and drug name: ________________________________________
Current dose: ______________________________________________________________________

**Questions about living arrangements:**

a) Tell us about the community in which you live?

❑ Mostly Rural ❑ Mostly Urban ❑ Mixed

b) Does your home have more than one level, i.e., flights of stairs?

❑ No ❑ Yes - if yes, how many? _________

c) Are you able to drive yourself to medical appointments?

❑ Yes ❑ No longer drive, rely on __________________ ❑ No vehicle

d) Do you have children?

❑ No ❑ Yes - number of children _____________

e) Would you say you are a follower of a particular religious tradition? e.g., Christianity, Judaism, Islam, etc.

❑ No ❑ Yes ________________________ If Christian, denomination ______________

f) How important are these beliefs to you at this point in your life?

❑ Unimportant ❑ Somewhat unimportant ❑ neither important nor unimportant ❑ Somewhat important ❑ Important

g) Do you have an advance directive (living will or power of attorney for health care decisions)?

❑ No ❑ Don't know ❑ Yes: advance directive ___; power of attorney _____

h) If you were given the choice, where would you prefer to die (for example: at home, in hospital, elsewhere)?

❑ Don't know ❑ at home ❑ in hospital ❑ elsewhere (please specify) _____________

**For coordinator/interviewer:**

Qualitative interview completed: No _____ Yes ________ date: ________

Completed scales/questionnaires:

VAS……………………..……☐ Summary questions…….…..…☐

QoL…………………………..☐ HADS…………………..........☐

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CRQ………………………… ☐ NOSE…………………………. ☐

*Sign and date this form*

Name of Site Research Coordinator/Interviewer: ______________________________________________

Signature: ______________________________ Date Completed: _________ _________ _______

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CG STATUS AND DEMOGRAPHICS Form — Study CID Number: __ __ -- __ __ __
Post-Opioid Experience Study ……………………………………………………… Site # Sequence#

---

*Definition of CAREGIVER* in this study: anyone (related or not) who provides care for someone who is seriously ill and is not paid to do so.

*What we mean by CARE*: anything done for the person because he or she has a serious illness.
*Some examples are*: household chores you took over; household chores that now take more time (for example, extra laundry or preparing special foods); outside chores (yard work, snow removal, running errands, shopping) that you took over or now take more time; banking and paperwork that are new, you took over, or now take more time; direct care for the care recipient (bathing, feeding, skin care, giving medications, wound care, toileting, transferring between bed and chair; additional time you spend with the care recipient, including keeping him or her company and being present for safety reasons; arranging appointments, arranging for help from paid or unpaid others; attending health care appointments; transportation; time spent in the hospital. *Please note that this is just a partial list.*

Caregiver Initials: ______ -- _______ -- ______
First Middle Last

Date of Birth: ________ -- _______ -- ________
Year Month Day

Gender (circle one): F *or* M

| | Marital status of Caregiver: | (√) one |
|---|---|---|
| 1 | Married or living as married | |
| 2 | Widowed | |
| 3 | Never married | |
| 4 | Divorced or separated; not remarried | |
| 5 | Other (specify): | |

| | Relationship to care recipient. You are caring for your ... | (√) one |
|---|---|---|
| 1 | Husband/ wife/ partner | |
| 2 | Parent | |
| 3 | Parent-in-law | |
| 4 | Daughter/ son | |
| 5 | Sister/ brother | |
| 6 | Other (specify): | |

Do you presently live with the care recipient?

❑ No *or* ❑ Yes – *complete below*

*If Yes:*
For *how long have you lived with* the care recipient?

________ months *or* ______ years

For *how long have you been a caregiver* for the care recipient?

_____ months
*or*
_____ years

In the past month, how many hours *on average* have you spent caregiving for the care recipient?

_______ hours per week

Comments:

Are there other family members, friends, or neighbours involved in unpaid caregiving for the care recipient?

❑ No – none
*or*
❑ Yes – *specify how many and number of hours per week*:

_______ family members _______ hours per week
_______ friends _______ hours per week
_______ neighbours _______ hours per week

*Please continue on page 2* ------------------->

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.
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| | Ethnic/ Racial Group – *self assessed* | (√) one |
|---|---|---|
| 1 | Asian/ Pacific Islander | |
| 2 | African/ Black North American | |
| 3 | Caucasian | |
| 4 | East Indian | |
| 5 | Native Canadian | |
| 6 | Other (specify); | |

| | Education -- *highest level achieved* | (√) one |
|---|---|---|
| 1 | Elementary school or less | |
| 2 | Some high school | |
| 3 | High school graduate | |
| 4 | Some college (including CEGEP)/ trade school | |
| 5 | College diploma (including DEC)/ trade school | |
| 6 | Attended university | |
| 7 | University degree | |
| 8 | Post graduate degree | |
| 9 | Other (specify): | |

Employment Status

Has your employment status changed as a result of your caregiving role? ❑ No *or* ❑ Yes – *complete below*:

| | Current Employment Status | (√) one |
|---|---|---|
| 1 | Employed full time | |
| 2 | Employed part time | |
| 3 | On paid leave | |
| 4 | On unpaid leave | |
| 5 | Self-employed | |
| 6 | Retired | |
| 7 | Not employed | |
| 8 | Other (specify): | |

| | If YES: What was your previous employment status? | (√) one |
|---|---|---|
| 1 | Employed full time | |
| 2 | Employed part time | |
| 3 | On paid leave | |
| 4 | On unpaid leave | |
| 5 | Self-employed | |
| 6 | Retired | |
| 7 | Not employed | |
| 8 | Other (specify): | |

| | Does your current employment status allow you to take time to provide care? | (√) one |
|---|---|---|
| 1 | Yes, completely | |
| 2 | Yes, partially | |
| 3 | No, not at all | |

Comments:

**Questions for Caregiver:**

Would you say you are a follower of any particular religious tradition? e.g., Christianity, Judaism, Islam, etc.

❑ No ❑ Yes ________________________ If Christian, denomination ______________

How important are these beliefs to you at this point in your life?

❑ Unimportant ❑ Somewhat unimportant ❑ neither important nor unimportant ❑ Somewhat important ❑ Important

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Do you know if the person you are caring for has an advance directive (living will or power of attorney for health care decisions)?

❑ No ❑ Don't know ❑ Yes: advance directive ___; power of attorney _____

Do you know where the person you are caring would prefer to die (for example: at home, in hospital, elsewher) if he/she had a choice?

❑ No ❑ Don't know ❑ Yes: at home _____ in hospital _____ elsewhere (please specify)

__________________________________________

**For coordinator/interviewer:**

Qualitative Interview completed: No _______ Yes ________ date: _______

Questionnaires completed:

QoL…………………………☐ HADS…………………….......☐

CRA…………………………☐

*Instruction to Site Research Coordinator/ Interviewer: Sign and date this form*

Name of Site Research Coordinator: ______________________________________________

Signature: ________________________________ Date Completed: ________ ________ ______
Year Month Day

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Appendix 2

## STATUS AND DEMOGRAPHICS Form

Study CID Number: __ __ -- __ __ __

Post-Opioid Experience Study (post-bereavement) ................................... Site # Sequence#

---

*Definition of CAREGIVER* in this study: anyone (related or not) who provided care for someone who was seriously ill and was not paid to do so.

*What we mean by having provided CARE*: anything done for the person because he or she had a serious illness. *Some examples are*: household chores you took over; household chores that took more time (for example, extra laundry or preparing special foods); outside chores (yard work, snow removal, running errands, shopping) that you took over or took more time; banking and paperwork that you took over, or took more time; direct care provided for the care recipient (bathing, feeding, skin care, giving medications, wound care, toileting, transferring between bed and chair; additional time you spent with the care recipient, including keeping him or her company and being present for safety reasons; arranging appointments, arranging for help from paid or unpaid others; attending health care appointments; transportation; time spent in the hospital. *Please note that this is just a partial list.*

Caregiver Initials: ______ -- _______ -- ______
First Middle Last

Date of Birth: ________ -- _______ -- _______
Year Month Day

Gender (circle one): F *or* M

| Were there other family members, friends, or neighbours involved in unpaid caregiving for the care recipient? | Yes ❑ No ❑ |
|---|---|
| Did you feel that you had the respite/relief that you needed? | Yes ❑ No ❑ |

| Relationship to care recipient. You were caring for your ... | | (√) one |
|---|---|---|
| 1 | Husband/ wife/ partner | |
| 2 | Parent | |
| 3 | Parent-in-law | |
| 4 | Daughter/ son | |
| 5 | Sister/ brother | |
| 6 | Other (specify): | |

Did you live with the care recipient?

❑ No *or* ❑ Yes – *complete below*

*If Yes:*
For *how long did you live with* the care recipient?

_______ months *or* ______ years

For *how long were you a caregiver* for the care recipient?

_____ months
*or*
_____ years

*Please continue on page 2* ------------------->

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| | Ethnic/ Racial Group – *self assessed* | (√) one |
|---|---|---|
| 1 | Asian/ Pacific Islander | |
| 2 | African/ Black North American | |
| 3 | Caucasian | |
| 4 | East Indian | |
| 5 | Native Canadian | |
| 6 | Other (specify); | |

| | Education -- *highest level achieved* | (√) one |
|---|---|---|
| 1 | Elementary school or less | |
| 2 | Some high school | |
| 3 | High school graduate | |
| 4 | Some college (including CEGEP)/ trade school | |
| 5 | College diploma (including DEC)/ trade school | |
| 6 | Attended university | |
| 7 | University degree | |
| 8 | Post graduate degree | |
| 9 | Other (specify): | |

Employment Status

Did your employment status change as a result of your caregiving role? ❑ No *or* ❑ Yes – *complete below*:

| | Current Employment Status | (√) one |
|---|---|---|
| 1 | Employed full time | |
| 2 | Employed part time | |
| 3 | On paid leave | |
| 4 | On unpaid leave | |
| 5 | Self-employed | |
| 6 | Retired | |
| 7 | Not employed | |
| 8 | Other (specify): | |

| | If YES: What was your previous employment status? | (√) one |
|---|---|---|
| 1 | Employed full time | |
| 2 | Employed part time | |
| 3 | On paid leave | |
| 4 | On unpaid leave | |
| 5 | Self-employed | |
| 6 | Retired | |
| 7 | Not employed | |
| 8 | Other (specify): | |

| | Did your employer (if applicable) allow you to take time to provide care? | (√) one |
|---|---|---|
| 1 | Yes, completely | |
| 2 | Yes, partially | |
| 3 | No, not at all | |

Comments:

**For coordinator/interviewer:**

Qualitative Interview completed: No _______ Yes ________ date: _______

*Instruction to Site Research Coordinator/ Interviewer: Sign and date this form*

Name of Site Research Coordinator: ______________________________

Signature: ______________________ Date Completed: _________ _________ _______
Year Month Day

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