۲t	STATUS AND DEN	10GRA	APHIC	JS Forn	n		Study PID Number:		
								3equ	enc
Р	atient Initials: First M	iddle	Last	-	N	Лa	rital status of Patient:	(v	
					1		Married or living as married		
	Date of Birth: Year	-			2)	Widowed		
	Year	Month	Day	,	3	}	Never married		
					4		Divorced or separated		
	Gender (circle one): F	= or	M		5	,	Other (specify):		
0	xygen therapy: No	Yes _		. Flowrate			Saturation% FEV1		
 Eth	nic/ Racial Group – self ass	sessed	(√) one	E	Educat	io	n highest level achieved		(√) one
1	Asian/ Pacific Islander		Onc		1 Ele	en	nentary school or less	+	<i>3</i> 110
2	African/ Black North Amer	ican					e high school		
3	Caucasian						school graduate		
4	East Indian			T .	4 Sc	m	e college (including CEGEP)/ trade school		
5	Native Canadian				5 Co	olle	ege diploma (including DEC)/ trade school		
6	Other (specify);				6 At	ter	nded university		
					7 Ur	ιiν	ersity degree		
					8 Pc	st	graduate degree		
					9 Ot	he	er (specify):		
En	nployment Status			· <u>:</u>	•		tatus changed as a result of your illness	?	
Cu	rrent Employment Status	(√) one	If YE				previous employment status?	(√) one	
1	Employed full time		1	Employed					
2	Employed part time		2	Employed		im	e		
3	On paid leave		3	On paid l					
4	On unpaid leave		4	·					
5									
6	Retired		6	Retired					
7	Not employed		7	Not empl					
8	Other (specify):		8	Other (sp	ecify):				
	1			i)				1	

0	None	Со	morbid Illnesses – circle all nui	mber co	odes 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	29	Metastatic solid tumour
	Vascular		kg/ ht in metres) ²		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)		even with healing altry

	Palliative Pe	rformance Scale (PPS) – F	Please circle the applica	ble % 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

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 ----->

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 See - 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
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

CRQ	OSE
Sign and date this form	
Name of Site Research Coordinator/Interviewer:	
Signature:	Date Completed:

C	CG STATUS /	AND DEMOC Experience (RAPH Study .	ICS	Apper Form			Study CID Number:	 Site #	 Sequence	- #
n V S la o th c	Definition of CAF ot paid to do so. What we mean be come examples a aundry or prepar ver or now take ne care recipient hair; additional t	PEGIVER in this Y CARE: anything are: household ing special food more time; bank (bathing, feeding you spend)	study: ar ng done chores y s); outsic king and ng, skin c with the c	for the poutook de chore paperwo are, givi	elated or no berson beca over; house s (yard work ork that are ng medicati pient, includ	use h hold k, sno new, ons, ling k	o pro chor ow re you woul eepi	she has a serious illness. es that now take more time moval, running errands, sh took over, or now take mor nd care, toileting, transferring ing him or her company and r unpaid others; attending h	e (for exanopping) te time; dong between die being p	ously ill and is ample, extra that you took lirect care for een bed and present for	_
	ppointments; tra	·		n the ho		se no		nat this is just a partial list.	:		(√) one
[Date of Birth: _	Year I	Month	 Day	,		1 2 3	Married or living as married Widowed Never married	ed		
	Gender (cir	cle one): F	or	М			5	Divorced or separated; no Other (specify):	ot remar	ried	
	elationship to ca u are caring fo		() one	D	o you pres	ently	/ live	with the care recipient?		For <u>how lor</u> have you be	een
1	Husband/ wife	/ partner			☐ No	or]	Yes – complete below		a caregive	er:
2	Parent						-			for the	n+0
3	Parent-in-law			1	<i></i>	/		Yes:		care recipier	ill f
4	Daughter/ son			1	For <u>no</u>			nave you lived with e recipient?		mon	ths
5	Sister/ brother					lile	Care	e recipient:		or	
6	Other (specify):				_ mc	onth	or years		yea	rs
		onth, how man re you spent c e care recipier _ hours per v	aregiving nt?		invo or	lved No –	in u non - <i>sp</i> fan frie	ner family members, frien npaid caregiving for the e ecify how many and number nily members nds ghbours	er of hou hour hour	cipient?	

Please continue on page 2 ----->

			•		
Ethnic/ Racial Group - self assessed				Ec	lucation highest level achie
1	Asian/ Pacific Islander			1	Elementary school or less
2	African/ Black North American			2	Some high school
3	Caucasian			3	High school graduate
4	East Indian			4	Some college (including CEGE
5	Native Canadian			5	College diploma (including DE
6	Other (specify);			6	Attended university
				7	University degree
				8	Post graduate degree
				9	Other (specify):

Ed	Education highest level achieved						
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):						

En	nployment Status			Has your employment status changed as a result of your caregiving role? No or Yes – complete below:					
Cu	rrent Employment Status	(√) one	If YI	ES: What was your <u>previous</u> employment status?	(√) one				
1	Employed full time		1	Employed full time					
2	Employed part time		2	Employed part time					
3	On paid leave		3	On paid leave					
4	On unpaid leave		4	On unpaid leave					
5	Self-employed		5	Self-employed					
6	Retired		6	Retired					
7	Not employed		7	Not employed					
8	Other (specify):		8	Other (specify):					
1 2 3	es your <u>current</u> employmer Yes, completely Yes, partially No, not at all mments:	nt status a	llow yo	ou to take time to provide care?	(√) one				
<u>C</u>	Questions for Caregiver	<u>:</u>							
V	Vould you say you are a Islam, etc.	follower o	of any	particular religious tradition? e.g., Christianity, Jud	laism,				

Would you s	say you	are a foll	ower of an	y particular	religious	tradition?	e.g.,	Christianity,	Judaism,
Islam, et	C.				-				

☐ No	☐ Yes		If Christiar	n, denomination	
How important a	re these belie	efs to you at this p	point in your life?		
	Jnimportant	Somewhat	neither important	Somewhat	☐ Important
		unimportant	nor unimportant	important	

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

	if the person you ar or health care decis	re caring for has an advance directive (living will or power of sions)?
☐ No	☐ Don't know	☐ Yes: advance directive; power of attorney
	where the person y elsewher) if he/she I	ou are caring would prefer to die (for example: at home, in had a choice?
☐ No	☐ Don't know	☐ Yes: at home in hospital elsewhere (please specify)
For coordin	ator/interviewer:	
Qualitative In	nterview complete	ed: No Yes date:
Questionnai	res completed:	
QoL		HADS
CRA		
Instruction to S	ite Research Coordin	nator/ Interviewer: Sign and date this form
Name of Site F	Research Coordinator:	; <u> </u>
Signature:		Date Completed: Month Day

Pc	st-Opioid Experience S	tudy (pos	t-bereaveme	ent)	Site #	Seque	ence#
	finition of CAREGIVER in this s s not paid to do so.	tudy: ar	nyone	e (related or not)	wh	o provided care for someone who	was se	riously ill	and
or too (ba you ap	me examples are: household coreparing special foods); outside k more time; banking and pape thing, feeding, skin care, giving a spent with the care recipient, i	hores y e chore rwork th medica ncluding om paig	ou to s (ya nat yo ations g kee d or i	ok over; househ rd work, snow re ou took over, or t s, wound care, to eping him or her unpaid others; at	old emo took oilet con	person because he or she had a sechores that took more time (for eval, running errands, shopping) the more time; direct care provided ing, transferring between bed and apany and being present for safet ding health care appointments; transferring between the safet ding health care appointments; transferring the safet ding health care appointment ding health care appointment ding health care appointment ding health din	xample, nat you t for the cand d chair; a dy reasor	extra lau ook over are recip additional as; arranç	or ient time ging
Ca	regiver Initials: First M	iddle		Last		Were there other family men friends, or neighbours involv unpaid caregiving for the car recipient?	ed in	Yes No	
Da	ate of Birth: Year M	onth	 C	Day		Did you feel that you had the respite/relief that you needed		Yes	<u> </u>
	Gender (circle one): F	or	М						
		ı	7				_		
Relationship to care recipient. ($$) one				Did you live with the care recipient?			For <u>how long</u> were you a		
	Husband/ wife/ partner			☐ No	or	☐ Yes – complete below		careg	
	Parent		1] ,	for th are reci	
	Parent-in-law	For			If Yes: car ow long did you live with			a. 0 1001	Piorit
	Daughter/ son					ne care recipient?		months	
	Sister/ brother					•			or
;	Other (specify):		1		mo	onths <i>or</i> years	.	\	years

Please continue on page 2 ----->

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

Education highest level achieved		
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):	

role? No or Yes – complete below: Current Employment Status	Employment Status		Did your employment status change as a result of your caregiving				
Employed full time			role? ☐ No or ☐ Yes – complete below:				
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? 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	I Content Entolognient Status I			If YI	If YES: What was your <u>previous</u> employment status?		
2 Employed part time 3 On paid leave 4 On unpaid 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? 1 Yes, completely 2 Yes, partially 3 No, not at all Comments: For coordinator/interviewer: Qualitative Interview completed: No Yes date:	1	Employed full time	0110				
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? 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		. ,		2			
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? 1 Yes, completely 2 Yes, partially 3 No, not at all Comments: For coordinator/interviewer: Qualitative Interview completed: No Yes date:		. , .					
5 Self-employed 6 Retired 7 Not employed 8 Other (specify): Did your employer (if applicable) allow you to take time to provide care? 1 Yes, completely 2 Yes, partially 3 No, not at all Comments: For coordinator/interviewer: Qualitative Interview completed: No Yes date:		-			·		
6 Retired 7 Not employed 8 Other (specify): 8 Other (specify): 8 Other (specify): 7 Not employed 8 Other (specify): 8 Other (specify): 8 Other (specify): 7 Not employed 8 Other (specify): 8 Other (specify): 7 Not employed 8 Other (specify):	5			5	•		
7 Not employed 8 Other (specify): Did your employer (if applicable) allow you to take time to provide care? 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							
8 Other (specify): B Other (specify): Did your employer (if applicable) allow you to take time to provide care? (\(\frac{1}{		Not employed		7	Not employed		
Did your employer (if applicable) allow you to take time to provide care? 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							
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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							
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	Dic	d your employer (if applicable	e) allow yo	ou to t	take time to provide care?	(√)	
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		[X				one	
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	1	Yes, completely					
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	2	O. Vas postially					
Comments: For coordinator/interviewer: Qualitative Interview completed: No Yes date: Instruction to Site Research Coordinator/ Interviewer: Sign and date this form	_	z res, partially					
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Instruction to Site Research Coordinator/ Interviewer: Sign and date this form		or coordinator/intervi	ewei.				
	Qualitative Interview completed: No Yes date:						
	Instruction to Site Becograph Coordinator/ Interviouser: Size and data this form						
Name of Site Research Coordinator:	instruction to Site Research Coordinator/ interviewer: Sign and date this form						
Name of Site Research Coordinator:							
	Name of Site Research Coordinator:						
	_						
Signature: Date Completed: Year Month Day	S	Signature: Date Completed:					