Online Data Supplement

A Formative Evaluation of Patient and Family Caregiver Perspectives on Early Palliative Care in COPD across Disease Severity

Anand S. Iyer, MD, MSPH; J. Nicholas Dionne-Odom, PhD, RN; Stephanie M. Ford; Sheri L. Crump Tims, BSN, RN, CHPN; Elizabeth D. Sockwell, CRNP; Nataliya V. Ivankova, PhD, MPH; Cynthia J. Brown, MD, MSPH; Rodney O. Tucker, MD; Mark T. Dransfield, MD; and Marie A. Bakitas, DNSc, CRNP

No.	Item	Guide Questions/Description	Manuscript Page
Domai	n 1: Research Team and R	eflexivity	
Person	al Characteristics		-
1.	Interviewer/facilitator	Which author/s conducted the	8
		interview or focus group?	
2.	Credentials	What were the researcher's	8, Title Page
		credentials? E.g. PhD, MD	
3.	Occupation	What was their occupation at the	8, Title Page
		time of the study?	
4.	Gender	Was the researcher male or	8
		female?	
5.	Experience and	What experience or training did	8
	training	the researcher have?	
Relatio	onship with Participants	I	I
6.	Relationship	Was a relationship established	8
	established	prior to study commencement?	
7.	Participant	What did the participants know	8
	knowledge of the	about the researcher? e.g. personal	
	interviewer	goals, reasons for doing the	
		research	
8.	Interview	What characteristics were reported	8
	characteristics	about the interviewer/facilitator?	
		e.g. Bias, assumptions, reasons and	
		interests in the research topic	
Domai	n 2: Study Design	· ·	
	etical Framework		
9.	Methodological	What methodological orientation	8, 10
	orientation Theory	was stated to underpin the study?	,
		e.g. grounded theory, discourse	
		analysis, ethnography,	
		phenomenology, content analysis	
Partici	pant Selection	· · · · ·	
10.	Sampling	How were participants selected?	7
		e.g. purposive, convenience,	
		consecutive, snowball	
11.	Method of approach	How were participants	7
		approached? e.g. face-to-face,	
		telephone, mail, email	
12.	Sample size	How many participants were in the	11
		study?	

13.	Non-participation	How many people refused to	11
		participate or dropped out?	
		Reasons?	
Setting	1		
14.	Setting of data	Where was the data collected? e.g.	8
	collection	home, clinic, workplace	
15.	Presence of non-	Was anyone else present besides	8
	participants	the participants and researchers?	
16.	Description of sample	What are the important	11
		characteristics of the sample? e.g.	
		demographic data, date	
Data C	ollection	r	
17.	Interview guide	Were questions, prompts, guides	8, Table E2
		provided by the authors? Was it	
		pilot tested?	
18.	Repeat interviews	Were repeat interviews carried	No
		out? If yes, how many?	
19.	Audio/visual	Did the research use audio or visual	8
	recording	recording to collect the data?	
20.	Field notes	Were field notes made during	No
		and/or after the interview or focus	
		group?	
21.	Duration	What was the duration of the	8
		interviews or focus group?	
22.	Data saturation	Was data saturation discussed?	10-11
23.	Transcripts returned	Were transcripts returned to	10
		participants for comment and/or	
		correction?	
	n 3: Analysis and Findings	6	
	nalysis		
24.	Number of data	How many data coders coded the	10
	coders	data?	
25.	Description of the	Did authors provide a description	10
	coding tree	of the coding tree?	
26.	Derivation of themes	Were themes identified in advance	10
		or derived from the data?	
27.	Software	What software, if applicable, was	10
		used to manage the data?	
28.	Participant checking	Were participant quotations	
		presented to illustrate the themes	11-13, Tables, Figures
		/ findings? Was each quotation	, , , , , , , , , , , , , , , , , ,
		identified? e.g. participant number	
Report	ing		

29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	11-13, Tables, Figures
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	11-13, Tables, Figures
31.	Clarity of major themes	Were major themes clearly presented in the findings?	11-13, Tables, Figures
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	11-13, Figures

Table E2. Sample Interview Guide Questions

What does palliative care mean to you?

What does hospice mean to you?

(After defining early palliative care) Now that you have an idea of early palliative care, what is

your reaction to hearing about this program?

What are your biggest needs living with COPD? What are your biggest challenges?

What are the most challenging symptoms you struggle with? Why are these symptoms

challenging? How has your life changed due to symptoms?

How could early palliative care help you or your loved one living with COPD? Are there any

particular aspects of early palliative care that could be helpful?

When do you think palliative care should be started in COPD?