QODD: SIGNIFICANT OTHER AFTER DEATH INTERVIEW

Part I: Circumstances

Part II: Seven day version

Last month version

Demographics

Interviewee assessment Interviewer assessment

1

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE



QODD: SIGNIFICANT OTHER AFTER DEATH INTERVIEW

* CIRCUMSTANCES - PART 1 *

QUESTIONNAIRE FOR ADMINISTRATION

For Non-University of Washington Sites

PATIENT ID:					
SIGNIFICANT OTHER ID:					
INTERVIEW DATE	/	DAY	<i>I</i>	YEAR -	
START TIME STOP TIME	:				
TOTAL MINUTES:					
VERSION:	7 day recall 30 day recall	7 30			

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INTRODUCTION

During this interview, I will ask you a variety of questions about the last days of your loved one's life. I realize that this may be a difficult topic to discuss given all that has happened for you recently. So, if you feel uncomfortable answering a question or need to stop the interview and reschedule for another time, please let me know. Everything you say is kept confidential. If you do not understand a question, stop me and I will try to explain it to you.

			CIRCUM	ISTANCES	OF DEATH			
1.		ding to our	records, y	our loved o	one died on:	/ MONTH	DAY	_/YEAR
	/	1 YES 2 NO →	What is	the correct	date?	/ MONTH	DAY	_/YEAR
DEAT	TH. FILL IN	BEFORE THE	INTERVIE	W WITH THE	AY FOR THE VI E FAR LEFT D. EE OF DEATH.,	ATE THE F		
this	up in the ca	alendar and	she/he die	ed on	e last 7 days	_ so we w	ant to lool	k from
	/_ date/day	/_ date/day	/_ date/day	/_ date/day	/ date/day	/ date/day	/ / date/	/ /day
(7 th da	ay before de	ath)					(day	of death)
2.					's death, NDENT SAW F		days did	you see
	1	2	3	4	5	6	3	7

Less 6.	1	1-4 hours 2 ar, how often d At least once a week	3	nce Less than o	999 nce DON'T KNOW
	1	2	3	4	
Less					
Less	than 1 hour	1-4 hours	4-8 hours.	8 or more hours	DON'T KNOW
	with her/him	in one day?	(DOES NOT INC	CLUDE DAYS NOT SEEN	v)
5.	On the days	that you saw <u>X</u>	, what	is the least number o	f hours you spent
	1	2	3	4	999
Les	ss than 1 hour	1-4 hours	4-8 hours.	8 or more hours	DON'T KNOW
4.	On the days with him/her		our loved one, v	vhat was the most tim	e you spent
	DAY 7			-	
	DAY 6			-	
	DAY 5			-	
	DAY 4			_	
	DAY 3			-	
	DAY 2			-	

Where was your loved one on each of these days?

(FILL IN NAME OF PLACE. USE "IF PLACE REMAINS SAME.)

3.

7. In your opinion, how long before X 's death was s/he aware that s/he was dying?....

Never	One week	2-4 weeks	2-6 months	6-12 months	DON'T KNOW
Aware	before death	before death	before death	before death	
1	2	3	4	5	999

SCREENING QUESTION

At any time during the last seven days of X 's life, did s/he talk with you in a way that you could understand her/him?

- 1 YES (CONTINUE WITH LAST SEVEN DAYS INTERVIEW)
- 2 NO (CONTINUE WITH LAST MONTH INTERVIEW)

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE



QODD: SIGNIFICANT OTHER AFTER DEATH INTERVIEW

* LAST SEVEN DAYS/LAST MONTH - PART 2 *

PATIENT ID:			
SIGNIFICANT OTHER ID	:		
INTERVIEW DATE	/	/ / Day	 Year

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Seven Day Version

			QUALI	ITY OF DE	ATH AN	ID DYIN	NG (QODI	D)			
The next set	of que	estions a	asks ab	oout the q	uality of	f X	<u>'s</u> (experie	nce	of dying a	and
death during	the la	st sever	n days	of her/his	life.						
l:!!! aala	-l	4	. f .		a a 41a a 4 3			b		J : 4l	
l will ask you				experience	es that <u>z</u>		ma	ay nave	e nac	in the	
last seven da	ys or	ner/nis i	iite.								
Each questio	n has	two par	ts. The	e first par	t will as	k you h	ow often	X		ехр	erienced
each item usi	ing a s	scale wh	ere 0 i	s 'none o	f the tim	e' and	5 is 'all o	f the ti	me'.	(SHOW C	ARD # 1)
The second p	art w	ill ask yo	ou to ra	ate this as	spect of	<u>X</u>		<u>'s</u> c	lying	experien	ice
on a scale fro	m 0 t	o 10, wh	ere 0 is	s a 'terribl	le exper	ience',	and 10 is	an 'a	lmos	t perfect	
experience'.	(SHO	N CARD	# 2)								
Let's start wi	th an i	ovamnla									
		•									
In the last se	ven da	ays of he	er/his li	ife, how o	ften did	<u>X</u>	lis	ten to	mus	ic?	
l'd like you to	use t	he first	scale t	o tell me l	how ofte	n <u>X</u>	lis	tened t	to m	usic durir	ng the
last seven da	ys of	her/his l	ife, wit	th 0 being	"none	of the t	ime" and	5 beir	ng "n	nost of th	е
time" (POI	NT TO	CARD V	VHILE F	READING D	DIRECTIC	NS)					
None of the	A L	ittle Bit	Son	ne of the	A Goo	d Bit	Most of	f the	All	of the	DON"T
Time	of t	he Time	•	Time	of the	Time	Time	е	-	Γime	KNOW
0		1		2	3	ı	4			5	999
Then I will as	k you	how YO)U wou	ıld rate thi	is aspec	t as it :	relates to	the qu	ality	of X	<u>'s</u>
dying experie	ence.	Just kee	ep in m	nind that y	our rati	ng res _l	onse sh	ould be	e bas	sed on ho	w YOU
think this asp	ect a	ffected t	he qua	lity of her	/his life	during	X	<u>'s</u> c	lying	experien	ice.
For this ques	tion, () is a "te	errible	experienc	e" and	10 is ar	ı "almost	perfec	t ex	perience"	
(POINT TO CA	RD WI	HILE REA	DING E	DIRECTION	IS)						
Terrible Experience										Almost Perfect	DON"T KNOW
0	1	2	3	4	5	6	7	8	9	10	999

Do you have any questions before we begin?

SECTION A

During the last seven days of X 's life, 1a. How often did X appear to have her/his pain under control?.... DON'T NO None of A Little Some of A Good Most of All of **KNOW RESPONSE** the Time Bit of the the Time Bit of the the Time the Time Time Time 0 1 2 3 4 5 999 777 How would you rate this aspect of X 's dying experience?.... **Almost** DON'T **Terrible** NO **KNOW** RESPONSE Perfect **Experience** 1 2 3 5 6 7 8 9 10 999 777 2a. How often did X appear to have control over what was going on around her/him?.... DON'T NO None of A Little Some of A Good Most of All of **KNOW RESPONSE** the Time Bit of the the Time Bit of the the Time the Time Time Time 0 2 3 1 4 5 999 777 b. How would you rate this aspect of X 's dying experience?.... DON'T NO **Terrible** Almost **RESPONSE** KNOW **Experience** Perfect 2 5 6 8 1 3 7 10 999 777 0 How often was X able to feed her/himself? 3a. None of A Little Some of A Good Most of All of DON'T NO **KNOW RESPONSE** Bit of the the Time Bit of the the Time the Time the Time Time Time 0 1 2 3 999 777 4 5 How would you rate this aspect of X 's dying experience? **Terrible** DON'T NO Almost **KNOW RESPONSE Experience** Perfect 3 5 999 1 2 6 7 8 9 10 777

(NOTE: IF THE RESPONDENT UNDERSTANDS THE RESPONSE OPTIONS, IT IS NOT NECESSARY TO READ THEM AFTER EACH QUESTION. HOWEVER, SOME RESPONDENTS MAY NEED THE REPETITION.)

During the last seven days of X______'s life,

4a.	How	often	did 2	<u>X</u>		_ have	s blad	der or	bowels?	••				
None the Ti	Time Bit of the th Time					me of Time		A God Bit of t	the		Most of All of the Time the Time		DON'T KNOW	NO RESPONSE
0			1			2		3			4	5	999	777
b.	How	would	d you	ı rate	e this	aspec	t of <u>></u>	(<u>'s</u> d	lying e	experie	nce?		
Terrible Experien 0		2	<u>)</u>	3	4	5	6	7	8	9		most rfect	DON'T KNOW 999	NO RESPONSE 777
5a.	How	often	did 2	X		_ brea	the c	omfort	tably?					
	None of A Little Some of A Good Most of the Time Bit of the Time Time Time Time A Good Time Time Time											DON'T KNOW	NO RESPONSE	
0			1			2		3			4	5	999	777
b.	How	would	d you	ı rate	e this	aspec	t of <u>></u>	(<u>'s</u> d	lying e	experie	nce?		
Terrible Experien 0		2	2	3	4	5	6	7	8	9		most rfect	DON'T KNOW 999	NO RESPONSE 777
6a.	How	often	did 2	X		_appe	ar to	feel a	t peac	e with	dying	?		
None the Ti		Bit	Little of th			ne of Time		A Goo Bit of t	the		st of Time	All of the Time	DON'T KNOW	NO RESPONSE
0			1			2		3			4	5	999	777
b.	How	would	d you	ı rate	e this	aspec	t of <u>></u>	(<u>'s</u> d	lying e	experie	nce?		
Terrible Experien		2	<u>)</u>	3	4	5	6	7	8	9		most rfect	DON'T KNOW 999	NO RESPONSE 777

During the last seven days of X_____'s life,

7a.	How o	ften did	I <u>X</u>	6									
None the Tir		Bit of the the Time Bit of the the Time						st of Time	All of the Time	DON'T KNOW	NO RESPONSE		
0		1		2	2		3			4	5	999	777
b.	How w	ould yo	ou rate	e this a	spect	of <u>2</u>	Χ	<u>'s</u> d	ying e	experie	nce?		
Terrible Experience	се									Pe	nost rfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10		999	777
8a.	How o	ften did	۱ <u>X</u>	la	augh	and	smile?						
None the Tir		A Litt Bit of t	the	Some the T			A Goo Bit of th Time	ne		st of Time	All of the Time	DON'T KNOW	NO RESPONSE
0		1		2	2		3			4	5	999	777
b.	How w	ould yo	ou rate	this a	spect	of <u>2</u>	X	<u>'s</u> d	ying e	experie	nce?		
Terrible Experience											nost rfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10		999	777
		ften did d to do?		6	appea	ar to	have th	ne ene	ergy t	o do m	ost things	that s/he	
None the Tir		A Litt Bit of t	the	Some the T			A Goo Bit of th Time			st of Time	All of the Time	DON'T KNOW	NO RESPONSE
0		1		2	2		3			4	5	999	777
b. How would you rate this aspect of X 's dying experience?													
Terrible						8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777		
Ü	•	-	J	•	•	•	•	J	J				

During the last seven days of X 's life, 10a. How often did X appear to be worried about strain on her/his loved ones?.... DON'T NO None of A Little Some of A Good Most of All of KNOW **RESPONSE** the Time Bit of the the Time Bit of the the Time the Time Time Time 0 1 2 3 5 999 777 b. How would you rate this aspect of X 's dying experience?.... **Terrible Almost** DON'T NO KNOW **RESPONSE Experience Perfect** 1 2 3 5 6 7 9 999 0 10 777 11a. How often did X appear to keep her/his dignity and self-respect? DON'T NO None of A Little Some of A Good Most of All of KNOW **RESPONSE** the Time Bit of the the Time Bit of the the Time the Time Time Time 0 1 2 3 5 4 999 777 b. How would you rate this aspect of X 's dying experience? DON'T NO **Terrible Almost KNOW RESPONSE Perfect Experience** 3 5 1 6 7 9 10 777 999

12 a,b Did X_____ have a living spouse or partner?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).

1 YES
2 NO ______ (SKIP TO QUESTION 13)

12a. How often did X spend time with her/his spouse or partner?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b.	Н	w v	woul	d yo	u rat	e this	aspec	t of X		<u>'s</u> d	ying e	xperie	nce?		
Terrib Experie 0	nce	1	:	2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777
Duri	ng t	he la	ast s	seve	n day	s of X	<u> </u>		's life,						
13a,	b. E	oid 2	x			_ have	living	g child	dren?						
						ER TO NSE PA			DO NC	T ASK	BUT C	IRCLE	THE CORR	ECT NUMB	ER
	- 1		YES	6											
	2		NO				-	(SKII	P TO Q	UESTI	ON 14)				
\downarrow															
13a.	Н	ow o	often	ı did	<u>X</u>		_sper	ıd tim	e with	her/h	is chile	dren?			
Non the T				Litt t of t Time	he		me of Time		A Goo Bit of t	he		st of Time	All of the Time	DON'T KNOW	NO RESPONSE
C)			1			2		3		4	4	5	999	777
b.	Н	ow v	woul	d vo	ou rate	e this	aspec	t of X	T	's d	vina e	xperiei	nce?		
Terrib Experie 0	le nce	1		2	3	4	5	6	7	8	9	Aln	nost rfect	DON'T KNOW 999	NO RESPONSE 777
14a.	Н	ow (often	ı did	X		_sper	ıd tim	e with	other	family	and fr	riends?		
Non the T			Bit	Litt t of t Time	he		me of Time		A Goo Bit of t	he		st of Time	All of the Time	DON'T KNOW	NO RESPONSE
C)			1			2		3		4	4	5	999	777
b.	Н	ow v	woul	d yo	u rat	e this	aspec	t of X		<u>'s</u> d	ying e	xperie	nce?		
Terrib Experie 0	nce	1	·	2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777

During the last seven days of X 's life, 15a. How often did X spend time alone?.... DON'T NO None of A Little Some of A Good Most of All of **KNOW RESPONSE** the Time Bit of the the Time Bit of the the Time the Time Time Time 0 1 2 3 4 5 999 777 b. How would you rate this aspect of X 's dying experience?.... DON'T **Terrible Almost** NO **KNOW RESPONSE** Perfect **Experience** 1 2 5 6 7 8 9 10 999 777 0 16,a,b. Did X have pets? (IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN). - 1 YES NO (SKIP TO SECTION B) How often did X spend time with pets? DON'T NO None of A Little Some of A Good Most of All of **KNOW RESPONSE** Bit of the the Time Bit of the the Time the the Time Time Time Time 0 1 2 3 4 5 999 777

Terrible

Experience 0

1

2

3

b. How would you rate this aspect of X 's dying experience?

6

7

8

9

5

NO

RESPONSE

777

DON'T

KNOW

999

Almost

Perfect

10

SECTION B

for a	"YES" 0 indic	or "Nating	NO" res _l "a terri	oonse ble exp	first. Derien	Then, ce" an	l'll asl d 10 i	k you t ndicat	o rate ing " <i>a</i>	lid a certain acti the quality of th an almost perfect SE CARD #2 FOR	e experien	ce
Durin	g the	last s	even da	ys of X	<u> </u>	,	s life,					
17a.	Did <u>></u>	(арре	ar to fi	nd me	aning	and p	ourpos	e in h	er/his life?		
		1 2 999 777								UESTION 18) UESTION 18)		
b.	How	would	d you ra	te this	aspec	t of X		<u>'s</u> d	ying ex	xperience?		
Terrible Experien 0	_	2	2 3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
18a.	Was	X		_ toucl	ned or	hugg	ed by	her/hi	s love	d ones?		
b.	How	1 2 999 777 would	REFU	「KNOW SED, N te this	O RES		E		(GO	TO QUESTION 1 TO QUESTION 1 xperience?	,	
Terrible Experien 0		2	2 3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777

During	g the I	ast se	ven day	ys of X	<u> </u>		s life,					
19a.		irthda		_ atten	d any	import	tant e	events -	- for ex	cample weddings	s, graduat	ions,
		1 2 999 777	YES NO DON'T REFUS			SPONSE	[-			TO QUESTION 20) TO QUESTION 20)		
b.	How	would	you rat	te this	aspe	ct of X		<u>'s</u> dy	ing ex	perience?		
Terrible Experien		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
20a.	Were	all of 2	X	<u>'s</u> l	nealth	n care c	osts	taken (care of	f?		
		1 2 999 777	YES NO DON'T REFUS			SPONSE				TO QUESTION 21) TO QUESTION 21)		
b.	How	would	you rat	e this	aspe	ct of X		<u>'s</u> dy	ing ex	perience?		
Terrible Experien		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
21a.	Did <u>X</u>		_ say g	oodby	e to l	oved o	nes?					
		1 2 999 777	YES NO DON'T REFUS			SPONSE	<u> </u>	\Rightarrow	•	TO QUESTION 22) TO QUESTION 22)		
b.	How	would	you rat	te this	aspe	ct of X		<u>'s</u> dy	ing ex	perience?		
Terrible Experien		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777

22a.	Did X		_ have	one or	more	visits	from	a reliç	gious d	or spiritual adv	isor?	
		1 2 999 777	YES NO DON'T REFUS						· (GO	TO QUESTION TO QUESTION	23) 23)	
b.	How	would	you rat	e this	aspec	ct of X		<u>'s</u> d	ying ex	xperience?		
Terrible Experien 0		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
23a.	Did <u>X</u>	,	_ have	a spiri	tual s	ervice	or ce	remor	y befo	ore his/her deaf	th?	
		1 2 999 777	YES NO DON'T REFUS	KNOW SED, NO	/ O RES	PONSE	≣			TO QUESTION TO QUESTION		
b.	How	would	you rat	e this	aspec	t of <u>X</u>		<u>'s</u> d	ying ex	xperience?		
Terrible Experien		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
24a.	Was	a mech	nanical	ventila	ator o	r kidne	ey dia	lysis u	sed to	prolong <u>X</u>	<u>'s</u> life?	
		1 2 999 777	YES NO DON'T REFUS			PONSE	≣			TO QUESTION TO QUESTION		
b.	How	would	you rat	e this	aspec	t of X		<u>'s</u> d	ying ex	xperience?		
Terrible Experien 0		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777

During the last seven days of X______'s life,

25a.	5a. Did X have the means to end her/his life if s/he needed to?												
		1 2 999 777		KNOW SED, N		PONSE	Ē			TO QUESTION 2 TO QUESTION 2			
b.	How	would	l you ra	te this	aspec	t of X		<u>'s</u> dy	ing e	xperience?			
Terrible Experien	_	2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777	
26a.	Did <u>X</u>			_clear	up an	y bad	feelir	ngs with	n othe	ers?			
		1 2 999 777				PONSE				O TO SECTION C, O TO SECTION C,			
b.	How	would	l you ra	te this	aspec	t of X		<u>'s</u> dy	ing e	xperience?			
Terrible Experien		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777	
SECT	ION C												
The n	ext se	t of q	uestion	s does	not u	se a tiı	melin	e of the	e last	seven days of <u>></u>	(<u>'s</u>	
life. I	nstead	d, thes	se ques	tions a	sk if <u>></u>	(_ has	s EVER	done	an activity. Fo	r the first pa	art of	
-		•								part of the que	• •		
										ith the same rat			
		•				•				"an almost per	rfect experie	ence".	
(USE)	CARD 1	#3 FUI	K PAKI	A,IF	NEEDE	D, AND	CAR	D #2 FO	K PA	KID)			
27a.	Did X		have	her/hi	s fune	ral arr	ange	ments i	n ord	er prior to deatl	h?		
		1 2 999 777		KNOW SED, N		PONSE		\Rightarrow	•	O TO QUESTION :	,		

D.	HOW	would y	ou rat	e this	aspe	Ct Of <u>X</u>	<u> </u>	<u> </u>	ying e	xperience?		
Terrible Experien										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777
28a.	Did X			discu	uss he	er/his v	wishe	s for e	nd of I	ife care with he	r/his docto	rfor
	exam	ple, res	uscita	tion o	r inte	nsive	care?					
		2 I 999 I		KNOV SED, N		SPONS	E		•	TO SECTION D)		
b.	How	would y	ou rat	e this	aspe	ct of X		<u>'s</u> d	ying e	xperience?		
Terrible Experien	ce			_	_		_	•		Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777
	ION D	•	ask a	bout v	where	, with	whom	ı, and l	how <u>X</u>	died.		
29a.	Wher	e did yo	ur lov	ed on	e die	? (CIRC	CLE TH	IE NUN	IBER A	ND FILL IN BLAN	IKS AS NEEL	DED)
	1	PATIEN	NT'S C)WN F	IOME							
	2	SURRO	OGATI	E'S HO	OME (IF OTH	IER T	HAN P	ATIEN	T'S HOME)		
	3	OTHER Whose										
	4	HOSPI		al?								
	5	IN-PAT Which i			_	·						
	6	Which I	nursin	g hom	е					FACILITY)		
	7	OTHER Which		olace?								
	999	DON'T I	KNOW	,				-	(GO	TO QUESTION :	30)	
	777	REFUS	ED, NO) RESI	PONSE	Ξ		-	(GO	TO QUESTION :	30)	

b.	Ho	w w	ould	you ra	ate this	aspe	ct of <u>X</u>		<u>'s</u> d	leath?	••		
Terrible Experience											Almost Perfect	DON'T KNOW	NO RESPONSE
0		1	2	3	4	5	6	7	8	9	10	999	777
30a.	Wa	s aı	nyon	e pres	ent at t	the mo	oment	of <u>X</u>		<u>'s</u> de	eath?		
		,	1 2 999 777		T KNOW JSED, N		SPONS	E		•	TO QUESTION : TO QUESTION :	,	
b.	Но	w w	ould	you ra	ate this	aspe	ct of <u>X</u>		<u>'s</u> d	leath?			
Terrible Experience	се	1	2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
J		•	_	J	7	Ü	O	,	Ü	J	10	000	,,,
31a.	In t	he i	mom	ent be	fore <u>X</u>		<u>'s</u> de	eath, w	as he	/she			
				1	Awak	(e							
				2	Asle	∍p							
				3	In a c	:oma/เ	ıncon	scious	3				
				999 777	_	T KNOV ISED, N		SPONS	SE		(GO TO SECT		
b.	Но	w w	ould	you ra	ate this	aspe	ct of <u>X</u>		<u>'s</u> d	leath?			
Terrible Experience	се										Almost Perfect	DON'T KNOW	NO RESPONSE
0		1	2	3	4	5	6	7	8	9	10	999	777

SECTION E

The last two questions in this section ask for your overall rating of the last seven days of X 's life and her/his moment of death. (SHOW CARD #2)

32. How would you rate the quality of X 's life during the last seven days of her/his life?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
. 0	1	2	3	4	5	6	7	8	9	10	999	777

33. How would you rate the quality of X 's moment of death?....

Terrible										Almost	DON'T	NO
Experience										Perfect	KNOW	RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777

Last Month Version

QUALITY OF DEATH AND DYING (QODD)													
The next set o	of ques	tions a	ısks a	bout the q	uality of <u>X</u>		's ex	perien	ıce	of dying a	ınd		
death during t	he last	montl	h of he	er/his life.									
I will ask you last month of			er of	experience	es that <u>X</u>		may	have	hac	I in the			
Each question	n has tv	wo par	ts. Th	ne first part	will ask	you how	often <u>X</u>			exp	erienced		
each item usi	ng a sc	ale wh	ere 0	is 'none of	the time	and 5 is	s 'all of t	he tim	ıe'.	(SHOW CA	ARD # 1)		
The second p	art will	ask yo	ou to r	ate this as	pect of <u>X</u>			<u>'s</u> dy	/ing	experien	ce		
on a scale fro	m 0 to	10, wh	ere 0 i	is a 'terribl	e experie	nce', an	d 10 is a	n 'aln	nos	t perfect			
on a scale from 0 to 10, where 0 is a 'terrible experience', and 10 is an 'almost perfect experience'. (SHOW CARD # 2)													
Let's start wit	h an ex	ample											
In the last month of her/his life, how often did X listen to music?													
I'd like you to	I'd like you to use the first scale to tell me how often X listened to music during the												
last month of	her/his	ilife, w	rith 0 k	being "non	e of the t	ime" and	— d 5 being	g "mo	st o	f the time	"…		
(POINT TO CAF	RD WHII	LE REA	DING I	DIRECTION	S)								
None of the Time		tle Bit e Time		me of the Time	A Good of the T		lost of th	ne		of the Time	DON"T KNOW		
0		1		2	3		4			5	999		
Then I will ask	c you h	ow YO	U wou	uld rate thi	s aspect a	as it rela	ates to th	ne qua	ality	of X	<u>'s</u>		
dying experie	nce. J	ust kee	ep in n	nind that y	our rating	, respon	se shou	ld be	bas	ed on ho	w YOU		
think this asp	ect affe	ected t	he qua	ality of her	/his life d	uring <u>X</u>		<u>'s</u> dy	/ing	experien	ce.		
For this quest	ion, 0 i	s a "te	rrible	experience	e" and 10	is an "a	almost p	erfect	exp	perience".	ı		
(POINT TO CAF	RD WHII	LE REA	DING I	DIRECTION	S)								
Terrible Experience										Almost Perfect	DON"T KNOW		
0	1	2	3	4	5	6	7	8	9	10	999		

Do you have any questions before we begin?

SECTION A

Durin	g the la	ast mon	th of	X			's life,	1						
1a.	How o	ften die	<u> </u>		_ appe	ar to	have l	her/his	s pain	under	control?			
None the Ti		A Litt Bit of Time	the		me of Time		A Goo Bit of t	he		st of Time	All of the Time	DON'T KNOW	NO RESPONSE	
0		1			2		3		4	4	5	999	777	
b.	How v	vould y	ou rat	e this	aspec	t of <u>X</u>	(<u>'s</u> d	lying e	xperie	nce?			
Terrible Experien		2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777	
2a.	her/him?													
	None of A Little Bit of the Time				me of Time		A Goo Bit of t	he		st of Time	All of the Time	DON'T KNOW	NO RESPONSE	
0		1			2		3		2	4	5	999	777	
b.	How v	vould y	ou rat	e this	aspec	t of <u>X</u>	(<u>'s</u> d	lying e	xperie	nce?			
Terrible Experien		2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777	
3a.	How c	often wa	ıs <u>X</u>		able	to fee	ed her/	himse	elf?					
	3a. How often was X None of A Little the Time Bit of the Time				me of Time		A Goo Bit of t	he		st of Time	All of the Time	DON'T KNOW	NO RESPONSE	
0	0 1				2		3		4	4	5	999	777	
b.	How v	vould y	ou rat	e this	aspec	t of <u>></u>	(<u>'s</u> d	lying e	xperie	nce?			
	Terrible Experience				5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777	

(NOTE: IF THE RESPONDENT UNDERSTANDS THE RESPONSE OPTIONS, IT IS NOT NECESSARY TO READ THEM AFTER EACH QUESTION. HOWEVER, SOME RESPONDENTS MAY NEED THE REPETITION.)

During the last month of X			X			's life,							
4a.	How	often di	d <u>X</u>		_ have	con	trol of	her/his	s bladd	ler or l	bowels?		
None the Ti		A Lit Bit of Tim	the		me of Time		A Goo Bit of t	he	Mos the	st of Time	All of the Time	DON'T KNOW	NO RESPONSE
0		1			2		3		4	1	5	999	777
b.	How	would y	ou rat	e this	aspec	t of <u>></u>	(<u>'s</u> d	ying ex	xperie	nce?		
Terrible Experien		2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777
5a.	How	often di	d <u>X</u>		_ breat	the c	omfort	ably?					
	None of A Little the Time Bit of the Time			me of Time		A Goo Bit of t	he		st of Time	All of the Time	DON'T KNOW	NO RESPONSE	
0				2		3		4	1	5	999	777	
b.	How	would y	ou rat	e this	aspec	t of <u>></u>	(<u>'s</u> d	ying ex	xperie	nce?		
Terrible Experien		2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777
6a.	How	often di	d <u>X</u>		_ appe	ar to	feel at	peac	e with	dying?	?		
	None of A Little the Time Bit of the Time			me of Time		A Goo Bit of t	he	Mos the	st of Time	All of the Time	DON'T KNOW	NO RESPONSE	
0		1			2		3		4	1	5	999	777
b.	How	would y	ou rat	e this	aspec	t of <u>></u>	(<u>'s</u> d	ying ex	xperie	nce?		
Terrible Experien		2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777

7a. How often did	X appe	ar to be unafraid	l of dying?			
None of A Little the Time Bit of th Time		A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0 1	2	3	4	5	999	777
b. How would you	ı rate this aspec	t of X 's	dying experie	nce?		
Terrible Experience 0 1 2	3 4 5	6 7 8	Pe	most rfect	DON'T KNOW 999	NO RESPONSE 777
8a. How often did	Xlaugh	and smile?				
None of A Little the Time Bit of th Time		A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0 1	2	3	4	5	999	777
b. How would you	ı rate this aspec	t of X 's	dying experie	nce?		
Terrible Experience 0 1 2	3 4 5	6 7 8	Pe	nost rfect	DON'T KNOW 999	NO RESPONSE 777
9a. How often did wanted to do?	X appe	ar to have the e	nergy to do m	ost things	that s/he	
None of A Little the Time Bit of th Time		A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0 1	2	3	4	5	999	777
b. How would you	ı rate this aspec	t of X 's	dying experie	nce?		
Terrible Experience	2 4 5	6 7 0	Pe	most rfect	DON'T KNOW	NO RESPONSE
0 1 2	3 4 5	6 7 8	9 10		999	777

During the last month of X ______''s life,

During the last month of X 's life, 10a. How often did X appear to be worried about strain on her/his loved ones?.... Some of DON'T NO None of A Little A Good Most of All of **KNOW RESPONSE** the Time Bit of the the Time Bit of the the Time the Time Time Time 0 1 2 3 5 999 777 b. How would you rate this aspect of X 's dying experience?.... DON'T **Terrible Almost** NO KNOW **RESPONSE Experience Perfect** 1 2 3 5 6 7 9 10 999 0 777 11a. How often did X appear to keep her/his dignity and self-respect? DON'T NO None of A Little Some of A Good Most of All of KNOW **RESPONSE** the Time Bit of the the Time Bit of the the Time the Time Time Time 0 1 2 3 5 4 999 777 b. How would you rate this aspect of X 's dying experience? DON'T NO **Terrible** Almost **KNOW RESPONSE Perfect Experience** 3 1 5 6 7 9 10 777 999 12 a,b Did X_____ have a living spouse or partner? (IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN). - 1 YES



12a. How often did X spend time with her/his spouse or partner?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. Ho	w would y	ou rate	e this	aspec	t of X		<u>'s</u> d	ying e	xperie	nce?		
Terrible Experience 0	1 2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777
During th	e last mor	nth of 2	X			's life,						
13 a,b.	Did X			_ have	e livin	g chile	dren?					
	NOW THE OW THE R					DO NO	T ASK	BUT C	IRCLE	THE CORR	ECT NUMB	ER
1	YES				,							
2	NO —				(SKIF	P TO Q	UESTI	ON 14)				
\downarrow												
13a. Ho	w often di	d <u>X</u>		_spen	d tim	e with	her/h	is child	dren?			
None of the Time	None of A Little the Time Bit of the Time			me of Time		A Goo Bit of t				All of the Time	DON'T KNOW	NO RESPONSE
0	1			2		3		4	1	5	999	777
h Ho	w would y	ou rate	e this	asneo	et of X		h e'	vina e	xnerie	nce?		
Terrible Experience 0	1 2	3	4	5	6	7	<u> </u>	9	Alr	nost rfect	DON'T KNOW 999	NO RESPONSE 777
14a. Ho	w often di	d <u>X</u>		_spen	d tim	e with	other	family	and fi	riends?		
None of the Time				me of Time		A Goo Bit of t Time	the	Mos the	st of Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1			2		3		۷	1	5	999	777
b. Ho	w would y	ou rat	e this	aspec	t of X		<u>'s</u> d	ying e	xperie	nce?		
Terrible Experience 0	1 2	3	4	5	6	7	8	9		nost rfect	DON'T KNOW 999	NO RESPONSE 777

During the last month of X_____'s life,

15a. How often did X spend time alone?....

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X 's dying experience?....

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
. 0	1	2	3	4	5	6	7	8	9	10	999	777

16,a,b. Did X_____ have pets?

(IF YOU KNOW THE ANSWER TO THIS ITEM, DO NOT ASK BUT CIRCLE THE CORRECT NUMBER AND FOLLOW THE RESPONSE PATTERN).



16a. How often did X spend time with pets?

None of the Time	A Little Bit of the Time	Some of the Time	A Good Bit of the Time	Most of the Time	All of the Time	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	999	777

b. How would you rate this aspect of X 's dying experience?

Terrible Experience										Almost Perfect	DON'T KNOW	NO RESPONSE
. 0	1	2	3	4	5	6	7	8	9	10	999	777

SECTION B	SE	CT	ΊO	Ν	В
-----------	----	----	----	---	---

for a with ("YES" o) indica	or "NC ting " 3 IF N)" resp a terrib	onse f le exp	irst. T	Γhen, ∣ ce" an	l'll ask d 10 ii	you to	o rate ng " a	id a certain acthe quality of n almost perf	the experien	ce
Durin	g the la	st mo	nth of	x		's life,						
17a.	Did X		_ appea	ar to fi	nd me	aning	and p	urpos	e in he	er/his life?		
h		1 2 999 777	YES NO DON'T REFUS	SED, NO	O RESI			→	(GO	TO QUESTION TO QUESTION	,	
		ouiu	you rat	e uns	aspec	1 01 <u>7</u>		<u> </u>	ilig ex	xperience?	DON'T	NO
Terrible Experien		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	RESPONSE
18a.	Was <u>X</u>			touch	ed or	hugge	ed by	her/his	s loved	d ones?		
		1 2 999 777	YES NO DON'T REFUS	_		PONSE				TO QUESTION TO QUESTION		
b.	How w	ould	you rat	e this	aspec	t of <u>X</u>		<u>'s</u> dy	ring ex	perience?		
Terrible Experien 0		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777

Durin	g the	last m	onth of	X		's life,						
19a.		(oirthd		_atten	d any	impor	tant e	events -	for ex	ample weddings	s, graduat	ions,
		1 2 999 777	YES NO DON'T REFUS	KNOW SED, N		PONSE	Ē			TO QUESTION 20) TO QUESTION 20)		
b.	How	would	d you rat	te this	aspec	ct of X		<u>'s</u> dy	ing ex	perience?		
Terrible Experien 0		2	2 3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
20a.	Were	all of	F <u>X</u>	<u>'s</u> l	health	care	costs	taken o	are of	?		
		1 2 999 777	YES NO DON'T REFUS	KNOW SED, N	/ O RES	PONSE	Ē			TO QUESTION 21, TO QUESTION 21,		
b.	How	would	d you rat	te this	aspec	ct of X		<u>'s</u> dy	ing ex	perience?		
Terrible Experien 0		2	2 3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
21a.	Did <u>X</u>	(say g	oodby	e to lo	oved o	nes?					
		1 2 999 777		KNOW SED, No		PONSE	Ē	=		TO QUESTION 22) TO QUESTION 22)		
b.	How	would	d you rat	te this	aspec	ct of X		<u>'s</u> dy	ing ex	perience?		
Terrible Experien		2	2 3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
U	ı	2	. 3	7	J	U	,	J	J	10	999	111

22a.	Did	<u>X</u>			have o	one oi	r more	visits	fron	n a religi	ious d	or spiritual advis	or?	
			1 2 999 777		YES NO DON'T REFUS	KNOW ED, N	/ O RES	PONSE	<u> </u>	=) TO QUESTION 23) TO QUESTION 23		
b.	Но	w v	voul	d y	ou rate	e this	aspec	t of X		<u>'s</u> dy	ing ex	cperience?		
Terrible Experien	се	1	2	2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
23a.	Did	<u>X</u>			have a	a spiri	itual s	ervice	or c	eremony	/ befo	re his/her death	?	
			1 2 999 777		YES NO DON'T REFUS	KNOW ED, No	/ O RES	PONSE	Ξ	\Rightarrow	•) TO QUESTION 24) TO QUESTION 24	,	
b.	Но	w v	voul	d y	ou rate	e this	aspec	t of X		<u>'s</u> dy	ing ex	cperience?		
Terrible Experien 0	се	1	;	2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
24a.	Wa	s a	me	cha	anical v	ventila	ator o	r kidne	y dia	alysis us	sed to	prolong <u>X</u>	<u>'s</u> life?	
			1 2 999 777		YES NO DON'T REFUS			PONSE	<u> </u>	=	•) TO QUESTION 25) TO QUESTION 25	,	
b.	Но	w v	voul	d y	ou rate	e this	aspec	t of X		<u>'s</u> dy	ing ex	rperience?		
Terrible Experien				•			_		_			Almost Perfect	DON'T KNOW	NO RESPONSE
0		1	2	2	3	4	5	6	7	8	9	10	999	777

During the last month of X_____'s life,

25a.	Did X		have	the m	eans t	o end	her/h	is life if	s/he	needed to?		
		1 2 999 777		「KNOV SED, N		PONSE	Ē	=	•	O TO QUESTION 2 O TO QUESTION 2	,	
b.	How	would	l you ra	te this	aspec	t of X		<u>'s</u> dy	ing e	xperience?		
Terrible Experien 0		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
26a.	Did <u>X</u>	,		_clear	up an	y bad	feeliı	ngs witl	n othe	ers?		
		1 2 999 777	YES NO DON' ¹ REFU	KNOV SED, N	V O RES	PONSE	Ē	\Rightarrow	(GC (GC	O TO SECTION C) O TO SECTION C)		
b.	How	would	l you ra	te this	aspec	t of X		<u>'s</u> dy	ing e	xperience?		
Terrible Experien		2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
SECT	ION C											
The n	ext se	t of q	uestion	s does	not u	se a tiı	melin	e of the	e last	month of X	<u>'s</u> life).
Instea	ad, the	se qu	estions	ask if	X		_ has	s EVER	done	an activity. For	the first p	art of
_		_								part of the ques	_	
										ith the same rat		
		•				•				s "an almost per	fect experie	ence".
(USE	CARD i	#3 FOF	R "PART	A", IF I	NEEDE	D, AND	CAR	D #2 FO	R "PA	RIB")		
27a.	Did X	<u>, </u>	have	her/hi	s fune	ral arr	ange	ments i	n ord	er prior to death	1?	
		1 2 999 777		「KNOV SED, N		PONSE	Ē	\Rightarrow		O TO QUESTION 2 O TO QUESTION 2	,	

D.	HOW	would y	ou rat	e tnis	aspe	Ct Of <u>X</u>	<u> </u>	<u> </u>	ying ex	xperience?		
Terribl Experier										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777
28a.	Did <u>X</u>			discu	ıss he	er/his v	wishe	s for e	nd of l	ife care with he	er/his docto	rfor
	exam	ıple, resi	uscita	tion o	r inte	nsive	care?					
		2 1 999 [KNOW SED, N		SPONS	E			TO SECTION D		
b.	How	would y	ou rat	e this	aspe	ct of <u>X</u>		<u>'s</u> d	ying e	xperience?		
Terribl Experier										Almost Perfect	DON'T KNOW	NO RESPONSE
0	1	2	3	4	5	6	7	8	9	10	999	777
	ΓΙΟΝ D next qu		ask a	bout v	where	, with	whom	ı, and l	how <u>X</u>	died.		
29a.	Wher	e did yo	ur lov	ed on	e die	? (CIRC	CLE TH	IE NUM	IBER AI	ND FILL IN BLAN	IKS AS NEED	PED)
	8	PATIEN	NT'S C	WN H	IOME							
	9	SURRO	OGATE	E'S HO	OME (IF OTH	HER T	HAN P	ATIEN [®]	T'S HOME)		
	10	OTHER Whose										
	11	HOSPI		al?								
	12	IN-PAT Which i				?						
	13	Which r	nursing	g hom	е					FACILITY)		
	14	OTHER Which o		olace?								
	999	DON'T I	KNOW						(GO	TO QUESTION	30)	
	777	REFUSI	ED, NO) RESF	PONS	Ξ		-	(GO	TO QUESTION	30)	

b.	Н	ow v	vould	l you ra	ate this	aspe	ct of X	<u> </u>	<u>'s</u> c	leath?.			
Terribl Experier		1	2	3	4	5	6	7	8	9	Almost Perfect 10	DON'T KNOW 999	NO RESPONSE 777
30a.	W	as a	nyon	e pres	ent at	the mo	oment	of X		<u>'s</u> d	eath?		
			1 2 999 777		T KNO\ JSED, N		SPONS	E			O TO QUESTION TO QUESTION :		
b.	Н	ow v	vould	l you ra	ate this	aspe	ct of <u>X</u>	<u> </u>	<u>'s</u> 0	leath?			
Terribl Experier		ı	•			_	0	_	•	0	Almost Perfect	DON'T KNOW	NO RESPONSE
0		1	2	3	4	5	6	7	8	9	10	999	777
31a.	In	the	mom	ent be	fore X		's de	eath, w	vas he	/she			
				1	Awal			·					
				2	Asle	ер							
				3	In a d	coma/ı	uncon	scious	6				
				999 777		T KNO JSED, I	W NO RE	SPONS	SE		(GO TO SEC (GO TO SEC		
b.	Н	ow v	vould	l you ra	ate this	saspe	ct of <u>X</u>	<u> </u>	<u>'s</u> d	leath?			
Terribl Experier											Almost Perfect	DON'T KNOW	NO RESPONSE
0		1	2	3	4	5	6	7	8	9	10	999	777

SECTION E

1111	e la	ast two	questi	ons in	this	sectio	n ask t	for yo	ur ove	rall ra	ting of the last	month of	
X		•	<u>s</u> life a	and he	r/his	mome	nt of c	leath.	(SHOV	V CARI	D #2)		
32.		How w	_		e the	qualit	y of <u>X</u>		<u>'s</u> li	fe duri	ng the last mor	nth of	
Terr Exper	-	_									Almost Perfect	DON'T KNOW	NO RESPONSE
LAPEI	0	1	2	3	4	5	6	7	8	9	10	999	777
33.		How w	ould y	ou rat	e the	qualit	y of <u>X</u>		<u>'s</u> m	nomen	t of death?		
Terr Exper											Almost Perfect	DON'T KNOW	NO RESPONSE
Terr Exper			2	3	4	5	6	7	8	9		_	_
Exper	ien 0	ice	_		BAL CU						Perfect	KNOW	RESPONSE

CONCLUDING ITEMS FOR BOTH SEVEN DAY AND LAST MONTH

		SIGNIFICANT OTHE	ER DEMOGR	RAPHICS	
For th	ne fina	I part of the interview, I would like	to ask you	a few questions	about yourself.
1.	What	is your relationship to X		? (CIRCLE	ONE NUMBER)
	1	SPOUSE/PARTNER			
	2	CHILD			
	3	SIBLING			
	4	FRIEND			
	5	PARENT			
	6	OTHER RELATIVE			
	7	OTHER			
		What other relationship?			<u> </u>
2.	Wha	t is your birthdate?	I_ MONTH		YEAR
3.	Hov	v long does it take you to get to X_		_'s home?	
	(EN7	TER 00/00 FOR HOUR/MINUTES IF SUI		/ES W/PATIENT)	
		HOURS MINUTES	-		
4.	How	long have you known X	?		
		YEARS MONTHS	-		
5.	(NOT	TE THE SURROGATE'S GENDER AND	CIRCLE THE	CORRECT NUM	BER)

FEMALE

MALE

1

YES NO 1 2 **NON-HISPANIC WHITE BLACK OR AFRICAN AMERICAN** 1 2 **HISPANIC** ASIAN OR PACIFIC ISLANDER NATIVE AMERICAN 1 2 1 2 OTHER

(FILL IN IF 'OTHER' SPECIFIED)

7. What is the highest year of schooling you have completed? (CIRCLE ONE)

- 1 NO FORMAL SCHOOL
- 2 KINDERGARTEN THRU GRADE 8
- 3 SOME HIGH SCHOOL
- 4 HIGH SCHOOL DIPLOMA OR G.E.D.
- 5 SOME COLLEGE
- 6 4-YEAR COLLEGE DEGREE (B.A., B.S.)
- 7 GRADUATE OR PROFESSIONAL SCHOOL

We are now finished with the interview. Thank you for your time in answering all of my questions.

NOTE: STOP TIME : .

INITE	R\/IE\M/EE	ASSESSMENT
1141 -	\mathbf{r}	A. J. JE . J. JIVIE IN I

We are now finished with the formal part of the questionnaire. For these last questions, we are looking for your help to guide us in future research. We are interested in your impressions in your own words.

Would y	you like to	continue?
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- 1 YES
- 2 NO

2. Overall, how much of a burden on you was this questionnaire?....

No Moderate Burden Burden							Terrible Burden			
at all 0	1	2	3	4	5	6	7	8	9	10

3. Is there anything about the quality of X 's death that we should have asked but didn't?

(PROBES: WAS THERE ANYTHING ELSE THAT WAS IMPORTANT IN THE LAST SEVEN DAYS OR LAST MONTH OF LIFE THAT WE DIDN'T ASK ABOUT? IS THERE ANYTHING ELSE YOU THINK WE SHOULD KNOW ABOUT THAT HAPPENED TO YOUR LOVED ONE DURING HIS/HER LAST WEEK/LAST MONTH OF LIFE THAT COULD HAVE BEEN IMPROVED?)

4. Is there anyway that we could have made this questionnaire easier on you?

(PROBES: WOULD IT HAVE BEEN BETTER TO WAIT LONGER BEFORE WE COMPLETED THIS WITH YOU? WOULD IT HAVE BEEN BETTER TO DO IT EARLIER? SHOULD WE HAVE ASKED THE QUESTIONS IN A DIFFERENT WAY?)

Do you have any other questions or comments for us?

Thank you again for your help. We appreciate your time and willingness to help us improve experiences at the end of life.

INTERVIEWER ASSESSMENT

THE FOLLOWING SECTION IS TO BE COMPLETED AFTER EVERY INTERVIEW BY THE INTERVIEWER.

CIRCLE THE NUMBER OF THE BEST ANSWER FOR EACH QUESTION

- 1. Was the interview complete?
 - 1 YES
 - 2 NO
- 2. If NO, Please note reason(s):

YES	NC)
-----	----	---

- 1 2 RESPONDENT'S ILLNESS
- 1 2 RESPONDENT'S FATIGUE
- 1 2 RESPONDENT'S POOR MENTAL STATUS
- 1 2 RESPONDENT'S UNCOOPERATIVENESS
- 1 2 RESPONDENT INSULTED, UPSET BY QUESTIONS
- 1 2 UNSATISFACTORY INTERVIEW CONDITIONS
- 3. Rate the quality of data
 - 1 POOR PLEASE COMMENT ON OTHER SIDE/BELOW
 - 2 FAIR PLEASE COMMENT ON OTHER SIDE/BELOW
 - 3 GOOD
- 3b. Comments
- 4. This interview was conducted:
 - 1 IN PERSON
 - 2 BY TELEPHONE
- 5. This interview was conducted by:

INTERVIEWER'S NAME:

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE



QODD QODD Response Cards AFTER-DEATH INTERVIEW

NOTE: Cards are produced as single pages so they can be laminated and presented to patients. Card number is at bottom left of page.

ALL OF THE TIME	5
MOST OF THE TIME	4
A GOOD BIT OF THE TIME	3
SOME OF THE TIME	2
A LITTLE OF THE TIME	1
NONE OF THE TIME	0

Experience

Perfect

6

 ∞

9

S

7

0

Terrible

Experience

Almost

Card 2

10
6
∞
7
9
5
4
8
2
_
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