Supplement Appendix 1. Carers' end-of-life question set

HSE 2017 questions

1. **In the past five years, has anyone close to you died of a terminal illness like cancer, motor neurone disease, or emphysema? If yes, could you say what that illness was?**
   (Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.)
   1. No
   2. emphysema/lung disease
   3. end stage heart failure
   4. end stage liver failure
   5. cancer
   6. motor neurone disease/multiple sclerosis
   7. end stage kidney failure
   8. HIV/AIDS
   9. other (specify) _____
   10. Don't know the illness

2. **Where did they die?**
   (Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.)
   1. Home (theirs)
   2. Home (yours)
   3. Home (we lived together)
   4. hospital
   5. hospice
   6. nursing care home
   7. residential care home
   8. other (specify) _____

What was your relationship to this person?

(Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.)

This person was my....

   1. spouse/partner
   2. parent
   3. child
   4. brother/sister
   5. other relative
   6. friend
   7. other (specify) _____

3. **Did you provide <u>personal care</u> to this person?**
(Interviewer: by personal care I mean things like helping with washing, dressing, going to the toilet, helping them to move around or eating.)

Yes/No

(Interviewer: If yes, thinking about the time when you were providing help like this, how long was this for?)
1. 1 - 6 days
2. 1 - 4 weeks
3. 1 – 3 months
4. 4 – 6 months
5. 7 – 9 months
6. 10 – 12 months
7. More than a year (specify in years) _____

Interviewer:

  (If less than a year): thinking about the period of time you provided care, how often did you provide care?

  (If more than a year): thinking about the last year of care, how often did you provide care?

In general I provided personal care …
1. every day
2. every week; **(interviewer - roughly how many days per week?)**
3. every month; **(interviewer - roughly how many days per month?)**
4. less frequently; **(interviewer - roughly how many days in total?)**

Interviewer:

  (If less than a year): thinking about the period of time you provided care, roughly how long each day did you spend?

  (If more than a year): thinking about the last year of care, roughly how long each day did you spend?

1. less than half a day
2. half a day
3. all day
4. all day and evening
5. at night**; (interviewer - roughly how many hours per night?)**
6. all night
7. all day and all night

4. Did you look after or give special help to them in any other way?
(Interviewer: Examples are: keeping company, visiting, errands, laundry, shopping, giving lifts, helping with money or legal issues, taking to appointments or out for recreation, etc.)

Yes/No

(Interviewer: If yes, thinking about the time when you were providing help like this, how long was this for?)
1. 1 - 6 Days
2. 1 - 4 Weeks
3. 1 – 3 months
4. 4 – 6 months
5. 7 – 9 months
6. 10 – 12 months
7. More than a year (specify in years) _____

Interviewer:

    (If less than a year): thinking about the period of time you provided this kind of help, how often did you give help?

    (If more than a year): thinking about the last year of providing help, how often did you give help?

In general I helped …
1. every day
2. every week; **(interviewer - roughly how many days per week?)**
3. every month; **(interviewer - roughly how many days per month?)**
4. less frequently; **(interviewer - roughly how many days?)**

Interviewer:

    (If less than a year): thinking about the period of time you provided this kind of help, roughly how long each day did you spend?

    (If more than a year): thinking about the last year of care, roughly how long each day did you spend?

8. less than half a day
9. half a day
10. all day
11. all day and evening
12. at night**; (interviewer - roughly how many hours per night?)**
13. all night
14. all day and all night

4. What services, if any, did this person who died use: (say all that apply)

1. Specialist palliative care service.

   (*Interviewer: "A palliative care service aims to comfort, not to cure, to relieve pain and distress for people who are dying and to support patients, families and friends in approaching death and coping with grief. Typical services include; hospice, visits from Marie Curie or/and Macmillan nurses."*)

2. Other services

   (Interviewer: Social services, voluntary groups, private care)

3. No other services
4. Don't know

5. Would you take on the role of caring again <u>in similar circumstances</u>?
1. I would definitely take on the caring role again
2. I would probably take on the caring role again
3. I would not take on the caring role again

Supplement Table 1. Spearman rank pairwise unweighted correlations – subset providing personal care (n=453)

	Intensity of care (personal)	Length of care (personal)	Intensity of care (general)	Length of care (general)	Max personal care cost	Min personal care cost	Max general help cost	Min general help cost
Intensity of care (personal)	1							
Length of care (personal)	0.16	1						
Intensity of care (general)	**0.53**	0.09	1					
Length of care (general)	0.07	**0.77**	0.05	1				
Max personal care cost	**0.53**	**0.83**	0.26	**0.61**	1			
Min personal care cost	0.46	**0.88**	0.24	**0.67**	**0.97**	1		
Max general help cost	0.25	**0.68**	0.44	**0.81**	**0.70**	**0.72**	1	
Min general help cost	0.20	**0.72**	0.38	**0.85**	**0.69**	**0.75**	**0.97**	1

Supplement Table 2. Spearman rank pairwise unweighted correlations – subset providing general help (n=1010)

	Intensity of care (general)	Length of care (general)	Max general help cost	Min general help cost
Intensity of care (general)	1			
Length of care (general)	0.06	1		
Max general help cost	0.36	**0.89**	1	
Min general help cost	0.31	**0.90**	**0.97**	1

Supplement Table 3. Multivariable regression model with weighted minimum costs for personal care (n=478)

Log minimum cost	Factor levels	n	exp(Coefficient)	Std. error	p-value	95% CI
Age Ref: 16-24 (n=18)	25-34	45	1.512	0.726	0.390	[0.588, 3.887]
	35-44	81	1.524	0.689	0.352	[0.627, 3.704]
	45-54	114	2.129	0.931	0.085	[0.901, 5.027]
	55-64	100	3.007	1.375	**0.016**	[1.225, 7.384]
	65-74	69	3.507	1.716	**0.011**	[1.341, 9.173]
	75+	52	5.611	2.996	**0.001**	[1.965, 16.022]
Place of death Ref: Home (we lived together) (n=38)	Home (theirs)	126	0.231	0.098	**0.0006**	[0.100, 0.534]
	Home (yours)	10	1.207	1.077	0.833	[0.209, 6.970]
	Hospital	177	0.395	0.160	**0.022**	[0.178, 0.875]
	Hospice	62	0.346	0.163	**0.025**	[0.137, 0.872]
	Nursing care home	51	0.566	0.274	0.241	[0.218, 1.467]
	Residential home	10	0.300	0.240	0.133	[0.062, 1.444]
	Other	5	2.318	2.079	0.349	[0.398, 13.503]
Deprivation Ref: Least deprived (n=96)	2	100	0.405	0.128	**0.005**	[0.217, 0.754]
	3	99	0.921	0.292	0.796	[0.494, 1.718]
	4	89	1.865	0.612	0.058	[0.979, 3.553]
	Most deprived	95	1.238	0.400	0.509	[0.656, 2.335]
Cause of death Ref: Cancer (n=322)	Non-cancer	157	1.940	0.429	**0.003**	[1.256, 2.997]
Religion Ref: Christian (n=282)	Other religion	40	0.442	0.151	**0.018**	[0.226, 0.867]
	None	157	0.964	0.225	0.875	[0.610, 1.524]

Supplement Table 4. Multivariable regression model with weighted minimum costs for general help (n=989)

Log minimum cost	Factor levels	n	exp(Coefficient)	Std. error	p-value	95% CI
Age Ref: 16-24 (n=43)	25-34	99	0.922	0.258	0.772	[0.533, 1.596]
	35-44	159	0.943	0.250	0.824	[0.560, 1.586]
	45-54	197	1.715	0.441	**0.036**	[1.035, 2.842]
	55-64	204	1.587	0.413	0.076	[0.952, 2.646]
	65-74	188	1.795	0.477	**0.028**	[1.065, 3.024]
	75+	99	2.695	0.837	**0.002**	[1.465, 4.957]
Sex Ref: Male (n=386)	Female	603	1.389	0.168	**0.007**	[1.096, 1.761]
Place of death Ref: Home (we lived together) (n=45)	Home (theirs)	254	0.139	0.044	**<0.0001**	[0.074, 0.260]
	Home (yours)	12	0.594	0.419	0.460	[0.149, 2.367]
	Hospital	368	0.221	0.068	**<0.0001**	[0.120, 0.405]
	Hospice	162	0.181	0.060	**<0.0001**	[0.094, 0.346]
	Nursing care home	105	0.286	0.101	**0.0004**	[0.143, 0.572]
	Residential home	28	0.260	0.120	**0.004**	[0.105, 0.644]
	Other	15	0.405	0.224	0.103	[0.136, 1.202]
Deprivation Ref: Least deprived (n=203)	2	236	0.951	0.175	0.783	[0.663, 1.363]
	3	193	0.954	0.182	0.804	[0.655, 1.388]
	4	165	2.009	0.403	**0.0005**	[1.355, 2.979]
	Most deprived	192	1.380	0.270	0.100	[0.940, 2.026]
Other care services Ref: Yes (n=351)	No	638	0.695	0.090	**0.005**	[0.540, 0.895]
Cause of death Ref: Cancer (n=673)	Non-cancer	316	1.744	0.236	**<0.0001**	[1.337, 2.276]

Supplement Table 5. Calculations for population scaled costs

Type of care	Study participants providing care for one decedent over the last 5 years n (%)	Those providing care scaled to the total adult population* 2017 n (6.5% of 44,981,459)	Application of minimum and maximum average cost per carer to the total adult population providing care	Cost per year per carer for care provided in the last year of life** (divide by 5) (in billions, to 1 dp)
Personal care				
minimum	521/7997 (6.5)	2,923,794.835	£18,557 x 2,923,794.835 = £54,256,860,753.095	£10.8 billion
maximum			£22,072 x 2,923,794.835 = £64,533,999,598.12	£12.9 billion
Other help				
minimum	1010/7997 (12.6)	5,667,663.834	£11,656 x 5,667,663.834 = £66,062,289,649.104	£13.2 billion
maximum			£13,697 x 5,667,663.834 = £77,629,991,534.298	£15.5 billion

*Assuming study sample is representative of the whole population

** Assuming the episodes of caregiving are evenly distributed over 5 years