Title

Community preferences for the care of older people at the end of life: How important is the disease context?

Journal

The Patient – Patient-Centered Outcomes Research

Authors

Patricia Kenny, Deborah Street, Jane Hall, Centre for Health Economics Research & Evaluation (CHERE) University of Technology Sydney.

Meera Agar, Improving Palliative, Aged and Chronic Care through Clinical Research and Translation **(IMPACCT),** University of Technology Sydney.

Jane Phillips, Centre for Healthcare Transformation, School of Nursing, Queensland University of Technology and IMPACCT, University of Technology Sydney.

Corresponding author

Patricia Kenny, patricia.kenny@uts.edu.au

Figure S1: Example choice set for the cancer survey

In the last 3 weeks of life

	Care option A	Care option B
Care was provided	in a palliative care unit most of the time with some time at home	at home most of the time with some time in hospital
Medical intervention was being given to prolong life	Antibiotics to treat infection	Antibiotics to treat infection
With pain control measures, the patient	had moderate pain all of the time with interrupted sleep	was completely pain free all of the time
During the day the patient was	conscious but sleepy	awake and able to interact
The accommodation when admitted was	a shared room	a shared room
Nurses were confident in helping patient and family prepare for death	No	Yes
When at home, nurses visited	10 hours per week	10 hours per week
When admitted, nurses were available all of the time and care was provided by	many different nurses	many different nurses
The cost to the patient was	$4,000	$4,000
The patient felt	calm all of the time	calm some of the time felt anxious at other times
The informal carer felt	in control all of the time	in control some of the time stressed at other times
The patient died	at home	in hospital
Which care option do you think is better?	○ Care option A	○ Care option B

Figure S2: Example choice set for the dementia survey (vignette 1 living at home)

In the last 3 weeks of life

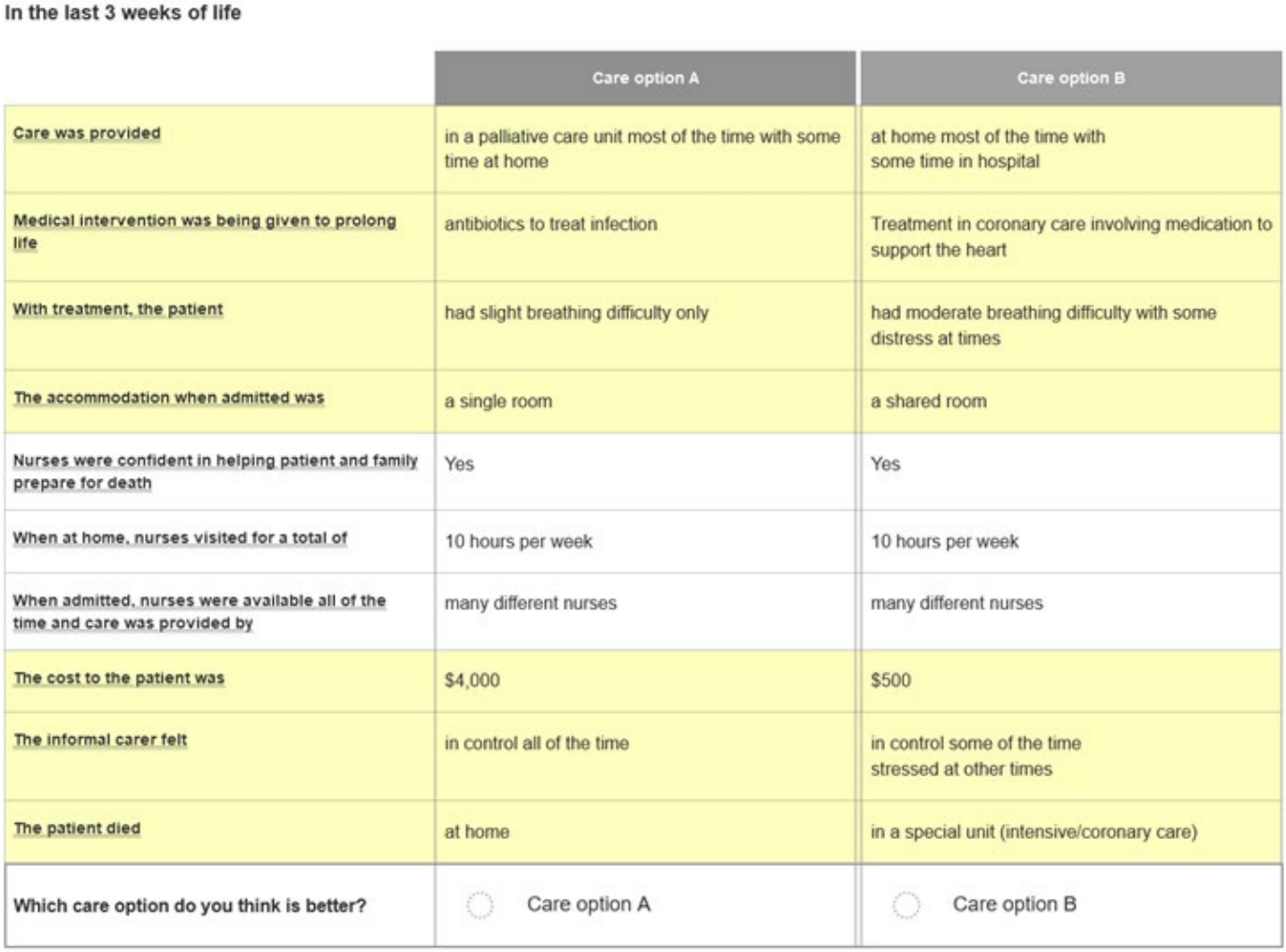
	Care option A	Care option B
Care was provided	at home most of the time with some time in a nursing home	at home most of the time with some time in hospital
Medical intervention was being given to prolong life	antibiotics to treat infection	antibiotics to treat infection
With treatment, the patient had	mild agitation	mild agitation
During the day the patient was	awake intermittently but confused	sleeping most of the time
The accommodation when admitted was	a single room	a single room
The care team members were confident in helping patient and family prepare for death	Yes	No
When at home, nurses visited for a total of	20 hours per week (including some overnight respite)	10 hours per week
When admitted, nurses were available all of the time and care was provided by	many different nurses	many different nurses
The cost to the patient over this period was	$4,000	$500
The informal carer felt	in control all of the time	in control some of the time stressed at other times
The patient died	in a nursing home	at home
Which care option do you think is better?	○ Care option A	○ Care option B

Figure S3: Example choice set for the dementia survey (vignette 2 living in a nursing home)

In the last 3 weeks of life

	Care option A	Care option B
Care was provided	in hospital most of the time with some time in the nursing home	in the nursing home most of the time with some time in a palliative care unit
Medical intervention was being given to prolong life	a feeding tube (through the abdomen)	a drip to give fluids
With treatment, the patient had	severe agitation	no agitation
During the day the patient was	awake intermittently but confused	awake intermittently but confused
The accommodation when admitted was	a shared room	a single room
The care team members were confident in helping patient and family prepare for death	Yes	Yes
When admitted, nurses were available all of the time and care was provided by	the same nurses who got to know the patient and family	the same nurses who got to know the patient and family
The cost to the patient over this period was	$0	$0
The informal carer felt	stressed all of the time	in control all of the time
The patient died	in hospital	in a nursing home
Which care option do you think is better?	○ Care option A	○ Care option B

Figure S4: Example choice set for the heart failure survey



In the last 3 weeks of life

	Care option A	Care option B
Care was provided	in a palliative care unit most of the time with some time at home	at home most of the time with some time in hospital
Medical intervention was being given to prolong life	antibiotics to treat infection	Treatment in coronary care involving medication to support the heart
With treatment, the patient	had slight breathing difficulty only	had moderate breathing difficulty with some distress at times
The accommodation when admitted was	a single room	a shared room
Nurses were confident in helping patient and family prepare for death	Yes	Yes
When at home, nurses visited for a total of	10 hours per week	10 hours per week
When admitted, nurses were available all of the time and care was provided by	many different nurses	many different nurses
The cost to the patient was	$4,000	$500
The informal carer felt	in control all of the time	in control some of the time stressed at other times
The patient died	at home	in a special unit (intensive/coronary care)
Which care option do you think is better?	○ Care option A	○ Care option B

Table S1: Mixed logit models for predicted probabilities in Figure 2: Coefficient (standard error)

	Cancer				Dementia (NH)				Dementia (Home)				Heart failure			
	Mean		SD		Mean		SD		Mean		SD		Mean		SD	
Home, some palliative care	-0.153	*	0.228		0.288	*	0.233		0.058		0.599	*	-0.019		0.760	***
	(0.077)		(0.237)		(0.121)		(0.396)		(0.120)		(0.298)		(0.096)		(0.151)	
Hospital, some home	-0.233	***	0.300		-0.061		0.295		-0.024		0.875	***	-0.245	**	0.877	***
	(0.062)		(0.243)		(0.118)		(0.871)		(0.093)		(0.243)		(0.077)		(0.135)	
Palliative care, some home	-0.185	*	0.385										-0.145		0.348	
	(0.077)		(0.199)										(0.098)		(0.358)	
Home, some nursing home									-0.037		0.094					
									(0.119)		(0.275)					
Antibiotics	0.123	*	0.536	***	0.028		0.317		0.238	**	0.013		0.172	**	0.120	
	(0.048)		(0.109)		(0.078)		(0.415)		(0.083)		(0.362)		(0.057)		(0.227)	
Drip for fluids	0.044		0.234		0.029		0.320		0.091		0.472					
	(0.045)		(0.163)		(0.090)		(0.352)		(0.094)		(0.364)					
Feeding tube					-0.499	***	0.922	***	-0.505	***	1.088	***				
					(0.089)		(0.203)		(0.095)		(0.216)					
ICU medication to support heart													0.077		0.152	
													(0.076)		(0.328)	
ICU breathing support													0.096		0.087	
													(0.074)		(0.385)	
Symptoms2	-0.568	***	0.479	***	-0.477	***	0.046		-0.405	***	0.370		-0.513	***	0.212	
	(0.047)		(0.109)		(0.076)		(0.274)		(0.075)		(0.346)		(0.049)		(0.187)	
Symptoms3	-1.112	***	0.813	***	-1.646	***	1.355	***	-1.632	***	1.692	***	-1.335	***	1.169	***
	(0.059)		(0.089)		(0.145)		(0.206)		(0.168)		(0.241)		(0.076)		(0.096)	
Alertness2	-0.283	***	0.400	***	0.519	***	0.871	***	0.447	***	0.302					
	(0.036)		(0.098)		(0.056)		(0.109)		(0.057)		(0.407)					
Patient anxious some of time	-0.563	***	0.017													
	(0.046)		(0.227)													
Patient anxious all of time	-1.511	***	1.078	***												
	(0.067)		(0.084)													
Carer stressed some of time	-0.368	***	0.012		-0.626	***	0.147		-0.662	***	0.427		-0.352	***	0.040	
	(0.045)		(0.291)		(0.077)		(0.345)		(0.093)		(0.329)		(0.050)		(0.112)	
Carer stressed all of time	-1.058	***	0.857	***	-1.664	***	0.897	***	-1.494	***	1.037	***	-1.154	***	0.943	***
	(0.058)		(0.087)		(0.133)		(0.213)		(0.154)		(0.238)		(0.070)		(0.084)	
Died in hospital	-0.178	**	0.758	***	0.210	**	0.911	***	-0.119		0.790	**	-0.388	***	0.696	***
	(0.062)		(0.130)		(0.078)		(0.143)		(0.094)		(0.254)		(0.071)		(0.116)	
Died in palliative care unit	-0.072		0.814	***	0.0180		1.410	***	0.126		1.010	*	-0.054		0.506	**
	(0.062)		(0.126)		(0.143)		(0.240)		(0.123)		(0.441)		(0.076)		(0.191)	
Died in a nursing home									-0.282	*	1.064	*				
									(0.130)		(0.453)					

Died ICU													-0.497	***	0.667	***
													(0.081)		(0.140)	
A shared room	-0.576	***	1.004	***	-0.633	***	0.574	***	-0.649	***	1.146	***	-0.645	***	0.779	***
	(0.043)		(0.059)		(0.065)		(0.169)		(0.081)		(0.157)		(0.045)		(0.059)	
Team not confident death	-0.326	***	0.330	***	-0.502	***	0.646	***	-0.474	***	0.643	**	-0.315	***	0.205	.
	(0.033)		(0.089)		(0.054)		(0.114)		(0.058)		(0.226)		(0.035)		(0.117)	
Care from same nurses	0.453	***	0.584	***	0.787	***	0.913	***	0.660	***	0.776	***	0.545	***	0.539	***
	(0.037)		(0.068)		(0.077)		(0.144)		(0.076)		(0.160)		(0.042)		(0.070)	
Nurse home visits 10hrs/week	-0.262	***	0.078						-0.300	***	0.686	**	-0.321	***	0.149	
	(0.045)		(0.131)						(0.078)		(0.262)		(0.048)		(0.216)	
Nurse home visits 4hrs/week	-0.454	***	0.096						-0.855	***	0.820	***	-0.641	***	0.455	***
	(0.047)		(0.259)						(0.113)		(0.245)		(0.055)		(0.105)	
$500	-0.390	***	0.020		-0.664	***	0.137		-0.678	***	0.663	*	-0.370	***	0.399	**
	(0.049)		(0.180)		(0.086)		(0.368)		(0.093)		(0.273)		(0.051)		(0.132)	
$4,000	-1.757	***	1.608	***	-2.312	***	1.974	***	-2.031	***	1.360	***	-1.722	***	1.522	***
	(0.078)		(0.083)		(0.187)		(0.213)		(0.187)		(0.197)		(0.091)		(0.102)	
Log likelihood	-9620				-5197				-5306				-6691			
AIC	19324				10462				10696				13462			
BIC	19649				10705				10996				13758			
Number respondents	1548				1549				1549				1003			
Number observations	17028				9294				9294				12036			

* p<0.05, ** p<0.01, *** p<0.001. NH Nursing Home (treated as home for dementia patients living in a nursing home); SD=Standard Deviation; ICU Intensive Care Unit. AIC= Akaike's Information Criterion; BIC=Bayesian Information Criterion. Symptoms: Cancer=pain; Dementia=agitation; Heart failure=breathlessness.

Table S2a: Mixed logit models including attribute and experience interactions (Cancer and Heart failure): Coefficient (standard error)

	CANCER								HEART FAILURE							
					Experience interactions								Experience interactions			
	Mean		SD		Death		Care		Mean		SD		Death		Care	
Home, some palliative care	-0.183		0.253		0.134		-0.073		-0.044		0.769	***	0.261		-0.224	
	(0.141)		(0.228)		(0.187)		(0.197)		(0.186)		(0.152)		(0.242)		(0.251)	
Hospital, some home	-0.259	*	0.285		0.084		-0.017		-0.424	**	0.885	***	0.176		0.342	
	(0.116)		(0.239)		(0.152)		(0.159)		(0.149)		(0.136)		(0.193)		(0.201)	
Palliative care, some home	-0.192		0.290		0.062		-0.059		0.039		0.481	*	-0.142		-0.352	
	(0.139)		(0.245)		(0.185)		(0.195)		(0.193)		(0.239)		(0.25)		(0.259)	
Antibiotics	0.221	*	0.551	***	-0.132		-0.127		0.343	**	0.014		-0.286	*	-0.156	
	(0.091)		(0.107)		(0.119)		(0.125)		(0.112)		(0.26)		(0.145)		(0.149)	
Drip for fluids	0.167	*	0.213		-0.137		-0.220									
	(0.083)		(0.173)		(0.11)		(0.116)									
ICU medication to support heart									0.334	*	0.179		-0.304		-0.378	
									(0.15)		(0.329)		(0.193)		(0.2)	
ICU breathing support									0.322	*	0.123		-0.261		-0.341	
									(0.146)		(0.318)		(0.188)		(0.194)	
Symptoms2	-0.499	***	0.476	***	-0.186	.	0.024		-0.529	***	0.262	.	0.062		-0.050	
	(0.087)		(0.109)		(0.112)		(0.118)		(0.093)		(0.159)		(0.119)		(0.124)	
Symptoms3	-0.939	***	0.805	***	-0.398	**	-0.063		-1.270	***	1.195	***	-0.160		-0.077	
	(0.099)		(0.089)		(0.128)		(0.135)		(0.132)		(0.098)		(0.164)		(0.169)	
Alertness2	-0.383	***	0.407	***	0.082		0.227	*								
	(0.067)		(0.096)		(0.087)		(0.091)									
Patient anxious some of time	-0.316	***	0.006		-0.379	***	-0.310	**								
	(0.082)		(0.227)		(0.107)		(0.113)									
Patient anxious all of time	-1.197	***	1.060	***	-0.468	***	-0.397	**								
	(0.106)		(0.085)		(0.134)		(0.142)									
Carer stressed some of time	-0.421	***	0.021		0.078		0.061		-0.358	***	0.045		0.017		-0.020	
	(0.082)		(0.262)		(0.107)		(0.113)		(0.097)		(0.114)		(0.124)		(0.129)	
Carer stressed all of time	-0.926	***	0.866	***	-0.248	*	-0.114		-1.292	***	0.941	***	0.077		0.258	
	(0.098)		(0.087)		(0.124)		(0.131)		(0.125)		(0.085)		(0.153)		(0.157)	
Died in hospital	-0.136		0.766	***	-0.130		0.031		-0.483	***	0.721	***	0.228		-0.016	
	(0.117)		(0.129)		(0.152)		(0.16)		(0.138)		(0.117)		(0.177)		(0.183)	
Died in palliative care unit	-0.046		0.832	***	-0.033		-0.024		-0.443	**	0.490	*	0.531	**	0.536	**
	(0.115)		(0.124)		(0.152)		(0.162)		(0.15)		(0.193)		(0.194)		(0.199)	
Died ICU									-0.720	***	0.667	***	0.419	*	0.115	
									(0.162)		(0.141)		(0.205)		(0.211)	

A shared room	-0.661	***	0.995	***	0.062		0.208	*	-0.512	***	0.783	***	-0.180	.	-0.207			
	(0.078)		(0.06)		(0.1)		(0.106)		(0.082)		(0.06)		(0.105)		(0.109)			
Team not confident death	-0.395	***	0.312	***	0.067		0.143		-0.230	***	0.193		-0.093		-0.150			
	(0.06)		(0.094)		(0.078)		(0.082)		(0.067)		(0.136)		(0.086)		(0.09)			
Care from same nurses	0.344	***	0.571	***	0.253	**	0.028		0.568	***	0.538	***	0.001		-0.028			
	(0.065)		(0.069)		(0.086)		(0.09)		(0.077)		(0.072)		(0.097)		(0.1)			
Nurse home visits 10hrs/wk	-0.356	***	0.070		0.201	.	0.026		-0.353	***	0.177		0.109		-0.035			
	(0.084)		(0.128)		(0.109)		(0.116)		(0.093)		(0.176)		(0.12)		(0.123)			
Nurse home visits 4hrs/wk	-0.526	***	0.152		0.168		0.009		-0.727	***	0.467	***	0.105		0.106			
	(0.088)		(0.223)		(0.115)		(0.12)		(0.102)		(0.103)		(0.128)		(0.134)			
$500	-0.514	***	0.021		0.176		0.176		-0.591	***	0.366	**	0.157		0.452	***		
	(0.09)		(0.179)		(0.118)		(0.124)		(0.1)		(0.142)		(0.127)		(0.132)			
$4,000	-1.998	***	1.610	***	0.193		0.518	**	-2.005	***	1.538	***	0.094		0.673	***		
	(0.13)		(0.083)		(0.157)		(0.166)		(0.16)		(0.104)		(0.189)		(0.195)			
Log likelihood	-9576								-6656									
AIC	19321								13472									
BIC	19971								14064									
Number respondents	1548								1003									
Number observations	17028								12036									

* p<0.05, ** p<0.01, *** p<0.001. SD=Standard Deviation; ICU Intensive Care Unit. Symptoms: Cancer=pain; Heart failure=breathlessness. Death=someone close died from life limiting illness; Care=helped with care for person at the end of life.

Table S2b: Mixed logit models including attribute and experience interactions (Dementia): Coefficient (standard error)

	DEMENTIA (NURSING HOME)				DEMENTIA (HOME)			
			Experience interactions				Experience interactions	
	Mean	SD	Death	Care	Mean	SD	Death	Care
Home, some palliative care	0.299	0.180	-0.165	0.175	0.087	0.643 *	-0.041	-0.096
	(0.233)	(0.474)	(0.295)	(0.312)	(0.227)	(0.278)	(0.288)	(0.309)
Hospital, some home	0.241	0.269	-0.378	-0.456	-0.244	0.847 ***	0.458 *	0.078
	(0.228)	(0.776)	(0.29)	(0.31)	(0.182)	(0.24)	(0.231)	(0.243)
Home, some nursing home					0.017	0.127	0.061	-0.236
					(0.225)	(0.277)	(0.286)	(0.305)
Antibiotics	0.075	0.196	-0.172	0.065	0.123	0.004	0.087	0.237
	(0.151)	(0.521)	(0.191)	(0.206)	(0.149)	(0.342)	(0.19)	(0.204)
Drip for fluids	0.065	0.273	-0.087	-0.021	-0.183	0.464	0.307	0.469
	(0.174)	(0.369)	(0.221)	(0.236)	(0.177)	(0.344)	(0.227)	(0.244)
Feeding tube	-0.349 *	0.863 ***	-0.131	-0.322	-0.279 .	1.045 ***	-0.273	-0.323
	(0.159)	(0.205)	(0.2)	(0.216)	(0.164)	(0.209)	(0.207)	(0.22)
Agitation2	-0.396 **	0.048	-0.248	0.069	-0.479 ***	0.230	0.088	0.142
	(0.131)	(0.251)	(0.163)	(0.174)	(0.136)	(0.504)	(0.164)	(0.177)
Agitation3	-1.489 ***	1.366 ***	-0.391	0.047	-1.349 ***	1.614 ***	-0.469 *	-0.172
	(0.196)	(0.204)	(0.213)	(0.226)	(0.202)	(0.229)	(0.223)	(0.234)
Alertness2	0.365 ***	0.865 ***	0.209	0.216	0.357 ***	0.310	0.175	0.031
	(0.091)	(0.106)	(0.114)	(0.122)	(0.09)	(0.428)	(0.109)	(0.116)
Carer stressed some of time	-0.733 ***	0.136	0.105	0.196	-0.678 ***	0.451	-0.018	0.079
	(0.135)	(0.38)	(0.165)	(0.176)	(0.151)	(0.307)	(0.177)	(0.188)
Carer stressed all of time	-1.504 ***	0.902 ***	-0.375	-0.017	-1.413 ***	0.995 ***	-0.295	0.223
	(0.177)	(0.211)	(0.192)	(0.202)	(0.196)	(0.235)	(0.201)	(0.211)
Died in hospital	0.150	0.907 ***	0.086	0.087	-0.075	0.768 **	-0.107	0.015
	(0.149)	(0.142)	(0.189)	(0.203)	(0.176)	(0.247)	(0.224)	(0.238)
Died in palliative care unit	-0.073	1.414 ***	0.294	-0.110	-0.267	0.833 .	0.584 *	0.504
	(0.274)	(0.236)	(0.348)	(0.372)	(0.227)	(0.486)	(0.294)	(0.315)
Died in a nursing home					-0.532 *	0.848 .	0.189	0.558
					(0.238)	(0.5)	(0.296)	(0.317)
A shared room	-0.559 ***	0.543 **	-0.176	0.010	-0.561 ***	1.110 ***	-0.200	0.041
	(0.103)	(0.171)	(0.124)	(0.132)	(0.122)	(0.151)	(0.145)	(0.154)
Team not confident death	-0.447 ***	0.637 ***	-0.062	-0.095	-0.352 ***	0.616 *	-0.221 *	-0.058
	(0.088)	(0.112)	(0.105)	(0.113)	(0.089)	(0.244)	(0.109)	(0.115)
Care from same nurses	0.630 ***	0.915 ***	0.327 *	0.049	0.648 ***	0.732 ***	0.032	-0.034
	(0.118)	(0.144)	(0.141)	(0.15)	(0.118)	(0.159)	(0.135)	(0.144)

Nurse home visits 10hrs/wk								-0.281	*	0.602	*	-0.183		0.172				
								(0.142)		(0.272)		(0.178)		(0.189)				
Nurse home visits 4hrs/wk								-0.643	***	0.847	***	-0.447	*	-0.039				
								(0.167)		(0.23)		(0.2)		(0.21)				
$500	-0.733	***	0.164		0.019	0.188		-0.882	***	0.635	*	0.275		0.285				
	(0.151)		(0.39)		(0.181)	(0.195)		(0.16)		(0.268)		(0.185)		(0.201)				
$4,000	-2.448	***	1.942	***	-0.113	0.650	**	-2.132	***	1.327	***	-0.105		0.555	*			
	(0.248)		(0.208)		(0.234)	(0.251)		(0.234)		(0.191)		(0.205)		(0.218)				
Log likelihood	-5169							-5267										
AIC	10475							10703										
BIC	10960							11302										
Number respondents	1549							1549										
Number observations	9294							9294										

* p<0.05, ** p<0.01, *** p<0.001. Nursing Home was treated as home for dementia patients living in a nursing home; SD=Standard Deviation. Death=someone close died from life limiting illness; Care=helped with care for person at the end of life.

Preference heterogeneity: Additional detail relating to differences by care experience groups

There was a general preference for care from the same nurses across all disease contexts (Figure 2) but in the contexts of cancer and dementia living in a nursing home, this preference was stronger among those who had experience of someone close to them dying but who had not provided care (the predicted probabilities were 0.63 and 0.69 respectively in the dementia context and 0.58 and 0.64 in the cancer context, see Figure 4). For cancer patients, respondents who reported that someone close to them died from a life limiting illness (irrespective of having a role in care) were less likely to prefer alternatives where the patient was feeling anxious (the predicted probabilities were 0.27, 0.20, and 0.21 for those with no experience, experience of death and experience of caregiving respectively, See Figure 4). This attribute was not included in the heart failure or dementia surveys. Respondents with experience of someone close dying but not providing care, had a stronger preference to not have alternatives where the patient symptoms were at the worst level for cancer patients and dementia patients living at home (the predicted probabilities were 0.23 and 0.30 respectively in the cancer context and 0.22 and 0.28 in the dementia context, see Figure 4).

There were some differences between those with and without the experience of having someone close who had died with respect to preferences for place of death in the heart failure and dementia contexts. Although on average there was no significant preference between death in the palliative care unit and death at home, for patients with dementia living at home, respondents with experience of death of someone close but not of providing care were more likely to prefer death in the palliative care unit (predicted probability 0.57 versus 0.44). For heart failure patients, the group with no experience of death from life limiting illness had a preference to not die in the palliative care unit while both 'experienced' groups viewed death in the palliative care unit more positively (predicted probability 0.52 for both experienced groups versus 0.40 for the group with no experience, see Figure 4). Also, for heart failure patients, those 'experienced' but who did not provide care were less concerned about death in intensive care than those without experience (predicted probability 0.43 versus 0.34).