Providing Informal Care in Terminal Illness: An Analysis of Preferences for Support Using a Discrete Choice Experiment

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Background: *The trend for terminally ill patients to receive much of their end-of-life care at home necessitates the design of services to facilitate this. Care at home also requires that informal care be provided by family members and friends. This study investigated informal carers' preferences for support services to aid the development of end-of-life health care services.* ***Methods:*** *This cross-sectional study used 2 discrete choice experiments to ascertain the preferences of carers supporting patients with different levels of care need, determined by the assistance needed with personal care and labeled High Care (HC) and Low Care (LC). The sample included 168 informal carers of people receiving palliative care at home from 2 palliative care services in Sydney, Australia. Data were collected in face-to-face interviews; carers chose between 2 hypothetical plans of support services and their current services. Data were analyzed with generalized multinomial logit models that were used to calculate the impact of each attribute on the probability of a carer choosing a service plan.* ***Results:*** *Preferred support included nursing services; the probability of choosing a plan increased significantly if it included nurse home visits and phone advice ($P < 0.001$). HC carers also wanted doctor home visits, home respite, and help with personal care ($P < 0.05$), and LC carers wanted help with household tasks, transport, and a case coordinator ($P < 0.001$). On average, both groups of carers preferred their current services, but this varied with characteristics of the carer and the caregiving situation.* ***Conclusions:****The most valued services are those that support carers in their caregiving role; however, supportive care preferences vary with the different circumstances of patients and carers.*

Key words: *informal care; preferences; discrete choice; palliative care.* (***Med Decis Making 2014;34:731–745)***

The need for end-of-life care is expected to produce increasing demands on health services as populations age[1]; whether this care is provided primarily in institutions or the community, it creates challenges for those charged with ensuring the availability of appropriate care and support services. The majority of patients with a terminal illness prefer to receive much of their care at the end of life in their own home,[2] and many also wish to die at home.[2-4] The availability of family and friends to provide care and support at home (informal carers) and access to (and intensity of) home care services have been identified as key determinants of the place of death for terminally ill cancer patients.[5] Dubenske and others[6] point to the importance of collaborative decision making based on effective information sharing among patient, family, and the clinical team for effective care planning in life-threatening illness. Many countries now have standards of care or clinical guidelines for palliative care that involve meeting the needs of the family as well as those of the

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patient.[7-9] The development of effective services for patients at home, therefore, must consider the role of the family members as informal carers.

Informal care research in the palliative care context has described the extent of caregiving tasks,[10-12] identified a wide range of adverse effects on carers,[13-18] and reported some of the satisfactions and rewards experienced by carers.[19,20] Although perceived access to supportive care services has been found to be an important predictor of caregiver strain among informal carers providing end-of-life care,[21] the evidence about effective programs to support informal carers in the palliative care context is limited.[22-24]

Economic analyses have largely focused on methods to value the time of informal caregivers for inclusion in economic evaluation.[25,26] The methods available have been reviewed by Koopmanschap and others.[27] Recent work, including a report in this journal, has distinguished between the caregiving effect (i.e., the consequence on health and well-being of the burden of providing care) and the family effects (i.e., the result of having someone in the family with a serious illness or disability).[28-31] Both effects are emphasized in the palliative care research setting; the family effects are intensified as family members face the imminent death of a loved one, and the caregiving effects increase as the carers are faced with an increasing burden attributable to the deterioration of the patient's physical health. However, the impact of caregiving can go beyond the opportunity cost of time and can provide benefits as well as impose burdens on caregivers. Indeed, carers have frequently reported satisfaction with their caregiving role.[19,20,32,33] The estimation of caregiving effects does not provide guidance to those responsible for making decisions on service delivery, and the failure to recognize the satisfaction involved can reduce the effectiveness of health services by attempting to replace rather than support informal carers.

Al-Janabi and others[34] developed a carer experience scale with weights for use in economic evaluation. The scale covered 6 dimensions of carer experience, but as only 1 of these applied to ''assistance from organizations and the government,'' the scale has limited relevance for decision makers. To design the most relevant models of supportive care services for terminally ill patients and their carers, policy makers and health service planners require information about the goals of carers and patients and their preferences for specific types of support. Investigations of the experiences of carers can be informative but do not generally tell us what carers want. Research into the services preferred by carers is limited. Canadian informal carers of terminally ill patients identified home nursing, medical care, and housekeeping as the most valued services they had received; carer respite was one of the services most frequently identified as a service that carers would have liked to have had or to have had more of.[35] An Australian qualitative study found that carers valued the reassurance, information, and education provided by the palliative care nurses.[36] A review of the literature on carer needs for practical support in end-of-life cancer care found that studies consistently reported the need for practical nursing support and nursing-based information; the need for carer education and training related to medication management and symptom control was particularly prominent.[37]

One of the approaches that can be used to assess strengths of preference for attributes of goods or services is conjoint analysis or discrete choice experiments (DCEs). The general methods have been well described elsewhere.[38,39] Despite early interest in the value of this approach,[40] its use in the context of informal care or palliative care has been limited. Van den Berg and colleagues have used stated preference methods, both contingent valuation[41] and conjoint measurement,[42] to assess the value of informal care to estimate the monetary value of a marginal hour of care; they did not investigate differences in the type of care provided. Mentzakis and others[43] estimated the willingness to accept monetary compensation per hour of care for personal care, supervising, and household tasks; Al-Janabi and others[34] in the study referred to above used a best–worst scaling DCE to estimate preference weights for a carer experience scale. Douglas and others[44] used a DCE to investigate patient preferences for the different services provided in palliative day care. So far, the approach has not been used to measure preferences for services at home during end-of-life care.

This paper reports a study using a DCE to investigate carers' preferences for support services in home-based palliative care. The study adds to the existing work by focusing on palliative care services provided to patients at home, ascertaining carer preferences for those services, and studying whether preferences vary with the caregiving context. The study aimed to estimate the relative value that carers place on different types of palliative care services, in order to inform policy decision making in the planning of services for end-of-life care. It was also intended to clarify aspects of the value of informal care from the perspective of carers of palliative care patients,

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specifically regarding tasks that carers wanted to do themselves or preferred formal service providers to help with.

METHODS

A cross-sectional study was conducted in Sydney, Australia, between May 2005 and November 2006. Ethical approval was provided by the institutional ethics committees at the participating palliative care services and at the University of Technology, Sydney.

Recruitment

The nominated informal carers of new patients registering with 2 specialist community palliative care services in central and eastern Sydney during the study period were invited to participate. Carers were eligible if they spoke English, if they currently provided assistance to a patient receiving palliative care at home from one of the participating services, and if both the patient and the carer provided consent. Patients and carers were invited to join the study by the palliative care nurses or other health professionals during home visits. Patients were asked to nominate the person providing the most help with their care. The contact information for patients and carers who agreed to be contacted was provided to the research nurse, who telephoned to make an appointment for the interview. Written consent was obtained from the carer and the patient by the research nurse prior to commencement of the carer interview.

We recruited 178 informal carer/recipient pairs, 21% of those eligible. Following are reasons for nonparticipation: carer refused (12%), patient died or was hospitalized before the interview (11%), or carer was not invited to participate by the palliative care team (56%). Following are reasons that carers were not invited: the patient was too ill (33%), the carer was too stressed or overwhelmed (13%), or the clinical staff were too busy or forgot (10%). Ten participants were unable to complete the DCE interview, leaving 168 (20% of eligible) with complete data. While the study aimed to recruit 200–300 respondents, this is a challenging context for research and a somewhat smaller sample was achieved in the recruitment period. Sample size estimation for DCE or conjoint analysis studies is complex[45]; our study is consistent with recent applications in health that have typically reported sample sizes of 100–300,[46] and it improves on some earlier applications where sample size was as low as 30.[47]

Data Collection

Data were collected through face-to-face interviews with carers and from patient medical records. The interviewer was a research nurse with extensive palliative care experience, and the interviews were conducted in the patient's home unless the carer requested another location. The interview included the DCE; questions about current service use (in terms of the DCE attributes); questions about the help needed by the patient (adapted from Schofield and others[48]); the Australian version of the SF-36v2 Health Survey[49,50]; and questions regarding the carer's relationship to the patient, the time spent on caregiving, support from other informal carers, and sociodemographic characteristics. Patient clinical and sociodemographic information was obtained from the palliative care service's patient records.

DCE Attributes and Experimental Design

Two separate experiments were conducted, one for carers of patients needing a high level of care (High Care) and one for those with relatively low care needs (Low Care). This was done to avoid offering support services providing patient care that was not currently relevant to the condition of a substantial number of patients. Guidelines for conducting DCE studies recommend that attributes be relevant to the decision context[45] and that the important attributes for the majority of respondents be included.[51] A Phase I exploratory study[52] revealed that a number of services were potentially very important to a substantial number of carers supporting patients at an advanced stage of functional decline, such as the services of a personal care assistant and respite services, although the same services were of no use whatsoever for many other carers supporting a more functionally independent patient (albeit requiring help with symptoms and many activities such as household tasks). This extent of variation comes about because of the typical illness trajectory for people with terminal cancer (the diagnosis for the majority of patients seen by the participating palliative care services), where the major loss of function occurs in the final 2 to 3 months of life.[53,54] A single experiment would have required a larger number of attributes and levels than either of the 2 experiments and a more complex analysis (with many interaction terms) to disentangle carer preferences for a service from the

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capacity to use the service because of the patient's current care needs.

On the recommendation of 2 specialist palliative care nurse advisors, we used the question about the patient's need for help with bathing or showering to determine High or Low Care status; this indicated the potential to use the personal care assistant and was also expected to reflect the patient's state of deterioration and the potential for the carer to benefit from other services such as respite. Patients were considered ''High Care'' if they needed ''quite a bit'' or ''a lot'' of help with bathing or showering, as reported by the carer.

Both experiments were unlabeled. Each hypothetical choice set comprised 2 packages of services (plan A and plan B, see online appendix for sample choice sets). After reading each choice set, carers were asked 2 questions: 1) to choose between service plan A or service plan B to replace their current support services and 2) to choose between their chosen service plan and the support services they were currently receiving. These 2 questions together provide the respondent's choice out of 3 options, the current services and 2 hypothetical service plans (A and B). The attributes and levels used in each experiment (Table 1) were developed for the study, based on the published literature describing the role and support needs of informal carers in the palliative care context and the Phase 1 study.[52] A definition board was used during the interview to illustrate the attribute components in more detail, clarifying the nature of the help provided by each service (see the appendix).

The Phase 1 study used quantitative and qualitative methods to describe the carers' role, the perceived impact of caregiving, and the support that carers found or thought they would find helpful. Informal carers (n = 82) were recruited through the same palliative care services as the current study, using the same recruitment procedures.[52] The process for attribute development involved first compiling the relevant information from the Phase 1 study; this included patient care needs and care provided by carers, the type and quantity of the services currently used, and information about the types of help carers wanted (including information about tasks they preferred to do and preferred not to do). Further, 33 of the 82 Phase 1 carers also returned a 48-hour diary that allowed assessment of the most frequently performed tasks and the most time-consuming tasks. From this information, a list of services was compiled that included the services already used by the carers and those covering the additional help that the carers wanted. The framing of the attribute wording and the selection of levels were done with input and advice from 2 palliative care nurses, to ensure that they were feasible within the current service provision context and encompassed an appropriate range of services. The initial DCE interviews were intended as a pilot study to assess the acceptability to carers and the ease of completion but were included in the main study when no changes were required.

The High Care experiment used 14 attributes (6 with 2 levels and 8 with 4 levels) and the Low Care used 10 (6 with 2 levels and 4 with 4 levels), see Table 1. The use of all possible combinations of attributes and levels (full factorial) would result in too many choice sets to group into versions for a practicable experiment, so a fractional factorial design was used to define the first option in the choice sets for each DCE. The High Care experiment needed 64 choice sets in the fractional factorial design and the Low Care experiment needed 32. The second option in each choice set was determined using systematic techniques that have been developed to find optimal or near-optimal designs for choice experiments.[55] Both designs had a statistical efficiency of 96% for the null hypothesis using the multinomial logit (MNL) model and avoided dominated or dominating options. Choice sets were randomly assigned to versions; there were 8 versions of 8 for the High Care experiment and 2 versions of 16 for the Low Care.

Analysis

The analysis of discrete choice data is based on random utility models,[56] which are derived under the assumption of utility-maximizing behavior by the decision maker. When J alternatives are repeated under S scenarios or choice situations, the utility that individual i derives from alternative j in scenario s is denoted by

$$U_{isj} = X'_{isj}\beta + \varepsilon_{isj};\ i = 1, \ldots, n;\ j = 1, \ldots, J;\ s = 1, \ldots, S. \quad (1)$$

$X'_{isj}\beta$ is the deterministic or systematic part of the utility specified to be linear in parameters, where X'_{isj} is a vector of observed variables relating to the alternative j in scenario s and β is a vector of coefficients for those variables. It is assumed that in a given scenario, the respondent would choose the alternative that provides the greatest utility, hence choosing alternative j if and only if $U_{isj} > U_{ish}\ \forall\ h \neq j$.

This gives the standard MNL specification, conditional on β, and assuming the error terms ε_{isj} to be identically and independently distributed (IID) as

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Table 1 Discrete Choice Experiment Attributes[a] and Levels[b]

Attribute	High Care Levels	Low Care Levels
A personal care assistant visits	Every second day Daily Twice daily	—
A general community nurse visits	Daily	Weekly
A palliative care nurse visits	Daily	Weekly
Phone advice from palliative care nurse	Available 24 hours a day	Available 24 hours a day
Help with general household tasks	2 hours per week 4 hours per week 8 hours per week	1 hour per week 2 hours per week 4 hours per week
Meals cooked and delivered	2 per week 4 per week 6 per week	2 per week 4 per week 6 per week
Someone to do household shopping	Provided	Provided
Someone will come to the home during the day to give the carer a break	4 hours per week 8 hours per week 12 hours per week	—
A nurse will come to the home overnight to give the carer a break	2 nights over the next month 4 nights over the next month 8 nights over the next month	—
Care recipient can go into a palliative care hospital to give the carer a break	2 nights over the next month 4 nights over the next month 8 nights over the next month	—
A doctor visits the home	Once a fortnight Once a week Twice a week	—
Transport to medical appointments and treatment	—	Provided
Emotional support for carers from	Group meetings with carers in the same situation A counselor at a clinic A counselor doing home visits	Group meetings with carers in the same situation A counselor at a clinic A counselor doing home visits
Emotional support for care recipient from	A counselor doing home visits	Group meetings with others in the same situation A counselor at a clinic A counselor doing home visits
A coordinator assigned to care recipient's case is	Provided	Provided

a. A definition board was used to illustrate the nature of the help provided by each service.
b. ''Not provided'' was the base level for all attributes.

extreme value.[57] The probability that individual i chooses j in scenario s is then given by

$$P_{isj} = \frac{\exp(X'_{isj}\beta)}{\sum_h \exp(X'_{ish}\beta)}. \qquad (2)$$

Evidence from the Phase 1 study suggested that carers differed in their need for additional support services and in their preferences to do or not do certain caregiving tasks; for example, 13% preferred not to provide personal care whereas another 13% preferred to do this rather than have a service provider do it.[52] We therefore thought it important to investigate individual heterogeneity to the extent that was feasible with our data. The MNL specification can be generalized to account for heterogeneity that is a result of the inherent differences among individuals that can be attributed to their differences in tastes and decision-making processes. It can also be extended to allow for individual differences in scale. We used the generalized multinomial logit model (G-MNL),[58,59] which accounts for both taste heterogeneity and individual scale heterogeneity. We specified a G-MNL model with only the alternative

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specific constant (ASC) for current services as random, and that also estimated individual scale heterogeneity around the fixed attributes only (but not the ASC). This gives the G-MNL model specification in Equation 3:

$$U_{isj} = (\beta_{0j} + \eta_{0ij} + \gamma_j z_i') + X_{isj}'(\beta\sigma_i) + \varepsilon_{isj}; i = 1, \ldots, n; \quad j = 1, \ldots, J; s = 1, \ldots, S, \tag{3}$$

where β_{0j} is the mean parameter vector for alternative j, η_{0ij} is the individual specific deviation from the mean, and σ_i is a positive value that scales all coefficients for an individual relative to his or her own error term. The η_{0ij} are assumed to follow standard normal distributions, independent of each other and of the ε_{isj}. Z contains individual characteristics interacted with the ASC, and the coefficient γ is interpreted as a shift in mean preference for current services from the base case for individuals with characteristic z. The distribution of σ_i is assumed lognormal(1,τ); the model estimates the parameter τ. If all σ_i are assumed to equal 1 (i.e., $\tau = 0$), then the mixed logit (MXL) model is returned.[57]

The 2 experiments were analyzed separately using the same modeling framework. The random ASC was fitted to capture individual taste heterogeneity for or against the current services the carers were receiving and to account for correlation between repeated observations within individuals (8 High Care and 16 Low Care). The effects of individual characteristics (described below) on preferences for current services were tested in a simpler MXL model, and the characteristics identified as significant were then included in the final G-MNL models. The estimates for the ASC and individual characteristics were not scaled, as recommended by Fiebig and others.[58] Estimation by maximum simulated likelihood (MSL) was undertaken in Stata[60] using the mixlogit command[61] and the gmnl command.[62] All estimation results were generated using 1000 Halton draws to simulate the likelihood functions to be maximized.[57] Only the G-MNL results are presented.

The effects of a number of characteristics of the carer, the patient, and the caring situation, which had the potential to explain variation in preferences, were tested in the models and retained as covariates if statistically significant. The variables included carer sociodemographic characteristics, the carer's health measured with the SF-36v2 health survey, characteristics of the caregiving situation that might influence carer burden, and measures of patient dependency; the variables tested are listed in Table 2. Given the small sample size and large number of potential covariates, the less computationally demanding MXL model was used to test for significant characteristics; interaction effects with attributes were only tested where there was a specific hypothesized effect. There was only 1 covariate (carer-patient relationship) in the High Care experiment that was expected to affect preferences for a specific attribute (personal care assistant visits). We hypothesized that spousal carers would be more likely to choose to provide personal care themselves. This interaction was not statistically significant and was removed from the model.

Predicted Probabilities

The probability of choosing each option, as predicted by the models, was estimated using simulation with the gmnlpred command in Stata.[62] To account for the effect of taste heterogeneity for current services on choice probabilities, 1000 draws were taken from the estimated normal distribution of the random intercept. The drawn values were the estimated individual β_0 (ASC) used for calculating the choice probabilities for each draw. To account for scale heterogeneity, 1000 draws were taken from a truncated normal distribution with SD τ and were exponentiated to give the distribution of σ_i across the 1000 draws, such that

$$\sigma_i = \exp(-\tau/2 + \tau^{*}\varepsilon n_i),$$

where εn_i is drawn from a truncated normal distribution with truncation at ± 2.[58] All the attribute coefficients were multiplied by σ_i to give the scaled estimates for calculating the probabilities for each draw. The reported probability is the mean of these 1000 probabilities. The 95% confidence intervals were estimated by parametric bootstrapping, using the Krinsky-Robb method (described by Hole).[63] Base probabilities were estimated for each of the 3 choice options as the probability of that option with all attribute levels for all 3 choice options set to 0 (no service). Probabilities were then estimated for each option while changing the level of the selected attribute for one hypothetical plan only. These probabilities were estimated at the sample average level for the continuous covariates and at different combinations of dummy coded covariates. Attribute impact can then be assessed in terms of the change from the base probability.

RESULTS

Carer and Patient Characteristics

Of 168 respondents, 72 were classified as High Care and 96 as Low Care. Carers in the High and

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Table 2 Characteristics of Informal Carers and Patients (N = 168)

	High Care (n = 72)	Low Care (n = 96)
Carer sociodemographics		
Age, years, mean (SD)	63 (12)	60 (15)
Gender male, %	25	29
Speak English at home, %	72	80
Carer health		
Physical health (SF36 PCS), mean (SD)	45.6 (10.0)	47.6 (9.2)
Mental health (SF36 MCS), mean (SD)	39.1 (14.8)	39.6 (14.7)
Caregiving situation		
Years providing care, mean (SD)	2.5 (3.2)	2.0 (2.9)
Hours/day caring tasks, mean (SD)	11.4 (6.1)	6.3 (4.2)
Other informal carers, %	82	65
Spousal carer, %	57	56
Cohabiting, %	82	84
Employed (full-time/part-time/casual), %	28	33
Carer's household income declined, %	26	36
Patient		
Age, years, mean (SD)	76 (13)	70 (14)
Gender male, %	60	58
Died within 3 months, %	58	34
Diagnosis cancer, %	79	97
Needs help at night (most/every night), %	51	16
Needs technical nursing[a] (a little/quite a bit/a lot), %	54	24
Needs help because of incontinence (quite a bit/a lot), %	22	0
Needs help with medication (quite a bit/a lot), %	67	20
Needs emotional support (quite a bit/a lot), %	63	61

Note: PCS = physical components summary; MCS = mental components summary.
a. Injections, suppositories, dressings, catheter, or stoma care.

Low Care groups were similar for many characteristics but differed in average daily hours spent caregiving; High Care carers provided substantially more hours of care (Table 2). The majority of carers were female; more than half were spousal carers and had been providing informal care for 2–2.5 years on average. Patients were 10 years older than the carers on average; most patients were male and had metastatic cancer. The High and Low Care groups were defined by the patient's need for help with bathing or showering, which appears to have reflected the patient's condition more generally given that a higher proportion of patients in the High Care group died within 3 months of the interview; a higher proportion of High Care patients also required technical nursing care, help at night, help with medications, and help with incontinence (Table 2).

High Care DCE

On average, carers demonstrated a significant inherent preference for their current services over the hypothetical (mean intercept 6.41, $P < 0.001$), but the significant standard deviation of 5.49 (large relative to mean) indicates substantial variation among the carers in this (Table 3). Two covariates significantly affected the propensity to choose current services irrespective of attributes; working carers and carers whose patient needed help at night were less likely than other carers to choose their current services (Table 3). The time that the carer spent on caregiving tasks, although not statistically significant, was included in the final model as it was significant in the MXL model. The significant tau (Table 3) indicates that there was scale heterogeneity, suggesting that individuals varied in terms of their certainty regarding their choices.

Carers were significantly more likely to choose support service plans that provided palliative care nurse visits daily, community nurse visits daily, 24-hour phone advice, doctor home visits weekly, personal care assistant visits, and home respite during the day and overnight relative to plans with these attributes at zero (not provided). The personal care assistant was preferred at the middle level (daily) but not at the highest level (twice daily). Home respite

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Table 3 High Care Experiment: Percentage Currently Using Services and Generalized Multinomial Mixed Logit (G-MNL) Model for Service Preferences

			Model[a]		
Variable	**Description**	**Current Use, % (*n* = 72)**	**Coefficient**	**95% CI**	
Current services constant	Mean		6.41[b]	2.85	9.98
	Standard deviation		5.49[b]	3.06	7.93
Attributes					
Personal care assist	Every second day	13	0.60	–0.26	1.46
	Daily	4	1.55[c]	0.59	2.51
	Twice daily	1	0.28	–0.63	1.20
Community nurse	Daily visits	18	0.61[c]	0.18	1.05
Palliative care nurse	Daily visits	14	2.02[b]	1.12	2.93
Phone advice	Available 24 hours	86	2.16[b]	1.20	3.11
Household tasks	2 hours/week	14	0.07	–0.63	0.77
	4 hours/week	4	0.73	–0.10	1.56
	8 hours/week	3	0.01	–0.63	0.66
Meals provided	2/week	1	–0.13	–0.69	0.42
	4/week	1	0.45	–0.25	1.14
	6/week	1	0.51	–0.10	1.12
Shopping	Provided	4	0.32	–0.16	0.81
Home respite—daytime	4 hours/week	13	0.99[d]	0.16	1.83
	8 hours/week	0	1.20[c]	0.48	1.93
	12 hours/week	1	0.59	–0.08	1.26
Home respite—overnight	2 nights/month	1[e]	0.68	–0.25	1.61
	4 nights/month	0[e]	0.19	–0.58	0.96
	8 nights/month	1[e]	0.90[d]	0.09	1.70
Institutional respite	2 nights/month	0[e]	–0.45	–1.18	0.28
	4 nights/month	0[e]	0.32	–0.47	1.11
	8 nights/month	1[e]	0.84[d]	0.02	1.66
Doctor visits at home	1/fortnight	44	0.64	–0.02	1.31
	1/week	17	1.34[d]	0.27	2.42
	2/week	1	1.09[d]	0.26	1.92
Emotional support—carer	Peer group meetings	0	–0.30	–1.09	0.49
	Counselor at clinic	6	–0.16	–0.86	0.55
	Counselor at home	4	–0.46	–1.11	0.19
Emotional support—patient	Counselor at home	8	0.48	–0.07	1.03
Case coordinator		15	–0.52[d]	–0.97	–0.06
	Tau[f]		1.37[b]	0.89	1.84
Covariates					
Carer works	Full-time/part-time/casual		–4.20[c]	–7.20	–1.19
Patient needs help at night	Most/every night		–3.62[d]	–6.83	–0.40
Carer time spent on tasks	Daily hours/10		1.99	–0.60	4.58
Model					
Log-likelihood			–286.19		
Pseudo R^2			0.45		

Note: CI = confidence interval.
a. The reference level was "not provided" for all attributes.
b. $P < 0.001$.
c. $P < 0.01$.
d. $P < 0.05$.
e. Received this in the past month.
f. Only attributes were scaled.

during the day was statistically significant at the lower levels but not the highest level, while overnight home respite and institutional respite were significant at the highest level only. The case coordinator

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was the only attribute with a statistically significant negative coefficient, indicating a preference to not have this service (see Table 3).

Figure 1 illustrates the probability of choosing a hypothetical plan (gray bars) or the current services (white bars) for statistically significant attributes. There are 2 sets of probabilities: 1) for carers who are not working and not usually providing care during the night, 2) for carers who are working and usually provide care during the night; both sets are for a carer who provides care for 11.4 hours per day (sample mean). The base probability (when all attributes are set to zero) of choosing current services is 0.92 for a nonworking carer not providing care at night and 0.51 for a working carer providing care at night. The same base probabilities of choosing either of the hypothetical service plans are 0.04 and 0.24, respectively. If hypothetical plan A included overnight home respite while the other alternatives remained at the base level, the probabilities for choosing plan A would increase to 0.07 and 0.37, respectively. Phone advice and palliative care nurse visits had the largest impact on the predicted probability, increasing the probability of choosing hypothetical plan A from 0.24 to 0.53 and 0.52, respectively (if the other alternatives remain at base level), in the case of working carers providing care at night (Figure 1).

Low Care DCE

On average, carers in the Low Care experiment also demonstrated a significant inherent preference for their current services over the hypothetical (mean intercept 1.66, $P = 0.004$), but the significant standard deviation of 4.47 larger than the mean indicates substantial variation among these carers, suggesting that in fact many carers would prefer to not have their current services (Table 4). Three covariates significantly affected the propensity to choose current services irrespective of attributes; the preference for current services increased with the carer's age and physical health (SF-36 Physical Components Summary score), and carers whose patient needed technical nursing care were more likely than other carers to choose their current services (Table 4). The statistically significant estimate of tau (Table 4) indicates that there was scale heterogeneity, suggesting that Low Care carers also varied in terms of their certainty regarding their choices.

Carers were significantly more likely to choose service plans providing palliative care nurse visits weekly, community nurse visits weekly, 24-hour phone advice, help with household tasks (at all 3 levels), transport to medical appointments, and a case coordinator, relative to plans with these attributes at zero (not provided), see Table 4. All statistically significant attributes had positive coefficients, indicating a preference for the service.

Figure 2 illustrates the probability of choosing a hypothetical plan (gray bars) or the current services (white bars) for the statistically significant attributes. There are 2 sets of probabilities: 1) where the patient requires technical nursing care, 2) where the patient does not require technical nursing care; both sets are for a 60-year-old carer reporting a PCS score of 47.6 (sample mean). The base probability (when all attributes are set to zero) of choosing current services is 0.55 if the patient does not require technical nursing care and 0.84 if technical nursing care is required. The same base probabilities of choosing either of the hypothetical service plans are 0.23 and 0.08, respectively. If hypothetical plan A included a case coordinator while the other alternatives remained at the base level, the probability of choosing plan A would increase to 0.29 and 0.10, respectively. Like the High Care experiment, phone advice and palliative care nurse visits produced the largest impact on the predicted probability. If technical nursing care was not required and the other alternatives remained at the base level, these attributes increased the probability of the carer choosing hypothetical plan A from 0.23 to 0.42 and 0.49, respectively (Figure 2).

DISCUSSION

This study found similarities and differences in preferences between the carers of patients with high or low personal care needs. Both groups valued access to phone advice and visits from community and palliative care nurses, which is consistent with the limited available literature on this topic. Brazil and others[35] found ''in-home nursing care'' to be the most highly valued service by carers of terminally ill patients, while the review by Bee and others[37] found that carers of cancer patients at the end of life needed nursing support and information, particularly information about symptom management and medications. The telephone advice attribute in our study was described as ''Phone advice from a palliative care nurse about managing pain and other problems and about care generally'' (see definition board in the appendix). Neither group wanted additional emotional support for the patient, possibly perceiving themselves, visiting nurses, or a chaplain as

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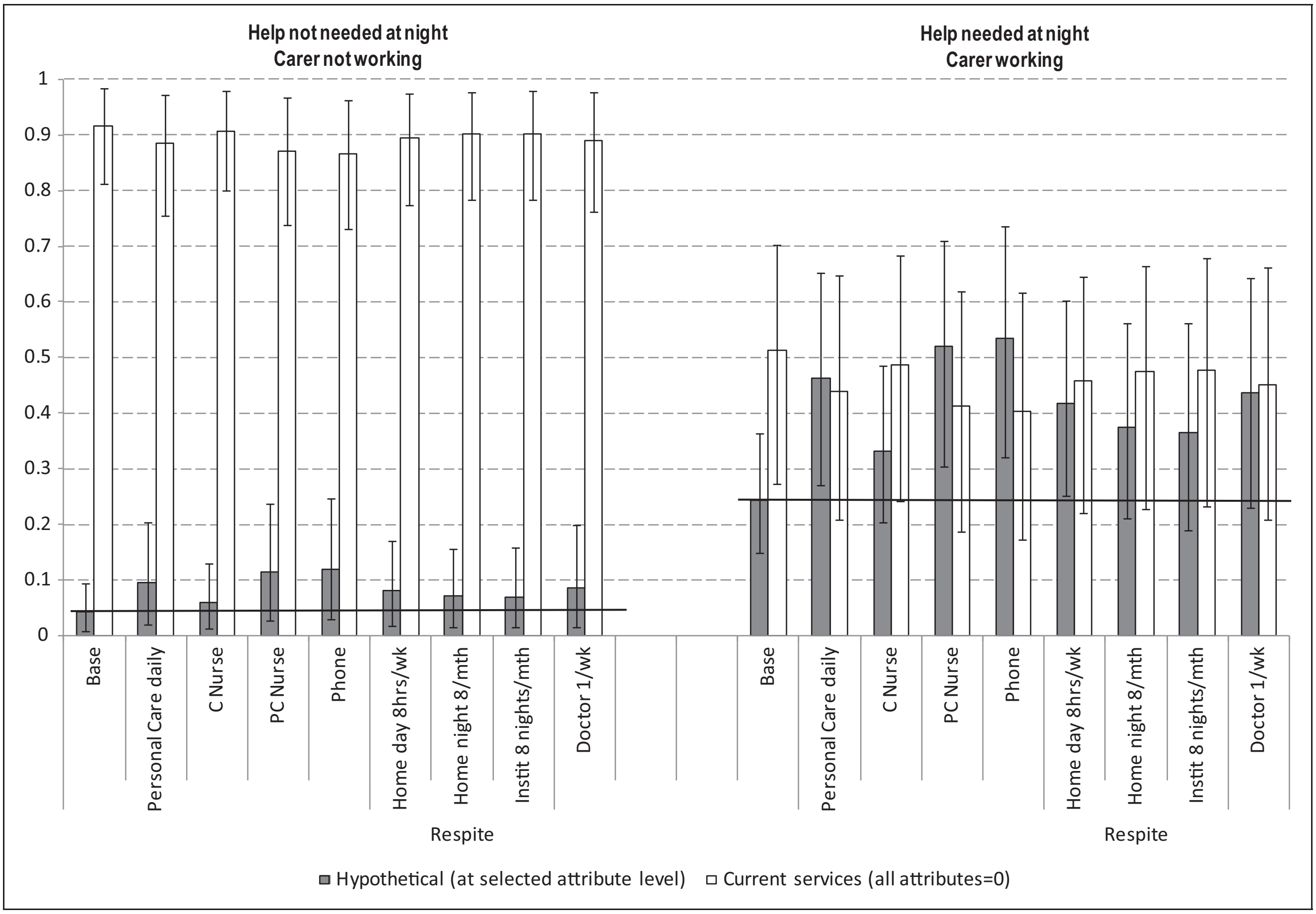

Figure 1 *High Care experiment: effect of selected statistically significant attributes on the predicted probability of choosing a hypothetical service plan or current services and 95% confidence intervals. ''Probability'' refers to the probability of choosing alternative service plans when one hypothetical plan is set to the attribute level and the other options (current services and the other hypothetical plan) remain at the base level for a carer providing care 11.4 hours per day. The probabilities are presented for working carers where the patient needs help at night and for nonworking carers where the patient does not need help at night. Base = probability of choosing a support option when all attributes are set to zero (no service); the line represents the base level for a hypothetical plan. C Nurse = community nurse; PC Nurse = palliative care nurse; Instit = institutional.*

providing this. It is also possible that the term *counselor* required clarification, although this was not raised by any of the respondents during the interview.

The nature of the attributes on which the preferences of the High and Low Care groups differed suggests changing priorities with different phases of the palliative process. At an early phase, recipients attend medical appointments and receive therapy while both carer and recipient may continue to participate in some or all usual activities. At the more advanced phase, patients are nearer death and likely to be confined to the home, with the carer also reducing activities outside the home due to increasing hands-on caregiving. Consistent with this, the Low Care group wanted help with transport, a case coordinator, and help with household tasks, while the High Care group wanted help with personal care and respite but did not want a case coordinator or help with household tasks. The preference for overnight respite appeared to have a threshold where small amounts do not make a difference to carers; moreover, some carers and patients may be reluctant to accept it.[64]

Carers (High and Low Care) were more likely to choose the current service package than to switch to a hypothetical alternative. This is likely to reflect the familiarity and quality of the relationship with the current providers, which is difficult to capture

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Table 4 Low Care Experiment: Percentage Currently Using Services and Generalized Multinomial Mixed Logit (G-MNL) Model for Service Preferences

Variable	Description	Current Use, % (n = 96)	Model[a] Coefficient	Model[a] 95% CI	
Current services constant[b]	Mean		1.66[c]	0.52	2.80
	Standard deviation		4.47[d]	3.42	5.52
Attributes					
Community nurse	Weekly visits	18	0.75[d]	0.50	1.01
Palliative care nurse	Weekly visits	55	1.91[d]	1.48	2.34
Phone advice	Available 24 hours	93	1.34[d]	1.01	1.67
Household tasks	1 hour/week	5	0.50[c]	0.14	0.85
	2 hours/week	5	0.79[d]	0.38	1.20
	4 hours/week	7	0.71[d]	0.32	1.10
Meals provided	2/week	0	0.06	–0.27	0.40
	4/week	0	0.11	–0.29	0.51
	6/week	3	0.32	–0.04	0.69
Shopping		2	0.14	–0.08	0.36
Transport to medical appointments		7	0.54[d]	0.29	0.80
Emotional support carer	Peer group meetings	0	0.16	–0.21	0.53
	Counselor at clinic	6	0.11	–0.24	0.46
	Counselor at home	5	0.24	–0.11	0.59
Emotional support patient	Peer group meetings	0	0.11	–0.25	0.47
	Counselor at clinic	5	–0.23	–0.60	0.13
	Counselor at home	5	0.02	–0.31	0.36
Case coordinator		13	0.43[d]	0.21	0.65
Tau[e]			0.69[d]	0.45	0.92
Covariates					
Patient needs technical care	Injection/dressing/catheter/stoma care		4.29[d]	2.21	6.36
Carer age	Age/10		1.21[d]	0.60	1.82
Carer physical health	SF36-PCS/10		1.72[d]	0.76	2.68
Model					
Log-likelihood			–782.30		
Pseudo R^2			0.48		

Note: CI = confidence interval; PCS = physical components summary.
a. The reference level was "not provided" for all attributes.
b. Represents utility when age and PCS are at the sample mean level and other variables are 0.
c. $P < 0.01$.
d. $P < 0.001$.
e. Only attributes were scaled.

adequately in a discrete choice experiment. Nonetheless, these respondents did trade; the hypothetical alternative was chosen over the current in 43% of Low Care and 36% of High Care scenarios. This varied with measures of recipient dependency, carer sociodemographic characteristics, and factors contributing to burden. Low Care carers were more likely to choose current services if they were older, if they were in good physical health, and when the recipient required injections, dressings, or other technical nursing care. High Care carers were more likely to choose current services when the carer was not working, when the recipient did not require care during the night, and when the carer spent a lot of time on caregiving tasks.

We hypothesized that preferences for support services would vary with the relationship of the carer and patient, in particular that spouses would be more ready to take on personal care tasks than would children. Our results did not demonstrate this, possibly due to the small sample size or the stronger influence of other carer characteristics. It may also be due to self-selection, where carers who do not wish to perform personal care tasks cease to provide care at home when the patient enters this stage. The gender of the carer and patient may be an important

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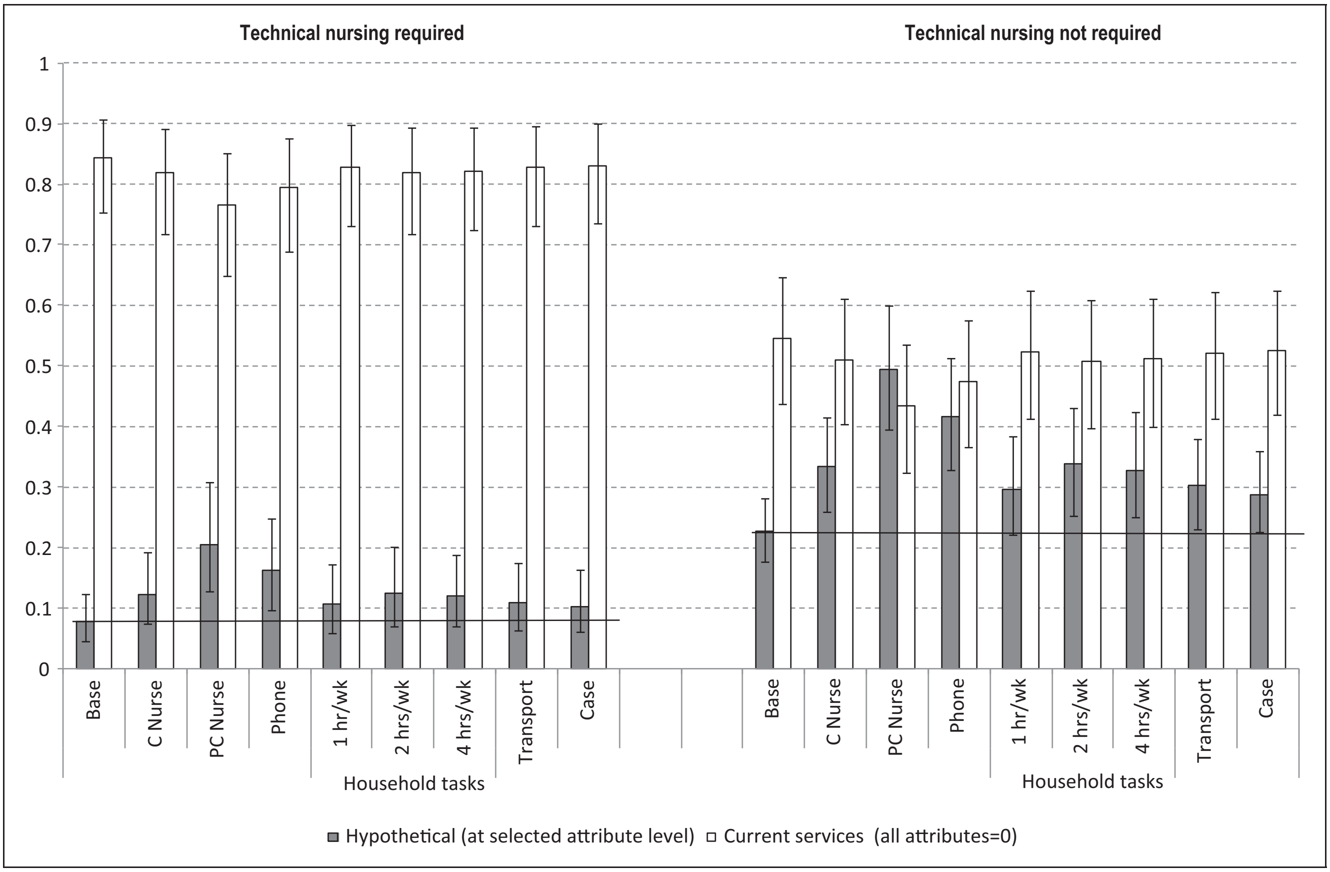

Figure 2 *Low Care experiment: effect of statistically significant attributes on the predicted probability of choosing a hypothetical service plan or current services and 95% confidence intervals. "Probability" refers to the probability of choosing alternative service plans when one hypothetical plan is set to the attribute level and the other options (current services and the other hypothetical plan) remain at the base level for a carer aged 60 years reporting SF-36 Physical Components Summary score of 47.6. The probabilities are presented for carers whose patient requires technical nursing care and those whose patient does not require technical care. Base = the probability of choosing a support option when all attributes are set to zero (no service); the line represents the base level for a hypothetical plan. C Nurse = community nurse; PC Nurse = palliative care nurse; Transport = transport to medical appointments; Case = case coordinator.*

component of this issue; however, we were unable to test a 3-way interaction with carer gender because of the small number of nonspousal male carers in our High Care sample.

Carers and the services that support them are crucial to achieving death at home,[5] and the timely provision of appropriate in-home palliative care services is essential to minimizing the impact of caregiving on informal carers. In the palliative care context, carers provide many of the same care tasks as carers in other contexts, such as assisting with personal care, mobility, household tasks, transport, and management of finances; liaising with health professionals; and providing emotional support.[52] Anxiety related to symptom management and administering medications has been identified as a particularly important issue for carers in the end-of-life cancer care context.[37] Although many carers derive satisfaction from the role,[19,20] these carers are also coping with the emotional stresses associated with the impending death of a loved one; in the current study more than half of the High Care patients and a third of Low Care patients died within 3 months of the carer interview. It is therefore not surprising that informal carers providing end-of-life care have been found to have substantially worse mental health than general populations of the same age and gender.[65,66]

In Australia, palliative care services are provided as inpatient services or in the community. Inpatient services may be provided in specialist palliative care units or in acute care hospitals with or without specialist palliative care advice.[67] In larger centers,

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home-based palliative care is usually provided by palliative care specialist medical, nursing, and other health professionals, in conjunction with general nurses and medical practitioners. In rural areas, home-based care is usually provided by generalist medical and nursing teams. Domestic and other types of support are generally provided by services outside of the health care system, but medical practitioners and nurses will usually advise carers and patients about the availability of these services and help to arrange them if required. While the arrangements for end-of-life care may vary between health systems, our findings were consistent with the limited international literature, suggesting that they have relevance for other countries.

Limitations

The palliative care context is a particularly difficult context for conducting research[68,69]; patients are extremely ill and approaching death, and informal carers are under considerable stress. This has consequences for recruitment and data collection. Typical of palliative care research, our sample will not include those having the most difficulty coping, as we relied on nurses to approach carers and they were reluctant to burden those whom they perceived as under great stress. The second issue for research in this context is responder burden, which we endeavored to minimize; the DCE presented complex choice sets (14 and 10 attributes for the High Care and Low Care groups, respectively), but fewer attributes would not have captured a realistic representation of the available palliative care services or the range of desired support.[52] Thus, while comprehensive measures of carer burden and satisfaction may have been informative covariates, they were omitted to reduce interview demands.

Additional attributes or attribute levels might have provided more specific information, but more complex choice sets would have created too great a respondent burden in this context. The selection of attributes and levels was well-founded in previous research with similar carers and with advice from experienced palliative care nurses. Further, the consistency of our results with studies using different methods suggests that the most important attributes were included.

Our sample was recruited through specialist palliative care services located in a major city and comprised mainly carers of patients with cancer. Carers caring for patients with other terminal conditions, and those located in rural areas with predominantly generalist medical and nursing support, may face different challenges and have different preferences. The sample was smaller than anticipated; nonetheless, we were able to estimate quite complex models, and coefficients for many attributes were statistically significant. The study is cross-sectional, and although a longitudinal study investigating how preferences changed as the patient's condition deteriorated would have been more informative, this would impose an unacceptable burden on this group of carers and was practically difficult because of the short time until death for many patients.

Future Research and Policy Implications

This study extends what is known about the role and preferences of this group of carers, who have been less well studied than the carers of the aging and chronically ill. Further research is required to explore issues arising from this study. These include understanding more about the differences in choices within this group of carers, the extent to which they are based on underlying preferences, and the extent to which they are determined by the circumstances of the patient (including poorer health and more advanced disease) or the carer (including the carer's own health, his or her labor force participation, and the availability of other family members and friends). It would be useful to further explore the influence of the relationship between the carer and patient on the patient's and carer's preferences and to investigate the change in demands, coping ability, and desired support over time with disease progression.

Policy makers and health service planners face the challenge of developing services to meet the increasing demand for end-of-life care at home. Demographic and social changes will affect the availability of carers in the future. Aging of the population will mean an increasing number of elderly carers with poorer health, and the increasing workforce participation of women will see more carers juggling paid employment and caring responsibilities. This research demonstrates that carers in the palliative care context value most highly those services that directly support them in giving care. It also shows that service design should reflect not only the health state and needs of the patient but also the circumstances of carers, such as whether they are working. Meeting the social expectations of dying at home will require a greater range of support services designed to meet the differing preferences of informal carers.

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