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University of Technology, Sydney
City campus, Haymarket
PO Box 123 Broadway NSW 2007
Tel: +61 2 9514 4720
Fax: + 61 2 9514 4730
Email: mail@chere.uts.edu.au
www.chere.uts.edu.au

# The provision of informal care in terminal illness: an analysis of carers' needs using a discrete choice experiment

Jane Hall[1], Patricia Kenny[1], Ishrat Hossain[1]

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1. Centre for Health Economics Research and Evaluation
Faculty of Business
University of Technology, Sydney

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## Abstract

There is an increasing expectation that families will provide care at home for those with chronic, acute and terminal illness. There is a range of services available to support the home care of these patients. Carers of those in the terminal phase of illness face different demands and challenges than those caring for the chronically ill, disabled or aging; the patient's health is deteriorating, often rapidly, and death is imminent. Yet the needs and requirements of this group of carers has been far less studied than those caring for people with chronic and continuing conditions. We argue that considering the reciprocal nature of relationships is important in understanding the provision of informal care. Carers' feelings for which tasks and responsibilities are most difficult are not the same as their preferences for additional support services. Carers preferences are influenced by their relationship with the patient.

This study investigates carers' preferences for services to support their caregiving role. Carer preferences were investigated using a discrete choice experiment, in which 168 carers were asked first to choose between two packages of care and then between the chosen package and their current support. Data were analysed using mixed logit.

The DCE results showed that the support most wanted was palliative care nursing, general nursing, and telephone advice available 24 hours. Carers providing high levels of care wanted respite care provided at home and help with the patient's personal care. Where the care-giving need was relatively low, carers wanted help with household tasks, transport and a case co-ordinator. Overall, carers appeared to be satisfied with the support they received from palliative care services, but this varied with the personal circumstances of the carer.

This study provides useful insights for those who plan and deliver palliative care in the community. It supports the view that effective support for carers must recognise the differing needs of individual carers. While our results do not provide any insight into how the pre-existing relationship between carer and recipient may affect preferences for care, it points to the need to explore further differences in preferences across respondents both in discrete choice work in general, and in designing services to support rather than replace informal carers.



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## Introduction

Informal care is the care provided at home by family members and friends to the ill, disabled and elderly. It is largely unpaid, though carers may receive a government benefit. There are over 2.5 million carers, or 13% of Australians, assisting the elderly and disabled to live outside of institutions. (1) Increasing attention has been paid to the role and needs of these carers, though research has primarily focused on the burden of care-giving, establishing the scope and intensity of the tasks undertaken. (2, 3) Less attention has been paid to carers looking after those with terminal illness, although as end of life care has moved from the institutional setting to the home, and death at home is often preferred by both patients and carers, there are increasing demands on this group of carers.(4)

The economic analysis of informal care has also been quite limited. While the cost of providing informal care should be recognized in any economic evaluation that adopts a societal perspective, in practice it is often overlooked. (5) Current approaches to economic evaluation recommend that the time of informal caregivers should be valued, and included as a non-health care cost. The monetary valuation of informal care relies on the replacement cost or opportunity cost method. The replacement cost method identifies a market (close) substitute for informal care, and values the informal care time at the market rate; whereas the opportunity cost is based on the labour market wage foregone by the provider of care. Both these approaches imply that informal carers are just a resource, albeit generally a cost saving one, to be used in the production of health care.

Economists have paid little attention to interdependencies in health, the effect that one person's health has on the wellbeing of their significant others, the so called 'family effects'. (6) Similarly, this interdependency will also affect how individuals choose to use their time, a phenomenon that Sugden explained as 'fellow feeling': "The fact that human beings so often choose to do things together is, if not quite a puzzle from the perspective of rational choice theory, at least a regularity that theory cannot explain.".(7) Providing informal care is a choice to spend time with the other person. Another aspect of this fellow feeling is that one person will gain satisfaction not just from seeing an improvement in the wellbeing of a significant other but also from knowing that their efforts have contributed to that sense of improvement. If this is the case, caregivers should report some satisfaction from their caregiving role. Empirical studies do report this, (8) (9, 10)and (11) place this in the context of process utility.

Caregivers provide the time and experience the stress associated with the tasks they perform. The physical and emotional impact of caring may be expected to influence carers' own health. Many caregivers are themselves in poor health. (1) Care-giving for the elderly has been shown to affect mortality. (12) Thus there is a carers' effect that is over and above the family effect. (6)

The broader conceptualization of informal care then must start with the notion of care-giving in the context of an established relationship. Individuals care for one another, and so there are interdependencies in terms of their wellbeing and their health. Providing informal care is a choice of spending time with the other person as well as an input of labour. In addition, the tasks involved in informal care will also affect the physical and mental health outcomes of the caregiver. In particular, those caring for patients close to death are providing physical care that is difficult and time consuming, emotional support to the dying person as well as dealing with their own feelings of grief. Therefore, the care-giving role has both positive and negative aspects to it, although these will be difficult to separate empirically.

From the policy perspective, the relevant question is what should be done for caregivers. As we have argued previously, " the challenge for service providers is … to provide programs where carers feel supported in their role, but not replaced." (13)This means that the burdensomeness or difficulty that carers find in particular tasks is not necessarily a good guide to the support services that will most help them in their care-giving role. Further, caregivers' responses to their care-giving role may well differ according to the needs of the patient, the situation of the caregiver, and the context of the relationship. For example, van Exel et al show that informal caregivers' attitudes differ quite distinctly, with one group having ambivalent views of respite care, influenced by the care recipients' reluctance to be cared for by others and their own (caregivers') stress. (14)Therefore the design of effective support services should recognize carers' preferences and not be limited to the needs of the patients.

We chose to investigate caregivers' preferences for support services in the context of palliative care, as the desirability of dying at home is increasing, the palliative phase of illness presents a complex array of family effects, fellow-feeling aspects, and carer effects. The first phase of the study used qualitative and quantitative methods to explore carers' perceptions of the impact of providing care and the type of care they were providing. Our results have been reported elsewhere; (13). The major findings were that:

- Carers spent a median of 8 hours per day in caring tasks;
- Carers' response to providing personal care varied with their relationship. Spouses preferred to do this rather than have others take over this aspect of care, while children preferred not to do it;
- Although carers' physical health as measured by the SF-36 was similar to the Australian average, their mental health scores were lower;
- Most respondents thought their caregiving role was important and satisfying.

It was also clear that the needs of patients varied, even though all were receiving palliative care, particularly in terms of their needs for assistance with personal care and technical nursing.

The second phase of the study reported here uses the discrete choice experiment approach to investigate carer preferences for support services. The general methods have been well described elsewhere.(15)(16) In spite of their usefulness in exploring preferences, the approach has not been well used in the context of informal care or palliative care. Van den Berg et al used stated preference methods to assess the value of informal care. They were interested in a monetary valuation of a marginal hour of care, and did not investigate differences in the type of care provided. (17) (18) Douglas et al used a DCE in palliative care; they investigated patient preferences for the different services provided in palliative day care. (19)This study adds by focusing on palliative care services provided to patients at home, and on carer preferences for those services.

## Methods

A cross-sectional study of the preferences of the informal carers of community palliative care patients was conducted in Sydney, Australia between May 2005 and November 2006. A discrete choice experiment (DCE) was used to investigate the informal carers' preferences for different support services. Ethical approval was provided by the institutional ethics committees at the participating palliative care services and at the University of Technology, Sydney.

*Recruitment*

Participants were recruited through two specialist community palliative care services in Central and Eastern Sydney, which provide multidisciplinary support for patients receiving palliative care at home. The nominated informal carers of new patients registering with the two services during the study period were invited to Participate. Written consent was obtained from the carer and the patient prior to commencement of the carer interview. Carers were deemed eligible if they were English-speaking and their care recipient was able to provide informed consent.

*Data collection*

Data were collected through face-to-face interviews with carers and from patient medical records. The interviews were conducted in the care recipient's home or at another location if requested by the carer. In addition to the DCE questions, the interview consisted of questions about their current service use in terms of the DCE attributes, questions about the help needed by the care recipient (adapted from (20)), the Australian version of the SF-36v2 Health Survey,(21, 22) questions about the carer's relationship to the care recipient, the time spent on caring, support from other informal carers and socio-demographic characteristics. Clinical and socio-demographic information about the care recipient was obtained from the palliative care service's patient records.

*DCE attributes and experimental design*

Two separate experiments were conducted, one for the carers of care recipients who needed a high level of care (High Care) and one for the carers of care recipients with relatively low care needs (Low Care). This was done to avoid offering carers support that was not relevant to the care recipient's needs. Care recipients were defined as "High Care" if they needed "quite a bit" or "a lot" of help with bathing or showering, as reported by the carer.

Both high and low care experiments were unlabelled and each hypothetical scenario comprised two packages of services (Plan A and Plan B). After reading each scenario, carers were asked two questions; 1) they were asked to choose between service plan A or service plan B to replace their current support services and 2) they were asked to choose between their chosen service plan and the support services they were currently receiving. The attributes and levels used in each experiment (Tables 1 and 2) were developed based on a review of the literature and a pilot study which used quantitative and qualitative methods to describe the carers' role, the perceived impact of caring and the support carers would find helpful (13). A definition board was used during the interview to illustrate the attribute components in more detail. See the appendix for a sample of a scenario from each experiment.

A separate fractional factorial design was used in each experiment to select scenarios. Each design was constructed using systematic techniques that have been developed to find optimal or near-optimal designs for choice experiments (23). Both designs had a statistical efficiency of 96% and avoided dominated or dominating options. The High Care experiment included 14

attributes (6 x 2 levels and 8 x 4 levels, see Table 1) and used a design of 64 pairs which were randomly assigned to 8 versions of 8 scenarios. The Low Care experiment included 10 attributes (6 x 2 levels and 4 x 4 levels, see Table 2) and used a design of 32 pairs which were randomly assigned to 2 versions of 16.

*Analysis*

The analysis of discrete choice data is based on random utility models (24), which are derived under the assumption of utility-maximizing behaviour 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

$$(1) \qquad U_{isj} = X'_{isj}\beta + \varepsilon_{isj}$$

$X'_{isj}\beta$ 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 $\beta$ 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 multinomial logit specification, conditional on $\beta$, and assuming the disturbance terms $\varepsilon_{isj}$ to be identically and independently distributed (IID) as extreme value (25). The probability that individual *i* chooses *j* in scenario *s* is then given by:

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

Heterogeneity is a result of the inherent differences among individuals that can be attributed to their differences in tastes and decision making processes. Therefore, respondents with same observed characteristics may value and weight attributes of a product differently when making a decision. The MNL specification can be generalized to account for this heterogeneity by allowing components of coefficients ($\beta$) to randomly vary over individuals but not over the repeated choices made by an individual by setting:

$$(3) \qquad \beta_i = \overline{\beta} + \mu_i$$

where $\overline{\beta}$ is the mean parameter vector for the population and $\mu_i$ is the individual specific deviation from the mean. The $\mu_i$ are assumed to follow standard normal distributions, independent of each other and of the $\varepsilon_{isj}$. This specification introduces error correlation across choice situations, accounting for the dependence structure in unobserved utility among the repeated choices of an individual which comes from the panel structure of the data. We therefore estimated the random parameter or mixed logit (MXL) model using maximum simulated likelihood (MSL).

The responses to the two questions were combined to create a multinomial response variable (1=Current Services, 2=Hypothetical Plan A, 3=Hypothetical Plan B). Responses to the questions about the support services the care recipient was receiving currently were used to code the attribute levels for the "Current Services" option. The MXL models were estimated in Gauss using a program downloaded from Kenneth Train's website (26). All estimation results were generated using 1000 Halton draws to simulate the likelihood functions to be maximized (25, 27-29). Although the High care and Low care experiments were analysed separately, the same modelling framework was used. Both the High Care and Low Care models included an intercept for the "Current Services" option which was allowed to be random. They also included fixed effects for each attribute level, except for the base level which was the "not provided" level for all attributes. The effects of a number of characteristics of the carer, the care recipient and the caring situation, which had the potential to explain variation in preferences, were tested in the models and retained if statistically significant.

The probability of choosing each option, as predicted by the model, was estimated using simulation. The simulation took 1000 random draws from the estimated distribution of the random intercept and the probability in equation 2 was estimated for each. The reported probability is the mean of the 1000 replications. Base probabilities were estimated for each of the three choice options as the probability of that option with all attributes set to 0 (no service). The probability of choosing each option when hypothetical Plan A is at the attribute level and "Current Services" and hypothetical Plan B are 0 was also estimated. These probabilities were estimated at the sample average level for the continuous covariates and at different combinations of dummy coded covariates. The attribute impact can than be assessed in terms of the change from the base probability.

## Results

The study recruited 178 informal carers, representing 21% of those eligible. Reasons for non-participation included: the carer refused (12%), the patient died or was hospitalised before the interview (11%) or the carer was not invited to participate by the palliative care team because 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; 72 High Care and 96 Low Care.

*Carer and care recipient characteristics*

The carers in the High and Low Care groups were similar for many characteristics but differed in the average daily hours spent on caring tasks where the High Care group provided substantially more hours of care (Table 3). The majority of the carers in both groups were female, more than half were the spouse of the care recipient and had been providing informal care for 2-2.5 years on average. The care recipients were ten years older than the carers on average. More than half of care recipients were male and the majority had metastatic cancer. Compared with the Low Care group, a higher proportion of the care recipients in the High Care group died within three months of the interview (Table 3).

*High Care DCE*

On average the High Care carers demonstrated a significant preference for their current services over the hypothetical service plans, but this varied between carers (intercept 5.0, sd 4.6, Table 4). The High Care carers were significantly more likely to choose hypothetical plans if they included: palliative care nurse visits, community nurse visits, 24 hour phone advice, personal care assistant visits and home respite during the day and overnight. The personal care assistant was preferred at the lower levels (2$^{nd}$ daily and daily) which were statistically significant, but not at the highest level (twice daily). The respite attributes were statistically significant at the highest level (highest 2 levels for daytime home respite), but not the lower levels. Single levels of several attributes (shopping, institutional respite, doctor visits and emotional support for carer) were weakly significant and one of these (emotional support for the carer from a counsellor at home) was the only significant negative coefficient (indicating a preference to not have it). Three covariates significantly affected the preference for current services; the number of hours carers spent on care-giving was positively associated with choosing current services, while working carers and carers who were providing care at night were less likely to choose their current services (Table 4).

The probability of choosing each of the three options in the High Care experiment, as predicted by the model, is reported in Table 5 for several illustrative attributes. For a carer providing care for 11.4 hours per day (sample mean), the base probability of choosing current services is 0.92 for a non-working carer not providing care at night, 0.77 for a non-working carer providing care at night, 0.76 for a working carer not providing care at night and 0.52 for a working carer providing care at night. The same base probabilities of choosing either of the hypothetical service plans are 0.04, 0.12, 0.12 and 0.24 respectively. If the hypothetical plan included overnight home respite, these would increase to 0.06, 0.17, 0.18 and 0.34 respectively. Phone advice and palliative care nurse visits had the largest impact on the predicted probability, increasing the probability of choosing the hypothetical from 0.24 to 0.43 and 0.42 respectively in the case of working carers providing care at night (Table 5).

*Low Care DCE*

While the statistically significant negative intercept suggests that on average the Low Care carers did not prefer their current services, this is somewhat misleading because the preference for current services had a significant positive association with three covariates (age, physical health and the need for technical nursing care, Table 6). The Low Care carers were significantly more likely to choose hypothetical plans if they included: palliative care nurse visits, community nurse visits, 24 hour phone advice, help with household tasks (at all three levels), transport to medical appointments and a case coordinator. Single levels of two attributes (meals and emotional support for the carer) were weakly significant; meals at the highest level and emotional support for the carer at home from a counsellor (Table 6). All significant attributes in the Low Care experiment had positive coefficients indicating a preference for the service.

The probability of choosing each of the three options in the Low Care experiment, as predicted by the model, is reported in Table 7 for several illustrative attributes. For a 60 year old carer reporting a Physical Components Summary (PCS) score of 47.6 (sample mean), the base probability of choosing current services is 0.60 if the care recipient does not require technical nursing care and 0.82 if technical nursing care is required. The same base probabilities of choosing either of the hypothetical service plans are 0.20 and 0.09 respectively. If the hypothetical plan included a case coordinator, these would increase to 0.26 and 0.12 respectively. Like the High Care experiment, phone advice and palliative care nurse visits produced the largest impact on the predicted probability in the Low Care experiment. If technical nursing care was not required, these attributes increased the probability of the carer choosing a hypothetical plan from 0.20 to 0.34 and 0.39 respectively (Table 7).

## Discussion

Informal carers, based on these respondents, want telephone advice from a palliative care nurse available on a 24 hour basis. They also value regular visits from both community and palliative care nurses. For patients requiring low levels of personal care, carers valued a case co-ordinator, domestic help, assistance with transport, and emotional support. These patients were generally at a relatively early phase in the palliative process and some were still receiving palliative therapies which may involve multiple providers in different locations. So it is not surprising that both help with transport to appointments and a care co-ordinator to assist with information provision and arranging services were significant. These carers identified help with domestic chores but not with shopping, which at first may seem inconsistent. However, these patients may still be quite active and shopping may provide a shared experience that both patient and carer can enjoy while getting out of the house, However, domestic chores are less readily undertaken jointly. Interestingly, these results also indicate the emotional needs of carers at this stage, while more emotional support for the patient was not significant. This should not be interpreted as a lack of any need for emotional support for these patients; rather it is likely that patients' needs are largely met by the other services, particularly the palliative care nurses.

Generally those in the high care group were at a more advanced stage of illness and thence closer to death. These carers valued a personal care assistant, shopping and respite care. Patients at this stage require substantial help with activities such as washing, toileting and dressing, which can be both physically and emotionally demanding on carers, so it is not unexpected that they value assistance with personal care. Unlike the low care group, these carers want help with shopping but not provision of meals or help with other domestic tasks. This too can be explained. As patients are increasingly confined to the home, carers do not want to be taken way from the home. However, domestic chores within the home seem much less important as their attention is focussed on the immediate needs of the patient. Meals are both less important and more likely to be provided by other members of the family and friends who become aware of the progression of the illness. Carers in this group also preferred packages which provided respite care but there appears to be a threshold; small amounts of respite care do not make a difference.

Carers were most likely to choose the current service package than to switch to a hypothetical alternative. This could be construed as high levels of satisfaction with the current services provided but this is likely to be an over-interpretation. Other studies have demonstrated that respondents are likely to stay with their current treatment. In a study of preferences for asthma medications, we have shown that respondents' choices are influenced by the effectiveness of their current treatment; and we have argued that what appears as a status quo bias is probably due to the effect of unobserved factors. This is likely to be even more strongly the case in this setting, where the familiarity and quality of the relationship with the existing community and palliative care staff is important but difficult to capture adequately in a discrete choice experiment. Nonetheless, these respondents did trade; with the hypothetical alternative chosen over the current in 43% of low care and 36% of high care scenarios. This points to the need to ensure that the attribute levels selected cover a sufficiently wide range to encourage trading.

Further, these results do show variations in the extent of respondents' preferences for current services. In the low care group, younger carers, those in better physical health and where the patient did not require injections, dressings or other technical nursing care were less likely to choose current services. For the high care group, preference for the current package of care

decreases when the carer is working, and when the patient requires care during the night. This suggests that support services need to be responsive to both patient and carer circumstances.

We hypothesised 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 children. Our results did not support this. This may be a limitation of our sample size and the stronger influence of other carer characteristics. It may also be influenced by other processes such as adaptation (where the carer adjusts to performing tasks when it becomes necessary) or self-selection (where carers who do not wish to perform personal care tasks cease to be carers when the care recipient enters this stage).

This study surveyed 168 informal carers of patients who had been newly referred for community palliative care. This is a particularly difficult context for conducting research (30, 31) where care recipients are extremely ill and informal carers under considerable stress. Recruiting the respondents required close co-operation with the palliative care services and relied on the palliative care nurse to gain the consent of the carer to an approach from the research team. This reduced the number of carers approached but it was considered unethical to approach carers directly, given that the referral to palliative care also marks for many families the acceptance of impending death. Consequently our respondents may be coping better than those not referred to the research team; and this will limit the generalisability of our results.

Respondents were presented with a complex choice, with 14 and 10 attributes for the high care and low care groups respectively. However, fewer attributes would not have captured a realistic representation of palliative care services. All except ten respondents (four high care and 6 low care) completed the discrete choice component of the survey. This suggests that researchers should not attempt to reduce the number of attributes presented to meet some arbitrary desired number but should aim for realism.

This study provides useful insights for those who plan and deliver palliative care in the community. It demonstrates that respondents can handle complex choice scenarios in situations where they are familiar with the context. It also points to the need to explore further differences in preferences across respondents both in discrete choice work in general, and in designing services to support rather than replace informal carers.

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Table 1: Attributes and levels used in the High Care experiment

| **ATTRIBUTE** | **LEVELS** |
|---|---|
| A personal care assistant visits | **3** twice daily<br>**2** daily<br>**1** every second day<br>**0** not provided |
| A general community nurse visits | **1** daily; **0** not provided |
| A palliative care nurse visits | **1** daily; **0** not provided |
| Phone advice from a palliative care nurse | **1** available 24 hours a day<br>**0** not provided |
| Help with general household tasks | **3** 8 hours per week<br>**2** 4 hours per week<br>**1** 2 hours per week<br>**0** not provided |
| Meals cooked and delivered | **3** 6 per week<br>**2** 4 per week<br>**1** 2 per week<br>**0** not provided |
| Someone to do household shopping | **1** provided; **0** not provided |
| Someone will come to the **home during the day** to give the carer a break | **3** for 12 hours per week<br>**2** for 8 hours per week<br>**1** for 4 hours per week<br>**0** not provided |
| A nurse will come to the **home overnight** to give the carer a break | **3** for 8 nights over the next month<br>**2** for 4 nights over the next month<br>**1** for 2 nights over the next month<br>**0** not provided |
| <*Care recipient*> can go into a palliative care **hospita**l to give the carer a break | **3** for 8 nights over the next month<br>**2** for 4 nights over the next month<br>**1** for 2 nights over the next month<br>**0** not provided |
| A doctor visits the home | **3** twice a week<br>**2** once a week<br>**1** once a fortnight<br>**0** not provided |
| Emotional support for carers | **3** from a counsellor doing home visits<br>**2** from a counsellor at a clinic<br>**1** from group meetings with carers in the same situation<br>**0** not provided |
| Emotional support for <*care recipient*> | **1** from a counsellor doing home visits<br>**0** not provided |
| A coordinator assigned to <*care recipient's*> case is | **1** provided; **0** not provided |

Table 2: Attributes and levels used in the Low Care experiment

| **ATTRIBUTE** | **LEVELS** |
|---|---|
| A general community nurse visits | **1** weekly<br>**0** not provided |
| A palliative care nurse visits | **1** weekly<br>**0** not provided |
| Phone advice from a palliative care nurse | **1** available 24 hours a day<br>**0** not provided |
| Help with general household tasks | **3** 4 hours per week<br>**2** 2 hours per week<br>**1** 1 hour per week<br>**0** not provided |
| Meals cooked and delivered | **3** 6 per week<br>**2** 4 per week<br>**1** 2 per week<br>**0** not provided |
| Someone to do household shopping | **1** provided<br>**0** not provided |
| Transport to medical appointments and treatment | **1** provided<br>**0** not provided |
| Emotional support for carers | **3** from a counsellor doing home visits<br>**2** from a counsellor at a clinic<br>**1** from group meetings with carers in the same situation<br>**0** not provided |
| Emotional support for *<care recipient>* | **3** from a counsellor doing home visits<br>**2** from a counsellor at a clinic<br>**1** from group meetings with others in the same situation<br>**0** not provided |
| A coordinator assigned to *<care recipient's>* case is | **1** provided<br>**0** not provided |

Table 3: Characteristics of informal carers and care recipients (n=168)

| | High Care n=72 | Low Care n=96 |
|---|---|---|
| Carers | | |
| Age – mean (sd) | 63 (12) | 60 (15) |
| Gender male | 25% | 29% |
| Employed (FT/PT/casual) | 28% | 33% |
| 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) |
| Spousal carer | 57% | 56% |
| Years providing care | 2.5 (3.2) | 2.0 (2.9) |
| Hours/day caring tasks | 11.4 (6.1) | 6.3 (4.2) |
| Cohabiting | 82% | 84% |
| Other informal carers | 82% | 65% |
| | | |
| Care recipients | | |
| Age – mean (sd) | 76 (13) | 70 (14) |
| Gender male | 60% | 58% |
| Died within 3 months | 58% | 34% |
| Diagnosis cancer | 79% | 97% |
| Need help: | | |
| - with medicine (quite a bit/a lot) | 67% | 20% |
| - at night (most/every night) | 51% | 16% |
| - incontinence (quite a bit/a lot) | 22% | 0 |
| - technical nursing (a little/quite a bit/a lot) | 54% | 24% |

Table 4: Estimated multinomial mixed logit model for the High Care experiment

| Variable | Description | Current services %(n=72) | Coefficient | Standard error |
|---|---|---|---|---|
| Current services intercept | Mean | | 5.030*** | 1.689 |
| | SD | | 4.571 | 0.765 |
| Personal care assist | 2nd daily | 12.5 | 0.538* | 0.293 |
| | Daily | 4.2 | 0.840** | 0.329 |
| | Twice daily | 1.4 | 0.411 | 0.267 |
| Community nurse daily | | 18.1 | 0.616*** | 0.200 |
| Palliative care nurse daily | | 13.9 | 1.210*** | 0.253 |
| Phone advice - 24 hours | | 86.1 | 1.293*** | 0.231 |
| Household tasks | 2 hours/week | 13.9 | -0.124 | 0.291 |
| | 4 hours/week | 4.2 | 0.414 | 0.341 |
| | 8 hours/week | 2.8 | 0.487 | 0.300 |
| Meals provided | 2/week | 1.4 | -0.099 | 0.269 |
| | 4/week | 1.4 | 0.169 | 0.312 |
| | 6/week | 1.4 | 0.434 | 0.292 |
| Shopping | | 4.2 | 0.276* | 0.166 |
| Home respite - daytime | 4 hours/week | 12.5 | 0.530 | 0.344 |
| | 8 hours/week | 0.0 | 1.089*** | 0.340 |
| | 12 hours/week | 1.4 | 0.724** | 0.364 |
| Home respite - overnight | 2 nights/month | 1.4 | 0.489 | 0.335 |
| | 4 nights/month | 0.0 | 0.288 | 0.294 |
| | 8 nights/month | 1.4 | 0.699** | 0.350 |
| Institutional respite | 2 nights/month | 0.0 | -0.025 | 0.289 |
| | 4 nights/month | 0.0 | 0.567 | 0.356 |
| | 8 nights/month | 1.4 | 0.644* | 0.361 |
| Doctor visits at home | 1/fortnight | 44.4 | 0.117 | 0.262 |
| | 1/week | 16.7 | 0.605* | 0.352 |
| | 2/week | 1.4 | 0.420 | 0.338 |
| Emotional support for carer | Peer group meetings | 0.0 | -0.065 | 0.295 |
| | Counsellor at a clinic | 5.6 | 0.064 | 0.308 |
| | Counsellor at home | 4.2 | -0.433* | 0.253 |
| Emotional support for patient | Counsellor at home | 8.3 | 0.301 | 0.205 |
| Case coordinator | | 15.3 | -0.050 | 0.212 |
| Carer works | Fulltime/parttime/casual | 27.8 | -3.441** | 1.502 |
| Patient needs help at night | Most/every night | 51.4 | -3.333** | 1.331 |
| | | Mean (sd) | | |
| Carer time spent on tasks | Daily hours/10 | 11.4 (6.1) | 2.397** | 1.105 |
| Pseudo $R^2$ | 0.445 | | | |
| Log-likelihood | -290.569 | | | |

***Significant at 1% level; **Significant at 5% level; *Significant at 10% level.

Table 5: Effect of selected attributes on the predicted probability of choosing alternative service plans in the High Care experiment for carers providing care 11.4 hours per day

| Attribute | Hypothetical Plan A set to this level | Current services | Plan A | Plan B |
|---|---|---|---|---|
| *Carer not working, patient does not need help at night* | | | | |
| Base (all attributes=0) | | *0.92* | *0.04* | *0.04* |
| Personal care assistant | 2nd daily | 0.91 | 0.06 | 0.03 |
| | Daily | 0.90 | 0.07 | 0.03 |
| Community nurse | Daily | 0.91 | 0.06 | 0.03 |
| Palliative care nurse | Daily | 0.89 | 0.08 | 0.03 |
| Phone advice - 24 hours | Provided | 0.89 | 0.09 | 0.02 |
| Home respite - daytime | 8 hours/week | 0.90 | 0.08 | 0.03 |
| | 12 hours/week | 0.90 | 0.06 | 0.03 |
| Home respite - overnight | 8 nights/month | 0.91 | 0.06 | 0.03 |
| *Carer not working, patient needs help at night* | | | | |
| Base (all attributes=0) | | 0.77 | 0.12 | 0.12 |
| Personal care assistant | 2nd daily | 0.75 | 0.16 | 0.09 |
| | Daily | 0.74 | 0.19 | 0.08 |
| Community nurse | Daily | 0.75 | 0.17 | 0.09 |
| Palliative care nurse | Daily | 0.72 | 0.22 | 0.07 |
| Phone advice - 24 hours | Provided | 0.72 | 0.22 | 0.06 |
| Home respite - daytime | 8 hours/week | 0.72 | 0.21 | 0.07 |
| | 12 hours/week | 0.74 | 0.18 | 0.09 |
| Home respite - overnight | 8 nights/month | 0.74 | 0.17 | 0.09 |
| *Carer working, patient does not need help at night* | | | | |
| Base (all attributes=0) | | 0.76 | 0.12 | 0.12 |
| Personal care assistant | 2nd daily | 0.74 | 0.16 | 0.10 |
| | Daily | 0.73 | 0.19 | 0.08 |
| Community nurse | Daily | 0.74 | 0.17 | 0.09 |
| Palliative care nurse | Daily | 0.71 | 0.22 | 0.07 |
| Phone advice - 24 hours | Provided | 0.71 | 0.23 | 0.06 |
| Home respite - daytime | 8 hours/week | 0.72 | 0.21 | 0.07 |
| | 12 hours/week | 0.73 | 0.18 | 0.09 |
| Home respite - overnight | 8 nights/month | 0.74 | 0.18 | 0.09 |
| *Carer working, patient needs help at night* | | | | |
| Base (all attributes=0) | | 0.52 | 0.24 | 0.24 |
| Personal care assistant | 2nd daily | 0.50 | 0.32 | 0.19 |
| | Daily | 0.48 | 0.36 | 0.16 |
| Community nurse | Daily | 0.49 | 0.33 | 0.18 |
| Palliative care nurse | Daily | 0.46 | 0.42 | 0.12 |
| Phone advice - 24 hours | Provided | 0.45 | 0.43 | 0.12 |
| Home respite - daytime | 8 hours/week | 0.47 | 0.40 | 0.14 |
| | 12 hours/week | 0.49 | 0.35 | 0.17 |
| Home respite - overnight | 8 nights/month | 0.49 | 0.34 | 0.17 |

Table 6: Estimated multinomial mixed logit model for the Low Care experiment

| Variable | Description | Current services %(n=96) | Coefficient | Standard error |
|---|---|---|---|---|
| Current services intercept | Mean | | -12.005*** | 4.543 |
| | SD | | 4.566 | 0.585 |
| Community nurse - weekly | | 17.7 | 0.651*** | 0.118 |
| Palliative care nurse - weekly | | 55.2 | 1.452*** | 0.185 |
| Phone advice - 24 hours | | 92.7 | 1.055*** | 0.167 |
| Household tasks | 1 hour/week | 5.2 | 0.409*** | 0.149 |
| | 2 hours/week | 5.2 | 0.867*** | 0.159 |
| | 4 hours/week | 7.3 | 0.694*** | 0.170 |
| Meals provided | 2/week | 0 | 0.075 | 0.162 |
| | 4/week | 0 | 0.059 | 0.183 |
| | 6/week | 3.1 | 0.291* | 0.162 |
| Shopping | | 2.1 | 0.120 | 0.111 |
| Transport to medical appts | | 7.3 | 0.524*** | 0.120 |
| Emotional support for carer | Peer group meetings | 0 | 0.221 | 0.173 |
| | Counsellor at a clinic | 6.3 | 0.163 | 0.193 |
| | Counsellor at home | 5.2 | 0.322* | 0.172 |
| Emotional support for patient | Peer group meetings | 0 | 0.112 | 0.158 |
| | Counsellor at a clinic | 5.2 | -0.182 | 0.150 |
| | Counsellor at home | 5.2 | 0.054 | 0.155 |
| Case coordinator | | 15.6 | 0.463*** | 0.101 |
| Patient needs technical care | Injection/dressing/catheter/stoma | 24.0 | 3.425*** | 1.232 |
| | | Mean (sd) | | |
| Carer age | Age/10 | 60.0 (14.6) | 1.027** | 0.424 |
| Carer physical health | SF36-PCS/10 | 47.6 (9.2) | 1.645*** | 0.614 |
| Pseudo $R^2$ | 0.474 | | | |
| Log-likelihood | -795.728 | | | |

***Significant at 1% level; **Significant at 5% level; *Significant at 10% level.

Table 7: Effect of selected attributes on the predicted probability of choosing alternative service plans in the Low Care experiment for carers aged 60 years reporting a PCS score of 47.6.

| Attribute | Hypothetical Plan A set to this level | Current services | Plan A | Plan B |
|---|---|---|---|---|
| *Care recipient does not need technical care* | | | | |
| Base (all attributes=0) | | 0.60 | 0.20 | 0.20 |
| Community nurse | Weekly | 0.57 | 0.28 | 0.15 |
| Palliative care nurse | Weekly | 0.52 | 0.39 | 0.09 |
| Phone advice - 24 hours | Provided | 0.55 | 0.34 | 0.12 |
| Household tasks | 1 hour/week | 0.58 | 0.25 | 0.17 |
| | 2 hours/week | 0.56 | 0.31 | 0.13 |
| | 4 hours/week | 0.57 | 0.29 | 0.14 |
| Transport to medical appts | | 0.58 | 0.27 | 0.16 |
| Case coordinator | Provided | 0.58 | 0.26 | 0.16 |
| *Care recipient needs technical care* | | | | |
| Base (all attributes=0) | | 0.82 | 0.09 | 0.09 |
| Community nurse | Weekly | 0.80 | 0.13 | 0.07 |
| Palliative care nurse | Weekly | 0.77 | 0.19 | 0.04 |
| Phone advice - 24 hours | Provided | 0.79 | 0.16 | 0.06 |
| Household tasks | 1 hour/week | 0.81 | 0.12 | 0.08 |
| | 2 hours/week | 0.79 | 0.15 | 0.06 |
| | 4 hours/week | 0.80 | 0.13 | 0.07 |
| Transport to medical appts | Provided | 0.81 | 0.12 | 0.07 |
| Case coordinator | Provided | 0.81 | 0.12 | 0.07 |

**Appendix 1: Examples of scenarios and interview questions**

**HIGH CARE**

| | Plan A | Plan B |
|---|---|---|
| A personal care assistant visits | not provided | every second day |
| A general community nurse visits | not provided | daily |
| A palliative care nurse visits | daily | not provided |
| Phone advice from a palliative care nurse is | available 24 hours a day | not provided |
| Help with general household tasks | 2 hours per week | 4 hours per week |
| Meals cooked and delivered | not provided | 2 per week |
| Someone to do household shopping | not provided | provided |
| Someone will come to the home during the day to give you a break | not provided | for 4 hours per week |
| A nurse will come to the home overnight to give you a break | for 2 nights over the next month | for 4 nights over the next month |
| The sick person can go into a palliative care hospital to give you a break | for 4 nights over the next month | for 8 nights over the next month |
| A doctor visits the home | not provided | once a fortnight |
| Emotional support for you | from a counsellor doing home visits | not provided |
| Emotional support for the sick person | not provided | from a counsellor doing home visits |
| A case coordinator is | not provided | provided |

**LOW CARE**

| | Plan A | Plan B |
|---|---|---|
| **A general community nurse visits** | **not provided** | **weekly** |
| **A palliative care nurse visits** | **not provided** | **weekly** |
| **Phone advice from a palliative care nurse is** | **not provided** | **available 24 hours a day** |
| **Help with general household tasks** | **2 hours per week** | **4 hours per week** |
| **Meals cooked and delivered** | **2 per week** | **4 per week** |
| **Someone to do household shopping** | **provided** | **not provided** |
| **Transport to medical appointments and treatment** | **not provided** | **provided** |
| **Emotional support for you** | **not provided** | **from group meetings with carers in the same situation** |
| **Emotional support for the sick person** | **not provided** | **from group meetings with others in the same situation** |
| **A case coordinator is** | **provided** | **not provided** |

**HIGH CARE AND LOW QUESTIONS**

Imagine that the plan you choose will replace all the services <*care recipient*> currently receives.

**1.1** If you were offered one of these service plans today at no cost to you, which plan would you choose?
1. Plan A
2. Plan B

**1.2** If you were given a choice between Plan <*chosen plan*> or the services <*care recipient*> currently receives, which would you choose?
1. Plan <*chosen plan*>
2. Current services