# 6 South Brisbane and Gold Coast Innovative Dementia Care Pilot

## 6.1 Project description

The Islamic Women's Association of Queensland received an allocation of 20 flexible care places to operate the South Brisbane and Gold Coast Innovative Dementia Care Pilot for a period of three years. The Association works in partnership with the Multicultural Communities Council of the Gold Coast and the Queensland Transcultural Mental Health Centre to deliver the project. The project was established in November 2003 to service eligible residents of Brisbane South and the Gold Coast.

Both the Islamic Women's Association and the Multicultural Communities Council of the Gold Coast are experienced providers of community aged care services. The Islamic Women's Association has been delivering HACC and CACP services since 1995, and operates a day respite unit servicing around 90 clients every week. Services are delivered to eligible recipients on a non-denominational basis. The Multicultural Communities Council began providing HACC and CACP services in 1996, and also operates a day respite centre which services approximately 70 clients per week in three different cultural clusters. Many Council clients are post-World War II immigrants of German, Austrian, Finnish or Polish origin.

For the purposes of the Innovative Pool project, the service catchment area is split between the partner organisations, with Islamic Women's Association servicing Brisbane South and the Multicultural Communities Council servicing clients on the Gold Coast. Project coordination is divided accordingly. The Queensland Transcultural Mental Health Centre provides clinical, education and training support to the Association and Council.

A project steering committee comprises:

- the Management Committees of the Islamic Women's Association of Queensland and the Multicultural Communities Council, Gold Coast
- two ACAT representatives
- a representative of the Australian Government Department of Health and Ageing
- a representative of the Aged Care Mental Health Team based at the Princess Alexandra Hospital, Brisbane
- a representative of the Alzheimer's Association of Queensland
- a representative of the Queensland Health Mental Health Unit with responsibility for Aged Care.

### Project objectives and target group

The South Brisbane and Gold Coast Innovative Dementia Care Pilot is designed to meet the dementia care needs of people from culturally and linguistically diverse backgrounds through the provision of culturally appropriate care, including personal care, short-term

intensive interventions, carer support and respite care. People selected to join the Pilot must have an ACAT assessment for high level residential care, live in the catchment areas, and have a primary health condition of dementia.

The stated objectives of the project are to:

- meet the dementia care needs of people from culturally and linguistically diverse backgrounds through the provision of culturally appropriate and flexible care including short-term intensive interventions, carer support and respite care
- provide appropriate care and support to carers through psychologically focused individual support strategies, for example, psycho-education, development of coping strategies and group support
- increase access to culturally appropriate dementia health care for people from culturally and linguistically diverse backgrounds
- increase awareness in mainstream dementia care and other relevant mainstream services about the dementia care needs of people from culturally and linguistically diverse backgrounds.

## Needs of the target group

An important characteristic of the targeted communities is a strong desire to maintain family members with age-related frailty or disability at home. The Islamic Women's Association and Multicultural Communities Council of the Gold Coast operate Community Aged Care Packages services that deliver 6 to 8 hours of care per week, although both organisations have, through goodwill, delivered up to 12 hours per week to very high needs CACP clients. Funding for mainstream community care packages has been found to be insufficient to support a high needs dementia client and the family carer for an extended period of time.

Needs in the target group reflect both cultural and linguistic diversity and a range of psychosocial factors associated with separation, resettlement and, in some cases, the aftermath of war and persecution. After people immigrate to Australia, many strive to maintain their cultural practices. Continuity in language, food and meal patterns, religious observation, family roles, and living at home is central to cultural identity. For many such older people a move away from the family home to a setting that is not sympathetic to language and cultural observance or acceptance usually entails loss of home and identity. Language barriers in institutional settings impact on socialisation and more fundamental functioning such as food and fluid intake and psychological wellbeing. Providing access to a bilingual care worker means that the client is more likely to eat well and medicate safely. It may be equally difficult for many members of the target group to accept help from outsiders, particularly in the presence of language barriers and lack of cultural and experiential awareness.

Project coordinators remarked on a widespread scarcity of culturally specific care services for older people. A small number of culturally specific residential facilities are in operation but they generally service a limited geographic area. Culturally specific community care is very hard to access. The Gold Coast is said to have no multicultural aged care services apart from the South Brisbane and Gold Coast Pilot.

It is thought that, typically, the family carer pays the price for this lack of formal support. Given the cultural reluctance to use residential care even when needs are at an extremely high level, carers struggle on to their detriment. Carers feel the pressure from other family members and the multicultural community at large to continue in the caring role without

seeking outside support. Any sign of not coping is perceived as failing the care recipient and failing the community. Carers in culturally and linguistically diverse communities who have not had access to culturally sensitive services have become used to not seeking help. In most cases, the caring role falls to wives and daughters. It can be a long process to bring a carer to the point of willingness to accept help. Carer support is thus an important aspect of providing a culturally sensitive service to high needs clients.

## Care model

The Pilot offers comprehensive packages of care to people with dementia from culturally and linguistically diverse backgrounds who require bilingual support and a culturally sensitive approach to care. Following referral of a client to the project coordinators, if confirmation of dementia is required the Queensland Transcultural Mental Health Centre is able to provide a bilingual mental health consultant from the same cultural background as the client.

The project has devoted time to developing processes and procedures which allow the coordination and integration of care services, a task complicated by the need to source and deploy suitably qualified and experienced staff across a wide range of cultural and language groups and a distributed geographical catchment area.

Whenever possible, clients are matched with care workers from their own culture and language group. This means care workers are able to communicate with clients in their first language, and understand and support clients' social, cultural, religious and culinary needs and preferences. This is particularly important in light of evidence that dementia can cause asymmetrical language loss in bilingual people and has the greatest effect on a person's more recently acquired language (Mendez et al 1999).

Flexible respite care is offered to assist family carers to maintain social participation. This extends to weekends, for example, to allow carers to attend religious services or impromptu outings with friends at shorter notice than is normally possible through mainstream respite services where bookings need to be made in advance and for pre-defined periods of time. Respite care often involves two bilingual workers—one to stay with the person with dementia and one worker to accompany the carer to assist with shopping and appointments, as many carers have limited command of English.

The project provides a 24-hour emergency call service.

## Successes and challenges

There are many challenges that arise in delivering care to older people from culturally diverse backgrounds, particularly in relation to dementia care. Some cultures have entrenched views on who should provide care to older family members and this can lead to excessive levels of carer strain. Dementia carries social stigma in some communities which can result in denial and resistance to accepting help from people outside the family. The South Brisbane and Gold Coast Innovative Dementia Care Pilot employs and trains care workers who are familiar with these issues through their own cultural exposure.

Assessment and care planning are complicated by the need to provide bilingual workers and/or translation services for all face-to-face sessions and paperwork (including specialist and allied health assessments), which increases the resources that need to be dedicated to each client's care.

Considerable progress has been made in assisting family carers to look after themselves and reduce the strain and isolation that is often associated with the caring role. Bilingual support for care recipients makes it easier for formal assistance to be introduced or for higher levels of assistance to be accepted. In turn, this eases pressure on family carers.

The project has worked to educate ACAT assessors on approaches to the assessment of people from culturally and linguistically diverse backgrounds, for example, to promote an understanding that it is in some cases inappropriate for a male ACAT member to assess a female client, or that the shame associated with letting a visitor see an untidy house or with 'failing' in the culturally assigned role of caring for a relative can lead carers and families to go to extreme lengths to maintain the impression that they are coping despite high strain.

The AIHW was made aware that the project encountered delays in obtaining referrals from ACATs in its early days, stemming largely from the fact that ACATs were not familiar with the type of service on offer. It was apparent that, at that stage, care recipients were commencing services prior to completion of ACAT assessment. Some clients were said to be transferring from a CACP, having received ACAT approval some time ago. It is not clear that these approvals would have been for high care in all cases, or that each ACAT approval for CACP clients was current at the time of transfer. However, the evaluation data reflect mostly sound referral and assessment patterns, with only one client recording an invalid ACAT approval.

## Evaluation issues

Data collection for the evaluation has proved to be a significant challenge for the South Brisbane and Gold Coast Innovative Dementia Care Pilot. Interim services data, due in October 2004, were not supplied. Services data were made available for the first time in April 2005, some four months after the specified deadline. Repeated requests were necessary to extract these data.

As at 4 April 2005, the AIHW was still awaiting a completed evaluation database, the due date for which was 20 December 2004. Socio-demographic and client assessment data are patchy and of inconsistent quality. Identified errors and inconsistencies have been corrected where possible in consultation with the project coordinators.

The project supplied an occupancy report for an incorrect reporting period; hence these data cannot be used. Requested financial reports were not submitted.

Project coordinators expressed dissatisfaction with the lack of information provided by the Department of Health and Ageing on evaluation requirements at the time the project was established and the short period of time to prepare for evaluation prior to its commencement in 2004. English as a second language has made it more difficult for coordinators in this project to manage comprehensive evaluation.

# 6.2 Client profiles

The South Brisbane and Gold Coast Innovative Dementia Care Pilot provided data for 26 clients, with equal numbers of men and women.[10]

## Age and sex

The ages of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients ranged from 63 years to 94 years during the evaluation (mean 79.6 years). Six of the 26 clients were aged 85 years or over (Table B6.1).

**Table B6.1: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by age group and sex**

| Age (years) | Males | Females | Persons |
|---|---|---|---|
| | | (number) | |
| Less than 65 | 1 | — | 1 |
| 65–74 | 4 | 1 | 5 |
| 75–84 | 6 | 8 | 14 |
| 85+ | 2 | 4 | 6 |
| **Total** | **13** | **13** | **26** |
| | | (per cent) | |
| Less than 65 | 3.8 | — | 3.8 |
| 65–74 | 15.4 | 3.8 | 19.2 |
| 75–84 | 23.1 | 30.8 | 53.8 |
| 85+ | 7.7 | 15.4 | 23.1 |
| **Total** | **50.0** | **50.0** | **100.0** |

— Nil

## Language and communication

Eleven clients had little or no effective means of communication. Another 11 clients had effective spoken communication and two had effective non-spoken means of communication. Means of communication was not stated for two clients.

All clients spoke a language other than English—15 national languages are represented in the evaluation group (Table B6.2). This linguistic (and cultural) diversity makes the South Brisbane and Gold Coast Innovative Dementia Care Pilot unique among the Innovative Pool Dementia Pilot projects.

Linguistic diversity has had an impact on some of the client assessments required for evaluation. In particular, the project reported difficulty in administering the MMSE.

10 Two clients recorded leave days in excess of their length of stay in the project. One client was admitted to hospital and entered high level residential aged care after 63 days. It is not possible to tell whether the other client accumulated the 30 leave days during the evaluation period. These two clients are not included in the evaluation because it is not clear that they were actively receiving services from the project during the evaluation period.

**Table B6.2: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by language spoken at home and English language proficiency**

| | How well does client communicate in English? | | | | |
|---|---|---|---|---|---|
| **Language spoken at home** | **Very well or well** | **Not well** | **Not at all** | **Not stated** | **Total** |
| Bosnian | — | 1 | 5 | — | 6 |
| Arabic | 1 | — | 2 | — | 3 |
| German | — | 1 | 1 | — | 2 |
| Spanish | — | — | 2 | — | 2 |
| Hungarian | — | 1 | 1 | — | 2 |
| Polish | 2 | — | — | — | 2 |
| Greek | — | — | 1 | — | 1 |
| Italian | — | — | 1 | — | 1 |
| Czech | — | 1 | — | — | 1 |
| Finnish | 1 | — | — | — | 1 |
| Latvian | 1 | — | — | — | 1 |
| Romanian | — | — | 1 | — | 1 |
| Serbian | — | 1 | — | — | 1 |
| Ukranian | — | — | — | 1 | 1 |
| Urdu | — | — | 1 | — | 1 |
| **Total** | **5** | **5** | **15** | **1** | **26** |

— Nil.

## Accommodation and living arrangement

Clients were living in private residences or retirement villages (Table B6.3). Two clients were in hospital at the time of referral to the project.

**Table B6.3: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by usual accommodation setting and living arrangement**

| | Usual living arrangement | | | |
|---|---|---|---|---|
| **Accommodation setting** | **Alone** | **With family** | **With others** | **Total usual accommodation** |
| Private residence | 4 | 18 | 1 | 23 |
| Retirement village—self-care | 1 | — | — | 1 |
| Not stated | 2 | — | — | 2 |
| **Total** | **7** | **18** | **1** | **26** |

— Nil.

Years at usual place of residence ranged from one to 32 years. Six clients had been living in the same home for 10 or more years. Two clients changed residence in the two years prior to entering the project.

## Carer availability

Twenty-one clients had a carer, 16 of whom were living with the care recipient at the time of the evaluation (Table B6.4).

Carers' ages ranged from 25 to 82 years, averaging 60.2 years. Seven carers were aged 75 years or over (Table B6.5).

**Table B6.4: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by carer availability, carer relationship to client and carer co-residency status**

| Relationship of carer to client | Carer lives with client | Carer does not live with client | Not stated | Total |
|---|---|---|---|---|
| Spouse or partner | 10 | — | — | 10 |
| Son or daughter | 6 | 3 | — | 9 |
| Other relative | — | 1 | — | 1 |
| Not stated | — | — | 1 | 1 |
| *Total clients with a carer* | *16* | *4* | *1* | *21* |
| **Total clients** | | | | **26** |
| Per cent of clients with a carer | | | | 80.7 |

— Nil.

**Table B6.5: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of carers by age group and sex.**

| Age (years) | Males | Females | Persons |
|---|---|---|---|
| 25–44 | 3 | 2 | 5 |
| 45–54 | 1 | 2 | 3 |
| 55–64 | 1 | 2 | 3 |
| 65–74 | — | 2 | 2 |
| 75–84 | 1 | 6 | 7 |
| Not stated | — | 1 | 1 |
| **Total** | **6** | **15** | **21** |

— Nil.

## Income and concession status

The age pension was the primary source of cash income for all 26 clients (Table B6.6). All but one client held a health care concession card. Eighteen clients received a discounted weekly contribution rate for the South Brisbane and Gold Coast Innovative Dementia Care Pilot due to financial hardship.

**Table B6.6: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by principal source of cash income, health care card status and project concession status**

| | Number | Per cent |
|---|---|---|
| **Principal source of cash income** | | |
| Age pension | 26 | 100.0 |
| **Total** | **26** | **100.0** |
| Health care concession card holder | 25 | 96.1 |
| Project concession status | 18 | 69.0 |

Client co-payments ranged from nil to $7 per day, with a median of $4.50 per day.

## Previous use of government community care programs

Four clients were not receiving assistance from government community care programs when they entered the South Brisbane and Gold Coast Innovative Dementia Care Pilot (Table B6.7). Sixteen clients had been receiving assistance through CACP prior to joining the project, and three clients were receiving HACC-funded services. One client was receiving assistance through the EACH program, and one carer had accessed the National Respite for Carers Program. Project coordinators reported that clients were transferred from mainstream programs to receive higher hours of care and/or dementia-specific care with bilingual support.

**Table B6.7: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by previous use of government support programs**

| Previous use of government support programs | Number of clients | Per cent |
|---|---|---|
| **Government support program** | | |
| Community Aged Care Packages | 16 | 61.5 |
| Extended Aged Care At Home | 1 | 3.9 |
| Home and Community Care | 3 | 11.5 |
| National Respite For Carers Program | 1 | 3.9 |
| Other program | 1 | 3.9 |
| *Total clients with previous government program support* | *22* | *84.6* |
| Clients without previous government program support | 4 | 15.4 |
| **Total** | **26** | **100.0** |
| **Use of respite care in the 12 months prior to project** | | |
| Respite care needed but not used | 11 | 52.4 |
| Respite care used | 4 | 19.0 |
| Respite care not needed | 3 | 14.3 |
| Not stated | 3 | 14.3 |
| **Total** | **21** | **100.0** |

All of the carers who had accessed any form of respite in the 12months prior to entering the project had used mainly residential respite (four carers). Eleven carers indicated that they had not needed respite but had not accessed respite services. Three carers said that they had not need respite services in the 12 months prior to entering the pilot. Previous respite care use is not recorded for three carers.

Four clients were reported to be on a waiting list for residential aged care when they started with the project.

## Assessment and referral

The majority of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients were existing clients of the Islamic Women's Association or Mutlicultural Communities Council, were known to these organisations or were referred by an ACAT (Table B6.8). Six clients were referred by another agency.

**Table B6.8: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by source of referral**

| Referral source | Number of clients |
|---|---|
| Islamic Women's Association/Multicultural Communities Council | 9 |
| Aged Care Assessment Team | 8 |
| Other agency | 6 |
| Hospital | 1 |
| Family | 1 |
| Not stated | 1 |
| **Total** | **26** |

Nine clients completed an ACAT assessment on the same day or prior to referral to the project ACAT assessment was completed after referral to the project for 17 clients. In most of these cases, the pattern of referral and assessment involved, firstly, a referral to the project, followed soon after by initial needs assessment (screening) by a project coordinator. ACAT assessment would be completed within a short timeframe and services commenced shortly thereafter, subject to ACAT approval. In some cases there was a lengthy delay between approval and commencement of services. Thus, referral date in many cases did not coincide with service commencement.

**Table B6.9: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by days between completion of ACAT assessment and date of referral to project**

| Completion date of ACAT assessment | Number of clients |
|---|---|
| **Before referral to project** | |
| 0–20 days | 5 |
| 21–120 days | — |
| 121–180 days | 3 |
| Over 180 days | 1 |
| *Total* | *9* |
| **After referral to project** | |
| Between 6 and 337 days post-referral | 17 |
| **Total** | **26** |

— Nil.

The care of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients is managed by a social worker (14 clients), a nurse manager (six clients) or a welfare and community worker (six clients).

## Health conditions and health status on entry

The number of health conditions recorded for clients at entry to the project ranged from two to nine. Fifteen of the 26 clients had five or more health conditions. Table B6.10 shows that dementia is the most frequently recorded primary health condition.

**Table B6.10: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by primary health condition**

| Primary health condition | Number of clients |
|---|---|
| Dementia (includes Alzheimer's and other types of dementia) | 22 |
| Neurotic, stress related and somatoform disorders | 1 |
| Mental and behavioural disorders | 1 |
| Diseases of the circulatory system | 1 |
| Diseases of the kidney and urinary system | 1 |
| **Total** | **26** |

Twenty-five of the 26 clients were assessed as being at risk of falls due to impaired gait or balance and 25 displayed signs of disorientation. Eighteen clients had a diagnosis of depression (Table B6.11).

**Table B6.11: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by selected sensory, mental and physical conditions**

| Health condition | Number of clients |
|---|---|
| Impaired gait or balance—at risk of falls | 25 |
| Disorientation/confusion | 25 |
| Diagnosis of depression | 18 |
| Vision impairment | 9 |
| Hearing impairment | 6 |
| Missing or non-functional limbs | 2 |
| Total or partial paralysis | 3 |

Clients were taking between zero and 21 different medications. Ten of the 26 clients were taking 10 or more different medications.

Clients and carers were asked to rate client health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). Proxy reports were given by 13 carers and by a care worker in seven cases. One client self-reported. Self-reported health status is missing for all other clients. Seventeen clients were reported to be in poor health.

Two respondents indicated that the client was in a better state of health than a year earlier and four clients were said to be in about the same state of health. Ten respondents said that the client was in a worse state of health than 12 months earlier (four much worse).

These results suggest that the care needs of at least half of the clients may have increased in the 12 months prior to entering the project.

## Level of core activity limitation

Most South Brisbane and Gold Coast Innovative Dementia Care Pilot clients experienced severe to profound activity limitation in all three core activity areas: self-care, mobility and communication (Table B6.12).

Twenty-one clients are reported to have experienced severe or profound activity limitation in at least one core area at the time of the evaluation.

**Table B6.12: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of core activity limitation**

| | Level of activity limitation | | | | |
|---|---|---|---|---|---|
| Core activity | No limitation | Mild | Moderate | Severe or profound | Total |
| Self-care | — | 1 | 4 | 21 | **26** |
| Mobility | 1 | 3 | 5 | 17 | **26** |
| Communication | — | 6 | 5 | 15 | **26** |

— Nil.

### Use of medical and hospital services prior to entry

Use of medical and hospital services in the 6 months before joining the project was recorded for 25 clients. Among these clients, 22 had visited a medical practitioner at least once. The reported number of visits to a medical practitioner in the 6-month period varied from zero to 25 per client. Cumulatively, the 22 clients recorded 187 visits to a medical practitioner outside of a hospital setting over an estimated 3,960 person days.

Less than 25% of clients were recorded as having used hospital services in the 6 months prior to entering the project. Five clients contributed to a total of 11 hospital admissions in the pre-entry period. The four clients who recorded unplanned hospital admissions collectively accumulated 69 unplanned hospital bed days over approximately 720 person days. Individually, they recorded between 5 and 35 days in hospital for unplanned admissions.

Conditions recorded as occasioning admission to hospital for South Brisbane and Gold Coast Innovative Dementia Care Pilot clients in the pre-entry period include:

- falls
- heart disease
- other diseases of the digestive system.

One client recorded a fall with injury, one client was rendered immobile and without assistance for more than 30 minutes, and one client suffered another serious medical emergency during the pre-entry period. Another client suffered a serious medical emergency and was rendered immobile without assistance in the same period.

## 6.3 Client assessment results

### Cognitive function

MMSE scores were recorded for 21 clients when they entered the South Brisbane and Gold Coast Innovative Dementia Care Pilot. A score of zero was recorded for eight clients. Non-zero scores range between 3 and 22 out of a possible 30 points (mean of non-zero scores 10.1; standard deviation 6.1; median 8.5). The Gold Coast arm of the project recorded missing values (five) or scores of zero (four) or 6 points (three) only. The AIHW has concerns that this pattern of scores may not reflect real entry levels of cognitive function, particularly in view of known limitations of the MMSE for use in culturally and linguistically diverse groups. MMSE scores from the Gold Coast arm and zero scores from the Brisbane arm of the South Brisbane and Gold Coast Innovative Dementia Care Pilot were excluded from analysis of the data, leaving 10 valid MMSE scores from this project.

Cut-points to account for educational attainment were applied to valid entry MMSE scores (Uhlmann & Larson 1991). This indicated that all 10 clients for whom a valid score was recorded were likely to have had cognitive impairment when they entered the project. It is noted that application of the MMSE has not been validated in culturally and linguistically diverse populations and therefore these results should be interpreted with caution.

## Activities of daily living (ADL)

At entry to the project at least half of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients needed assistance in tasks involving self-care and mobility (Figure B6.1). MBI scores at entry range from 5 to 18 out of a total 20 points. The mean score was 11.3 points with a standard deviation of 4.3 (median 11).

Using a classification scheme for the Barthel Index (Shah et al. 1989), the entry scores indicate that five clients were totally dependent in self-care and mobility when they commenced with the project, 15 clients exhibited severe dependency, and four clients exhibited moderate dependency. Twenty of the 23 clients for whom MBI entry scores are recorded were either sometimes or always bowel incontinent and 18 clients were sometimes or always bladder incontinent at the time of entry. Twenty-two clients were unable to bathe or shower without assistance. Most clients needed help in the areas of dressing, grooming, feeding and transfers.

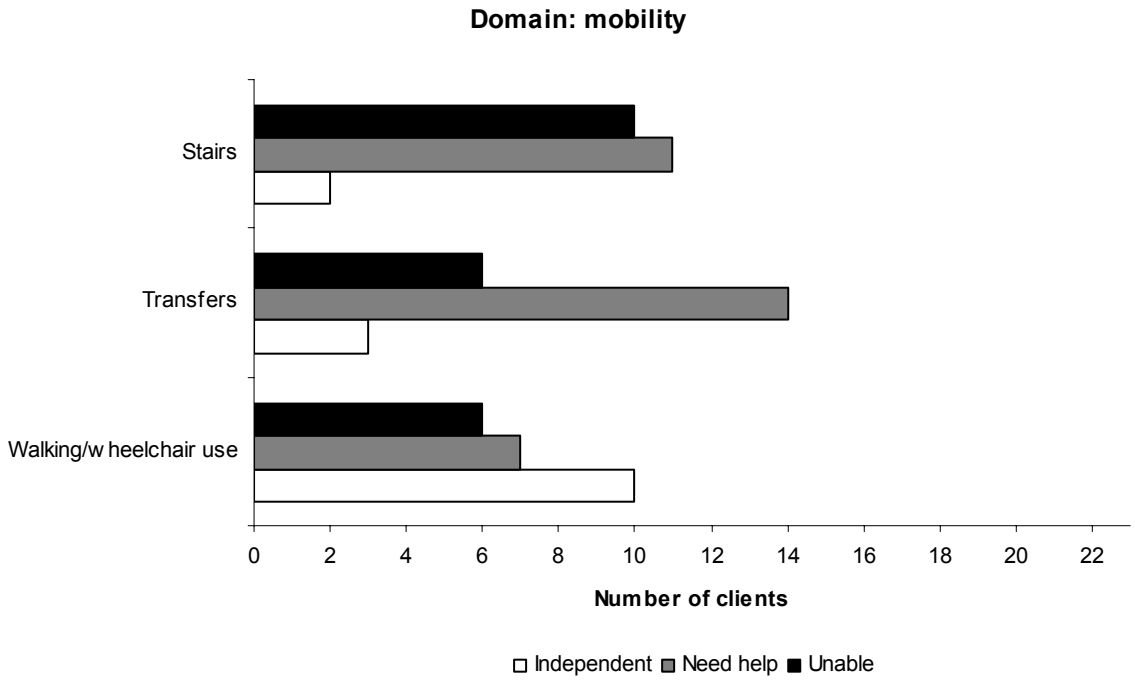
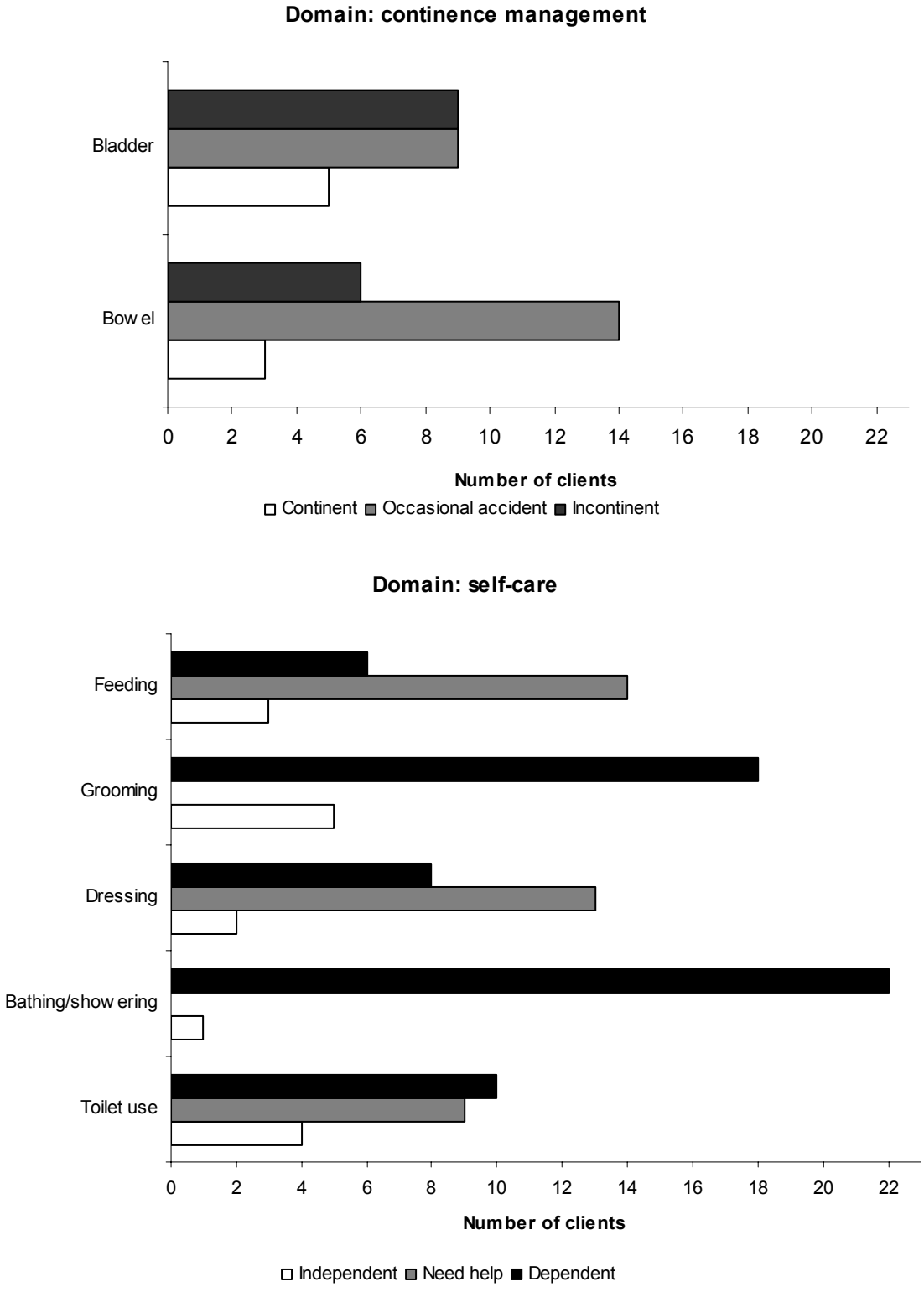



**Figure B6.1 continued: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of ADL function at entry**

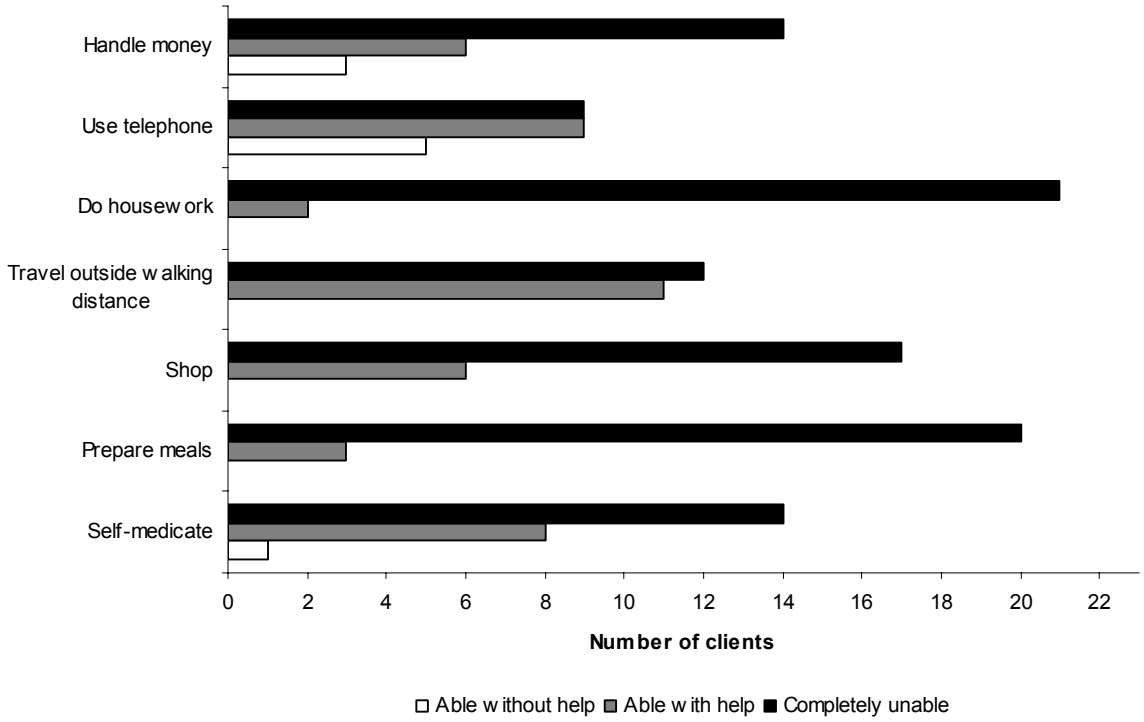
*(continued)*




*Source:* Appendix Table B17.

**Figure B6.1 continued: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of ADL function at entry**

Most clients were highly dependent in IADL when they entered the project (Figure B6.2). On average, clients were totally dependent in between four and five out of seven IADL. Although 10 clients could mobilise independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all cases, independent mobility was limited to the home environment.




*Source:* Appendix Table B18.

**Figure B6.2: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of IADL function at entry**

The project was asked to take two more assessments after entry. In some cases only one further assessment result was recorded. Figure B6.3 shows the MBI scores for clients at baseline, interim and final assessments for clients in the community at follow-up. Clients in the community were either still with the project, in other community care or were not accessing formal care. Only three clients exited to an aged care facility, one of whom had an MBI score of 10 points at entry and 8 points at final assessment. The other two clients recorded MBI scores of zero at all assessments.

A wide range of functioning in ADL at entry is evident, as is marked variation in change in functioning over time. A considerable number of clients continued to be supported at home despite low baseline levels of ADL function and/or significant deterioration between the interim and final assessment points.

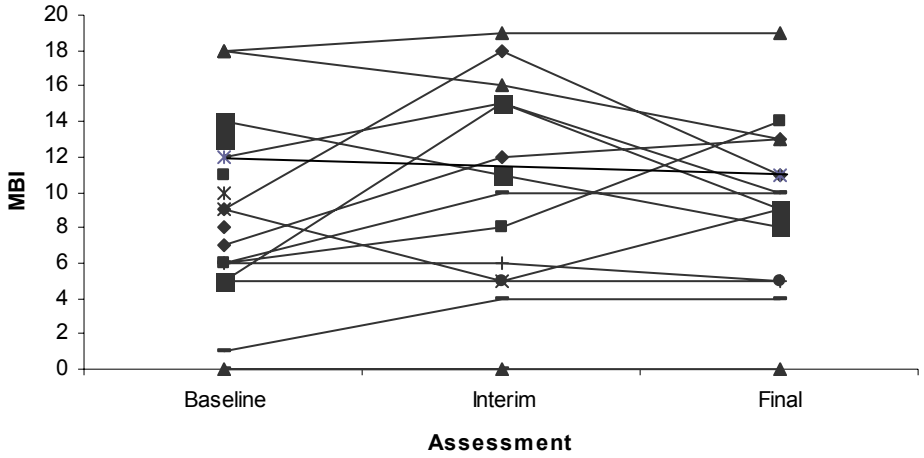



**Figure B6.3: South Brisbane and Gold Coast Innovative Dementia Care Pilot clients, MBI at baseline, interim and final for clients living in the community at follow-up (one symbol per client)**

## Psychological and behavioural symptoms

Baseline behavioural data were recorded for 23 clients. Sixteen clients showed signs of memory loss on an intermittent or extensive basis when they entered the project (Figure B6.4). Thirteen clients showed intermittent or extensive signs of emotional or psychological symptoms of dementia. One client was reported to be physically aggressive most of the time, and eight others displayed intermittent or occasional physical aggression. Seven clients wandered or displayed intrusive behaviour on an intermittent or extensive basis. Six clients presented a danger to self or others intermittently or extensively. Around half of the clients are recorded to have exhibited other, unspecified, dementia-related behaviour, either intermittently or extensively. Eight clients exhibited two or more psychological and behavioural symptoms on an extensive basis.

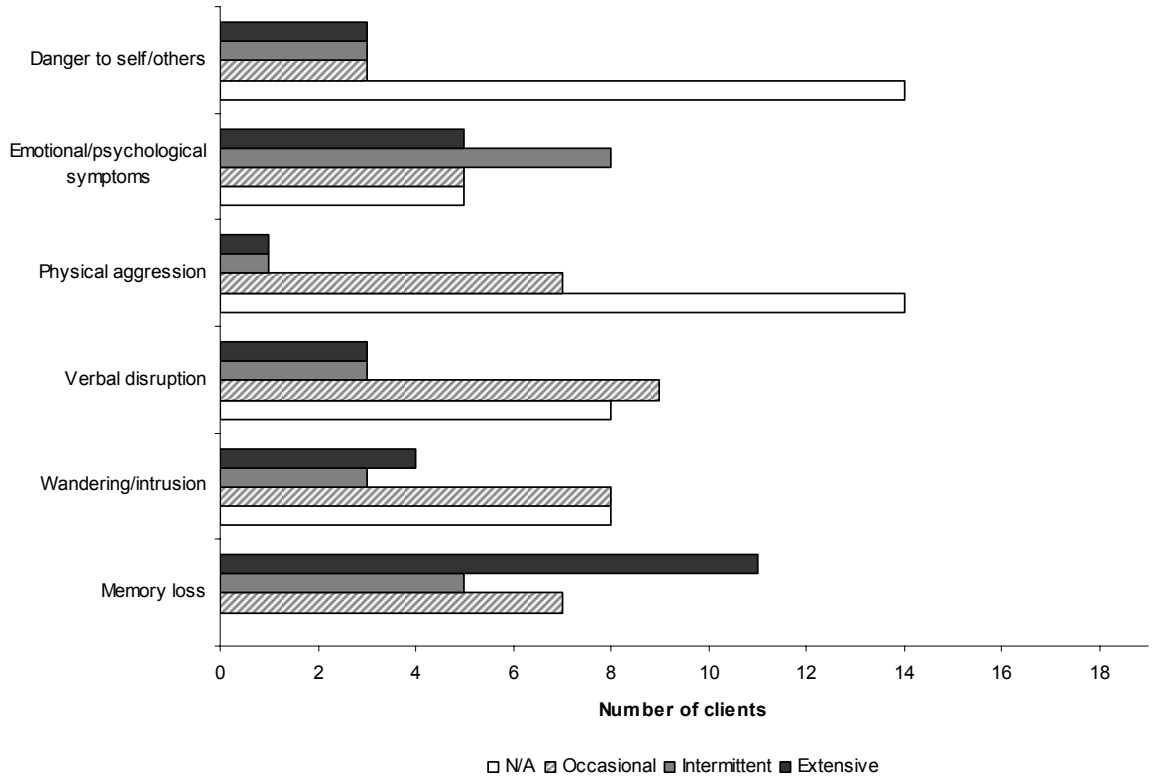



**Figure B6.4: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by frequency of behavioural and psychological symptoms at entry**

## 6.4 Carer assessment results

Three of the 21 carers reported that they were in good health at the time that their care recipient entered the South Brisbane and Gold Coast Innovative Dementia Care Pilot, eight reported fair health, and five reported poor health. Self-reported health status was not recorded for five carers.

Fourteen carers completed the CSI to generate a mean score of 9.9 points. Scores ranged from 3 points to 13 points. All but one carer recorded a score above the threshold for high carer strain. Ten of these carers completed a second assessment. The median change score (final score minus baseline score) was zero (mean –0.1 point). Individual change scores range from –2 to 3 points.

The 14 carers also completed the GHQ-28. Four carers scored above 14 points on at least one sub-scale. Three carers recorded scores of 14 points or higher for somatic symptoms; four carers recorded scores of 14 points or higher for anxiety and insomnia, one of whom scored the maximum 21 points; and two carers scored over 14 points for social dysfunction. No carers scored 14 points or higher for severe depression.

Eleven carers completed the GHQ-28 at a final assessment. Three of these carers scored 14 points or higher on at least one sub-scale.

Analysis of change in CSI and GHQ-28 scores was performed across the projects due to small sample sizes in individual projects.

## 6.5 Service profile

South Brisbane and Gold Coast Innovative Dementia Care Pilot recorded a wide range of service types during the evaluation. Higher numbers of clients received personal assistance, domestic assistance, respite care, social support, nursing care and allied health care and transport (Table B6.13). The project also reported a considerable level of activity in transporting clients to medical appointments, arranging referrals to health care providers and providing advocacy and bilingual support to clients and carers on these occasions.

Respite care provision in this project is likely to be relatively expensive because of the bilingual support requirements and provision of two workers for many respite care sessions; however, the project declined to provide financial data and a breakdown of costs of care by service type is not available.

**Table B6.13: South Brisbane and Gold Coast Innovative Dementia Care Pilot, summary of services per client per week**

| Service type | Service unit | Clients | Minimum | Median | Maximum | Mean | Standard deviation |
|---|---|---|---|---|---|---|---|
| Personal assistance | Hours | 21 | 0.2 | 3.2 | 8.4 | 3.6 | 2.5 |
| Domestic assistance | Hours | 21 | 0.4 | 2.4 | 10.2 | 3.2 | 2.4 |
| Respite (in-home and day)[(a)] | Hours | 18 | 0.0 | 2.6 | 16.4 | 5.3 | 5.6 |
| Social support | Hours | 18 | 0.0 | 1.0 | 6.5 | 1.7 | 1.8 |
| Food service other | Hours | 17 | 0.3 | 1.6 | 4.9 | 1.8 | 1.3 |
| Allied health[(b)] | Hours | 17 | 0.0 | 0.1 | 0.2 | 0.1 | 0.1 |
| Nursing care | Hours | 14 | 0.0 | 0.3 | 9.6 | 1.2 | 2.5 |
| Aids and equipment | Dollars | 12 | 6.2 | 17.5 | 73.6 | 21.9 | 16.9 |
| Interpreter/translator | Dollars | 8 | 3.3 | 10.4 | 21.0 | 11.8 | 6.6 |
| Home modifications and maintenance | Dollars | 1 | 1.7 | 1.7 | 1.7 | 1.7 | — |
| Assist.—GP consultation | No. contacts | 14 | 0.1 | 0.4 | 1.3 | 0.5 | 0.4 |
| Community mental health service | No. contacts | 3 | 0.0 | 0.1 | 0.1 | 0.1 | 0.0 |
| Assist.—GP–EPC consultation[(c)] | No. contacts | 2 | 0.6 | 0.6 | 0.6 | 0.6 | 0.0 |
| Geriatrician | No. contacts | 2 | 0.0 | 0.1 | 0.1 | 0.1 | 0.0 |
| Assist.—psychiatrist consultation | No. contacts | | 0.1 | 0.1 | 0.1 | 0.1 | — |
| Assist.—neurologist consultation | No. contacts | 1 | 0.0 | 0.0 | 0.0 | 0.0 | — |
| Recreation/leisure programs | No. days/nights | 3 | 0.1 | 0.1 | 1.0 | 0.4 | 0.5 |
| Rehabilitation service | No. days/nights | 1 | 0.2 | 0.2 | 0.2 | 0.2 | — |
| Living skills development | No. days/nights | 1 | 0.0 | 0.0 | 0.0 | 0.0 | — |
| Medication review | No. events | 21 | 0.1 | 0.6 | 1.9 | 0.8 | 0.5 |
| Information advice and referral | No. events | 12 | 0.0 | 0.2 | 3.2 | 0.5 | 0.9 |
| Carer support other than respite combined | No. events | 12 | 0.1 | 0.3 | 1.2 | 0.5 | 0.9 |
| Allied health other | No. events | 1 | 0.1 | 0.1 | 0.1 | 0.1 | — |
| Delivered meals | No. meals | 1 | 0.6 | 0.6 | 0.6 | 0.6 | — |
| Community transport | No. one-way trips | 18 | 0.2 | 1.8 | 11.2 | 2.7 | 2.6 |
| Dementia care, memory and behaviour management | No. referrals | 11 | 0.1 | 0.3 | 3.8 | 0.8 | 1.1 |
| Dietetics | No. referrals | 6 | 0.1 | 0.1 | 0.4 | 0.2 | 0.1 |

(a) Assumes one-day respite equivalent to 5 hours. .

(b) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

(c) EPC—Enhanced Primary Care

— Nil.

# 6.6 Accommodation outcomes

South Brisbane and Gold Coast Innovative Dementia Care Pilot follow-up was completed by 8 June 2005. Table B6.14 shows accommodation setting and government support program for all clients at follow-up (that is, between approximately 9 and 12 months from the start of the evaluation period).

Fourteen clients were still living in the community and being supported by the South Brisbane and Gold Coast Innovative Dementia Care Pilot project.

Formal follow-up was not completed for the three clients who were discharged to hospital during the evaluation. The project coordinator was able to report that one client who was discharged to hospital after approximately 2 weeks in the project eventually returned home with HACC services. One other client who was discharged to hospital subsequently entered residential aged care after approximately 2 months. These two clients are included in the 'Not located at follow-up' category in Table B6.14, as no formal follow-up was conducted and consequently the accommodation setting and government support status at the time of follow-up is unknown.

**Table B6.14: South Brisbane and Gold Coast Innovative Dementia Care Pilot, client accommodation setting and government program support at follow-up, June 2005**

| Location and program support at follow-up | Number of clients |
|---|---|
| **At home** | |
| Receiving services from the Pilot service | 14 |
| Community Aged Care Packages | 1 |
| Home and Community Care | 1 |
| *Total living at home* | *16* |
| Residential aged care—high care | 1 |
| Deceased | 5 |
| Not located at follow-up | 4 |
| **Total** | **26** |

*Notes*

1. One client left the project to be admitted to hospital and returned home with HACC services after 2 months in hospital.
2. One client moved out of the area and could not be contacted.
3. Two clients transferred to another agency (type of agency not stated) and were not contacted for follow-up.
4. The client listed as being in high level residential care had been discharged from the project to hospital and entered an aged care facility via hospital.

# 7 Ozcare Innovative Dementia Care Packages

## 7.1 Project description

Ozcare in Queensland received an allocation of 30 flexible care places to operate the Ozcare Innovative Dementia Care Packages project for three years. The project services the cities of Bundaberg, Rockhampton and Gladstone and their surrounding regions, a catchment area that extends approximately 350 km from Ridgelands, north-west of Rockhampton, south to Bundaberg, and 100 km inland from Bundaberg to Mt Perry.[11] Service is coordinated from centres in Bundaberg and Rockhampton.

Ozcare is a large and long established not-for-profit provider of community and residential aged care services in Queensland (Ozcare formerly operated as St Vincent's Community Services). The organisation delivers HACC, CACP, EACH, Veterans' Home Care, and National Respite for Carers Program services from over 20 locations state-wide. Community nursing is delivered with funding from HACC and the Department of Veterans' Affairs. A range of other services cater to the needs of special needs groups such as services for homeless people, women's shelters, and drug and alcohol rehabilitation programs.

Approval to commence services was received on 13 October 2003 and the first care recipients were accepted into the project over the following week.

### Project objectives and target group

The stated objectives of the project are to:

- provide a comprehensive approach to dementia services for people with behaviours that normally would be difficult to manage in a community setting
- provide a service that focuses on the maintenance of clients' and carers' social capacity and functioning through behaviour management programs for clients
- increase support to carers of people with dementia and associated challenging behaviours living in the community through delivery of flexible service options such as live-in respite, weekend and evening respite and emergency in-home respite
- reduce premature admission of clients to residential care.

The project targets people with a primary diagnosis of dementia who wish to remain living in the community and who have a current ACAT approval for residential high care. A mix of frail aged and middle-aged ambulatory clients with advanced dementia was anticipated. It was also expected that the project would support clients with or without a family carer. Most people accepted into the Pilot had been receiving assistance from family or friends.

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11 The catchment area for the Bundaberg arm includes Isis, Kolan and Mt Perry Shires; Rockhampton/Gladstone arm includes Mt Morgan, Gracemere, Capricorn Coast, Alton Downs, Ridgelands, Gladstone, Boyne Island and Tannum Sands.

In addition to high hours of care, delivered flexibly, key innovative features of the service include:

- access to alternative therapies
- flexible hours
- block respite care for overnight and weekends
- multiple service encounters per day.

## Identified areas of unmet need

Ozcare reported on past experience in servicing high care community clients. A typical pattern was described as a person with ACAT approval for high level residential care who is waitlisted for placement at one or more aged care facilities. Many family carers would prefer their partner or parent to remain living with them in the community, however, limited hours of care and limited access to respite care can leave the carer with little alternative but to actively pursue permanent placement, particularly when faced with increasing behaviour management difficulties. Thus, the primary area of unmet need in the target group is access to high hours of community care with flexible delivery. In this respect, the project does not represent a significant departure from Ozcare's existing service model for the client group, but it allows Ozcare to deliver an adequate level of service to an existing client base more effectively and efficiently through flexible funding.

The spread of resources over a large geographic region, which involves high travel costs to rural and remote areas, has a considerable impact on service delivery in the region.

On the question of specific issues that impact on older people with dementia-related needs and their carers, Ozcare made a number of observations:

1. People can experience great difficulty in obtaining a medical diagnosis of dementia and this limits their timely access to appropriate community services. For example, at the time of reporting, people in the region had no access to a geriatrician; a neurologist visited Rockhampton once a month; Bundaberg had no visiting neurologist. By the time services receive a referral, more than likely the care recipient is exhibiting advanced behavioural symptoms.
2. Many people with dementia and their families and carers would benefit from earlier introduction to formal services through the National Respite for Carers Program together with CACP or HACC services. Diagnosis and medical management are critical to implementing appropriate care pathways.
3. There is a lack of access to memory clinics.
4. Family members and carers are generally reluctant to use advisory services that are located in the south, for example, the Dementia Advisory Service call centre that operates from South Australia.
5. Carers can be reluctant to use residential respite services because of the time constraints that are often involved. Many residential respite services offer care for a minimum of 7 days and many care recipients do not respond well to a prolonged period away from home and familiar faces. Day respite centres are an alternative respite option but are not available in all areas and travel time to regional centres can be prohibitive.

## Care model

The project provides ongoing comprehensive dementia-specific care in order to cater for clients with high care dementia needs under a single package of care rather than multiple funding categories or multiple service providers, and to improve continuity of care and case management. A multidisciplinary approach to care planning places an emphasis on carer involvement, carer support and respite services. In particular the project aims to fill identified gaps for dementia-specific respite care services (residential and in-home) and transport services.

All client assessments are conducted by a project coordinator (care manager) or assistant coordinator. Specialised assessments are brokered to the appropriate professionals, for example, occupational therapist or social worker. Initial needs assessment typically takes 1.5 to 2 hours in the home. Record keeping, obtaining informed consent, care planning and scheduling following an initial assessment can take up to an additional 2 hours. This activity often extends to organising enduring power of attorney and referrals to outside providers for additional services (medication management, meals on wheels, home nursing). Care plans are reviewed 1 month after commencement and then every 2 to 3 months. Carers are consulted in the first fortnight to check on progress.

The range of services available to approved recipients includes but is not limited to the following, in addition to case management and coordination:

- personal care
- nursing and allied health care
- respite care, including block respite and overnight care
- domestic assistance
- meal preparation and nutrition management
- assistance with minor home modifications and access to aids and equipment
- transport
- emergency medical alarm
- carer education.

Salaried employees deliver personal and domestic assistance service and Ozcare brokers to other organisations for nursing care, alternative therapy and allied health, home maintenance and delivered meals.

The project aims to increase social participation for people with dementia and provide dementia-specific care plus short-term residential respite options.

At the outset it was anticipated that care recipients would need an average of 15–20 hours of care per week. An upper limit of 20 hours per care recipient per week was set, with scope for adjustment depending on the prevailing needs of the client group.

Care workers trained in manual handling and behaviour management are available to assist carers with special needs. Carer support also involves referral to and provision of information on other assistance programs, for example, the Dementia Hotline and education offered through Queensland Council of Carers and Alzheimer's Association.

## Staffing

Four care managers (two full-time equivalent staff) are responsible for assessment, care planning and service coordination for project clients in addition to clients in other programs. The 30 places are divided evenly between the Rockhampton and Bundaberg regions so that each care manager would normally be responsible for seven or eight clients. One full-time equivalent staff member provides administrative support.

Care workers for the project work across the range of Ozcare community care programs. In mid-2004, approximately 30 individuals (12 full-time equivalent staff) were delivering client care. Care managers aim to limit to three the number of care workers who attend an individual client. Covering staff leave is usually manageable with this system. Registered nursing and allied health services are brokered as needed.

The Pilot has highlighted workforce issues in working with the target group. There is a need for higher levels of training, in particular. A Certificate III is a very basic qualification and may not adequately equip staff to work with clients who have high dementia-related needs. Numbers of staff had to be increased to ensure that several workers became sufficiently familiar with every client and the staff roster needs to be flexible enough to provide after-hours services, including overnight care.

## Successes, challenges and lessons

The Ozcare Innovative Dementia Care Packages has demonstrated that it is possible to maintain high care clients with dementia at home with a comprehensive care package and a dementia-specific focus to care provision. Notable successes include two clients who returned home from aged care facilities to take up a package and another client who received a package at a time of crisis in care (while waiting for residential placement) and decided to continue with the package rather than take a residential place when one became available. Based on past experience, it has been observed that comprehensive care packages and high level care management enable Ozcare to support clients at home for longer. Families of clients who have died or entered residential care have stated that, were it not for the care package, the care recipient would likely have died in hospital or entered into care via hospital. Many package clients have accessed residential respite care in the past but families have expressed much higher satisfaction with package care at home. Such examples demonstrate a strong preference for high care at home provided appropriate formal supports are in place.

Overall, the service model has developed in line with Ozcare expectations, although social support and community access aspects of the service have expanded in response to needs within the target group. The client base for the Pilot is what was expected from the Ozcare experience of operating dementia-specific services for the National Respite for Carers Program and CACP. Limited access to aids and equipment and high hours for care coordination have presented two practical constraints to flexible service delivery.

It was suggested that the type of service offered through the Pilot could be mainstreamed into the EACH program.[12] Key factors said to distinguish this service from most currently available service models for the target group are attention to dementia-specific needs through knowledge and understanding of the needs of people with dementia, their carers and families; skills in assessment and care planning; maintaining the group as a service

12 Dementia-specific EACH packages were announced subsequent to these discussions.

target to prevent care recipients from being relegated to the 'too hard' category; and access to staff training for specialised areas of care. It was suggested that this target group should be classified as a special needs group.

Ozcare identified lack of early referral and timely intervention as a main challenge to maintaining clients in community care. Many people have reached crisis point by the time of their first ACAT assessment, so that it can be difficult or impossible for the client and family to consider community-based care. Alternatively, a package may be accepted as a perceived solution to the waiting for placement period. Many people in this situation expect that residential care is the only real longer term option. The project identified two factors which contribute to delays in referral to community-based services:

1. Difficulty gaining a definitive diagnosis of dementia means that referral to appropriate services is not timely for many members of the target group. People are often reluctant to discuss symptoms with their doctor and access to specialist geriatric practitioners is limited in rural areas. Diagnosis is typically triggered by a crisis event.
2. Some clients refuse services because of co-payment policy, even though the level of fee is negotiable. This can delay clients receiving appropriate care, which can increase the risk of an acute episode or sustained functional decline. Ozcare suggested that people do not always refuse services with a co-payment attached because of affordability, rather, as a matter of principle. Reference was made to a general resistance in Queensland to the 'user pays' philosophy.

Distance is another challenge in rural/remote regions such as those serviced by this project. Lack of access to allied health and specialist medical services, vehicle availability, and limited public transport all contribute to the tyranny of distance. Staff travel in the course of service delivery is expensive and time consuming: Ozcare estimates that one hour of staff travelling time is required for every 7.2 hours of care services delivered in the region.

Approximately half of the people accepted into the project have had a nursing assessment for continence management. The 'retraining' approach to continence management (regular toileting without the use of continence aids) creates a number of issues for services and family carers. Multiple home visits per day are usually required, with carer assistance on each occasion. Skilled continence nurses should attend for training purposes. Ozcare remarked that some family carers reject this care-intensive approach to continence management.

A number of risks to maintaining a person in the target group at home with high level support have been observed:

- pressure from family members for the person to enter residential aged care
- occupational health and safety issues, including unsafe home environments and client aggressive behaviour
- limited availability of aids and equipment—some clients require equipment such as a hoist and specially trained staff. The project supplies smaller pieces of equipment but not large items or major home modifications
- unsafe client behaviours, for example, wandering, in a client who lives alone. The project manages risks to the extent possible, for example for one client, the gas stove was disconnected and a microwave was installed. Risk needs to be assessed on a case-by-case basis and carer availability can be a major consideration in the assessment.

In conclusion, Ozcare believes that flexible, high care packages have enormous potential and views this type of service as offering potential for continual improvement and a means of

attracting new services to the region. The Pilot has allowed staff to further develop the skills to deliver some of the new initiatives in dementia care. Earlier intervention is thought to be one critical factor in achieving the desired outcomes for this target group and holds the promise of long-term benefits for clients and families, service providers and the health and aged care systems.

# 7.2 Client profiles

Ozcare Innovative Dementia Care Packages supplied evaluation data for 35 clients, including nine men and 26 women. These data, summarised below, describe the group during the evaluation (June to November 2004) or, where indicated, at date of entry to the project.

## Age and sex

Ages of Ozcare clients ranged from 55 years to 93 years (mean 80.2 years). Twelve clients were aged 85 years or over (Table B7.1).

**Table B7.1: Ozcare Innovative Dementia Care Packages, number of clients by age group and sex**

| Age (years) | Males | Females | Persons |
|---|---|---|---|
| | | (number) | |
| Less than 65 | — | 2 | 2 |
| 65–74 | 2 | 4 | 6 |
| 75–84 | 5 | 10 | 15 |
| 85+ | 2 | 10 | 12 |
| **Total** | **9** | **26** | **35** |
| | | (per cent) | |
| Less than 65 | — | 5.7 | 5.7 |
| 65–74 | 5.7 | 11.4 | 17.1 |
| 75–84 | 14.3 | 28.6 | 42.9 |
| 85+ | 5.7 | 28.6 | 34.3 |
| **Total** | **25.7** | **74.3** | **100.0** |

— Nil.

## Language and communication

Eight clients had little or no effective means of communication. Two national languages were represented (Table B7.2).

**Table B7.2: Ozcare Innovative Dementia Care Packages, number of clients by language spoken at home and proficiency in English**

| | How well does client communicate in English? | | | | |
|---|---|---|---|---|---|
| Language spoken at home | Very well or well | Not well | Not at all | Not stated | Total |
| English | 27 | 5 | 1 | 1 | 34 |
| Italian | — | 1 | — | — | 1 |
| **Total** | **27** | **6** | **1** | **1** | **35** |

— Nil.

## Accommodation and living arrangement

Clients were living in private residences and retirement villages (Table B7.3). Five clients were living alone.

**Table B7.3: Ozcare Innovative Dementia Care Packages, number of clients by usual accommodation setting, living arrangement and accommodation setting**

| | Usual living arrangement | | |
|---|---|---|---|
| Accommodation setting | Alone | With family | Total |
| Private residence | 4 | 26 | 30 |
| Retirement village—independent living | 1 | 2 | 3 |
| Other, not stated | — | 2 | 2 |
| **Total** | **5** | **30** | **35** |

— Nil.

Years at usual place of residence ranged from less than one to 58 years. Four clients had been living in the same home for over 40 years.

## Carer availability

Thirty-two clients had a carer, 28 of whom were living with the care recipient (Table B7.4). Recorded ages of carers range from 45 to 91 years with an average of 67.6 years. Seven carers were aged 75 years or over (Table B7.5).

**Table B7.4: Ozcare Innovative Dementia Care Packages, number of clients by carer availability, carer relationship to client and co-residency status**

| Relationship of carer to client | Carer lives with client | Carer does not live with client | Total |
|---|---|---|---|
| Spouse or partner | 20 | — | 20 |
| Son or daughter | 8 | 3 | 11 |
| Other relative | — | 1 | 1 |
| *Total clients with a carer* | *28* | *4* | *32* |
| Clients without a carer | | | 3 |
| **Total clients** | | | **35** |
| Per cent of clients with a carer | | | 91.4 |

— Nil.

**Table B7.5: Ozcare Innovative Dementia Care Packages, number of carers by age group and sex**

| Age (years) | Males | Females | Persons |
|---|---|---|---|
| 45–54 | 1 | 5 | 6 |
| 55–64 | 1 | 3 | 4 |
| 65–74 | 8 | 4 | 12 |
| 75–84 | 4 | 2 | 6 |
| 85+ | 1 | — | 1 |
| Not stated | 2 | 1 | 3 |
| **Total** | **17** | **15** | **32** |

— Nil.

## Income and concession status

Government pensions were the primary source of cash income for 31 clients (Table B7.6). Thirty clients held a health care concession card and six clients received a discounted weekly contribution rate for the project due to financial hardship.

**Table B7.6: Ozcare Innovative Dementia Care Packages, number of clients by principal source of cash income, health care card status and project concession status**

| Principal source of cash income | Number of clients | Per cent |
|---|---|---|
| Age pension | 27 | 77.1 |
| DVA pension | 4 | 11.4 |
| Superannuation | 3 | 8.6 |
| Spouse or partner | 1 | 2.9 |
| **Total** | **35** | **100.0** |
| Health care concession card holder | 30 | 85.7 |
| Project concession status | 6 | 17.1 |

Client co-payment amounts ranged between $1 and $6 per day (median $5 per day).

## Previous use of government community care programs

Twelve clients were not receiving assistance from government community care programs before they entered the project (Table B7.7). Six clients had been using a HACC service.

Two carers reported that, despite having had a need for respite care in the 12 months prior to the Ozcare project, they had not used a respite care service. Of the carers who had accessed respite care in the 12 months before entering the project, 15 had used mainly in-home respite and eight had used mainly residential respite. Six carers said they had not needed respite.

**Table B7.7: Ozcare Innovative Dementia Care Packages, number of clients by previous use of government support programs**

| Previous use of government support programs | Has a carer | No carer | Total | Per cent |
|---|---|---|---|---|
| **Government support program** | | | | |
| National Respite for Carers Program | 15 | 2 | 17 | 48.6 |
| Home and Community Care | 5 | 1 | 6 | 17.1 |
| *Total clients with previous government program support* | *20* | *3* | *23* | *65.7* |
| Clients without previous government program support | 12 | — | 12 | 34.3 |
| **Total** | **32** | **3** | **35** | **100.0** |

— Nil.

Nineteen clients were on a waiting list for residential aged care.

## Assessment and referral

The project receives most referrals from ACAT (Table B7.8).

**Table B7.8: Ozcare Innovative Dementia Care Packages, number of clients by source of referral**

| Referral source | Number of clients |
|---|---|
| Aged Care Assessment Team | 21 |
| Ozcare | 11 |
| Other health or community service | 2 |
| Family | 1 |
| **Total** | **35** |

Thirty clients had completed an ACAT assessment on the same day or prior to referral to the project. For these clients, the time between completion of an assessment and referral to the project varied from day of referral to 675 days (Table B7.9).

ACAT assessment was completed after referral to the project for five clients.

The project encountered some early difficulties that were associated with a lack of knowledge of the service and approval requirements among ACAT staff. Ozcare remarked that people seeking ACAT approval for placement might not have been given the option of a high care package and it is felt that slow early referrals were due to poor briefing and a lack of guidelines for referring ACATs.

**Table B7.9: Ozcare Innovative Dementia Care Packages, number of clients by days between completion of ACAT assessment and date of referral to project**

| Completion date of ACAT assessment | Number of clients |
|---|---|
| **Before referral to project** | |
| 0–20 days | 20 |
| 21–30 days | 2 |
| 31–60 days | 1 |
| 61–90 days | 2 |
| 91–120 days | — |
| 121–180 days | 1 |
| 181–365 days | 2 |
| Over 1 year | 2 |
| *Total* | *30* |
| **After referral to project** | |
| 1, 4, 12, 41 and 373 days post-referral | 5 |
| **Total** | **35** |

— Nil.

## Health conditions and health status on entry

The number of health conditions recorded for Ozcare clients ranges from one to nine. Twenty-six of the 35 clients had three or more health conditions at entry. Dementia was recorded as the primary health condition for 34 clients.

Twenty-nine clients out of 35 were assessed as being at risk of falls due to impaired gait or balance and 11 clients showed signs of disorientation (Table B7.10). Eight clients had been diagnosed with depression and the majority of clients were vision impaired.

**Table B7.10: Ozcare Innovative Dementia Care Packages, number of clients by selected sensory, mental and physical conditions**

| Health condition | Number of clients |
|---|---|
| Impaired gait or balance—at risk of falls | 29 |
| Vision impaired | 21 |
| Hearing impaired | 13 |
| Disorientation/confusion | 11 |
| Diagnosis of depression | 8 |
| Missing or non-functional limbs | 1 |
| Total or partial paralysis | 1 |

Clients were taking between zero and 14 different medications. Twenty-one clients were taking four or more different medications.

Clients and carers were asked to report on client health status and change in health status over the 12 months prior to entry using a five-point Likert scale (Short-Form 36). In most cases, a carer reported; two clients gave a self-report. In 18 cases, the response is missing or a care worker gave a proxy report—these are considered invalid for the purposes of self-assessment. Of the 17 valid responses, three indicate the client was in very good or excellent health; the remaining ratings are good (four clients), fair (six clients) or poor (four clients).

About half the raters said that the client's health was somewhat worse (six clients) or much worse (three clients) than one year earlier, which suggests that the care needs of these clients had increased in the 12 months prior to entry. Nine raters reported no change over the previous 12-month period and two raters reported improvement in health status. Reports are not available for 15 clients.

## Level of core activity limitation

Most Ozcare clients experienced moderate self-care limitation and mild to moderate mobility limitation at the time of the evaluation (Table B7.11). Around one-third of clients had a severe or profound communication limitation.

Sixteen clients had a severe or profound level of activity limitation in at least one area of core activity.

**Table B7.11: Ozcare Innovative Dementia Care Packages, number of clients by level of core activity limitation**

| | Level of activity limitation | | | | |
|---|---|---|---|---|---|
| Core activity | No limitation | Mild | Moderate | Severe or profound | Total |
| Self-care | — | 9 | 17 | 9 | **35** |
| Mobility | 5 | 11 | 12 | 7 | **35** |
| Communication | 12 | 8 | 4 | 11 | **35** |

— Nil.

## Use of medical and hospital services prior to entry

Twenty-nine clients had visited a medical practitioner at least once in the 6 months before joining the project. The reported number of visits to a medical practitioner in this period varied from zero to 50 per client. One client reported 50 medical consultations outside of a hospital setting, two emergency department visits and 20 unplanned hospital days in the 6months prior to entering the project. Cumulatively, the 28 clients recorded 244 visits to a medical practitioner outside of a hospital setting over an estimated 5,220 person days.

Thirteen clients were admitted to hospital in the 6months prior to entering the project. Detailed information on admissions is recorded for 11 clients, who collectively contributed to 20 hospital admissions in the pre-entry period. Information on the number of days for unplanned hospital admissions is available for 12 clients (including three clients who did not provide further details). These 12 clients collectively accumulated 153 unplanned hospital bed days over approximately 2,160 person days. Individually, they recorded between five and 29 days in hospital for unplanned admissions in a 6-month period.

Conditions recorded as occasioning admission to hospital include:

- diseases of the intestinal tract
- diabetes mellitus
- breast cancer
- heart disease
- transient cerebral ischaemic attacks
- other health conditions.

Thirteen clients experienced a serious medical emergency during the pre-entry period. Four clients experienced a fall with injury; three were rendered immobile and without assistance for more than 30 minute;s and nine clients suffered another type of medical emergency.

# 7.3 Client assessment results

The Ozcare project commenced in late 2003 and most clients in the evaluation were with the project before the evaluation commenced. Ozcare did not reconstruct baseline assessments for clients in the evaluation; therefore, baseline assessment information reported below pertains to the first assessment for each client during the evaluation.

## Cognitive function

MMSE scores were recorded for 26 clients at their first assessment (Table B7.12). Three zero scores were excluded when calculating summary statistics. Non-zero scores ranged from 1 to 26 points out of a possible 30 points (mean 16.2).

**Table B7.12: Ozcare Innovative Dementia Care Packages, number of clients by Mini-Mental State Examination score at first assessment**

| MMSE score | Number of clients |
|---|---|
| Zero | 3 |
| 1–15 | 11 |
| 16–18 | 1 |
| 19–24 | 8 |
| 25–30 | 3 |
| Missing | 9 |
| **Total** | **35** |

Cut-points to account for educational attainment were applied to the non-zero MMSE scores (Uhlmann & Larson 1991). Sixteen (16) of the 23 scores indicate probable cognitive impairment. Although the MMSE does not classify a proportion of clients as cognitively impaired, all but one of the 35 clients had some type of dementia recorded as their primary health condition.

## Activities of daily living

Most clients needed assistance in self-care activities at the time of their first assessment (Figure B7.1). MBI scores ranged from 1 to 19 points out of a possible 20 points. The mean score was 11.2 points.

A classification for Barthel Index scores (Shah et al. 1989) indicates that, at the first assessment, two clients were completely dependent in self-care and mobility, 16 clients exhibited severe dependency, 15 clients exhibited moderate dependency and one client showed slight dependency in ADL.

Twenty-four of the 34 clients for whom data are recorded had continence management needs. Seventeen clients were doubly incontinent. Most clients were unable to bathe or shower, groom, dress or use the toilet without assistance. Yet, most clients were independently mobile.

High levels of dependency in IADL were recorded (Figure B7.2). On average, clients were completely dependent in between three and four out of seven types IADL. Three clients were completely dependent in all seven IADL and most other clients either needed assistance or were unable to do things such as manage personal finances, self-medicate, shop, or do housework. Although 22 clients were able to mobilise independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all cases, independent mobility was limited to the home environment.

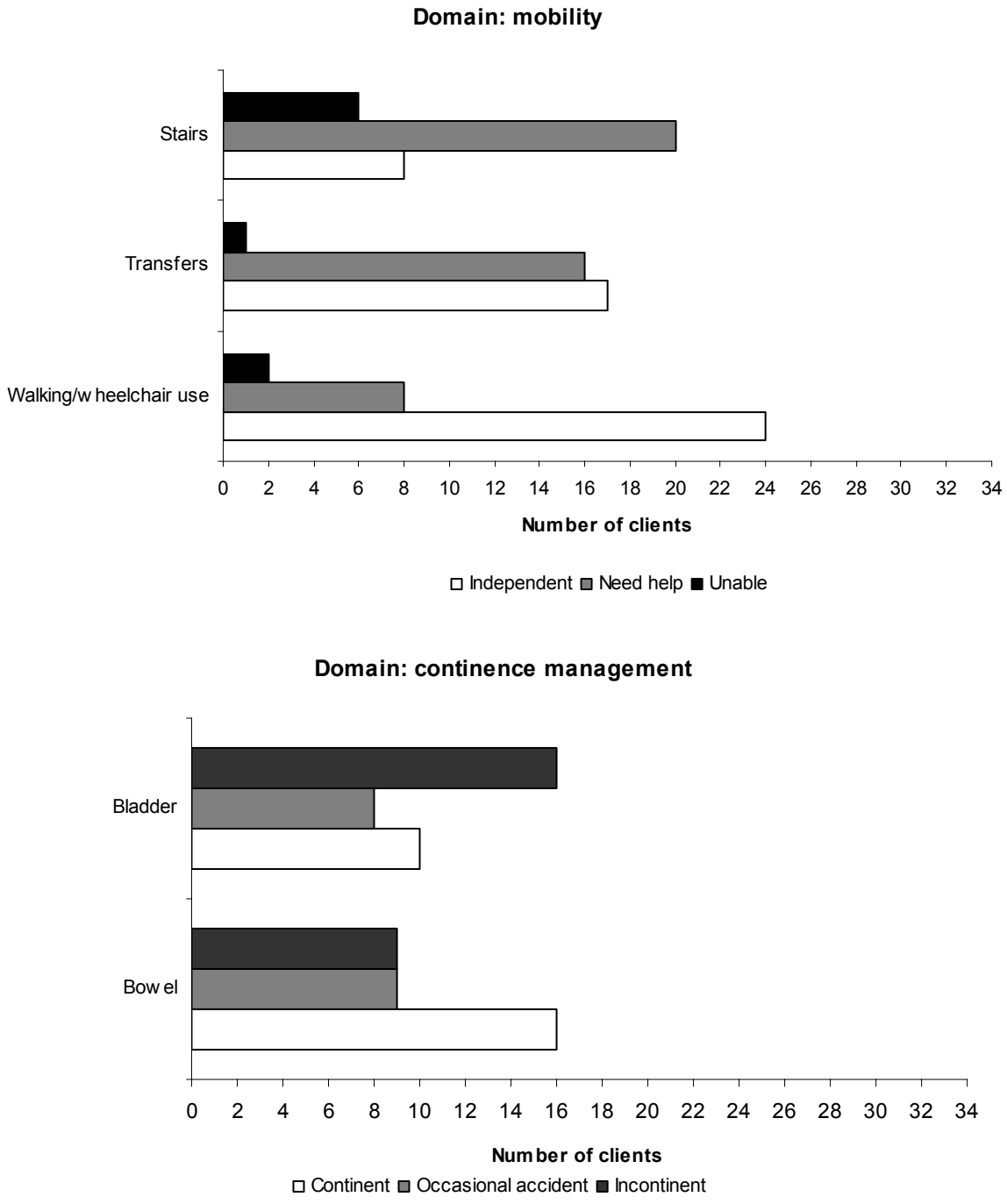
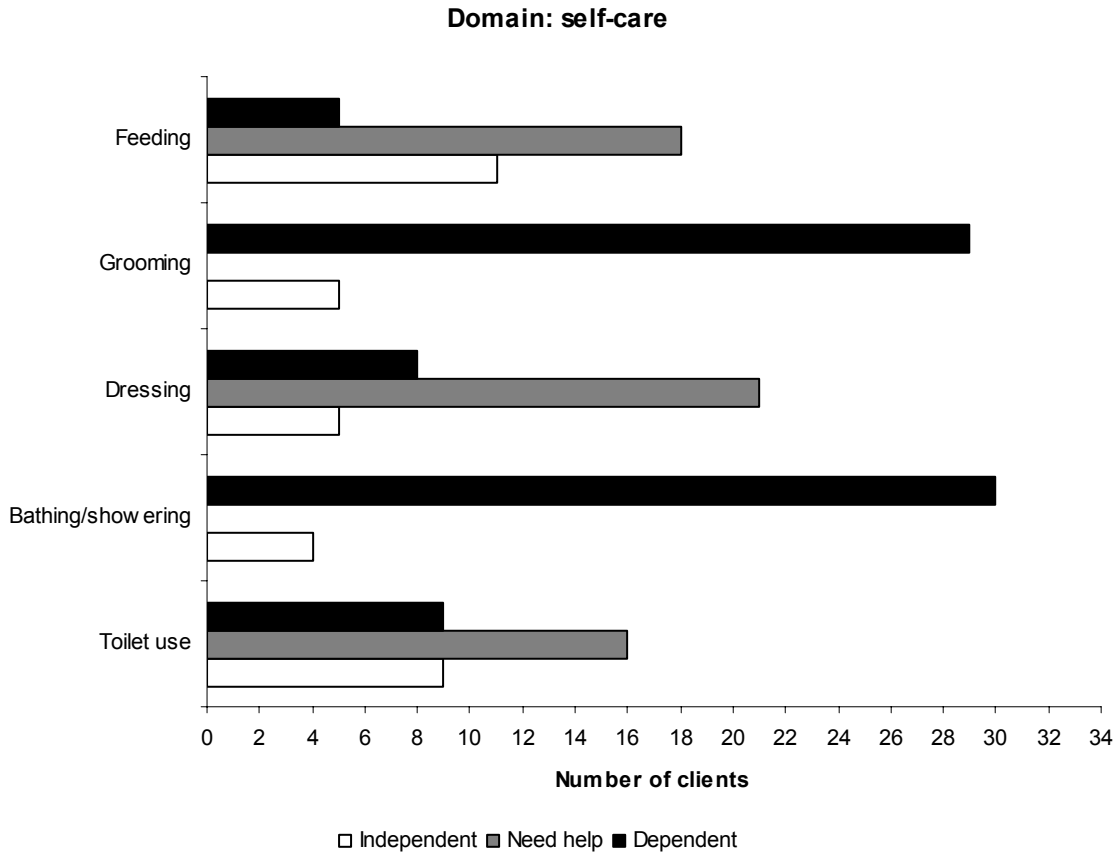


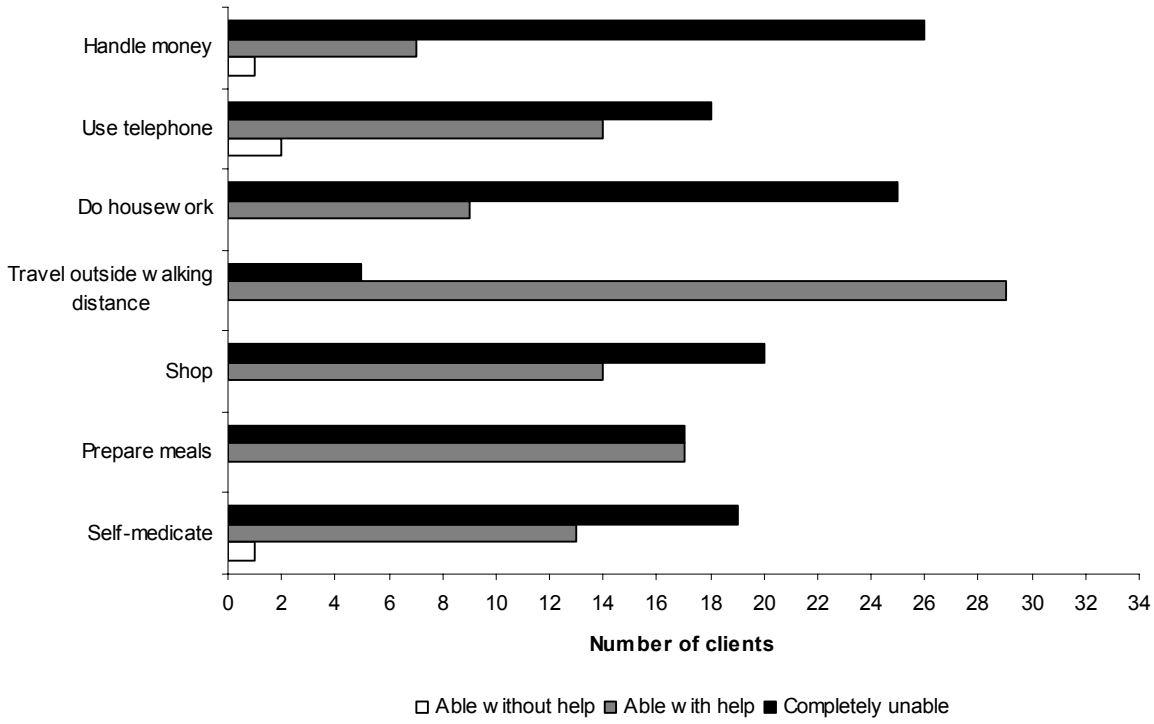

**Figure B7.1: Ozcare Innovative Dementia Care Packages, number of clients by level of ADL function at first assessment**

*(continued)*




*Source:* Appendix Table B19.

**Figure B7.1 continued: Ozcare Innovative Dementia Care Packages, number of clients by level of ADL function at first assessment**




*Source:* Appendix Table B20.

**Figure B7.2: Ozcare Innovative Dementia Care Packages, number of clients by level of IADL function at first assessment**

Ozcare was asked to record the results of three functional assessments in total. In some cases only one further assessment was possible. Figure B7.3 shows the MBI scores for clients at baseline, interim and final assessment by accommodation setting at follow-up. Clients in care at follow-up were either in residential high or low care, or in hospital. Clients in the community were either still with the Ozcare project, in other community care or were not accessing government-funded care.

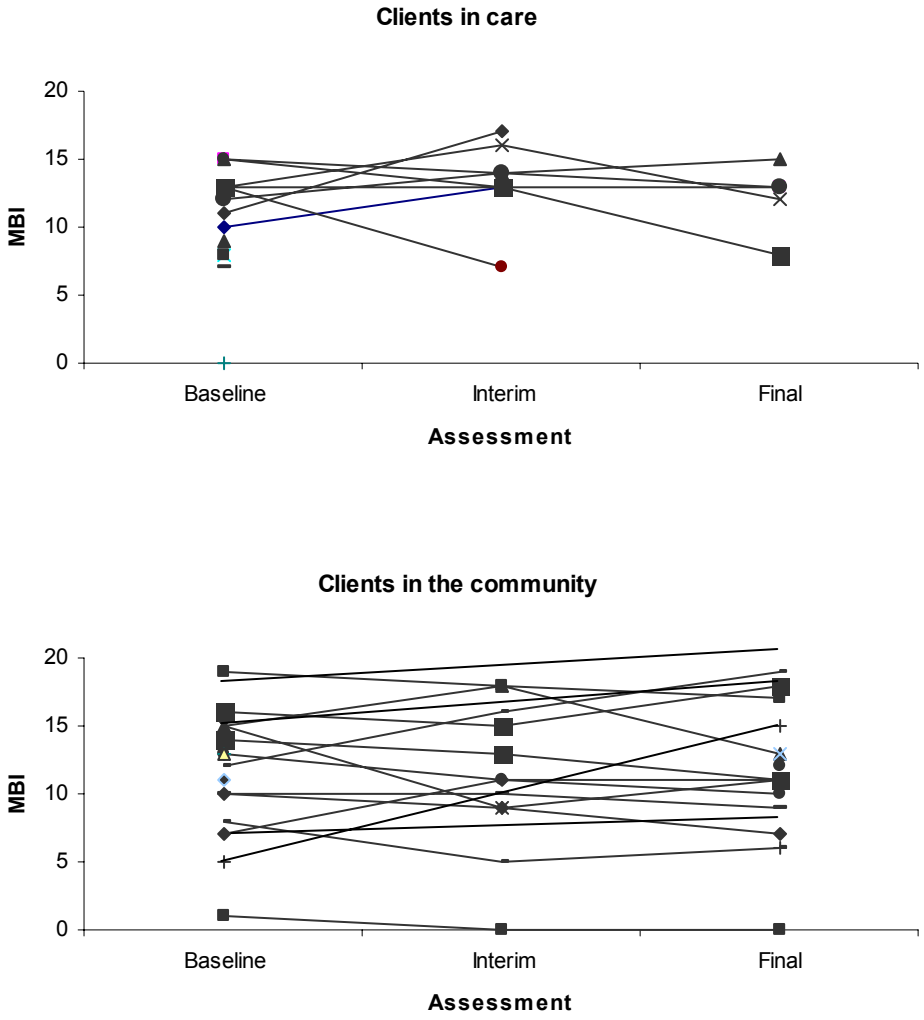



**Figure B7.3: Ozcare Innovative Dementia Care Packages, baseline, interim and final MBI scores by follow-up accommodation setting (one symbol per client)**

## Psychological and behavioural symptoms

Twenty-five clients showed signs of memory loss on an intermittent or extensive basis (Figure B7.4). Wandering or intrusive behaviour were present in half of the cases (17 clients) and seven clients wandered extensively. Seventeen clients showed signs of emotional or psychological symptoms at least occasionally. Fourteen clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, six of whom exhibited two or more symptoms on an extensive basis.

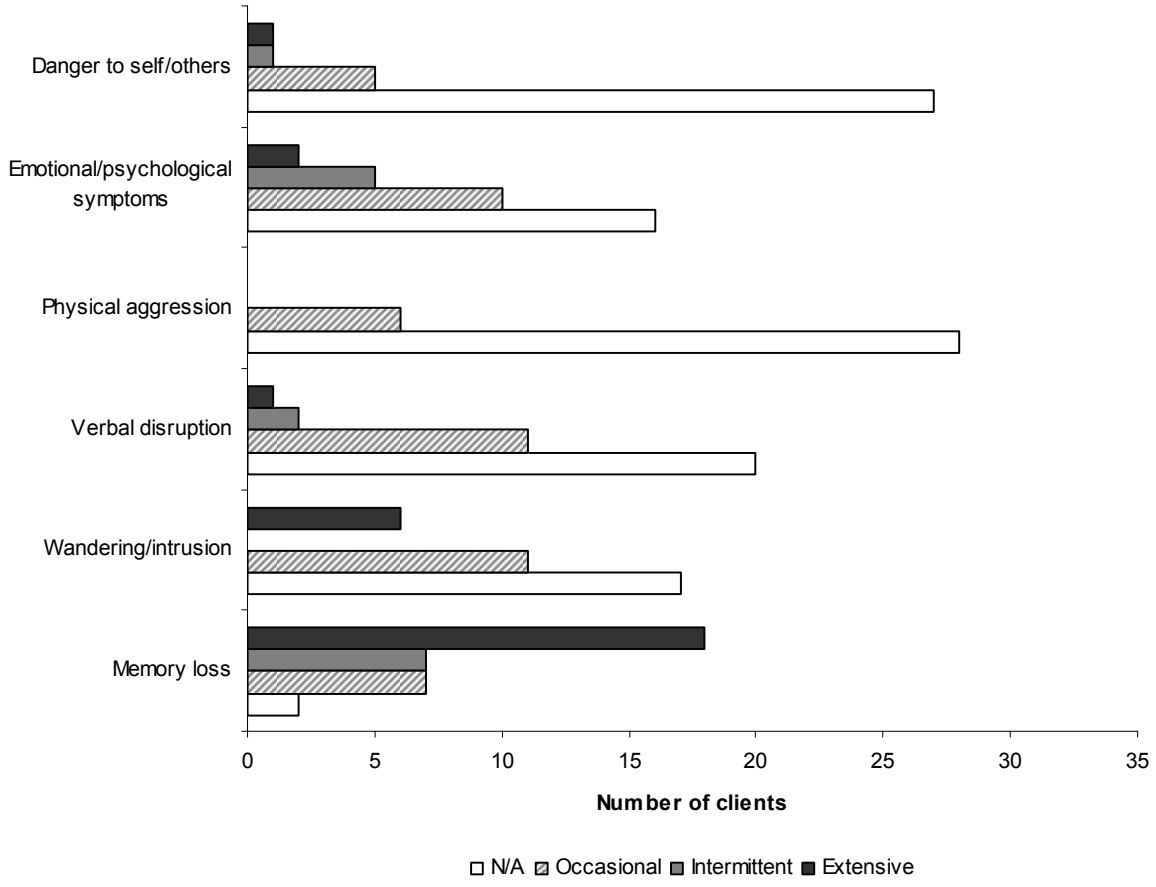



**Figure B7.4: Ozcare Innovative Dementia Care Packages, number of clients by frequency of behavioural and psychological symptoms, first assessment**

## 7.4 Carer assessment results

Thirteen carers reported that they were in excellent, very good or good health at the time of the first assessment. Ten carers reported fair health and four reported poor health. Two carers did not self-report.

Thirty carers completed the CSI at the first assessment to generate a mean score of 7.4 points. Scores ranged from 1 to 12 points. Nineteen carers recorded scores above the threshold for high carer strain and six more carers scored 1 point below the threshold. Twenty-one carers completed the CSI at a third assessment, on average 22 weeks after the first assessment. The median recorded change in CSI was –1 point. Individual carers recorded changes of between –5 (a 5-point reduction in carer strain) and 7 points (7-point increase) between the first and final assessments. At the final assessment, 11 of the 21 carers recorded a CSI score above the threshold for high carer strain. Thus, although the average level of carer strain was observed to decrease over the assessment period, there is evidence that a high proportion of carers continued to experience negative consequences from their caring roles.

Twenty-nine carers completed the GHQ-28 and another two carers completed all but the depression sub-scale of the GHQ at the baseline assessment. Four carers scored above 14 points on at least one sub-scale. Two carers recorded scores of 14 points or higher for somatic symptoms; three carers recorded scores of 14 points or higher for anxiety and insomnia and one carer scored over 14 points for social dysfunction. The results indicate that these carers were experiencing health and psychological symptoms associated with a recent change in circumstances. No carer scored over 14 points for severe depression.

Twenty-one carers completed the GHQ-28 at the final assessment. One carer scored above 14 points on one sub-scale at the final assessment. There is an overall reduction in high sub-scale scores, which may reflect a 'settling' of circumstances in which carers find themselves.

More detailed examination of CSI and GHQ-28 scores is included in the overall analysis of the Innovative Pool project data, due to small sample sizes in individual projects.

## 7.5 Service profile

During the evaluation, the types of services delivered to higher numbers of clients included respite care, personal assistance, domestic assistance, social support, food services and transport (Table B7.13). Some clients used transport assistance extensively, in one case an average of seven trips per week was recorded. This is seen to reflect the regional/rural location of the project in which clients and their carers may have to travel long distances for medical services and other appointments and services.

Follow-up needs assessment involved a median of approximately one visit or contact every month, but some clients required quite high levels of case management, for example, up to two contacts from a case manager per week.

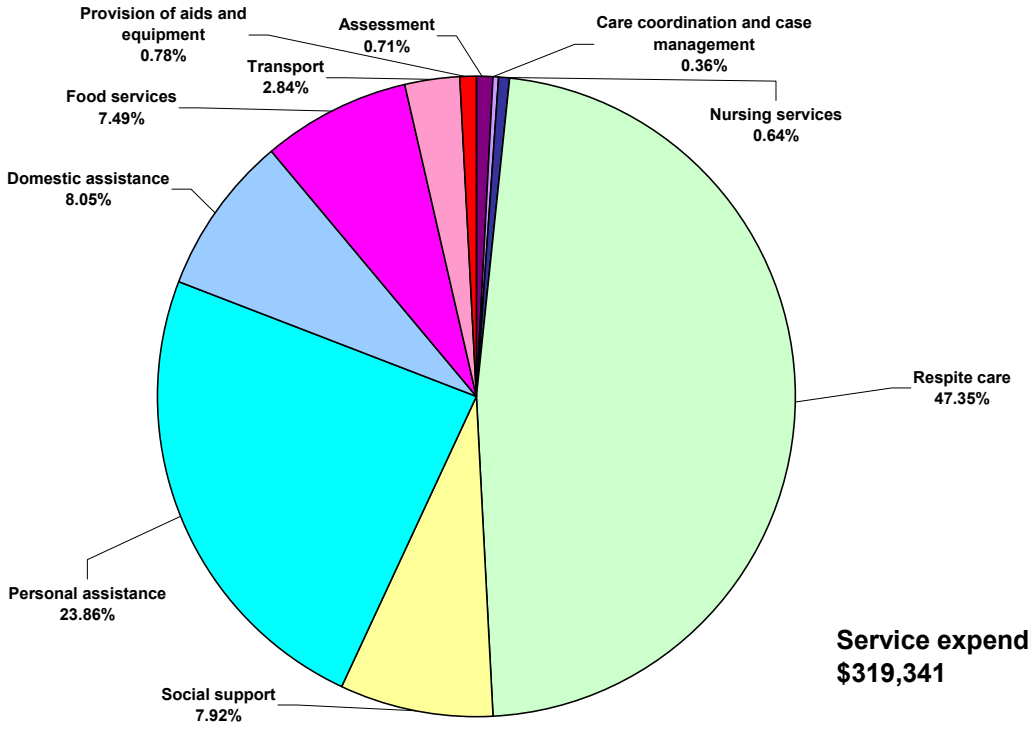
Respite care accounted for almost half of direct care expenditure in the 6 months from 1 July to 31 December 2004 (Figure B7.5).

**Table B7.13 : Ozcare Innovative Dementia Care Packages, summary of services delivered per client per week.**

| Service type | Service unit | Clients | Minimum | Median | Maximum | Mean | Standard deviation |
|---|---|---|---|---|---|---|---|
| Respite (in-home and day)[a] | Hours | 27 | 0.2 | 7.8 | 34.5 | 8.9 | 8.4 |
| Personal assistance | Hours | 25 | 0.1 | 2.4 | 16.9 | 4.1 | 4.4 |
| Domestic assistance | Hours | 23 | 0.0 | 1.0 | 4.4 | 1.2 | 1.2 |
| Social support | Hours | 19 | 0.1 | 1.1 | 3.6 | 1.4 | 1.1 |
| Food service other | Hours | 16 | 0.0 | 0.8 | 6.5 | 1.6 | 1.9 |
| Nursing care | Hours | 9 | 0.1 | 0.2 | 1.1 | 0.3 | 0.3 |
| Allied health[b] | Hours | 1 | 0.2 | 0.2 | 0.2 | 0.2 | . |
| Follow-up needs assessment | No. contacts | 14 | 0.1 | 0.2 | 2.0 | 0.4 | 0.5 |
| Community transport | No. one-way trips | 16 | 0.1 | 0.5 | 6.7 | 1.7 | 2.3 |
| Delivered meals | No. meals | 6 | 0.3 | 1.4 | 8.3 | 2.4 | 2.9 |
| Overnight respite | No. nights | 2 | 0.0 | 0.1 | 0.2 | 0.1 | 0.1 |
| Carer support other than respite | No. contacts/events | 2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.0 |

(a) Assumes one day respite date is 6 hours

(b) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.




*Source*: Appendix Table B26.

**Figure B7.5: Ozcare Innovative Dementia Care Packages, expenditure on services, 6 months ending 31 December 2004**

# 7.6 Accommodation outcomes

Ozcare conducted a follow-up of evaluation clients who were still with the project at 30 November 2004. Follow-up was completed between 24 February and 9 June 2005. Table B7.14 shows accommodation setting and government program support status for clients at time of follow-up (that is, between approximately 8 and 12 months since the start of the evaluation). By this time, three more clients had died and another five clients had entered residential care. Sixteen clients were still living in the community and being supported by the Ozcare project. Follow-up data are not available for the two clients who were discharged to hospital during the evaluation period.

**Table B7.14: Ozcare Innovative Dementia Care Packages, client location and government-funded support at follow-up, June 2005**

| Location at follow-up | Number of clients |
|---|---|
| **At home** | |
| On Ozcare Innovative Dementia Care Packages | 16 |
| **In care** | |
| Residential aged care—high care | 13 |
| *Total in care* | *13* |
| Deceased | 4 |
| Not located | 2 |
| **Total** | **35** |