



## An evaluation of two respite models for older people and their informal caregivers

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### Abstract

**Aim** To evaluate two case-management models of respite relief care at Waitemata District Health Board.

**Method** The evaluation consisted of semi-structured interviews and postal surveys for clients utilising respite care and staff members involved in both the North/West and Rodney models of respite care in Auckland, New Zealand. Across the two regions, a total of 2 older people and their informal caregivers, 2 respite coordinators, and the Needs Assessment Service Coordination (NASC) Manager were interviewed. In addition, postal surveys were received from 21 older people, 36 informal caregivers, 11 NASC workers, and 3 allied health professionals.

**Results** Findings revealed there was generally high satisfaction with both the respite models. Caregivers believed the respite service did give them a break, although it was insufficient. Caregivers reported concerns regarding how respite facilities could improve and the older person's deterioration post respite. Staff identified improvements for each of the models.

**Conclusions** The respite models are flexible and provide control in decision-making for informal caregivers leading to an increase in choice for home-based respite. Case-managers need to form strong partnerships with caregivers to ensure that the needs of both the informal caregiver and older person are met. Short-term placement in residential respite facilities for respite care may be linked to worsening functional ability of the older person.

New Zealand's population is continuing to age, and therefore the demand for and cost of health and disability services is increasing.<sup>1,2</sup> *Ageing in place* (the concept of supporting an older person to remain living in their own home until they die; reliant on adequate home care, caregiver support, and appropriate housing) allows the older person to remain in their home despite their health care needs increasing<sup>3</sup> and literature reveals that many older people prefer to live at home for as long as possible, which is beneficial in a variety of ways.<sup>3-5</sup> *Ageing in place* is strongly associated with participation, independence, and wellness—and is thought to be less expensive than long-term residential care.<sup>5,6</sup>

An informal caregiver is usually a family member or a friend who is unpaid and offers a wide range of assistance to an older person.<sup>2,7,8</sup> In contrast, a support worker is defined as a paid nursing assistant trained to provide coherent support for patient rehabilitation whose two major functions can be defined as the 'enabling' and 'assisting' role. *Enabling* encompasses housekeeping and administrative tasks, while *assisting* relates to technical tasks.<sup>9,10</sup>

Despite the benefits of *ageing in place*, research shows that informal caregivers experience considerable stress, which affects the health and quality of life of the older person.<sup>11,12</sup> Therefore, respite care has been developed and is defined as a service or services which provide temporary provision of care for the older person living at home, allowing the primary informal caregiver relief and rest from their caregiving responsibilities.<sup>11,12</sup> These services can be provided in different settings (such as nursing homes, the home, or day care centres) and range from a few hours to a few weeks, either on a regular or irregular basis.<sup>13,14</sup> The older people who utilise respite services are often frail, dependent, and have high needs. Consequently, respite care aims to alleviate the burden and stress experienced by the informal caregiver.<sup>13,14</sup> Respite services can lead to increased caregiver satisfaction, the ability to provide higher quality of care with increased confidence, and an improved understanding of the caregiver role.<sup>14</sup>

In New Zealand, the health and disability support services currently have gaps, overlaps, and inconsistencies, which results in inefficiency and confusion for older people and caregivers trying to utilise service options.<sup>2</sup> In addition, even if accessible services are available for older people living at home, there can still be duplication and gaps without appropriate coordination.<sup>5</sup> Therefore, case-management has been developed as it aids older people to identify and utilise the health and disability support services available to them while promoting ageing in place.<sup>3,5</sup>

For the past 15 years, the respite care programme at Waitemata District Health Board (DHB) has remained unchanged, with respite care and Needs Assessment and Service Coordination (NASC) operating as distinct services. This led to fragmentation for the client and caregiver as they had two separate service coordinators. Therefore, two case-management models have been developed which aim to improve the delivery of respite care services by having one person involved with coordination of all support services (for both the client and caregiver).

Previously, the respite service had little flexibility—as older people and caregivers were allocated a set block of respite every few weeks or months. When a ‘maximum rotation’ of 2 weeks in care every 6 weeks was no longer adequate, permanent rest home or private hospital care was considered. However, with the introduction of the two new respite models, the caregiver and older person can use their allocated respite funding as they choose—as the choice of home-based respite, the use of a respite facility, an increase in support services, or a combination of all three.

The first model has been implemented in the North and West region of the Waitemata DHB area. When high-needs clients and their caregivers require relief care (*relief care* is defined as over 50 days a year of carer support [respite funding over \$70 per week]), the client’s current Needs Assessment Service Coordination (NASC) worker refers them to a respite coordinator who manages their care.

The second model has been implemented in the Rodney region of the Waitemata DHB area. For this model, clients who require relief care will have their NASC Manager coordinate their support and care. The respite coordinator will have a caseload of intensive service coordination (ISC) clients, with the additional role of budget management for respite clients.

These two models were trialled for 12 months over 2002 and 2003. The aim of this research study was to evaluate the two respite models of relief care for clients and

their unpaid caregivers in the Waitemata DHB area. The balanced scorecard approach was used to ensure multiple groups and perspectives were assessed enabling a comprehensive evaluation.<sup>15</sup>

Five research questions were devised using the balanced scorecard framework:

- How do older people and informal caregivers view the respite models of relief care?
- How do the respite models of relief care look to funders?
- How can the respite models of relief care continue to improve?
- What must the respite models of relief care excel at?
- How do the respite models of relief care impact on the health status of older people and informal caregivers?

## Methods

### Participants

**Evaluation**—The evaluation consisted of semi-structured interviews and postal surveys directed to clients (utilising respite care) and staff members involved in both the North/West and Rodney models. Two older people and their unpaid caregivers (one from each region), two respite coordinators (one from each region), and the NASC Manager for Waitemata DHB were included in the interviews.

Several older people utilising the respite services are in poor health and often unable to communicate effectively. Therefore, the respite coordinator (for each model) identified an appropriate older person and carer who consented to being interviewed. The allied health professionals surveyed included nurses and occupational therapists from North Shore Hospital and Waitakere Hospital who may have been involved with respite care.

**Inclusion criteria**—All older people (65 years and over) and their full-time unpaid caregivers who received respite care services from the Waitemata DHB. These participants had already met the NASC eligibility criteria. The cost of their caregiver relief was above NZ\$70.00 per week (50 days per year of carer support). All staff that had some involvement in assessing, case-managing, or providing respite care for the older person meeting the above criteria.

**Exclusion criteria**—Older people or caregivers who had (or were recently recovering from) a serious mental or physical illness or injury.

### Interviews and postal surveys

The semi-structured interviews were audio taped, and lasted approximately 20 minutes. Interviews for older people and their caregivers were conducted in the participant's home. Other interviews were conducted in a private room at the participants' workplaces. After analysing the interviews (using a general inductive approach), relevant themes or categories were identified. From this data, postal surveys were then developed. The surveys consisted of approximately 10 questions using a five-point Likert scale (Strongly Disagree to Strongly Agree), with space for comments at the end.

### Evaluation tool

The evaluation tool used for this study was the balanced scorecard developed by Leggat and Leatt.<sup>15</sup> This scorecard is based on five key perspectives: customer, financial, innovation and learning, internal business, and community. Use of this framework ensured that multiple groups and perspectives were considered in the evaluation.

### Ethical approval

Ethical approval was sought and approved by the Auckland Regional Ethics Committee, New Zealand. Approval was also sought and approved by the Waitemata DHB and the Maori Research Advisory group. All participants were sent an information sheet providing information regarding the study and a

consent form. All participants were ensured confidentiality and informed they could withdraw at any stage without having their care or employment compromised.

## Results

This study displayed small sample sizes and low response rates for postal surveys, therefore only descriptive analysis was undertaken and no firm conclusions can be drawn from the results. There was a 100% response rate for all interviews. Across the two regions (North/West and Rodney), postal surveys were received from 21 older people (21.2% response rate), 36 informal caregivers (36.4% response rate), 11 NASC workers (50% response rate), and 3 allied health professionals (9.7% response rate).

The interview and survey findings of the older people and caregivers showed that a high percentage (94%) were satisfied with both of the respite models. Specifically, older people and caregivers (89%) felt satisfied with the availability, accessibility, and amount of contact they received from their case-manager (respite coordinator or NASC worker).

Several respondents wrote that the previous respite model was not flexible, and did not provide control in decision-making—as the older person and caregiver were told when and how they would receive respite (usually in a respite facility). However, older people and caregivers reported that the current respite services were flexible (87%) to meet their needs and they had more control in decision-making (79%).

Caregivers from the two respite models reported that, although they did receive a break, it was insufficient. One caregiver stated the *respite gave them a break 'physically' but not 'mentally'*.

Both interview and survey findings revealed that numerous older people and caregivers misinterpreted the respite service as the respite facility where the older person received respite. Consequently, many respondents (75% from interviews, 39% from surveys) identified improvements for the respite facility, rather than the respite service. In addition, caregivers made comments that the older person's condition deteriorated after staying at the respite facility and they did not believe it promoted independence. Survey comments from older people and caregivers in the North/West model identified the need for continuity of support workers with home-based respite.

Interviews with the NASC Manager and respite coordinators revealed there was high satisfaction with both respite models. Interviewees identified the following areas of excellence for the two models: Ageing in place, flexibility, client-centred, cost-effective, and case-management. In general, staff believed that the respite services do provide caregivers with a break to help alleviate their stress.

Both respite coordinators reported high job satisfaction, although they agreed it could be stressful at times. The NASC Manager and respite coordinators believed both respite services improved the health status of the older person and the caregivers.

Improvements were identified for both the respite models. In the North/West model, it was felt that there was a lack of back-up on a personal and professional level. It was suggested that two respite coordinators in the North region and two in the West region would be an improvement (at the time of this evaluation there was one coordinator in each of these areas). In the Rodney region, issues were raised regarding extra stress,

time, overlap, and resources spent on the NASC workers who had to learn the respite coordinator role. It was suggested that the NASC workers would benefit from an initial training programme, if the Rodney model were to be adopted.

NASC survey results found that NASC workers (38%) from both models reported allied health professionals require increased awareness about the respite service. Some NASC workers (25%) from the North/West region identified the requirement for extra staff to be trained in the respite coordinator role. A few NASC workers (25%) from the Rodney region stated that NASC workers should receive training for the respite coordinator role.

The Support Package Allocation (SPA) band is used to determine the amount of funding the respite coordinator can access to purchase services for the older person and their caregiver. The majority of older people having respite care are placed in the 'High' or 'Very High' SPA band category. For each individual area (i.e. Rodney, North, and West) the maximum SPA for clients is \$360 and \$600 per week for the 'High' and 'Very High' SPA band category, respectively. Financial findings revealed that the average actual expenditure of the SPA band, for older people in 'High' and 'Very High' categories combined, is 63% for the North/West model and 64% for the Rodney model, per week respectively

Since implementing the two new models of respite relief in 2002, the volume of older people receiving home-based respite has increased from less than 1% to 50% at the time of this evaluation. Although staff members reported their job as being stressful at times there still appeared to be high job satisfaction. At the time of this evaluation there was no staff turnover in respite care.

## **Discussion**

This section will discuss the results of this study in relation to the five research questions. Interestingly, results revealed that the two models were similar in several aspects and therefore it may appear they have not been compared. However, when differences were noted between the two respite models this has been stated. In addition, results showed that clients found both the new models more flexible than the previous "old" model. Although this was not a direct comparison between the two new models, it was still a significant finding to be included in the discussion.

**How do older people and informal caregivers view the respite models of relief care?**—Older people and caregivers reported high levels of satisfaction with various aspects of both models, such as increased flexibility and control in decision-making about how they used their allocated respite funding. Flexible service delivery is vital as it allows for client needs to be met.<sup>5</sup> Control in decision-making is significant—as a recent study revealed control over daily living is rated highly as an important need to be met for older people.<sup>16</sup> Interestingly, since changing the respite models of relief care to enable the caregiver to have more control in decision-making, the amount of older people receiving home-based respite has dramatically increased.

Informal caregivers appear to find their respite relief insufficient and still report stress, despite support from the respite services. This may have been related to comments made that the older person's condition deteriorated once they returned from the respite facility. This could place increased stress on the caregiver, particularly once the older person returns from respite. Research overseas has shown

respite services can increase caregiver stress due to the quality of care and deterioration of the older person post respite.<sup>17,18</sup> The issue of effectively meeting informal caregivers' needs and completely alleviating their stress requires further exploration. In addition, a strong partnership between case managers and informal caregivers should be developed to adequately meet their needs and alleviate stress.

When the North/West model was initiated, there were concerns regarding discontinuity—as coordination of care shifted from the NASC to the respite coordinator at a time when the client may be feeling particularly fragile and vulnerable. However, it was found that both clients and staff reported no problems when this shift in coordination of care occurred—possibly due to the successful teamwork of both the NASC and respite coordinator. Staff are aware of this potential problem and therefore work in effective collaboration to prepare each other and the client for this change.

**How do the models of relief care look to funders?**—For clients in the 'High' and 'Very High' SPA band categories the average actual expenditure for both the North/West and Rodney models was below the top range of the SPA band the older person was in. This means that the funders were spending less than the top range available on clients utilising respite care services.

In addition, there was little difference between the two models in terms of financial spending, as both spent very similar percentages of their SPA band. Although the actual expenditure was calculated by including expenses (such as personal care, household assistance, and caregiver support), the non-financial costs to the caregiver did not appear to be included. For example, these costs may include stress and isolation.<sup>8</sup>

**How can the respite models of relief care continue to improve?**—Comments about how the respite facilities could improve often related to the individual needs of the older person, and several caregivers appeared to be concerned with the care the older person received during their time at the respite facility. Research has shown that caregivers have found use of respite services stressful, as they are concerned about poor facilities and what happens to the older person while in care.<sup>17,19</sup> This area needs further exploration as it would not only be of benefit to the older person and the care they receive, but may also help relieve added stress experienced by the caregiver.

Furthermore, in addition to forming a strong partnership, case managers should expand their role into the community and monitor the older person's care closely when they are at a respite facility.

The strengths and weaknesses of home-based respite are often debated.<sup>3</sup> The benefits of home-based respite include the older person remaining in their own home, which is preferred as they feel independence and quality of life can be maintained.<sup>3</sup> Furthermore, moving to different settings results in mental and physical deterioration for the frail older person.<sup>3</sup>

In addition, previous research and findings from this study have shown that many caregivers find using respite facilities distressing due to concerns including quality of care and the impact that other unwell people (using the same facility) has on the older person.<sup>17,18</sup> This study, however, revealed that discontinuity of support workers is a drawback for using home-based respite. Caregivers often feel the support worker does

not understand the complexities involved with caring for the older person.<sup>17,18</sup> and discontinuity compounds this concern.

For the support worker to truly engage and develop meaningful relationships with the older person over time, continuity of care is critical.<sup>20</sup> In addition, continuity of care is strongly associated with high satisfaction levels for older people and informal caregivers who utilise outpatient services.<sup>21</sup> Moreover, to make home-based respite a more appealing option, case-managers need to facilitate the issues and ensure the caregiver and older person are satisfied with the care they receive at home.

Implementing changes to the two models, as suggested by staff, could prove effective long term, although further resource and cost would be required to employ extra staff and run a new programme.

**At what must the respite models of relief care excel?**—Staff members identified the same areas of excellence that both models achieved. In light of the evidence, these are all important areas that the models of respite care should be achieving.

In general, there appeared to be high job satisfaction for respite coordinators and NASC workers, although both of the respite coordinators who were interviewed agreed their job could be stressful at times. In addition, there was no turnover for respite staff since implementing the new models of respite care to the time of this evaluation.

**How do the respite models of relief care impact on the health status of older people and informal caregivers?**—Staff from both models believed that, if an older person's health deteriorated, appropriate referrals were made as part of the ongoing intensive service coordination function and the respite services provided informal caregivers with a break—thus reducing their stress, which had a positive impact on their health. Furthermore, research has shown that the health of the caregiver directly affects the health of the older person.<sup>12</sup> Therefore, by relieving the caregiver's stress and improving their health, the older person may benefit too.

A few informal caregivers felt the older person's condition deteriorated once returning from the respite facility. This does not relate to the respite models but reflects more on the individual respite facility, however it is an important point to mention. International research has shown that the older person can experience difficulties after the respite period due to factors such as the quality of care and poor facilities.<sup>17,18</sup> This situation could worsen the health status of the caregiver as they experience increased stress.<sup>17,18</sup> As previously mentioned, case managers should ensure that the older person is having their needs met at the respite facility, which assists in reducing caregiver stress.

This study was limited by small samples sizes and low response rates. As many older people who receive respite services have poor health and are highly dependent, it was expected there would be a low response rate from these participants. The reason for a low response rate from caregivers is unknown. This could have been related to many informal caregivers being stressed or burnt out and therefore reluctant to participate in the research. In particular, there was a very low response rate for allied health professionals.

The time constraints and short turn-around to wait for survey returns may have contributed to the low response rates, although it may have been avoided if follow-up

phone calls had been undertaken. Nevertheless, the results of this study are still important, and may give guidance for future respite care programmes and further research in this area.

In conclusion, several strengths and weaknesses were identified in the two models of respite relief care. Flexibility within the respite models of care, allows the caregiver more control over decision-making about the support services they receive. Continuity of support workers for home-based respite could make this option more appealing. Placement in respite facilities may be linked to the older person's condition deteriorating. Lastly, case managers need to form strong partnerships with caregivers to ensure that the needs of both the informal caregiver and older person are met.

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