Best practice counselling interventions for carers of people with dementia

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Acknowledgements

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1. BACKGROUND

The Centre for Health Policy, Programs and Economics at the University of Melbourne was contracted by Alzheimer’s Australia Victoria (AAV) to provide advice on the design of an evaluation of the counselling service which would help to work towards the development of a quality assurance framework. This project was to assist AAV in their program planning.

In order to achieve these aims, we have provided here:

1. A brief literature review of counselling interventions provided to carers of people with dementia, with emphasis on Australian studies published in the academic and grey literature in the last 5 years.
2. Clarification of the objectives of the counselling service. The objectives were developed based on the results of a program logic exercise with Alzheimer’s Association Victoria counselling staff and individual interviews with management where possible.
3. A discussion of options for the design of an evaluation with emphasis on the efficacy of the counselling service.

The literature review and staff discussions were conducted from December 2008 to March 2009. The preliminary data collection exercise in the staff consultation was a ‘program logic workshop’ (see Appendix). This was run at Alzheimer’s Australia Victoria on Wednesday 22nd October 2008. The aim of the workshop was to produce a preliminary, simple program logic model based on the views of stakeholders with a view to future planning of quality assurance processes. To ensure that the workshop was successful we provided participants with a workbook. We asked that staff read the workbook and attempt to answer the questions before the day of the workshop. Their answers then formed the basis of discussion on the day.

The discussions on the day were then summarised by the consultants. A number of individual booklets were also given to the consultants, and a summary of the workshop responses was provided to the AAV coordinator without identifying individual staff responses. The workshop responses were then put into the program logic format, circulated to staff, and revised twice in consultation with AAV.
2. LITERATURE REVIEW

Introduction

According to Ory (1999), dementia care is different from other types of caregiving. Compared to other caregivers, dementia caregivers spend significantly more hours per week providing care, and report more severe impacts in relation to:

- employment complications,
- caregiver strain,
- mental and physical health problems,
- decreased time for leisure and other family members, and
- family conflict.

These findings suggest a need to tailor interventions to the unique challenges faced by dementia caregivers.[1]

Because the experiences of dementia caregivers are unique, this review has focussed specifically on interventions for dementia caregivers. The overall aim was to examine the literature to determine which interventions have been demonstrated to be effective. Effectiveness is a central element of best practice. Therefore understanding which interventions have been proven to be effective is the first step towards developing a model of best practice or evidence-based care.

The following section provides a brief overview of the process undertaken in locating the literature. This is followed by a section detailing the results of the analysis of the literature in relation to effectiveness. Two questions were addressed in the review: ‘How has effectiveness been judged?’ and ‘Are caregiver interventions effective?’

Locating the Literature

There is a large amount of literature relating to interventions for caregivers of people with dementia. To ensure that this scoping of the literature presented the highest quality evidence, it focussed on systematic reviews and meta-analyses published in peer reviewed journals. Such reviews have been described as important ‘for guiding … practitioners in making evidence-based decisions’.[2, 3] Systematic reviews identify, appraise and synthesize research evidence from individual studies using a strict protocol. They embody a rigorous approach which ensures that all possible and relevant research databases are scrutinised in a search for the literature and they provide a transparent methodology which outlines the reasons for including and excluding individual studies. This transparency ensures that a systematic review can be replicated if desired.

There are two types of systematic reviews. The first is the meta-analysis in which uses statistical techniques to pool the evidence from the included studies to produce an effect size (ES). An ES of 0.2 is considered small, 0.5 is considered moderate and 0.8 large. If the 95% confidence interval (95% CI) for the ES contains zero (eg. 95% CI: -0.12 to +0.25) then the effect is not statistically significant.
The second method of synthesising the evidence is a narrative review of the literature with perhaps some quantitative information. For example, the review might contain statements of the following kind: ‘three of the six studies indicated that the intervention had a positive effect’. Both types of review have been included in this review of systematic reviews.

The databases searched were Web of Science, SCOPUS, MEDLINE, PsycINFO PubMed and CINAHL PLUS using a combination of the following search terms: dementia, intervention/s, counseling/counselling, carers/caregivers. The inclusion criteria were: (i) the article had to be written in English; (ii) it related to interventions involving informal caregivers of persons with dementia; and (iii) it was a systematic review or meta-analysis. A number of reviews not captured by the electronic searches were found when the citations were being summarised, and these have also been included. In all, sixteen citations spanning a fifteen year period from 1993 to 2008 were identified as relevant. Brief descriptions of these citations are included in the annotated bibliography in the Appendix 2.

Time and resource constraints precluded a review of the grey literature. According to Charlesworth (2001) results presented in peer reviewed journals are likely to demonstrate a larger impact or effect size than the unpublished studies. The implications of this, are that conclusions based on the peer reviewed literature may overstate the effectiveness of caregiver interventions – this is sometimes referred to as publication bias.

1 The grey literature covers all literature not published through formal channels. It includes such items as technical reports from government agencies or research groups, working papers from research groups, white papers, thesis and so on. Because data presented in the grey literature may not have been subject to peer review, the validity of its data has been questioned. The following are some of the searchable databases that can be used to identify citations or projects in the grey literature.

**Google and Google Scholar:** This is a popular search engine for finding resources on the World Wide Web. Google scans web pages to find instances of the keywords you have entered in the search box. Google Scholar is a freely-accessible Web search engine that indexes the full text of scholarly across an array of publishing formats and disciplines.

**OpenSIGLE:** OpenSIGLE - System for Information on Grey Literature in Europe provides access to SIGLE bibliographical references of reports and other grey literature (GL) produced in Europe until 2005. Examples of GL include technical or research reports, doctoral dissertations, some conference papers, some official publications, and other types of grey literature. OpenSIGLE covers pure and applied science and technology, economics, other sciences and humanities.

**The New York Academy of Medicine Grey Literature:** In 1999, the New York Academy of Medicine began collecting grey literature in an effort to better meet the needs of internal research staff. This project developed into the Grey Literature Report, an online report published bi-monthly by the Academy Library, which now serves a community of over 700 subscribers. The Report is intended primarily for researchers, practitioners, students and the lay public who are interested in public health, health and science policy, health of minorities and special populations (children, women, uninsured, elderly), and related disciplines. Materials are collected in health and science policy, public health, health of minorities and special populations and those areas of general medicine and disease in which the Academy has research interests. The focus is on research material, not consumer health material. The Report encompasses unindexed materials that are not produced by commercial publishers and are unavailable through normal, commercial distribution channels. This includes materials published by government agencies, non-profit non-governmental organizations, universities, independent research centres, and international organizations.1
Effectiveness

How has effectiveness been judged?

It was consistently pointed out that one of the difficulties in undertaking the systematic reviews and providing an evidence base for caregiver interventions was the wide range of outcomes and associated measures, both across and within the studies. Even when researchers examined the same outcomes they frequently used different instruments.[5, 6] The variety of instruments used to measure the outcomes is illustrated in Table 1.

Table 1: Instruments used in studies included in systematic reviews

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Instruments used in studies included in three systematic reviews (N= number of studies reviewed in the article; where the N is not included the information was not available in the review.)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Schulz, O’Brien, Czaja, Ory, Norris et al (2002)[7]</td>
</tr>
<tr>
<td></td>
<td>Brodaty, Green, Koschera (2003)[11]</td>
</tr>
<tr>
<td></td>
<td>Pinquart and Sörensen (2006)[12]</td>
</tr>
</tbody>
</table>
| Depressive Symptoms /Psychological Morbidity | o Beck Depression Inventory  
 o Brief Symptom Inventory  
 o Center for Epidemiologic Studies Depression Scale  
 o General Health Questionnaire  
 o Geriatric Depression Scale  
 o Hamilton Depression Rating Scale  
 o Hopkins Symptom Checklist  
 o Hospital Anxiety and Depression Scale  
 o Medical Outcomes Study Short Form  
 o Profile of Mood States                                                                                                                |
|                                | o Beck Depression Inventory (N=1)  
 o Brief Symptom Inventory (N=5)  
 o Cornell Depression Scale (N=2)  
 o Cornell Scale for Depression in Dementia (N=2)  
 o Center for Epidemiological Studies Depression Scale (N=3)  
 o General Health Questionnaire (N=6)  
 o Geriatric Depression Scale (N=1)  
 o Hamilton Depression Rating Scale (N=1)  
 o Hopkins Symptom Checklist (N=2)  
 o Positive and Negative Affect Scale (N=1)  
 o Self-Rating Depression Scale (N=1)                                                                                                    |
| Caregiver Burden               | o Caregiver Appraisal Scale  
 o Caregiver Burden Scale  
 o Caregiver Distress Scale  
 o Caregiver Hassles Scale  
 o Caregiver Task Checklist  
 o Consequences of Caregiving  
 o Given Burden Scale                                                                                                                      |
|                                | o Burden Interview (N=9)  
 o Ranking Scale  
 o Caregiver Appraisal Tool (N=1)  
 o Caregiver Hassles Scale (N=2)  
 o Screen for Caregiver Burden (N=1)  
 o Rankin Scale (N=1)  
 o Objective Burden Scale (N=1)                                                                                                              |
|                                | o Zarit Burden Interview (N=32)  
 o Other scales (N=53)                                                                                                                      |
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Instruments used in studies included in three systematic reviews (N= number of studies reviewed in the article; where the N is not included the information was not available in the review.)</th>
<th>Brodaty, Green, Koschera (2003)[11]</th>
<th>Pinquart and Sörensen (2006)[12]</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Schulz, O’Brien, Czaja, Ory, Norris et al (2002)[7]</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Objective and Subjective Burden Revised Burden Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Screen for Caregiver Burden</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Zarit Burden Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective well-being</td>
<td>o Life Satisfaction Index  o Schedule of the Evaluation of Individual Quality of Life  o LEIPAD Quality of Life Assessment  o Quality of Life Scale  o Positive and Negative Affect Schedule  o Profile of Mood States</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability/knowledge</td>
<td>o Coping Response Inventory  o Revised Coping Strategies Inventory  o Ways of Coping Questionnaire</td>
<td>o Health Specific Family Coping (N=2)  o Alzheimer’s Disease Knowledge Test (N=2)  o Dementia Quiz (N=1)  o Knowledge Measure/Questionnaire (N=3)</td>
<td>o Coping abilities questionnaires (N=16)  o Caregiving-related self efficacy (N=14)  o Knowledge about dementia and available services (N=11)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>o Beck Anxiety Scale  o Brief Symptom Inventory  o Hospital Anxiety and Depression Scale  o State-Trait Anxiety Inventory  o Taylor Manifest Anxiety Scale</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Similarly, in the reviews and meta-analyses, different authors used different classifications for the outcomes. Table 2 provides a preliminary synthesis of the various outcomes reviewed.
Table 2: Outcome domains, associated factors and elements

<table>
<thead>
<tr>
<th>Field</th>
<th>Domain</th>
<th>Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td>Mental Health</td>
<td>Depression, Anxiety, Distress, General Mental Health</td>
</tr>
<tr>
<td></td>
<td>Well-Being</td>
<td>Subjective and Objective Well-Being, Quality of Life, Mood</td>
</tr>
<tr>
<td></td>
<td>Competence</td>
<td>Coping, Knowledge</td>
</tr>
<tr>
<td></td>
<td>Burden</td>
<td>Burden, Stress</td>
</tr>
<tr>
<td>Social</td>
<td>Significance</td>
<td>Service Utilization, Institutionalization</td>
</tr>
<tr>
<td></td>
<td>Validity</td>
<td>Ratings of acceptability and satisfaction</td>
</tr>
</tbody>
</table>


According to Schulz, O’Brien, Czaja, et al (2002), all the studies in their review that collected social validity data reported positive outcomes. A typical finding was that 80%-100% of participants rated the interventions as helpful, beneficial or valuable. [7] They also pointed out that, for a number of reasons, such results should be treated with caution. As well, the authors noted that although reporting social validity results may be necessary they are probably not sufficient to meet practical importance criteria. No other authors in this review included social validity outcomes as evidence of effectiveness. Some but by no means all authors included social significance outcomes in their reviews. Because all but some of the very early reviews have included one or more of the factors in the caregiver domain, the evidence in relation to effectiveness presented below has concentrated on outcomes in the caregiver domain.

A close reading of the reviews indicated that some of the authors’ conclusions presented in the abstracts tended to be more positive than the data warranted. Therefore in the summaries of the results presented below, only conclusions clearly supported by the data have been included.
Are caregiver interventions effective?

Following is an annotated bibliography of reviews that were found in the literature which addressed the question, ‘are caregiver interventions effective’? The numbers in square brackets [] refer to the reference number in the list of references at the end of this document.


This meta-analysis examined the impact of support groups, education, psycho-education counselling, respite care and multi-component interventions on caregiver burden. The only statistically significant result was for the multi-component interventions which had a small to medium effect in reducing caregiver burden. This conclusion was based on three multi-component interventions, so the results need to be treated with some caution.

The aim of the study was to evaluate, using meta-analytic techniques, the effectiveness of interventions to reduce caregiver burden. Literature up to and including 1999 (N=24 citations testing 27 treatments) was reviewed. Interventions were grouped into 6 categories:

- Support Group: Interactions and exchanges among members were used to normalise experience, give mutual support and increase connections among group members, with interaction unstructured and without specific content. They were usually led by lay persons with experience in care giving or group facilitation.
- Education: Designed to provide standardised information about the disease process, disruptive behaviours and care giving. They were usually delivered by trained professionals.
- Psycho-education: Participants received both education and support interventions.
- Counselling: Individual needs of the participants were identified and change facilitate by intensive work with care givers to increase the understanding of problematic behaviours and their reactions to the care giving experience. They were delivered via group meetings or during individual/family sessions and delivered by trained professionals.
- Respite: This involved care provided by others to give the primary caregiver a temporary break from care giving. It was provided by paid professionals or volunteers.
- Multi-component: Combinations of intervention strategies excluding psycho-education.

The results for the homogeneous studies in each group are shown in Table 3. An effect size of 0.20 was considered small, 0.5 medium and 0.8 large [9].
Table 3: Effect sizes and confidence intervals for homogeneous interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>N</th>
<th>Weighted Effect Size</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Interventions</td>
<td>21</td>
<td>-0.08</td>
<td>-0.19 - +0.02</td>
</tr>
<tr>
<td>Support Group</td>
<td>1</td>
<td>0.00</td>
<td>-0.54 - +0.54</td>
</tr>
<tr>
<td>Education</td>
<td>5</td>
<td>-0.52</td>
<td>-0.83 - -0.18</td>
</tr>
<tr>
<td>Psycho-education</td>
<td>10</td>
<td>-0.06</td>
<td>-0.21 - +0.10</td>
</tr>
<tr>
<td>Counselling</td>
<td>4</td>
<td>-0.07</td>
<td>-0.34 - +0.19</td>
</tr>
<tr>
<td>Respite Care</td>
<td>4</td>
<td>-0.02</td>
<td>-0.20 - +0.16</td>
</tr>
<tr>
<td>Multi-component</td>
<td>3</td>
<td>+0.46</td>
<td>+0.14 - +0.78</td>
</tr>
</tbody>
</table>

The meta-analysis indicates that, overall, the interventions had no effect on burden and in some cases the effect was negative indicating that the control group burden scores improved more than those in the treatment group. The authors indicated that recruitment it may be that recruitment of participants with problems that might be affected by the intervention would result in better outcomes. The authors indicated that recruitment precisions may need to be addressed as it was found that researchers in the studies rarely recruited participants who were known to need the experimental treatment or who were likely to benefit from the interventions. They also indicate that ‘burden’ may be too global and multidimensional to be affected by interventions.

**Reviewer’s Note:** The discussion explores issues for which there are no data. It is a form of hypothesising, and their hypotheses need further testing.


This review assessed the evidence relating to technology based, group based and individual based psychosocial interventions. The authors concluded that there was no evidence to support the use of technology based interventions but this conclusion was based on two methodologically weak studies so the results needed to be treated with caution. Twelve of the fourteen group based interventions and seven of the nine individual based interventions provided some evidence of effectiveness. However, methodological difficulties in the studies meant that the evidence of effectiveness was weak.

The aim of this review was to assess the quality of the evidence that could inform the development of an effective model of psychosocial interventions (PSI) for carers of people with dementia. Peer reviewed and grey literature was searched for citations published and including March 1999 (N=30). Interventions were heterogeneous but divided into four categories and results presented for each (see Table 4).

Table 4: Effectiveness of interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Number</th>
<th>Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technology Based</td>
<td>2</td>
<td>There was no evidence to support the use of PSI utilising computer based technology. It was not clear if the lack of effectiveness was due to the nature of the objectives of the intervention or the method of delivery. Methodological weaknesses mean that there is no strong evidence of ineffectiveness.</td>
</tr>
<tr>
<td>Group Based</td>
<td>14</td>
<td>Twelve provide some evidence of effectiveness but the methodological difficulties meant the evidence is weak.</td>
</tr>
<tr>
<td>Intervention</td>
<td>Number</td>
<td>Effectiveness</td>
</tr>
<tr>
<td>---------------</td>
<td>--------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Because of the weaknesses inherent in the studies that reported no effect, neither is there strong evidence of ineffectiveness.</td>
</tr>
<tr>
<td>Individual Based</td>
<td>9</td>
<td>Although 7 studies provided evidence of effectiveness, the methodological difficulties mean that there is no strong evidence that suggests efficacy of individual interventions.</td>
</tr>
</tbody>
</table>

The authors conclude that overall there is a paucity of strong evidence to support a definitive approach to interventions for informal carers of people with dementia living in the community. A possible explanation for this, is the methodological weakness in almost all of the studies including: (i) the variety of outcome measures used; (ii) the possibility of floor and ceiling effects, such that participants at either end of the scale have very little room for improvement. Heterogeneity among participants and interventions is also a problem. None of the interventions followed the model utilized with other severe and enduring mental illnesses; however, those that offered the ‘best’ evidence of efficacy were closest to the model and featured problem solving and a behavioural component [10].

Reviewer’s Note: This conclusions in the review seem to be supported by the evidence except for the conclusions with relation to the model.


The aim of this review was to determine how successful the different components of psychosocial and psycho-educational interventions were. Approximately two-thirds of the interventions did not produce the desired outcome although participants rarely exhibited deterioration in the measured outcomes. Increasing caregivers’ knowledge of dementia did not consistently lead to corresponding improvements in psychological well-being or burden.

Forty citations were included in the review from the 1980s up to and including the year 2000. Overall, the results of the authors’ analyses are:

- **Overall Effectiveness:** Approximately two-thirds of the interventions targeted at dementia caregivers do not produce the desired outcome. Although participants have rarely exhibited any deterioration in the outcomes measured.
- **Timing of Improvements:** When studies incorporating follow-up assessments reported immediate success in improving outcomes, the improvements are generally maintained over time. There is some evidence however, that it may take a period of time before improvements in outcome begin to take effect
- **Knowledge of Dementia:** increasing caregivers’ knowledge of dementia does not consistently lead to corresponding improvements in psychological well-being or burden.
- **Social Components Only:** Eight studies included nine interventions which examined psychological well-being as an outcome with an intervention which employed social components in the absence cognitive components – two-thirds of the intervention reported improvements in well-being.
• **Cognitive Components Only**: three studies used cognitive components in the absence of any social components, none of which reported improvements in psychological well-being and one of which reported improvement in levels of caregiver burden.

• **Social + Cognitive Components**: Sixteen interventions were evaluated within 14 studies that examined psychological well-being as an outcome and used a combination of both cognitive and social components. Eight of these (50%) showed improvements in measures of psychological well-being.

The authors conclude that there is little evidence that interventions consistently produce positive benefits for dementia caregivers in terms of improved psychological well-being, burden, or social outcomes. They indicate that the findings suggest that the inclusion of social components interventions or a combination of social and cognitive components appears to be ‘relatively’ effective in improving psychological well-being. However, there are major methodological shortcomings that mean these results need to be treated with caution [6].

**Reviewer’s Note**: It was difficult to replicate the findings regarding the social components, and the major studies in relation to this appears to be those that did not include a control group. The conclusions regarding overall effectiveness and knowledge appear sound, but the those relating to social and cognitive components need to be treated with caution.


This review looked at the practical importance or clinical significance of interventions in terms of symptomology (eg. symptoms of depression, anxiety, anger and hostility) and quality of life (eg. well-being, burden, mood, perceived stress). The authors concluded that interventions ‘showed promise’ of achieving clinically significant improvements in depressive symptoms and to a ‘lesser degree’ in reducing anxiety, anger and hostility. The ability to improve overall quality of life appeared to be limited but there was no evidence that burden, mood and perceived stress were responsive to interventions. Because nearly all interventions were multi-faceted the observed outcomes could not be attributed to any one component.

To examine the practical importance of reported intervention effects, the review included citations published in the period 1996-2001 inclusive which related to 43 individual studies. To be assessed as having practical importance (clinical significance) a study had to: (i) include clinically relevant and statistically significant outcomes; and (ii) have a treatment effect large enough to be practically meaningful. The authors note that assessing the practical importance is a subjective judgement that will vary by discipline and occupation. The results of the authors’ assessments are shown in Table 5.
Table 5: Assessment of the practical importance of outcomes for caregivers

<table>
<thead>
<tr>
<th>Outcome Domain</th>
<th>Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptomatology</td>
<td>Studies showed promise for achieving clinically significant outcomes in improving depressive symptoms and reducing anxiety, and possibly anger and hostility. Participants are generally not selected for levels of symptomatology that would characterize them as meeting criteria for clinical diagnosis. Therefore the magnitude of positive change may be inherently limited. Targeting individual high in depressive symptoms, for example, may be a way of achieving clinically significant outcomes in this domain. Interventions used to achieve effects in this domain included a variety of educational and psychotherapeutic interventions such as problem solving, coping skills training, behaviour management training, support groups, cognitive-behavioural therapy and other types of counselling. Because nearly all interventions were multi-faceted, the observed outcomes cannot be attributed to any one component.</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Although the ability to improve the general quality of life of caregivers appears to be limited, there is evidence that specific components such as burden, mood and perceived stress are responsive to caregiver interventions. Small to moderate positive effects have been reported with a range of interventions including psycho-educational interventions, behaviour management training, stress management, support programs and relaxation training. Positive effects were also reported in studies where care recipients were given donepezil, tacrine or metrifonate, caregivers reported enhanced quality of life. Effective service interventions included respite care, adult day care, geriatric evaluation and case management, and environmentally focused occupational therapy. With the exception of the medication trials, virtually all interventions were multidimensional including combinations of treatment that might include education and training, support and formal service. Attributing outcomes to specific components is difficult.</td>
</tr>
<tr>
<td>Social Significance</td>
<td>The most frequently studied outcome variable is residential care placement. Some impressive effects have been demonstrated in this regard. Achieving such effects typically requires very intense, multi-dimensional interventions that include heavy doses of counselling, support and education.</td>
</tr>
<tr>
<td>Social Validity</td>
<td>All the studies that collected social validity data reported positive outcomes, despite the variable content, intensity and duration of the interventions. A typical finding was that 80%-100% of participants rated the intervention as helpful, beneficial or valuable. The authors caution because: (i) conclusions can only be generalized to individuals who chose to participate in the study and remained long enough to provide the feedback; (ii) respondents may feel obligated to respond positively so as not to disappoint interventionists who have worked hard on their behalf; and (iii) have suffered through a challenging intervention, respondents may have a need to reduce dissonance. They conclude that from a public health perspective, these types of outcomes may be necessary – but are probably not sufficient - to meet clinical significance criteria.</td>
</tr>
</tbody>
</table>

The authors conclude that overall the data ‘suggest’ there is evidence of clinically significant outcomes – most studies met criteria for social validity. Interventions ‘show promise’ of achieving clinically significant outcomes in improving depressive symptoms.
symptoms, and, to a lesser degree in reducing anxiety, anger and hostility. The ability to improve overall quality of life for caregivers appears to be limited but there is evidence that specific components such as burden, mood and perceived stress are responsive to interventions. Also some impressive and clinically meaningful effects have been demonstrated for delayed institutionalization of the care recipient. The authors note that, compared with previous reviews, their conclusions are much more positive. They also point out that interventions were typically not well described in the studies and treatment implementation data were infrequently reported. They advise researchers to set as their goal the achievement of reliable and clinically significant outcomes, preferably in multiple domains [7].

Reviewer’s Note: It appears to be the social validity domain that makes the review more positive; the effectiveness in the other domains is quite limited. The authors use the terms clinical significance and practical significance interchangeably which can be quite confusing. Note also the broad range of interventions included – respite care, medication for the care recipient.


This meta-analysis examined the effectiveness of caregiver interventions and study factors associated with effectiveness. Six of twenty-six studies showed a statistically significant positive effect on psychological morbidity and only one study had a statistically significant impact on burden. Involvement of the caregiver and the care recipient in the interventions was the only study characteristic which showed an effect on the outcome measures. This result is based on a small number of studies and needs to be treated with caution. [11] 1985-2001, 30 studies.

The aim of the study was to review published reports of interventions for caregivers of persons with dementia (excluding respite care) and provide recommendations to clinicians. Thirty studies written in English covering the period 1985 -2001 were included. The main outcome measures were psychological morbidity, burden, and ‘any main outcome’ which included a variety of other outcome such as caregiver coping skills and social support. Effect sizes (ES) were calculated and post hoc analyses were used to test for possible predictors of a positive ES. Caregivers were predominantly spouses of the person with dementia, female and aged 55 and older.

The results were as follows:

- Effectiveness
  Five of twenty-six studies showed a statistically significant positive effect on psychological morbidity. Only one intervention showed a statistically significant on burden.

Statistically significant weighted Effect Sizes:
(i) psychological morbidity across 26 interventions was 0.31 (95% CI, 0.13 – 0.50)
(ii) changes in patient mood across 5 studies was 0.68 (95% CI, 0.30-1.06)
(iii) knowledge across 8 studies was 0.51 (95% CI, 0.05-0.98) and
(iv) ‘any main outcome measure’ across 30 studies was 0.32 (95% CI, 0.15-0.48). The ES for caregiver burden across 20 studies was not statistically significant.

(iii) Predictors of Effectiveness

‘Involvement of CG and patient in the intervention’ was the only study characteristic which showed an effect on the outcome measures (‘any outcome measure’, psychological morbidity, study success). However, these results were based on a small number of trials and should be interpreted with caution.

The caregiver interventions have a modest but significant benefit on knowledge, psychological morbidity and other main outcome measures. The authors conclude that short educational programs enhance of knowledge but are otherwise not successful. Support groups alone, single interviews and brief interventions or courses that were not supplemented with long-term contact were also unsuccessful. The implications is that caregivers interventions have the potential to benefits caregivers and patients but more high quality research is needed [11].

Reviewer’s Note: It is difficult to see where some of the conclusions and recommendations come from as the data and analysis to support them were not presented. There appear to be six, not five studies with a statistically significant impact on morbidity. The weighted effect sizes seem to mean very little in this context.


The aim of the review was to determine the effectiveness of interventions in enhancing the well-being of caregivers of elderly persons with dementia living in the community. The review included 11 high quality studies covering the period 1992 to April 2002 inclusive. Studies were categorised according to type of intervention: education (4), case management (4), psychotherapy (2) and computer networking (1) - see Table 6.

Table 6: Studies categorised by intervention type

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Assessment of Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>With one exception, results indicate that education interventions are insufficient to improve overall caregiver psychological well-being, such as decreasing strain and depression.</td>
</tr>
<tr>
<td>Case Management</td>
<td>Case management, on the whole, did not impact on levels of strain or depression for caregivers despite support from the case manager and access to community services.</td>
</tr>
<tr>
<td>Psychotherapy</td>
<td>The main outcome here was institutionalisation of the care recipient. There are no data related to caregiver well-being.</td>
</tr>
<tr>
<td>Computer Networking</td>
<td>The intervention group experienced a significant increase in decision-making confidence but there were no significant differences between the groups in relation to decision-making skills, social isolation, or use of health services.</td>
</tr>
</tbody>
</table>
The authors concluded that their review of high quality studies of caregiver interventions revealed few significant positive effects for the participants receiving the intervention.

This review examined the effectiveness of education, case management, psychotherapy and computer networking interventions. Only one of the four education studies had a positive impact on psychological well-being. The four case management interventions did not provide evidence of any impact on caregiver strain or depression. There were no caregiver outcomes for the two psychotherapy interventions. There was only one computer networking intervention and the only positive impact was on decision making confidence. The authors concluded that their review of high quality studies revealed few significant positive effects for participants receiving the intervention.

Review’s Note: Outcomes generally did not include components of well-being. The focus on high quality studies meant very few were included.


The aim of this meta-analysis was to determine the effectiveness of different types of caregiver interventions and which factors influence effectiveness. Psycho-education which involved the provision of information only has a positive effect on ability/knowledge but not on any of the other outcome variables. However, Psycho-education involving the active participation of caregivers had a statistically significant immediate positive effect on caregiver burden, depression, subjective well-being as well as ability/knowledge. CBT had a small positive effect on caregiver burden and a large effect on depression. Counselling had a moderate effect on caregiver burden. However, the results for CBT and counselling need to be treated with caution because of the small number of studies included in the analysis.

One hundred and twenty-seven studies published up to and including 2005 were included. The average of the caregivers in the studies was 63 years, 66% were women and 80% co-resided with the care recipient. Sixty percent were spouses and 39% were adult children, and only 17% reported their ethnicity as non-white. Caregivers had been providing care for an average of 3.6 years and they provided 83 hours/week of care. Both immediate (pre-post) and longer-term (approx 11 months post intervention) were studies. The results were as follows:

- Immediate Overall Effectiveness: There were statistically significant immediate effects for depression, subjective well-being and ability/knowledge and burden. However the size of the effect was very small for burden and small for the other outcomes.
- Longer-term Overall Effectiveness: In the longer-term, there were statistically significant positive effect for ability/knowledge was small and the positive effects for burden and depression were very small.
- Type of Intervention: When the impact of the different types of intervention were examined, psycho-education which involved the provision of information only has a positive effect on ability/knowledge but not on any of the other outcome
variables. However, Psycho-education involving the active participation of caregivers had a statistically significant immediate positive effect on caregiver burden, depression, subjective well-being as well as ability/knowledge. CBT had a small positive effect on caregiver burden and a large effect on depression. Counselling had significant and moderately sized effect on caregiver burden and counselling had significant and moderately sized effect on burden. However, the results for CBT and counselling need to be treated with caution because of the small number of studies included in the analysis.

- Study Characteristics: Studies with a higher percentage of women showed more improvements in depression and ability/knowledge but less improvement in subjective well-being. Non-randomized studies with small sample sizes and higher dropout rates had larger effect sizes. Longer interventions had a resulted in statistically significant improvements in short term depression but not on the other outcome measures.

The authors concluded that interventions with caregivers have small but meaningful effects on reducing burden and depressive symptoms, increasing ability/knowledge and subjective well-being. There is a need for more high quality research not only to test the impact of some of the interventions such but also to provide evidence relating to the longer-term impacts of the interventions. Differences between this meta-analysis and earlier ones with regard to the impact on some outcomes may be due to the inclusion of more recent, high quality studies [12].

**Reviewer’s Note**: There were a small number of studies included in some of the analysis so the results needed to be treated with caution. There were also considerable differences in the outcomes being measured. However, there is nothing in the analysis that repudiates the authors’ conclusions. Nicely presented tables showing effect sizes.


This review examined the effectiveness of randomised controlled trials involving the provision of support and/or information. Interventions were classified as technology based (N=4), individual (N=27) or group based (N=13). The results indicated that the group based interventions had a statistically significant, positive impact on psychological morbidity, but the clinical significance of the findings should be interpreted cautiously. No evidence was found for the effectiveness of any other form of intervention on a range of physical and psychological health outcomes.

The aim of this review was to assess the effectiveness of intervention based around the provision of information and support for caregivers of people with dementia living in community setting. It included a systematic review and meta-analysis of randomised controlled trials (RCT) of technology-based (N=4), individual (N=27) and group (N=13) interventions. The authors concluded that there is no evidence that
information and support-based interventions for caregivers are uniformly effective. There is limited evidence to support the argument that information and support in the context of group psycho-educational approached have a statistically significant positive effect on depression. There was no evidence that the technology based interventions were effective. However, there were considerable differences between the trials in terms the nature of the interventions and the outcomes being assessed. Because of the small number of trials used in the meta-analyses, the results need to be treated with caution. The authors also note the difficulty of classifying interventions which often contain elements of group and individual interventions [5].

Reviewer’s Note: No details were given about the participants in the RCT. The results of the analyses support the authors’ cautious conclusions.


This review examined the impact of dyadic interventions on caregivers’ mental health, burden and competence. The authors concluded that caregiver general mental health is positively affected by dyadic interventions, but the findings for other mental health outcomes and for burden are inconclusive. The authors point out a number of methodological difficulties encountered in doing the review, including the limited number and varying quality of the studies, as well as the heterogeneity of the studies with regard to measurement instruments and follow-up periods.

Literature included 25 citations of 22 programs for the period 1992-2005. Results for the citations were reported as: (i) significant effects, (ii) heterogeneous results indicating improvements in some indicators but not all, (iii) no effect. The results of the analysis are shown in Table 7.

Table 7: Outcome measures and effectiveness conclusions

<table>
<thead>
<tr>
<th>Outcome (Number of Citations)</th>
<th>Outcome Measures and Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health (N=14)</td>
<td>Depressive Symptoms: 2 citations reported significant +cve effects, 3 heterogeneous effects, 1 no significant effect, 1 an increase in symptoms</td>
</tr>
<tr>
<td></td>
<td>General Mental Health/Psychological/Psychosomatic Complaints: 3 citations reported significant improvement or trend, 1 no effect</td>
</tr>
<tr>
<td></td>
<td>Overall Well-Being: 1 citation reported significant positive effect or trend, 2 no effect</td>
</tr>
<tr>
<td></td>
<td>Other Measures: 4 citations reported significant positive effects, 1 heterogeneous results and 7 no effect</td>
</tr>
<tr>
<td>Caregiver Burden (N=13)</td>
<td>Subjective Burden: 1 citation reported positive effects, 2 heterogeneous effect, 3 no effect, 1 and increase in burden</td>
</tr>
<tr>
<td></td>
<td>Other measures: The number of studies was too small to draw any conclusions.</td>
</tr>
<tr>
<td>Competence (N=7)</td>
<td>2 citations reported positive effects, 4 heterogeneous effects and 1 no effect</td>
</tr>
</tbody>
</table>
The authors concluded that caregiver general mental health is positively affected by combined programmes but the findings for other mental health outcomes and for burden are inconclusive. The authors point to a number of methodological difficulties with the studies, including the limited number and varying quality of the studies, the limited number of studies using identical instruments and follow-up measurement points and the use of multiple measurement instruments. They point out that the modest effects on caregivers’ burden and depression of interventions aimed at caregivers has been noted before and must be seen in the context of a progressive degenerative condition. They point out that the results of their review do not suggest that intensive and long programmes are more effective than brief programmes [13].

**Reviewers’ Note**: A high quality review, although the conclusion with regard to general mental health appears to be optimistic given the small number of studies. Also there is little data given to support their conclusions on brief versus long/intense interventions.


This review compared the effectiveness of different types of interventions and the quality of the evidence on which the conclusions were based. The authors concluded that there was ‘excellent’ evidence for the effectiveness of individual behaviour management therapies lasting six or more sessions in reducing caregiver depression in both the short and longer term. There was also ‘good’ evidence for the effectiveness of individual and group coping strategy interventions in alleviating depression and distress in the short and longer term. However, caution needs to be exercised because some studies included the use of medication.

Sixty-two citations up to and including July 2003 were included. The caregiver interventions were grouped according to their major component into the following categories.

- **Education interventions** provided information about dementia only without any other form of intervention.
- **Coping Strategies**: These interventions involved teaching coping strategies, stress management, problem appraisal and problem solving and often included education about dementia.
- **Behavioural Managements Techniques (BMT)**: In these interventions caregivers were taught about behavioural management theory and how to manage problem behaviours in the care recipient, often combined with caregiver coping strategies.
- **Supportive Therapy**: These was considerable heterogeneity in these interventions, with support being offered for varying lengths of time and being delivered in a variety of ways by either health professionals or peer groups [14].

The results of the analysis are shown in Table 8.
Table 8: Interventions and effectiveness conclusions and confidence that can be placed in the conclusions (A=Highest, D=Lowest)

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Outcomes and Effectiveness Conclusions</th>
<th>Level of Confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education Only</td>
<td>Depression, Burden, Distress: No evidence of benefit. The results suggest that education by itself is NOT effective either immediately or some months later.</td>
<td>B</td>
</tr>
<tr>
<td>Coping: Group</td>
<td>Depression: Small number of high quality studies indicate this form of intervention was effective in reducing depressions immediately and up to 3 months later. Burden: Evidence was inconsistent for caregiver burden</td>
<td>B</td>
</tr>
<tr>
<td>Coping: Individual</td>
<td>Depression, Distress: Small number of high quality studies indicating this form of intervention was effective in reducing distress and depression and the benefit appeared to last up to 3 months post intervention. Burden: There were not enough studies to draw a definitive conclusion.</td>
<td>D</td>
</tr>
<tr>
<td>BMT: Group</td>
<td>Depression, Burden, Distress: High quality studies indicate this intervention was NOT effective either immediately or for up to eight months.</td>
<td>B</td>
</tr>
<tr>
<td>BMT: Individual &lt;6 Sessions</td>
<td>Depression, Burden, Anxiety, Stress: The evidence was inconclusive.</td>
<td>D</td>
</tr>
<tr>
<td>BMT: Individual ≥ 6 sessions</td>
<td>Depression: Very high quality studies indicating this intervention was effective immediately and for up to 32 months Burden: This type of intervention was NOT effective</td>
<td>A</td>
</tr>
<tr>
<td>Supportive Therapy</td>
<td>Depression, Burden, Anxiety: This was NOT an effective intervention showing no immediate improvements in outcomes.</td>
<td>B</td>
</tr>
</tbody>
</table>

The authors concluded that there ‘excellent’ evidence for the effectiveness of individual Behaviour Management Therapies lasting six or more sessions in reducing caregiver depression both in the short and longer term. There is also ‘good’ evidence for the effectiveness individual and group Coping Strategy interventions in alleviating depression and distress in the short and longer term. However, the findings are limited by the lack of good quality evidence and the fact that some studies included in the review involved the use of medication. The authors cannot comment on the effect of psychological approaches combined with medication. They also point out that providing individual treatment on a wide scale for caregivers has resource implications which will need to be addressed creatively.

**Reviewer’s Notes**: No obvious shortcomings with the review. The conclusions appear to be supported by the analysis. However, the medication issue may need to be explored in more detail.
The aim of this study was to research the impact of information and communications technology (ICT) interventions for carers of people with dementia. Telephone only interventions were excluded and the authors included 15 papers that described six studies of five interventions: ComputerLink, AlzOnline, Caring for Others, the CTIS Reach Study and the TLC Reach Study. All the studies were undertaken in North America, the interventions were complex and included various elements of networked support, usage varied between studies but was generally low. Outcomes were inconsistent. The results indicated that the interventions provided benefits for some but not all carers. The authors concluded that the results needed to be treated with caution and that further evaluation of the role of ICTs in supporting informal carers is needed in more robust trials with good follow-up. [16]

**Reviewer’s Note:** Very few interventions are included. The data supports the authors’ cautious conclusions.


The aim of the study to was synthesise evidence relating to interventions that reduce anxiety in caregivers. Twenty-four studies published prior to June 2004 were included (see Table 9).

**Table 9: Effectiveness of interventions to reduce caregiver anxiety and confidence that can be placed in the results (A=Highest, D=Lowest)**

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Effectiveness Conclusions</th>
<th>Level of Confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBT: Group</td>
<td>3 citations and the evidence was inconsistent</td>
<td>D</td>
</tr>
<tr>
<td>CBT: Individual/</td>
<td>Only investigated using low level studies and the results for anxiety were inconsistent or un-replicated.</td>
<td>D</td>
</tr>
<tr>
<td>Psychotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMT</td>
<td>There was no evidence to support the use of 8 to 10 BMT sessions to reduce caregiver anxiety</td>
<td>B</td>
</tr>
<tr>
<td>IT Support</td>
<td>1 citation which showed no evidence of positive effect</td>
<td>C</td>
</tr>
<tr>
<td>Professional Support</td>
<td>2 citations which showed no evidence of effectiveness</td>
<td>D</td>
</tr>
</tbody>
</table>

The authors concluded that there was little evidence of efficacy for any intervention to reduce anxiety in caregivers of people with dementia. The only psychological therapy to demonstrate efficacy for reducing anxiety was also the only one designed to target anxiety, suggesting that specific strategies may be required. The authors also point out the lack of conclusive evidence of efficacy does not necessarily mean inefficacy. For example, co-morbidity with depression may have affected the outcomes [16].

**Reviewer’s Note:** There are only a small number of studies included under each intervention type, anxiety does not appear to be an outcome measure for many of the studies.

**Author’s Conclusions:** Support groups, while rated helpful by caregivers, have not adequately addressed the affective needs of caregivers. Psycho-educational groups focusing on helping caregivers to identify a problem, brainstorm solutions, implement and monitor the solutions with the group, appear to be the most efficacious treatment for depressive disorders of persons caring for relative with AD. While research on individual therapy is limited, based on the initial success of cognitive therapy, continued research on cognitive therapies should be encouraged [18].

**Reviewer’s Note:** This is a low quality review with no information about the locating the literature or judging the quality of the articles. Conclusions must be treated with caution.


**Reviewer’s Note:** This review is predominantly about respite, adult day services and case management. There is very little reference to psychological interventions or educations. Perhaps the most useful comment relates to multi-component programs. ‘it is difficult to determine which specific components of these service programs might be helpful.’ [19]


Authors’ conclusions are shown in Table 10 [20].

**Table 10: Assessment of caregiver interventions**

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Appropriate For:</th>
<th>Impact</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>All caregivers</td>
<td>No known systematic studies</td>
<td>Should include access to local services</td>
</tr>
<tr>
<td>Support Groups</td>
<td>Caregivers displaying minimal distress</td>
<td>Equivocal effect on burden and depression</td>
<td>Not appropriate as sole intervention for very distressed caregivers</td>
</tr>
<tr>
<td>Respite Care</td>
<td>All caregivers</td>
<td>Equivocal effect on burden and depression</td>
<td>Caregivers require education about respite before using it effectively</td>
</tr>
<tr>
<td>Family Therapy</td>
<td>Families with unresolved issues affecting patient care</td>
<td>No known systematic studies</td>
<td>Can be reframed as education to engage more resistant families</td>
</tr>
<tr>
<td>Individual Treatment</td>
<td>Caregivers with overt distress, psychopathology</td>
<td>Strongest effect on caregiver outcome</td>
<td>Little consensus as to essential components of treatment</td>
</tr>
</tbody>
</table>
**Reviewer’s Note**: this is a low quality review with no information about locating the literature or judging the quality of the articles. Conclusions must be treated with caution.


This meta-analysis examined the impact of group and individual psychosocial interventions on caregiver ‘distress’. The only statistically significant positive effects in the caregiver domain was for individual psychosocial interventions which had a small impact on ‘dysphoric’ emotions. This conclusion was based on three studies, so the results need to be treated with some caution.

The review applied meta-analytic techniques to studies published in peer reviewed journal for the period 1980 to 1990 inclusive. Eighteen studies (20 citations) met the inclusion criteria and of these data were available for 15. The results of the meta-analysis are shown in Table 11. The only statistically significant results were for individual interventions on dysphoria (negative affect) and respite and other services. (The author’s state that a correct 95% CI of zero implies that all observed variation in effect sizes is due to sampling error.)

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Outcome Measure</th>
<th>Studies</th>
<th>Average Effect Size</th>
<th>Corrected 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group Psychosocial</td>
<td>Burden</td>
<td>5</td>
<td>0.15</td>
<td>±0.00</td>
</tr>
<tr>
<td></td>
<td>Dysphoria</td>
<td>7</td>
<td>0.31</td>
<td>±0.00</td>
</tr>
<tr>
<td>Individual Psychosocial</td>
<td>Burden</td>
<td>5</td>
<td>0.41</td>
<td>±0.00</td>
</tr>
<tr>
<td></td>
<td>Dysphoria</td>
<td>3</td>
<td>0.58</td>
<td>±0.36</td>
</tr>
<tr>
<td>Respite and Other Services</td>
<td>Burden</td>
<td>8</td>
<td>0.15</td>
<td>±0.54</td>
</tr>
<tr>
<td></td>
<td>Dysphoria</td>
<td>4</td>
<td>0.63</td>
<td>±0.00</td>
</tr>
</tbody>
</table>

The authors conclude that the results demonstrate a moderately strong effect for individual psychosocial interventions and the respite services that deliver more services to the intervention than the control group, compared with treatment as usual or uncontrolled use of community services [8].

**Reviewer’s Note.** The individual psychosocial interventions have heterogeneous effects, reducing dysphoria but not affecting burden. There were no sub-group analyses by outcome measure for the respite services.
**Discussion**

The evidence presented in the previous section was drawn from literature published in peer reviewed journals over the last fifteen years. Although the studies included in the reviews have improved in methodological terms over the years, the authors of the reviews are still pointing out the need for caution in interpreting the results, as well as the need for more high quality studies. It also needs to be remembered that the effectiveness of the interventions reported in this literature may be overstated due to publication bias. An overview of the strongest evidence in relation to effective interventions is shown in Table 12.

**Table 12: Overview of effective interventions**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Year</th>
<th>Intervention and Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health</td>
<td>1993</td>
<td>Psychosocial interventions had a small impact on dysphoric emotions</td>
</tr>
<tr>
<td></td>
<td>2002</td>
<td>Multi-component interventions decreased depressive symptoms</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>Individual behaviour management therapies lasting six or more sessions reduced caregiver depression</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>Individual and Group Coping Strategy interventions reduced depression and distress</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>Group based interventions had a positive impact psychological morbidity</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>Dyadic interventions had a positive impact on general mental health</td>
</tr>
<tr>
<td></td>
<td>2007</td>
<td>Group based interventions had positive effect on psychological morbidity</td>
</tr>
<tr>
<td>Burden</td>
<td>2001</td>
<td>Multi-component interventions had small to medium effect on burden</td>
</tr>
<tr>
<td></td>
<td>2006</td>
<td>Counselling had moderate sized effect on burden</td>
</tr>
<tr>
<td>Competence</td>
<td>2006</td>
<td>Psycho-education improved ability and knowledge</td>
</tr>
<tr>
<td>Multiple Domains</td>
<td>2006</td>
<td>Psycho-education involving the active participation of caregivers had positive effect on burden, depression, subjective well-being, ability and knowledge</td>
</tr>
<tr>
<td></td>
<td>2006</td>
<td>Cognitive Behaviour Therapy (CBT) had small effect on burden and a large effect on depression</td>
</tr>
<tr>
<td>General</td>
<td>2001</td>
<td>Involving the care recipient improved outcomes</td>
</tr>
</tbody>
</table>
3. Developing a program logic model for the counselling service

Program logic is a program’s theory of action. It is a model describing the causal linkages among the various components of a program. The components can include:

- resources
- activities
- outputs
- short-term impacts
- long-term outcomes.

There are many models of program logic and some are more complex than others (see some examples in Appendix 1). The complexity of the model will often depend on the reasons for developing the model – program design, program planning and/or program evaluation.

Program logic models can be developed in a number of ways including literature reviews, analyses of strengths, weaknesses, opportunities and threats (SWOT) and stakeholder analyses using a number of techniques. One of these techniques is the program logic workshop. This is useful for producing a preliminary program logic based on the information provided by workshop participants.

We used a program logic workshop model to develop the following diagram (Figure 1) in consultation with AAV staff. Staff found the workshop very challenging, and the following model was developed after two iterations in consultation with AAV. All components of the overall model may not be applicable to all work situations within the counselling service, as it was emphasised that staff working at different locations within the organisation have their own models of service provision.

The model can be considered a working document, which can be reviewed and revised as the service changes. The strength of the model is that is identified a number of outcome indicators which may be able to be used in future development of quality assurance processes.
FIGURE 1: ALZHEIMERS AUSTRALIA VIC COUNSELLING SERVICE – PROGRAM LOGIC MODEL - 2009

Main components

Entry/referral/intake function
- To provide screening assessment via intake
- To provide timely response to client referral
- To identify need for dementia specific information

Initial assessment and intervention plan
- To build rapport and trust with client and establish good foundations for therapeutic relationship
- To listen to client’s story and validate his/her experience
- To develop a counselling plan

Counselling and intervention

Face to face/telephone
- To provide clients with therapeutic approaches appropriate to their needs
- To apply micro counselling skills

Small group work
- To provide opportunity for group to discuss, offer feedback & support to each other
- To provide opportunity to share experiences for peer support and peer learning

Family counselling
- To provide opportunity to discuss & work through changes taking place in their lives
- To inform family of AAV services
- To increase the knowledge of extended family about dementia

Process objectives

Short term outcome objectives
- To increase clients’ awareness of service
- To increase community and service provider awareness of service
- To provide appropriate initial identification of need
- To increase clients’ satisfaction with services
- To increase clients’ understanding of their rights/responsibilities
- To increase clients’ motivation to enter into counselling relationship
- To increase clients’ confidence that AAV can help
- To establish agreement with client on objectives

Long term outcome objectives
- Improved communication between carer and the person living with dementia
- Increased sense of control, reduced feeling of helplessness
- Reduced social isolation
- Reduced depression
- Increased awareness and willingness to access support
- Improved quality of life for clients
- Improved psychological functioning and reduced psychological distress
- Improved confidence from empowerment

Evaluation of client/ counselling programs
- To review client progress/achievements against initial assessment and intervention plan
- Optimized client progress towards change
- Increased positive attitudes among clients
- Increased hope
- Increased confidence that AAV can assist

- Increased communication between carer and the person living with dementia
- Increased sense of control, reduced feeling of helplessness
- Reduced social isolation
- Reduced depression
- Increased awareness and willingness to access support
- Improved quality of life for clients
- Improved psychological functioning and reduced psychological distress
- Improved confidence from empowerment
4. Design of an evaluation with emphasis on the efficacy of the counselling service

A primary concern to all health providers is being able to demonstrate that the service that is offered to clients is of the best quality. As a counsellor, how can you tell that you are delivering a good quality counselling service? Fortunately there are processes and quality assurance procedures documented in the literature so we do not have to re-invent the wheel. A number of professional bodies have practice standards in place that are relevant to the AAV counselling service. There are also a number of standardised tools already published that can be of assistance in measuring efficacy of the service. And any framework can draw on a number of facets so that quality assurance can include a triangulation of evidence about the effectiveness of the service.

Models for self-regulation of psychotherapy and counselling

Schofield [17] summarised the state of regulation of psychotherapy and counselling in Australia. Some of the issues that she identified are very relevant to AAV counselling service, where staff of the service communicated that it is difficult to define competencies and scopes of practice because of the diversity of presenting issues and clients. Schofield also indicated that because counselling is a ‘talking therapy’, it is difficult to define certain procedures that can be used in a quality assurance framework. Also there is not a single professional background at AAV counselling which would make it easier to adopt practice standards from a single professional organisation.

Given these issues a multifaceted approach to quality assurance is recommended.

Schofield recommended that given a wide variation in training standards, it is important to specify what types of practice are best undertaken by counsellors with different levels and forms of training.

**Recommendation 1** - AAV Counselling service consider becoming affiliated with the Psychotherapy and Counselling Federation of Australia. This is a peak body for psychotherapy and counselling professional associations and provides a unifying self-regulation role for the field. Affiliation would allow access to consensus standards or practice adopted by 40+ associations currently belonging to PACFA and act as an umbrella to professional associations governing the practice of the wide professional backgrounds of AAV counselling staff.

**Recommendation 2** – AAV Counselling service develop a set of minimum practice standards specific to processes outlined in the program logic model which all staff use to underpin their work.
**Recommendation 3** – where AAV counselling staff are covered by their own health professional regulatory standards, the quality assurance framework being developed at AAV should include recognition of ongoing professional development and maintenance of professional registration requirements.

**Recommendation 4** – AAV Counselling service develop policies for:

- Minimum standards of training for staff
- Minimum ongoing professional development requirements
- Entry requirements
- Code of ethics
- Standards of practice
- Complaints and discipline procedures
- Information for clients about:
  - therapist training, qualifications
  - What to expect from therapy
  - What to do if they have concerns about the service

**An example of delivery standards for counselling programs**

The National Carer Counselling Program (NCCP) which is managed by Carers Australia may be a valuable example of development of quality assurance programs for AAV counselling services. NCCP is managed nationally by Carers Australia and delivered through the Commonwealth Carer Resource Centres located in each State and Territory. The NCCP provides counselling and emotional and psychological support services for carers in order to reduce carer stress, improve carers’ coping skills and facilitate the continuation of their caring role. A set of National Service Delivery Standards and Guidelines was developed for this service which contained criteria for delivering a high quality counselling service for carers (see Table 12)

The recent evaluation of the National Dementia Support Program by the LAMA consortium recommended that adoption of the ISO 2001 Quality Management Framework will provide a further degree of organisational quality assessment of NDSP programs which include counselling services. A draft workbook of performance indicators is also being developed to facilitate quality assurance for the Carers Australia counselling programs, which may be of benefit to Alzheimer’s Australia Victoria.

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2 In October 2009 a project was funded by DoHA for Carers Australia to review these standards and guidelines.
3 Final report submitted to Australian Government Department of Health and Ageing 2009
4 Personal communication, Carers Australia.
Table 13: Quality criteria for the National Carer Counselling Program

- Sensitive to individual carer’s needs:
  - safe and non-judgemental environment
  - non-discriminatory and tailored to suit carer’s circumstances.
- Confidential:
  - consistent with requirements of the Privacy Act 1988.
- Accessible to all Carers:
  - accessible to all carers and particularly ‘special needs’ groups, such as those from CALD backgrounds, rural and remote, and indigenous carers.
- Professional:
  - delivered by suitably qualified and supported professionals within a quality framework.
- Innovative:
  - open to innovative methods of delivery
  - aiming to achieve best practice wherever possible.
- Responsive:
  - dealing with calls and referrals in a timely way
  - open to carer feedback
  - dealing with any complaints sensitively and fairly.
- Effectively linked to the community:
  - having effective communication with local service providers, media and interest groups.
- Accountable:
  - meeting financial and data reporting requirements in a timely way
  - open to evaluation.
- Promote continuous improvement:
  - committed to continuous learning
  - informing ongoing policy development, evaluation and service delivery standards and practice.


Recommendation 5: AAV counselling service consider adapting the updated National Service Delivery Standards and Guidelines used in the National Carer Counselling Program for their own purposes, and liaise with Carers Australia to facilitate sharing quality assurance strategies across the two organisations.

Outcome indicators to evaluate the efficacy of the service

One advantage of adopting a program logic model for the counselling service is the identification of a number of outcome indicators which can be operationalised to assist in evaluating the efficacy of the service. Based on the above program logic model which was developed in consultation with AAV staff, a number of psychometric and other measures could be used to evaluate the efficacy of the service.
Table 14 provides a preliminary sample of measures relevant to outcomes shown in the program logic model. These specific measurement scales were chosen from the literature on the measurement of each construct on the basis of their well-established reliability and validity, brevity, and applicability to use with the carers who use the AAV services.

Table 14: Examples of standardised scales relevant to outcome measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support</td>
<td>Duke Social Support Index</td>
</tr>
<tr>
<td>Depression, hope for the future</td>
<td>Beck Depression Inventory</td>
</tr>
<tr>
<td></td>
<td>Even Briefer Assessment Scale for Depression</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Short Anxiety Screening Test</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>QOL-AD</td>
</tr>
<tr>
<td>Stress, carer wellbeing</td>
<td>Abcdes carer wellbeing scale (Molloy)</td>
</tr>
<tr>
<td></td>
<td>General Health Questionnaire</td>
</tr>
</tbody>
</table>

Recommendation 6: A short suite of standardised scales such as those shown above could be complemented with a questionnaire designed specifically for AAV clients to complete at commencement and during their contacts with the service. The questionnaire could then form part of documentation about the changes in the client associated with visiting the service. The client satisfaction questionnaire should be developed with expert guidance about questionnaire design to ensure that the result is acceptable and easily completed by a range of clients.
Appendix 1: PROGRAM LOGIC WORKBOOK FOR workshop on Clarifying Objectives for the Alzheimer's Australia Victoria Counselling Service

Information for the development of a simple program logic model

Inputs into the counselling service

What physical supports do you need to provide the counselling service? Eg clean space, lighting, noise levels

What organisational supports do you need? Eg ethics guidelines, mission statement, supervisor pre-meeting, types of admin support, community development supports

What supports does your professional background supply to help you provide the counselling service? Eg handbook, guidelines, professional development seminars

What personal supports do you need to provide the counselling service? Eg dress code, case note preparation, meditation, groundedness, debrief
**Clients of the AAV counselling service**

Who mostly uses the counselling service?

Think of a client who was helped a lot by your counselling – describe them, and how they were helped? How did you know they were helped greatly?

Think of a client who you felt you were unable to help – describe them, and what happened? How did you know counselling was not helping?

**Understanding the AAV counselling service (Use the examples provided in the Appendix to help you to answer these questions.)**

What are the major components and associated activities of the AAV counselling service?

Component 1 eg face to face counselling, telephone counselling, CBT

Activities

Component 2

Activities

Component 3

33
Activities
Component 4
Activities

**Client outcomes**

What happens after counselling? Eg review ethics, write up case notes, supervisor read notes, debriefing meeting, group meeting

What do you see as desirable short-term and long-term outcomes for the users of the counselling service?

Short-term .................................................................

Long-term .................................................................

What is the ultimate aim and objective of the AAV counselling service?

**Measuring outcomes**

How do you know when you’ve done a good job?
How do you know whether or not long-term outcomes have been achieved?

How do you determine whether or not the counselling service has achieved its aim?

**Quality assurance**

What are the indicators of a good quality AAV counselling service?

What quality assurance would you like to see in place for the AA counselling service?

**Examples of program logic models**

Sources: Available at [http://www.onthepoint.ca/kec/documents/ProgramLogicModel.pdf](http://www.onthepoint.ca/kec/documents/ProgramLogicModel.pdf) downloaded 2\(^{nd}\) October 2008
Addiction Assessment Services of Ottawa-Carleton -- Program Logic Model

All programs and services offered by the Addiction Assessment Services of Ottawa-Carleton are available in both official languages.

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REFERENCES


