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Guidelines for a palliative approach for aged care in the community setting —

Processes underpinning best practice recommendations

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Appendix A Process report for the systematic review

A.1 Objective

Two domains were designated to be addressed by systematic reviews to allow the development of evidence based guidelines in this project; these areas were deemed to be 'delivering a palliative approach in the community' and 'support for the family carer'. For these domains, questions to guide a systematic review were developed with reference to the needs for practice guidance identified in the national consultative process and by the reference group. These questions were then prioritised by the guideline development group (GDG). The five questions addressed are shown in Section A.2.

A.2 Questions

- Does the implementation of a postacute transitional care program lead to improved physical and/or psychological health of the client and/or the family carer?
- Does a model of care that includes 24 hour crisis care (access to after hours medical, nursing, and/or pharmaceutical support) improve physical and/or psychological health in clients and/or family carers as compared with a model of care that does not include this crisis care?
- Does a model of care that includes respite care improve physical and/or psychological health in clients and/or family carers as compared with a model of care that does not include this respite care?
- Does education for family carers in disease-specific areas (ie dementia care, heart failure, chronic obstructive pulmonary disease, cancer care, Parkinson's disease) improve family carer confidence, competence, physical, psychological and spiritual health when compared with a lack of this education?
- Does education for family carers in end-of-life care improve their experience of the death of their family member and their post bereavement health as compared with a lack of this education?

A.3 Search strategy

Databases

The literature was searched electronically using the following bibliographic databases: Medline, Cinahl, PsychInfo, Current Contents, Australian Health Databases (Australian Public Affairs Information Service — Health, Aboriginal and Torres Strait Islander Health Bibliography, Drug Database, E-Library, Health & Society Database, Meditext and Rural and Remote Health Database), Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trails, Health Technology Assessment Database (Technology Assessments), Database of Abstracts of Reviews of Effects (Other Reviews), AARP Ageline, and BMJ Clinical Evidence. The non-indexed journals available via CareSearch were searched and abstracts were checked of articles that included (anywhere in the text) the word 'old', 'older' or 'elderly'.

Inclusion and exclusion criteria

Each question addressed in the systematic review dictated whether older adults and/or their family carers were the population of interest. These question-specific criteria are documented, as definitions, in the results section under the heading for each question. However, broad population inclusion and exclusion criteria were defined and applied across all of the questions. Methodological inclusion and exclusion criteria were also defined across all questions.

Broad population inclusion and exclusion criteria

To be considered for inclusion, studies needed to have documented the investigation of older adults (meeting place of residence, age and health status criteria) and/or the investigation of their family carers. Studies not meeting these criteria were excluded.

Place of residence criterion

Older adults living in their homes, in the homes of friends or relatives, or in retirement villages were considered to meet this criterion.

Older adults living in residential aged care or receiving in-patient acute care (except prior to postacute transitional care) did not meet this criterion.

Age criterion

The study sample was required to have a mean or median age of at least 70 years to meet this criterion or, if the mean or median age was not reported, at least 80% of the sample needed to be aged over 65 years.

Health status criteria

To meet the first health status criterion, the study's participants needed to be experiencing progressive illness/disease or conditions causing physical and/or psychological symptoms likely to interfere substantially with life. Diseases and conditions causing such symptoms were considered to include cancer, organ system failure, frailty, dementia, stroke and advanced Parkinson's disease.

To meet the second health status criterion, at least 70% of the sample needed to be experiencing disease/symptom/disability as follows:

- Older adults described as frail or similar (eg having multiple comorbidities) needed to be documented as having (a) at least three comorbidities that fitted with our search terms or included unstable diabetes or arthritis *or* (b) at least three functional disabilities as classified by the Barthel Activities of Daily Living Index (Mahoney & Barthel 1965), or equivalent. If this was not clear, at least 50% of the sample needed to have died within three years, 25% within 18 months, or 12.5% within 9 months.
- Older adults with chronic obstructive pulmonary disease (COPD) needed to be in a severe or very severe stage of the disease as documented using the staging criteria of the Global Initiative for Chronic Obstructive Lung Disease (GOLD).
- Older adults with dementia needed to meet criteria for moderate or severe dementia, their Mini Mental State Examination (MMSE) (Folstein et al 1975, cited in Burns et al 2004) scores being between 0 and 17 (or equivalent).

- Older adults with chronic heart failure needed to meet Class III or IV staging criteria according to the New York Heart Association classification (NYHA) or at least 10% of the sample needed to have died within a year (or equivalent).
- Older adults with cancer needed to be described as having advanced, recurrent, metastatic, or end stage disease, or to be at the palliative stage of care.
- Older adults who had had a stroke needed to meet criteria for frailty and/or for dementia.

Methodological inclusion and exclusion criteria

Any document included needed to be a report of research or a systematic review providing Level I, Level II, Level III-1, or Level III-2 evidence (National Health and Medical Research Council (NHMRC) 2007). Cohort studies were required to be prospective, to have at least 200 participants, and to have defined a question of relevance to our review a priori.

Studies providing retrospective data or without a comparison group were excluded. Any comparator was considered acceptable. We excluded reviews that were not systematic (ie did not address a question, document search strategies and inclusion and exclusion criteria, and evaluate included studies).

Articles included were limited to those published in English from January 1997 onwards. The searches were completed on the 24 October 2007.

Search terms

The search terms relevant to health status were checked by the geriatrician from the reference group to ensure that they were sufficiently comprehensive. Details of the search terms for each database are shown below:

CINAHL

1. exp home health care/ or primary health care/ or home nursing/ or home nursing, professional/ or exp activities of daily living/ or home visits/ or homebound patients/) or (community hospice or home hospice or aging in place or community dwelling or home care or hospital in the home or housebound or self care)

2. exp terminal care/ or palliative care/ or hospice care/ or exp death/) or (end of life or palliat*)

3. exp aged/ or aged, 80 and over/ or geriatrics/) or (elder* or gerontolog* or old*)

4. 1 and 2

5. 4 or 1

6. 5 and 3

7. (chronic disease/ or exp lung diseases, obstructive/ or kidney failure, chronic/) or frail elderly/ or exp heart failure, congestive/ or exp kidney failure/ or exp kidney failure, acute/ or exp liver failure/ or liver failure, acute/ or exp liver diseases/ or exp heart diseases/ or pulmonary heart disease/ or pulmonary valve diseases/ or exp lung diseases/ or exp respiratory tract diseases/ or parkinson disease/ or exp dementia/ or exp delirium, dementia, amnestic, cognitive disorders/ or alzheimer's disease/ or exp

neoplasms/ or deglutition disorders/ or deglutition/ or pneumonia, aspiration/ or exp nutrition disorders/ or pressure ulcer/ or exp peripheral vascular diseases/ or gangrene/) or (respiratory disease* or renal failure or cancer or swallowing difficult* or pressure area* or decubitus ulcer* or malnutrition)

8. cerebrovascular disease

9. exp cerebrovascular disorders/rehabilitation/

10. exp cerebrovascular disorders/

11. 10 not 9

12. stroke and rehabilitation

13. stroke

14. 13 not 12

15. 7 or 8 or 11 or 14

16. 15 and 6

17. limit 16 to (publication year from: 1997–2007) and (language: english) and (age groups: aged, 65+ years, aged, 80 and over) and (special interest: gerontologic care, home health care, hospice/palliative care).

Medline

1. (exp home care services/ or exp home nursing/ or house calls/ or homebound persons/) or (community dwelling or domiciliary or home care or hospital in the home or home visit* or aging in place or housebound or community hospice or home hospice)

2. (exp primary health care/ or primary nursing care/ or activities of daily living/ or exp self care/ or exp terminal care/ or palliative care/ or exp death/) or (end of life care or dying or palliat*)

3. 1 and 2

4. 3 or 1

5. (aged or aged, 80 and over/ or geriatrics/) or (elder* or gerontolog* or old*)

6. 4 and 5

7. chronic disease/ or frail elderly/ or exp heart failure, congestive/ or exp kidney failure/ or kidney failure, chronic/ or exp liver failure/ or exp heart diseases/ or exp heart valve diseases/ or pulmonary heart disease/ or pulmonary disease (specialty/ or exp lung diseases/ or exp pulmonary disease, chronic obstructive/ or exp respiratory tract diseases/ or parkinson's disease/ or exp dementia/ or exp delirium, dementia, amnestic, cognitive disorders/ or alzheimer disease/ or exp liver diseases/ or exp neoplasms/ or exp kidney failure, acute/ or exp liver failure, acute/ or exp deglutition

disorders/ or deglutition/ or exp pneumonia, aspiration/ or exp malnutrition/ or pressure ulcer/ or peripheral vascular diseases/ or gangrene/

8. respiratory disease* or renal failure or cancer or swallowing difficult* or pressure area or decubitus ulcer* or dysphagia

9. exp cerebrovascular accident/

10. exp cerebrovascular accident/rehabilitation

11. 9 not 10

12. stroke not rehabilitation

13. 7 or 8 or 11 or 12

14. 13 and 6

15. limit 14 to (date of publication from: 1997- 2007) and (english language) and (age related: aged 65+; aged 80 and over)

PsychINFO

1. home care/ or primary health care/ or activities of daily living/ or self care skills/ or elder care/ or home visiting programs/ or homebound/ or aging in place/ or home environment/ or independent living programs/ or living alone/) or (home nursing or house call* or community hospice or home hospice or community dwelling or domiciliary or hospital in the home or housebound)

2. (palliative care/ or terminally ill patients/ or death and dying/) or (palliat* or end of life or terminal care or hospice care)

3. 1 and 2

4. palliative approach

5. 1 or 3 or 4

6. (geriatrics/ or gerontology/) or (elder* or old* or aged)

7. 5 and 6

8. exp chronic illness/ or health impairments/ or kidney diseases/ or exp liver disorders/ or exp heart disorders/ or exp lung disorders/ or exp respiratory tract disorders/ or exp lung disorders/ or parkinson disease/ or exp dementia/ or alzheimer disease/ or exp neoplasms/ or dysphagia/ or exp nutritional deficiencies/) or (chronic disease* or frail* or heart failure or kidney failure or liver failure or liver disease* or heart disease* or pulmonary disease* or lung disease* or respiratory tract disease* or renal failure or cancer) or (respiratory disease* or renal failure or cancer or swallowing difficult* or deglutition or aspiration pneumonia or malnutrition or pressure area* or pressure ulcer* or decubitus ulcer* or peripheral vascular disease* or gangrene)

9. (cerebrovascular accidents/ or exp cerebrovascular disorders/) or stroke

10. rehabilitation

11. 9 not 10

12. 8 or 11

13. 7 and 12

14. limit 13 to (publication year from: 1997–2007) and (english) and (age groups: aged 65 yrs & older; very old 85 yrs & older).

Cochrane Library

1. (exp home care services/ or exp home nursing/ or house calls/ or homebound persons/) or (community dwelling or domiciliary or home visit* or hospital in the home or aging in place or housebound or community hospice or home hospice)

2. (exp primary health care/ or primary nursing care/ or activities of daily living/ or exp self care/ or exp terminal care/ or palliative care/ or exp death/) or (end of life or dying or palliat*)

3. 1 and 2

4. 1 or 3

5. (aged/ or geriatrics/) or (elder* or gerontology* or old*)

6. 4 and 5

7. (chronic disease/ or frail elderly/ or exp heart diseases/ or exp heart failure, congestive/ or exp kidney failure/ or exp liver failure/ or exp heart valve disease/ or pulmonary heart disease/ or exp pulmonary disease, chronic obstructive/ or exp lung diseases/ or pulmonary disease (speciality)/ or exp respiratory tract diseases/ or parkinson disease/ or exp dementia/ or exp delirium, dementia, amnestic, cognitive disorders/ or alzheimer disease/ or exp liver diseases/ or exp neoplasms/ or liver failure/ or exp deglutition disorders/ or exp pneumonia, aspiration/ or exp malnutrition/ or pressure ulcer/ or peripheral vascular diseases/ or gangrene/) or respiratory disease* or renal failure or cancer or swallowing difficult* or pressure area* or decubitus ulcer* or dysphagia)

8. exp cerebrovascular accident/

9. exp cerebrovascular accident/ rehabilitation

10. 8 not 9

11. stroke not rehabilitation

12. 7 or 10 or 11

13. 12 and 6

14. limit 13 to (years 1997–2007)

Current Contents Connect

1. home care or primary health care or activities of daily living or self care skill* or home visit* or house call* or homebound or housebound or aging in place or home environment* or independent living or living alone or home nursing or community hospice or home hospice or community dwelling or domiciliary or hospital in the home or house bound

2. pallit* or terminally ill or death or dying or end of life

3. aged or elder* or old* or geriatric* or gerontology

4. 1 and 2

5. 4 or 1

6. chronic disease* or chronic illness or frail elder* or heart failure or heart disease* or kidney failure or kidney disease*or liver failure or liver disease* or pulmonary disease* or lung disease* or respiratory disease* or parkinson* disease or dementia or alzheimer* disease or renal failure or swallowing difficult* or deglutition or aspiration pneumonia or malnutrition or pressure area* or decubitus ulcer* or peripheral vascular disease* or gangrene or pressure ulcer*

7. stroke or cerebrovascular disease* or cerebrovascular accident* or cerebrovascular disorder*

8. rehabilitation

9. 7 not 8

10. 6 or 9

11. 3 and 5 and 10

Australian Health Databases

(including Australian Public Affairs Information Service — Health [APAIS-Health], Aboriginal and Torres Strait Islander Health Bibliography [ATSIhealth], Drug Database [DRUG], E-Library, Health & Society Database [H&S], Meditext, Rural and Remote Health Database [RURAL])

1 home care or primary health care or home nursing or activities of daily living or self care or house call* or home visit* or housebound or homebound

2 community dwelling or domiciliary or hospital in the home or aging in place or home hospice or community hospice

3 home environment or independent living program*

4 1 or 2 or 3

5 palliat* or terminal* or death or dying or end of life or hospice care

6 5 and 4

7 palliative approach

8 7 or 6 or 4

9 geriatric* or gerontology or aged or elder* or old* or aged

10 8 and 9

11 chronic disease* or chronic illness or frail elderly or heart failure or heart disease* or kidney failure or kidney disease* or liver failure or liver disease* or pulmonary disease* or lung diseases: or respiratory tract diseases or parkinson* disease or dementia or alzheimer disease or neoplasm* or respiratory disease* or renal failure or cancer or swallowing difficult* or deglutition or aspiration pneumonia or malnutrition or pressure area* or pressure ulcer* or decubitus ulcer* or peripheral vascular disease* or gangrene or dysphagia

12 (cerebrovascular accident* or cerebrovascular disease* or cerebrovascular disorder* or stroke) not (rehabilitation)

13 11 or 12

14 10 and 13

15 limit 14 to (publication year = 1997–2007)

AARP Ageline

1 home care/ or home health care/ or primary care/ or activities of daily living/ or self care/ or housebound/ or home delivered meals/ or aging in place/

2 chronic diseases/ or chronic obstructive pulmonary disease/ or chronic pain/ or chronically ill/ or frail elderly/ or frailty

3 heart failure/ or kidney diseases/ or respiratory diseases/ or parkinson's disease/ or dementia or alzheimer's disease/ or cancer/ or stroke/ or malnutrition/ or pressure sores/

4 aspiration pneumonia or swallowing difficult* or decubitus ulcers or peripheral vascular disease or gangrene

5 palliative care/ or terminal care/ or dying/ or death/ or hospice/

6 2 or 3 or 4

7 1 and 6

8 home care/ or home health care/ or housebound/ or home delivered meals/

9 8 and 5

10 7 or 9

11 limit 10 to (year 1997 -2007) and (audience type: research/ academic; professional/ provider)

BMJ Clinical Evidence

1 community or domiciliary or home care or home nursing or hospital in the home or activities of daily living or home visit* or aging in place or home environment or housebound or homebound

2 primary care or self care or chronic diseases or heart diseases or lung diseases

3 elderly

4 2 and 3

5 frail or kidney failure or dementia or parkinson's disease or chronic respiratory disorders or chronic obstructive pulmonary disease or depression or heart failure or pressure ulcers or chronic renal failure or peripheral arterial disease or stroke management or cardiovascular disorders or end stage renal disease or cancer or oncology or liver failure or liver diseases or alzheimer disease or deglutition disorders or swallowing difficulties or aspiration pneumonia or malnutrition or gangrene

6 palliative care or end of life or terminal care or hospice or dying

7 1 or 4 or 5 or 6

Assessment of citations

After an initial check of all citations received to exclude studies that clearly failed to meet inclusion criteria for study methodology, remaining citations for these studies were then checked to determine their possible relevance to one of more of the questions set for the review. Full text documents were retrieved if there seemed to be any possibility that they might need to be included.

The full text documents were then checked to see if they met inclusion criteria and triaged according to their relevance to each of the questions. If rejected, a reason for rejection was documented using a standardised and systematic approach (ie reasons were always addressed in the same order):

- duplicate (same material reported)
- wrong question
- wrong publication
- wrong population
- wrong intervention
- no comparison
- wrong outcome
- wrong design.

Some decisions regarding inclusion and exclusion at this stage were clear because they were guided by measurable criteria (eg age). In this instance, decisions were made by the first

named investigator. When this was not the case, the article was reviewed by two people, the first and third named investigators, with regard to inclusion. We wrote to authors for clarification if this was required. Any differences of opinion were resolved by discussion. If consensus was not achieved, a third person was to be consulted. However, this situation did not eventuate.

The reference list from every included study report was also checked and articles were retrieved for review if they met inclusion criteria. This step helped to ensure that articles not indexed for the databases that were searched were not overlooked. Articles cited in systematic reviews were also retrieved and reviewed if they met inclusion criteria. Other reports of research and reviews were retrieved because they were known to be pertinent by the investigating team. Included studies for each question are listed in Appendix B. Excluded studies and reasons for exclusion are in Appendix C.

A.4 Search results

Overall

The searches generated 11 788 unique citations. Following the initial check to find studies that might provide the required level of evidence, 3060 citations remained. After these citations were checked to determine their possible relevance to one of more of the questions, full text papers for 138 citations were considered and 31 of these were retained for the final review.

A further 216 papers were retrieved after reference lists were checked of articles retained from the search. There were 53 papers retained from this set of 216 for the final review.

Twenty nine other documents known to the investigators were also considered for inclusion; from these documents, 12 were retained for the final review.

The systematic review, therefore, was of 96 documents, 12 being reviewed for two questions and 84 for just one question (see Table A.1).

Table A.1 Search history

Database	Publication dates covered	Date of search	Hits
CINAHL	1997–2007	3.10.2007	2226
Medline	1997–2007	26.9.2007	3241
PsychINFO	1997–2007	6.10.2007	1070
Cochrane Library	1997–2007	16.10.07	1251
Current Contents Connect	1998–2007	24.10.07	5588
APAIS- Health	1997–2007	10.10.2007	4
Meditext	1997–2007	10.10.2007	156
Health & Society	1997–2007	10.10.2007	11
ATSI Health	1997–2007	10.10.2007	0
Rural	1997–2007	10.10.2007	0
DRUG	1997–2007	10.10.2007	0
E-Library	1997–2007	10.10.2007	7
AARP Ageline	1997–2007	13.10.2007	875
BMJ Clinical evidence	Not restricted	20.10.2007–22.10.2007	287 documents
Total hits			14 716
Unique citations from the search			11 788
Retrieved documents from the search			138
Retrieved documents from reference lists			216
Retrieved other documents			29
Total retrieved documents			383
Total rejected documents			287
Retained documents from the search			31
Retained documents from reference lists			53
Retained other documents			12
Total included documents			96

Note: From the included documents, 12 were each reviewed for two questions (3 from the search, 7 from reference lists, and two others). From the excluded documents, 28 were each rejected for two questions, 3 were rejected for 3 questions, and 3 were rejected for 4 questions.

Postacute transitional care

Question

Does the implementation of a postacute transitional care program lead to improved physical and/or psychological health of the client and/or the family carer?

Intervention definition

A postacute transitional care program was viewed as a program run either from the hospital or in the community with the primary aim of maintaining the client's health in the community following discharge from acute hospital care (including from the emergency department). Such a program was not viewed as including hospital in the home or a postacute service specifically facilitating *early* discharge, as these services essentially provide acute care in the home rather than enhancing a discharge after acute care is completed. Geriatric assessment and pharmacist support were not viewed as such programs if they were implemented alone; they were, however, viewed as potential program components.

Outcome definition

Carers' health was viewed as including anything measured in the study that would indicate their physical or psychological heath including burden, quality of life, and wellbeing. Clients' health was also seen to include anything measured in the study that would indicate their physical or psychological heath including function, quality of life, hospitalisation, emergency department (ED) visits, mortality, length of hospital stay and presentations to ED.

These definitions formed the basis for including or excluding articles that met overall inclusion criteria. Table A.2 shows numbers of included and excluded studies.

Table A.2 Papers for transitional care

	Reviewed	Rejected	Retained
Search	54	45	9
Reference lists	86	69	17
Other	14	10	4
Total	154	124	30

Crisis care

Question

Does a model of care that includes 24 hour crisis care improve physical and/or psychological health in clients and/or family carers as compared with a model of care that does not include this crisis care?

Intervention definition

Crisis care was viewed as access to after hours medical, nursing, and/or pharmaceutical support in the home. This kind of care was not seen to include hospital in the home because that was viewed as an alternative way of delivering hospital care, rather than an increase in access to care generally expected to be available in the community setting.

Outcome definition

Carers' health was viewed as anything related to their health including burden, quality of life, and wellbeing. Clients' health was viewed as anything related to their health including function, quality of life, hospitalisation, ED visits, mortality and length of hospital stay.

Table A.3 shows numbers of included and excluded studies.

Table A.3 Papers for crisis care

	Reviewed	Rejected	Retained
Search	15	13	2
Reference lists	13	12	1
Other	2	1	1
Total	30	26	4

Respite care

Question

Does a model of care that includes respite care improve physical and/or psychological health in clients and/or family carers as compared with a model of care that does not include this respite care?

Intervention

Respite care was viewed as comprising care provided for the client over a period of hours, days, or weeks to allow the family carer a break — it could be provided in the home, in another person's home, or in a care facility.

Outcome

Carers' health was regarded as anything related to their health including burden, quality of life, and wellbeing. Clients' health was regarded as anything related to health including function, quality of life, hospitalisation, ED visits, mortality, and length of hospital stay.

Table A4 shows numbers of included and excluded studies.

Table A.4 Papers for respite care

	Reviewed	Rejected	Retained
Search	26	18	8
Reference lists	46	37	9
Other	9	4	5
Total	81	59	22

Disease-specific education for family carers

Question

Does education for family carers in disease-specific areas (ie dementia, organ failure, chronic obstructive pulmonary disease, cancer, Parkinson's disease, stroke) improve family carer confidence, competence, physical, psychological and spiritual health when compared with a lack of this education?

Intervention

Disease specific education was viewed as addressing the understanding by the carer of the disease and its symptoms rather than just how to deal with the stresses of caregiving.

Outcome

Health outcomes related to physical and/or psychological health and/or spiritual health; these included anything related to health including wellbeing, burden, quality of life, and depression.

Table A.5 shows numbers of included and excluded studies.

Table A.5 Papers for disease specific education for family carers

	Reviewed	Rejected	Retained
Search	51	36	15
Reference lists	90	57	33
Other	12	8	4
Total	153	101	52

End-of-life care education for family carers

Question

Does education for family carers in end-of-life care improve their experience of the death of their family member and their postbereavement health as compared with a lack of this education?

Intervention

This intervention was viewed as any form of education relating to end–of-life care provided for the family carer.

Outcome

Relevant outcomes were seen to include reports of the bereavement experience, coping with death, or similar.

Table A.6 shows numbers of excluded studies.

Table A.6 Papers for end-of-life carer education

	Reviewed	Rejected	Retained
Search	3	3	0
Reference lists	13	13	0
Other	4	4	0
Total	20	20	0

A.5 Consideration of the evidence

A comprehensive data extraction form was completed for each included study (Appendix D) and provided to each member of the GDG. At the meeting held to consider the evidence, originals of all papers were also provided. One member of the GDG was unable to attend but

reviewed all of the decisions made afterwards, with reference to data extractions forms and/or articles. The guideline assessment registrar from the National Health and Medical Research Council (NHMRC) was present on the first day of the two day meeting to provide guidance. Each GDG member at the meeting completed an evidence statement summary form, independently rating the evidence and then contributing to a joint decision. Additional GDG teleconferences finalised decisions in some instances (Appendix E summarises the final decisions made by the GDG, which were all unanimous). Evidence tables are in the main document.

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Appendix B Studies retained for the systematic review

B.1 Postacute transitional care

Reviews

Ali, W. and P. Rasmussen (2004). What is the evidence for the effectiveness of managing the hospital / community interface for older people? A critical appraisal of the literature. NZHTA Report, New Zealand Health Technology Assessment: 1–164.

Bours, G., C. A. J. Ketelaars et al (1998). The effects of aftercare on chronic patients and frail elderly patients when discharged from hospital: a systematic review. Journal of Advanced Nursing 27(5): 1076–1086.

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McAlister, F. A., Stewart S et al (2004). Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials. Journal of the American College of Cardiology 44(4): 810–9.

Phillips, C. O., S. M. Wright et al (2004). Comprehensive discharge planning with postdischarge support for older patients with congestive heart failure — A meta-analysis. Jama-Journal of the American Medical Association 291(11): 1358–1367.

Taylor, S., J. Bestall et al (2005) Clinical service organisation for heart failure. Cochrane Database of Systematic Reviews Volume, DOI: 10.1002/14651858.CD002752.pub2

Visser-Meily, A., C. van Heugten et al (2005). Intervention studies for caregivers of stroke survivors: a critical review. Patient Education and Counseling 56(3): 257–267.

Individual studies

Blue, L., E. Lang et al (2001). Randomised controlled trial of specialist nurse intervention in heart failure. BMJ (Clinical Research Ed.) 323(7315): 715–718.

Clark, M. S., S. Rubenach et al (2003). A randomized controlled trial of an education and counselling intervention for families after stroke. Clin Rehabil 17(7): 703–12.

Cline, C. M., B. Y. Israelsson et al (1998). Cost effective management programme for heart failure reduces hospitalisation. Heart 80(5): 442–6.

DeBusk RF, Miller NH et al (2004). Care management for low-risk patients with heart failure: a randomized, controlled trial. Ann Intern Med 141(8): 606–13.

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Ekman, I., B. Andersson et al (1998). Feasibility of a nurse-monitored, outpatient-care programme for elderly patients with moderate-to-severe, chronic heart failure. Eur Heart J 19(8): 1254–60.

Harrison, M. B., G. B. Browne et al (2002). Quality of life of individuals with heart failure: a randomized trial of the effectiveness of two models of hospital-to-home transition. Medical Care 40(4): 271–282.

Inglis, S. C., S. Pearson et al (2006). Extending the horizon in chronic heart failure: effects of multidisciplinary, home-based intervention relative to usual care. Circulation 114(23): 2466–2473.

Jaarsma, T., R. Halfens et al (1999). Effects of education and support on self-care and resource utilization in patients with heart failure. European Heart Journal 20(9): 673–682.

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Stromberg, A., J. Martensson et al (2003). Nurse-led heart failure clinics improve survival and self-care behaviour in patients with heart failure: results from a prospective, randomised trial. Eur Heart J 24(11): 1014–23.

B.2 Crisis care

Reviews

Ali, W. and P. Rasmussen (2004). What is the evidence for the effectiveness of managing the hospital / community interface for older people? A critical appraisal of the literature. NZHTA Report, New Zealand Health Technology Assessment: 1–164.

Aminzadeh, F. and W. B. Dalziel (2002). Older adults in the emergency department: A systematic review of patterns of use, adverse outcomes, and effectiveness of interventions. Annals of Emergency Medicine 39(3): 238–247.

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B.3 Respite care

Reviews

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Acton, G. J. and M. A. Winter (2002). Interventions for family members caring for an elder with dementia. Annu Rev Nurs Res 20: 149–79.

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Lee, H. and M. Cameron (2004). Respite care for people with dementia and their carers. Cochrane Database Of Systematic Reviews (Online)(2): CD004396.

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McCann, J. J., L. E. Hebert et al (2005). The effect of adult day care services on time to nursing home placement in older adults with Alzheimer's disease. Gerontologist 45(6): 754–763.

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B.4 Disease-specific education for family carers

Reviews

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Harding, R. and I. J. Higginson (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. Palliative Medicine 17(1): 63.

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Sorensen, S., M. Pinquart et al (2002). How effective are interventions with caregivers? An updated meta-analysis. Gerontologist 42(3): 356–72.

Stoltz, P., G. Uden et al (2004). Support for family carers who care for an elderly person at home — a systematic literature review. Scand J Caring Sci 18(2): 111–9.

Visser-Meily, A., C. van Heugten et al (2005). Intervention studies for caregivers of stroke survivors: a critical review. Patient Education and Counseling 56(3): 257–267.

Individual studies

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Bourgeois, M. S., R. Schulz et al (2002). Skills Training for Spouses of Patients with Alzheimer's Disease: Outcomes of an Intervention Study. Journal of Clinical Geropsychology 8(1): 53–73.

Buckwalter, K. C., L. Gerdner et al (1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. Archives Of Psychiatric Nursing 13(2): 80–88.

Burgio, L., A. Stevens et al (2003). Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. Gerontologist 43(4): 568–79.

Burns, R., L. O. Nichols et al (2003). Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study. The Gerontologist 43(4): 547–555.

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Davis, L. L., L. D. Burgio et al (2004). A Comparison of In-Home and Telephone-Based Skill Training Interventions With Caregivers of Persons With Dementia Journal of mental health and aging 10(1): 31–44.

Done, D. J. and J. A. Thomas (2001). Training in communication skills for informal carers of people suffering from dementia: a cluster randomized clinical trial comparing a therapist led workshop and a booklet. International Journal Of Geriatric Psychiatry 16(8): 816–821.

Garand, L., K. C. Buckwalter et al (2002). A pilot study of immune and mood outcomes of a community-based intervention for dementia caregivers: the PLST intervention. Arch Psychiatr Nurs 16(4): 156–67.

Gerdner, L. A., K. C. Buckwalter et al (2002). Impact of a psychoeducational intervention on caregiver response to behavioral problems. Nursing Research 51(6): 363–374.

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Gitlin, L. N., W. W. Hauck et al (2005). Maintenance of effects of the home environmental skill-building program for family caregivers and individuals with Alzheimer's disease and related disorders. The journals of gerontology. Series A, Biological sciences and medical sciences 60A(3): 368–74.

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Hébert, R., L. Lévesque et al (2003). Efficacy of a psychoeducative group program for caregivers of demented persons living at home: a randomized controlled trial. The Journals Of Gerontology. Series B, Psychological Sciences And Social Sciences 58(1): S58–67.

Hepburn, K., M. Lewis et al (2007). The Savvy Caregiver program: the demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. Journal of Gerontological Nursing 33(3): 30–36.

Hepburn, K. W., J. Tornatore et al (2001). Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. Journal Of The American Geriatrics Society 49(4): 450–457.

Huang, H.-L., Y.-I. L. Shyu et al (2003). A pilot study on a home-based caregiver training program for improving caregiver self-efficacy and decreasing the behavioral problems of elders with dementia in Taiwan. International Journal Of Geriatric Psychiatry 18(4): 337–345.

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McCurry, S. M., R. G. Logsdon et al (1998). Successful behavioral treatment for reported sleep problems in elderly caregivers of dementia patients: A controlled study. The Journals of Gerontology 53B(2): p 122.

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Nobili, A., E. Riva et al (2004). The effect of a structured intervention on caregivers of patients with dementia and problem behaviors: a randomized controlled pilot study. Alzheimer Dis Assoc Disord 18(2): 75–82.

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Stolley, J. M., D. Reed et al (2002). Caregiving appraisal and interventions based on the progressively lowered stress threshold model. American Journal Of Alzheimer's Disease And Other Dementias 17(2): 110–120.

Smith, J., A. Forster et al (2004). A randomized trial to evaluate an education programme for patients and carers after stroke. Clin Rehabil 18(7): 726–36.

Teri, L., R. G. Logsdon et al (1997). Behavioral treatment of depression in dementia patients: A controlled clinical trial. The Journals of Gerontology 52B(4): p 159.

Teri, L., S. M. McCurry et al (2005). Training community consultants to help family members improve dementia care: a randomized controlled trial. Gerontologist 45(6): 802–11.

Wright, L. K., M. Litaker et al (2001). Continuum of care for alzheimer's disease: a nurse education and counselling program. Issues in Mental Health Nursing 22(3): 231–252.

Zanetti, O., T. Metitieri et al (1998). Effectiveness of an educational program for demented person's relatives. Archives of Gerontology and Geriatrics 26(Suppl 1): 531–538.

B.5 End-of-life care education for family carers

Reviews

None.

Individual studies

None.

Appendix C Articles rejected from the systematic review

C.1 Postacute transitional care

Duplicates (7)

Inglis, S., S. McLennan et al (2004). A new solution for an old problem? Effects of a nurse-led, multidisciplinary, home-based intervention on readmission and mortality in patients with chronic atrial fibrillation. The Journal Of Cardiovascular Nursing 19(2): 118–127.

Riegel, B., B. Carlson et al (2000). Which patients with heart failure respond best to multidisciplinary disease management? J Card Fail 6(4): 290–9.

Stewart, S. and J. D. Horowitz (2002). Detecting early clinical deterioration in chronic heart failure patients postacute hospitalisation-a critical component of multidisciplinary, home-based intervention? European Journal Of Heart Failure: Journal Of The Working Group On Heart Failure Of The European Society Of Cardiology 4(3): 345–351.

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Stewart, S., J. E. Marley et al (1999). Effects of a multidisciplinary, home-based intervention on unplanned readmissions and survival among patients with chronic congestive heart failure: a randomised controlled study. Lancet 354(9184): 1077–1083.

Stewart, S., S. Pearson et al (1998). Effects of a home-based intervention among patients with congestive heart failure discharged from acute hospital care. Archives Of Internal Medicine 158(10): 1067–1072.

Stewart, S., A. J. Vandenbroek et al (1999). Prolonged beneficial effects of a home-based intervention on unplanned readmissions and mortality among patients with congestive heart failure. Archives Of Internal Medicine 159(3): 257–261.

Wrong question (7)

Benbassat, J. and M. Taragin (2000). Hospital readmissions as a measure of quality of health care — Advantages and limitations. Archives of Internal Medicine 160(8): 1074–1081.

Bowler, S., D. Schollay et al (2001). Home vs hospital treatment of exacerbations of COPD: a randomised controlled trial. Respirology 6 (Suppl): A34.

Chuang, K., S. Wu et al (2005). Identifying factors associated with hospital readmissions among stroke patients in Taipei. Journal of Nursing Research 13(2): 117–128.

Gravolin, M., K. Rowell et al (2007) Interventions to support the decision-making process for older people facing the possibility of long-term residential care. Cochrane Database of Systematic Reviews Volume, DOI: 10.1002/14651858.CD005213.pub2

Lorenz, K., J. Lynn et al (2004). End-of-Life Care and Outcomes. Rockville, MD, Southern California Evidence-based Practice Center: 1–651.

Luzier, A. B., A. Forrest et al (2000). Containment of heart failure hospitalizations and cost by angiotensin-converting enzyme inhibitor dosage optimization. Am J Cardiol 86(5): 519–23.

Tsuyuki, R. T., M. L. Ackman et al (2002). Effects of the 1994 Canadian Cardiovascular Society clinical practice guidelines for congestive heart failure. Can J Cardiol 18(2): 147–52.

Wrong publication (13)

Ashton, C. M. (1999). Care of Patients with Failing Hearts Evidence for Failures in Clinical Practice and Health Services Research. Journal of General Internal Medicine 14(2): 138–140.

Davies, E. (2004). What are the palliative care needs of older people and how might they be met? Copenhagen, WHO Regional Office for Europe: 1–16.

Grancelli, H., S. Varini et al (2003). Randomized Trial of Telephone Intervention in Chronic Heart Failure (DIAL): study design and preliminary observations. J Card Fail 9(3): 172–9.

Griffiths, P. (2004). Advanced practice nurse directed transitional care reduced readmission or death in elderly patients admitted to hospital with heart failure. Evidence-Based Nursing 7(4): 116–116.

Harrison, M. B., C. Toman et al (1998). Hospital to home evidence-based education for CHF. Can Nurse 94(2): 36–42.

Konick-McMahan, J., B. Bixby et al (2003). Heart failure in older adults. Providing nursing care to improve outcomes. Journal Of Gerontological Nursing 29(12): 35–41.

McCauley, K. M., M. B. Bixby et al (2006). Advanced practice nurse strategies to improve outcomes and reduce cost in elders with heart failure. Disease Management 9(5): 302–310.

Naylor, M. D. (2002). Transitional care of older adults. Annu Rev Nurs Res 20: 127–47.

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Pinkowish, M. (2007). Managing transitions in care. American Journal of Nursing 107(2): 72C-d.

Showalter, S. E. (2004). Telehealth CHF Program cares for elders after discharge from home care. Remington Report 12(6): 20–22.

Swedberg, K., J. Cleland et al (2005). Guidelines for the diagnosis and treatment of chronic heart failure: executive summary (update 2005): The Task Force for the Diagnosis and Treatment of Chronic Heart Failure of the European Society of Cardiology. Eur Heart J 26(11): 1115–40.

Wrong population (66)

Azevedo, A., J. Pimenta et al (2002). Effect of a heart failure clinic on survival and hospital readmission in patients discharged from acute hospital care. Eur J Heart Fail 4(3): 353–9.

Benatar, D., M. Bondmass et al (2003). Outcomes of chronic heart failure. Archives Of Internal Medicine 163(3): 347–352.

Brand, C. A., C. T. Jones et al (2004). A transitional care service for elderly chronic disease patients at risk of readmission. Australian Health Review 28(3): 275–284.

Bull, M. J., H. E. Hansen et al (2000). A professional-patient partnership model of discharge planning with elders hospitalized with heart failure. Appl Nurs Res 13(1): 19–28.

Burns, R., L. O. Nichols et al (2000). Interdisciplinary geriatric primary care evaluation and management: two-year outcomes. J Am Geriatr Soc 48(1): 8–13.

Caplan, G. A., A. J. Williams et al (2004). A randomized, controlled trial of comprehensive geriatric assessment and multidisciplinary intervention after discharge of elderly from the emergency department--the DEED II study. J Am Geriatr Soc 52(9): 1417–23.

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Cleland, J. G., A. A. Louis et al (2005). Noninvasive home telemonitoring for patients with heart failure at high risk of recurrent admission and death: the Trans-European Network-Home-Care Management System (TEN-HMS) study. J Am Coll Cardiol 45(10): 1654–64.

Cole, M. G. (2001). The impact of geriatric post-discharge services on mental state. Age Ageing 30(5): 415–8.

Coleman, E. A., C. Parry et al (2006). The care transitions intervention: results of a randomized controlled trial. Archives Of Internal Medicine 166(17): 1822–1828.

Coleman, E. A., J. D. Smith et al (2004). Preparing patients and caregivers to participate in care delivered across settings: the Care Transitions Intervention. Journal Of The American Geriatrics Society 52(11): 1817–1825.

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Dai, Y. T., Y. Chang et al (2003). Effectiveness of a pilot project of discharge planning in Taiwan. Research in Nursing & Health 26(1): 53–63.

Dellasega, C. A. and T. M. Zerbe (2000). A multimethod study of advanced practice nurse postdischarge care. Clin Excell Nurse Pract 4(5): 286–93.

Dellasega, C. and T. M. Zerbe (2002). Caregivers of frail rural older adults: effects of an advanced practice nursing intervention. Journal of Gerontological Nursing 28(10): 40–49.

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Gagnon, A. J., C. Schein et al (1999). Randomized controlled trial of nurse case management of frail older people. Journal Of The American Geriatrics Society 47(9): 1118–1124.

Goldberg, G., M. E. Segal et al (1997). Stroke Transition after Inpatient Rehabilitation Topics in stroke rehabilitation 4(1): 64–79.

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Wrong outcome (1)

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C.2 Crisis care

Duplicate (1)

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Wrong question (1)

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Wrong outcome (0)

Wrong design (0)

C.3 Respite care

Duplicates (2)

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Wrong population (13)

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Wrong intervention (5)

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C.4 Disease-specific education

Duplicate (2)

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Wrong question (9)

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Wrong publication (19)

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Wrong population (35)

Beauchamp, N., A. B. Irvine et al (2005). Worksite-based Internet multimedia program for family caregivers of persons with dementia. Gerontologist 45(6): 793–801.

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Wrong intervention (15)

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No comparison (14)

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Bedard, M., D. W. Molloy et al (1997). 1997 IPA/Bayer Research Awards in Psychogeriatrics. Associations between dysfunctional behaviors, gender, and burden in spousal caregivers of cognitively impaired older adults. Int Psychogeriatr 9(3): 277–90.

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Millan-Calenti, J. C., M. Gandoy-Crego et al (2000). Helping the family carers of Alzheimer's patients: from theory…to practice. A preliminary study. Arch Gerontol Geriatr 30(2): 131–8.

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Wrong outcome (4)

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McMillan, S. C. and B. J. Small (2007). Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. Oncology Nursing Forum 34(2): 313–321.

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Wrong design (3)

Cooper, D. F., O. R. Granadillo et al (2007). Home-based primary care: the care of the veteran at home. Home Healthcare Nurse 25(5): 315–322.

Lowe, J. M., P. M. Candlish et al (1998). Management and outcomes of congestive heart failure: a prospective study of hospitalised patients. The Medical Journal of Australia 168(3): 115–118.

Mant, J., J. Carter et al (1998). The impact of an information pack on patients with stroke and their carers: a randomized controlled trial. Clin Rehabil 12(6): 465–76.

C.5 End-of-life care education

Duplicate (1)

Gysels, M., I. J. Higginson et al (2004). Improving supportive and palliative care for adults with cancer. Research Evidence Manual. London, King's College London: 1–384.

Wrong question (3)

Brumley, R., S. Enguidanos et al (2007). Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care. Journal of the American Geriatrics Society 55(7): 993–1000.

Lorenz, K., J. Lynn et al (2004). End-of-Life Care and Outcomes. Rockville, MD, Southern California Evidence-based Practice Center: 1–651.

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Wrong publication (4)

Davies, E. (2004). What are the palliative care needs of older people and how might they be met? Copenhagen, WHO Regional Office for Europe: 1–16.

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Kirk, T. W. (2007). Managing pain, managing ethics. Pain Management Nursing: Official Journal Of The American Society Of Pain Management Nurses 8(1): 25–34.

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Wrong population (3)

Clotfelter, C. E. (1999). The effect of an educational intervention on decreasing pain intensity in elderly people with cancer. Oncol Nurs Forum 26(1): 27–33.

Jepson, C., R. McCorkle et al (1999). Effects of home care on caregivers' psychosocial status. Image J Nurs Sch 31(2): 115–20.

Ringdal, G. I., K. Ringdal et al (2004). Health-related quality of life (HRQOL) in family members of cancer victims: results from a longitudinal intervention study in Norway and Sweden. Palliat Med 18(2): 108–20.

Wrong intervention (5)

Critchley, P., A. R. Jadad et al (1999). Are some palliative care delivery systems more effective and efficient than others? A systematic review of comparative studies. J Palliat Care 15(4): 40–7.

Higginson, I. J., I. G. Finlay et al (2003). Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? J Pain Symptom Manage 25(2): 150–68.

Jordhoy, M. S., P. Fayers et al (2000). A palliative-care intervention and death at home: a cluster randomised trial. Lancet 356(9233): 888–93.

Sampson, E. L., C. W. Ritchie et al (2005). A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. Int Psychogeriatr 17(1): 31–40.

Smeenk, F. W., J. C. van Haastregt et al (1998). Effectiveness of home care programmes for patients with incurable cancer on their quality of life and time spent in hospital: systematic review. BMJ 316(7149): 1939–44.

No comparison (2)

Bucher, J. A., M. Loscalzo et al (2001). Problem-solving cancer care education for patients and caregivers. Cancer Pract 9(2): 66–70.

Kwak, J., J. R. Salmon et al (2007). Benefits of training family caregivers on experiences of closure during end-of-life care. J Pain Symptom Manage 33(4): 434–45.

Wrong outcome (2)

Brumley, R. D., S. Enguidanos et al (2003). Effectiveness of a home-based palliative care program for end-of-life. J Palliat Med 6(5): 715–24.

Clark, D., C. Ferguson et al (2000). Macmillan Carers Schemes in England: results of a multicentre evaluation. Palliat Med 14(2): 129–39.

Wrong design (0)

Appendix D Data extraction forms for the development of evidence-based recommendations

See separate file

Appendix E Evidence summary forms for the development of evidence-based recommendations

E.1 Postacute transitional care

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program for an older adult with severe chronic heart failure lead to improved quality of life for that person?		**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*		
A	A	**Several Level I or II studies with low risk of bias**
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
	D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*		
C	A	**All studies consistent**
	B	**Most studies consistent and inconsistency can be explained**
	C	**Some inconsistency, reflecting genuine uncertainty around question**
	D	**Evidence is inconsistent**
	NA	**Not applicable (one study only)**
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*		
N/A	A	**Very large**
	B	**Moderate**
	C	**Slight**

	D	**Restricted**
4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	A	**Several Level I or II studies with low risk of bias**
2. Consistency	C	**Some inconsistency, reflecting genuine uncertainty around question**
3. Clinical impact	N/A	
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions None

RECOMMENDATION	GRADE OF RECOMMENDATION
There is insufficient consistent evidence to allow for a recommendation to be formulated in this area.	N/A

Although a number of studies have investigated the extent to which postacute transitional care impacts upon the quality of life of older adults with heart failure, findings are inconsistent, and the use of diverse intervention strategies, dimensions of quality of life investigated, and assessment tools used means that the evidence base is fragmented and does not provide a suitable basis for a recommendation in this area. There is, however, consistency in the fact that no major adverse quality of life outcomes were reported for these interventions, which may be implemented to meet primary objectives such as reduced readmissions. Increased consistency in measurement would be helpful in this area and it would seem to be appropriate to measure quality of life outcomes each and every time a postacute transitional care intervention is tested. The extent to which findings may be unique to older adults whose health is particularly poor is an important area of future investigation, given that education sessions are sometime lengthy and could be tiring. Also possible benefits obtained from involving family carers need to be determined	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? N/A	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? N/A	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? N/A	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? N/A	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program for older adults with severe chronic heart failure lead to their readmissions to hospital being reduced?		**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*		
A	A	**Several Level I or II studies with low risk of bias**
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
	D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*		
B	A	**All studies consistent**
	B	**Most studies consistent and inconsistency can be explained**
	C	**Some inconsistency, reflecting genuine uncertainty around question**
	D	**Evidence is inconsistent**
	NA	**Not applicable (one study only)**
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*		
A/B	A	**Very large**
	B	**Moderate**
	C	**Slight**
	D	**Restricted**

4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

Little research has been found in this area with people who have dementia or with culturally and linguistically diverse groups in the Australian context. The clinical impact of recommendations would be enhanced if it was determined that these groups could also be assisted to remain out of hospital using transitional care programs.

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	**Rating**	**Description**
1. Evidence base	A	**Several Level I or II studies with low risk of bias**
2. Consistency	B	**Most studies consistent and inconsistency can be explained**
3. Clinical impact	A/B	**Very large/moderate**
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions None

RECOMMENDATION	**GRADE OF RECOMMENDATION**
Postacute transitional care programs, comprising education and support, should be routinely implemented when older adults with advanced chronic heart failure are discharged from hospital into the community.	A

We recommend that a postacute transitional care program, comprising education and support, is implemented routinely when an older adult with heart failure is discharged from hospital to minimise their readmissions to hospital. There is good evidence to indicate that this strategy will be effective when the older adult's primary health problem is heart failure and when they are able to understand and apply management strategies. This evidence does not apply to people who have cognitive disability and a promising area of research would be to investigate transitional care programs with family carers of older adults who have dementia as well as heart failure. Furthermore, postacute transitional care may be useful in areas other than heart failure but most research concentrates on heart failure patients. Finally, more research is needed to ascertain whether or not postacute transitional care programs can also impact upon residential care placement in this population.

IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? It is not routine at present to implement this in older adults.	**YES**
Are there any resource implications associated with implementing this recommendation? Staff time is required. However, implementation leading to reduced readmission is highly likely to lead to reduced overall costs.	**YES**
Will the implementation of this recommendation require changes in the way care is currently organised? This is an addition to usual care for older adults.	**YES**
Are the guideline development group aware of any barriers to the implementation of this recommendation? The concern is that this would be viewed as a cost burden within the individual hospital rather than being seen in a system wide context.	**YES**

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program in older adults with severe chronic heart failure impact upon mortality in that population?			**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*			
A	A	**Several Level I or II studies with low risk of bias**	
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**	
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**	
	D	**Level IV studies or Level I to III studies with high risk of bias**	
2. Consistency *(if only one study was available, rank this component as 'not applicable')*			
C	A	**All studies consistent**	
	B	**Most studies consistent and inconsistency can be explained**	
	C	**Some inconsistency, reflecting genuine uncertainty around question**	
	D	**Evidence is inconsistent**	
	NA	**Not applicable (one study only)**	
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
N/A	A	**Very large**	
	B	**Moderate**	
	C	**Slight**	
	D	**Restricted**	

4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

If it was not for the inconsistency, the clinical impact would be rated more highly.

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	A	**Several Level I or II studies with low risk of bias**
2. Consistency	C	**Some inconsistency, reflecting genuine uncertainty around question**
3. Clinical impact	N/A	
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions None

RECOMMENDATION	GRADE OF RECOMMENDATION
There is insufficient consistent evidence in this area upon which to base a recommendation as sample sizes may have been too low to detect an effect on this variable.	N/A

The evidence of the impact upon the mortality of older adults with chronic heart failure of transitional care interventions is inconsistent. It may be that some interventions are more effective than others but this is unclear at this stage. Moreover, studies in this area have tended to exclude older adults who have dementia and the possibility of an improvement in mortality being linked with poor quality of life requires consideration.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? N/A	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? N/A	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? N/A	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? N/A	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program for people with advanced frailty or disability due to stroke lead to improved physical and/or psychological health of the client and/or the family carer?			**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*			
Carer B	**Care recipient C**	A	**Several Level I or II studies with low risk of bias**
		B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
		C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
		D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*			
Carer C	**Care recipient C**	A	**All studies consistent**
		B	**Most studies consistent and inconsistency can be explained**
		C	**Some inconsistency, reflecting genuine uncertainty around question**
		D	**Evidence is inconsistent**
		NA	**Not applicable (one study only)**
3. Clinical impact *(Indicate in the space below if the study results varied according to some unknown factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
Carer N/A	**Care recipient N/A**	A	**Very large**
		B	**Moderate**
		C	**Slight**
		D	**Restricted**

4. Generalisability			
Carer A	**Care recipient A**	A	**Evidence directly generalisable to target population**
		B	**Evidence directly generalisable to target population with some caveats**
		C	**Evidence not directly generalisable to the target population but could be sensibly applied**
		D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability			
Carer A	**Care recipient A**	A	**Evidence directly applicable to Australian healthcare context**
		B	**Evidence applicable to Australian healthcare context with few caveats**
		C	**Evidence probably applicable to Australian healthcare context with some caveats**
		D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Carer Recipient	Description
1. Evidence base	B C	**One or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias/Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
2. Consistency	C C	**Some inconsistency, reflecting genuine uncertainty around question**
3. Clinical impact	N/A N/A	
4. Generalisability	A A	**Evidence directly generalisable to target population**
5. Applicability	A A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions

RECOMMENDATION	GRADE OF RECOMMENDATION
There is insufficient consistent evidence to form a basis for a recommendation in this area.	N/A

Few studies have investigated out comes for stroke patients and their families from postacute transitional care and the findings for the work that has been done provide inconsistent findings. The most rigorous study we reviewed was conducted in South Australia (Clark et al 2003). This indicated better family functioning and patient function rather than any change in well being.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? N/A	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? N/A	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? N/A	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? N/A	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program in generally frail or unwell older adults[1] (rather than older adults with specific diagnoses) impact on quality of life in that population? [1] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.		**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*		
C	A	**Several Level I or II studies with low risk of bias**
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
	D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*		
A	A	**All studies consistent**
	B	**Most studies consistent and inconsistency can be explained**
	C	**Some inconsistency, reflecting genuine uncertainty around question**
	D	**Evidence is inconsistent**
	NA	**Not applicable (one study only)**
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*		
N/A	A	**Very large**
	B	**Moderate**

	C	**Slight**
	D	**Restricted**
4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

The only indication of a positive impact related to a very specific case management intervention mentioned in a review — the study was not in our date range and so could not be examined in detail — with respect to all other interventions no effect was consistently documented.

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
2. Consistency	A	**All studies consistent**
3. Clinical impact	N/A	
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence not applicable to Australian healthcare context**

RECOMMENDATION	GRADE OF RECOMMENDATION
Evidence is insufficient to underpin a recommendation in this area.	

There is a small amount of evidence concerning the impact of on well being of transitional care for older adults in general. The evidence is consistent with respect to most of the types of interventions tested, in that these have had no impact. One Australian study in a review (Ali & Rasmussen 2004) was reported to have tested a post-discharge case management intervention and found that it resulted in improved quality of life. This study was not eligible for inclusion in our review. Further investigation of this outcome is merited to expand the current knowledge base.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? N/A	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? N/A	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? N/A	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? N/A	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program in generally frail or unwell older adults[1] (rather than older adults with specific diagnoses) impact on hospital readmissions in that population? [1] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.			**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*			
A	A	**Several Level I or II studies with low risk of bias**	
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**	
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**	
	D	**Level IV studies or Level I to III studies with high risk of bias**	
2. Consistency *(if only one study was available, rank this component as 'not applicable')*			
C	A	**All studies consistent**	
	B	**Most studies consistent and inconsistency can be explained**	
	C	**Some inconsistency, reflecting genuine uncertainty around question**	
	D	**Evidence is inconsistent**	
	NA	**Not applicable (one study only)**	
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
N/A	A	**Very large**	
	B	**Moderate**	

	C	**Slight**
	D	**Restricted**
4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component		**Description**
Evidence base	A	**Several Level I or II studies with low risk of bias**
1. Consistency	C	**Some inconsistency, reflecting genuine uncertainty around question**
2. Clinical impact	N/A	
3. Generalisability	A	**Evidence directly generalisable to target population**
4. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions

None

RECOMMENDATION	**GRADE OF RECOMMENDATION**
There is insufficient evidence to underpin are commendation.	N/A

There is a small amount of evidence concerning the impact upon readmission of postacute transitional care for older adults in general, and this evidence is conflicting. Further investigation of this outcome is merited to expand the current knowledge base. However, it may be that particular types of intervention are more effective than others. For example, the Australian study conducted by Caplan and included in a systematic review (Hastings & Heflin 2005) indicated benefits from geriatric assessment and multi-disciplinary outreach. However, in this study, the older adults were not as frail or unwell as those targeted by our guidelines, therefore, this study was only included in our review in the form of a secondary reference.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? N/A	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? N/A	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? N/A	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? N/A	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program in generally frail or unwell older adults[1] (rather than older adults with specific diagnoses) impact on residential placements in that population? [1] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.			**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*			
B	A	**Several Level I or II studies with low risk of bias**	
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**	
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**	
	D	**Level IV studies or Level I to III studies with high risk of bias**	
2. Consistency *(if only one study was available, rank this component as 'not applicable')*			
B	A	**All studies consistent**	
	B	**Most studies consistent and inconsistency can be explained**	
	C	**Some inconsistency, reflecting genuine uncertainty around question**	
	D	**Evidence is inconsistent**	
	NA	**Not applicable (one study only)**	
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
B	A	**Very large**	
	B	**Moderate**	

	C	**Slight**
	D	**Restricted**
4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	B	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
2. Consistency	B	**Most studies consistent and inconsistency can be explained**
3. Clinical impact	B	**Moderate**
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions None

RECOMMENDATION	GRADE OF RECOMMENDATION
Postacute transitional care programs should be routinely implemented to support the hospital discharge into the community of other older adults with non-specific and advanced life limiting illness, frailty, or extreme old age.	C

The outcome of residential aged care placement is under-reported in studies examining ways in which transitional care impacts upon older adults in general. Further studies are needed to investigate this important outcome. Such investigations may need to consider the extent to which a hospital admission occurs as a part of the transition into residential aged care.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? YES as this is not yet routinely implemented.	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? YES because programs will need to be planned and implemented.	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? YES — see above	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? Possibly resources although delaying placement would lead to at least corresponding savings overall.	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does the implementation of a postacute transitional care program in generally frail or unwell older adults[1] (rather than older adults with specific diagnoses) impact on mortality in that population? [1] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.			**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*			
B	A	**Several Level I or II studies with low risk of bias**	
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**	
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**	
	D	**Level IV studies or Level I to III studies with high risk of bias**	
2. Consistency *(if only one study was available, rank this component as 'not applicable')*			
A	A	**All studies consistent**	
	B	**Most studies consistent and inconsistency can be explained**	
	C	**Some inconsistency, reflecting genuine uncertainty around question**	
	D	**Evidence is inconsistent**	
	NA	**Not applicable (one study only)**	
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
N/A	A	**Very large**	
	B	**Moderate**	

	C	**Slight**
	D	**Restricted**
4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
2. Consistency	A	**All studies consistent**
3. Clinical impact	N/A	
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence not applicable to Australian healthcare context**

Indicate any dissenting opinions — NONE

RECOMMENDATION	GRADE OF RECOMMENDATION
Evidence shows no effect on mortality. However, in the absence of evidence of a negative effect, no recommendation is made, given the benefits shown in terms of residential placement.	N/A

There is a small amount of consistent evidence that transitional care for older adults in general has no impact upon mortality. Further investigation of this outcome is merited to expand the current knowledge base.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? N/A	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? N/ A	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? N/A	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? N/A	**YES**
	NO

E.2 Crisis care

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does a model of care that includes 24 hour crisis care improve physical and/or psychological health in <u>older people</u> and their <u>family carers</u> as compared with a model of care that does not include this crisis care?			**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*			
Clients: B	**Family carers: B**	A	**Several Level I or II studies with low risk of bias**
		B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
		C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
		D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*			
Clients: B	**Family carers: N/A**	A	**All studies consistent**
		B	**Most studies consistent and inconsistency can be explained**
		C	**Some inconsistency, reflecting genuine uncertainty around question**
		D	**Evidence is inconsistent**
		NA	**Not applicable (one study only)**
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
Clients: C	**Family carers: C**	A	**Very large**
		B	**Moderate**
		C	**Slight**

		D	**Restricted**
4. Generalisability			
Clients: A	**Family carers: A**	A	**Evidence directly generalisable to target population**
		B	**Evidence directly generalisable to target population with some caveats**
		C	**Evidence not directly generalisable to the target population but could be sensibly applied**
		D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability			
Clients: A	**Family carers: A**	A	**Evidence directly applicable to Australian healthcare context**
		B	**Evidence applicable to Australian healthcare context with few caveats**
		C	**Evidence probably applicable to Australian healthcare context with some caveats**
		D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

The two individual studies examined interventions of which a component was crisis care, rather than the whole intervention being crisis care. Therefore, effects from crisis care itself cannot be assumed to match effects of the whole intervention. However we can look as crisis care as part of an intervention.

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	**Rating**		**Description**
	clients	carers	
1. Evidence base	B	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
2. Consistency	B	N/A	
3. Clinical impact	C	C	**Slight**
4. Generalisability	A	A	**Evidence directly generalisable to target population**
5. Applicability	A	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions No dissenters.

RECOMMENDATION *When implementing community based health care services for older adults with specific or non-specific life limiting illness, frailty, or extreme old age, access to crisis care should be included.*	**GRADE OF RECOMMENDATION** C
Comment: This is an important area that will need further investigation in the future to determine appropriate delivery of care to a vulnerable population. The study that provided clear evidence over most of the population groups of interest was one testing an intervention in a Veteran Affairs population in the US (Hughes et al 2000).	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? YES because this is not routinely implemented.	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? YES programs will need to be developed and implemented	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? YES — see above	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? Resources — but overall costs may actually be reduced because of the impact on readmissions and carer health.	**YES**
	NO

E.3 Respite care

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

<table>
<tr><td colspan="4">Key question(s): Does a model of care that includes respite care improve physical and/or psychological health in older adults who have moderate or severe dementia as compared with a model of care that does not include this respite care?</td><td>Evidence table ref:</td></tr>
<tr><td colspan="5">1. Evidence base (number of studies, level of evidence and risk of bias in the included studies)</td></tr>
<tr><td rowspan="2">Placement delay (ie residential care)</td><td rowspan="2">Behaviour</td><td rowspan="2">Function (physical and/or cognitive)</td><td>A</td><td>Several Level I or II studies with low risk of bias</td></tr>
<tr><td>B</td><td>one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias</td></tr>
<tr><td rowspan="2">D</td><td rowspan="2">D</td><td rowspan="2">D</td><td>C</td><td>Level III studies with low risk of bias or Level I or II studies with moderate risk of bias</td></tr>
<tr><td>D</td><td>Level IV studies or Level I to III studies with high risk of bias</td></tr>
<tr><td colspan="5">2. Consistency (if only one study was available, rank this component as ‘not applicable’)</td></tr>
<tr><td rowspan="2">Placement delay (ie residential care)</td><td rowspan="2">Behaviour</td><td rowspan="2">Function (physical and/or cognitive)</td><td>A</td><td>All studies consistent</td></tr>
<tr><td>B</td><td>Most studies consistent and inconsistency can be explained</td></tr>
<tr><td rowspan="2">D</td><td rowspan="2">D</td><td rowspan="2">D</td><td>C</td><td>Some inconsistency, reflecting genuine uncertainty around question</td></tr>
<tr><td>D</td><td>Evidence is inconsistent</td></tr>
<tr><td colspan="3"></td><td>NA</td><td>Not applicable (one study only)</td></tr>
</table>

3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*				
Placement delay (ie residential care)	*Behaviour*	*Function (physical and/or cognitive)*	A	**Very large**
			B	**Moderate**
N/A	N/A	N/A	c	**Slight**
			D	**Restricted**
4. Generalisability				
Placement delay	*Behaviour*	*Function (physical and/or cognitive)*	A	**Evidence directly generalisable to target population**
			B	**Evidence directly generalisable to target population with some caveats**
A	A	A	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
			D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability				
Placement delay	*Behaviour*	*Function (physical and/or cognitive)*	A	**Evidence directly applicable to Australian healthcare context**
			B	**Evidence applicable to Australian healthcare context with few caveats**
A	A	A	C	**Evidence probably applicable to Australian healthcare context with some caveats**
			D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	*Placement delay*	*Behaviour*	*Function (physical and/or cognitive)*	**Description**
1. Evidence base	D	D	D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency	D	D	D	**Evidence is inconsistent**
3. Clinical impact	N/A	N/A	N/A	
4. Generalisability	A	A	A	**Evidence directly generalisable to target population**
5. Applicability	A	A	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions NONE

RECOMMENDATION	**GRADE OF RECOMMENDATION**
There is insufficient evidence upon which to base a recommendation in this area.	N/A

High level evidence is lacking regarding the impact of respite care on people who have dementia and study findings are limited. Longer and multi-component interventions may be more effective at delaying placement. The issue of behavioural change following respite merits further, more rigorous, investigation. The likely impact upon the carer of behavioural symptoms and its possible translation into capacity to continue in the care giving role is clearly an important consideration.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? N/A	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? N/A	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? N/A	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? N/A	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s):): Does a model of care that includes respite care improve physical and/or psychological health in carers of clients who have moderate or severe dementia as compared with a model of care that does not include this respite care?		**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*		
A	A	**Several Level I or II studies with low risk of bias**
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
	D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*		
D	A	**All studies consistent**
	B	**Most studies consistent and inconsistency can be explained**
	C	**Some inconsistency, reflecting genuine uncertainty around question**
	D	**Evidence is inconsistent**
	NA	**Not applicable (one study only)**
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*		
D	A	**Very large**
	B	**Moderate**
	C	**Slight**
	D	**Restricted**

4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	A	**Several Level I or II studies with low risk of bias**
2. Consistency	D	**Some inconsistency, reflecting genuine uncertainty around question**
3. Clinical impact	D	**Slight**
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions

RECOMMENDATION	**GRADE OF RECOMMENDATION**
Respite care should be available to support carers of people with moderate or severe dementia.	D

Multiple outcomes for carers have been investigated in a large number of studies of the impact of respite. Overall, there are indications of benefits for carer health from respite, but the variability in study findings most likely reflects the varied types and dosages of respite interventions and the extent to which they are combined with other supportive interventions.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? Yes as respite care is not currently routinely available to all carers of people with moderate and severe dementia.	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? Yes — to provide this respite care routinely.	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? Yes — more resources will need to be mobilised.	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? There are costs associated with respite care, however, these costs will be minimised if respite is provided selectively. The individual needs of family carers need to be considered carefully as some carers will benefit more from other supportive alternatives. Also just knowing that respite available if really needed might be helpful.	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does a model of care that includes respite care improve physical and/or psychological health in carers of generally frail or unwell older adults[1] (non-specific population) as compared with a model of care that does not include this respite care? [1] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.				**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*				
Depression	*Burden*	A	**Several Level I or II studies with low risk of bias**	
		B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**	
A	A	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**	
		D	**Level IV studies or Level I to III studies with high risk of bias**	
2. Consistency *(if only one study was available, rank this component as 'not applicable')*				
Depression	*Burden*	A	**All studies consistent**	
		B	**Most studies consistent and inconsistency can be explained**	
A	B	C	**Some inconsistency, reflecting genuine uncertainty around question**	
		D	**Evidence is inconsistent**	
		NA	**Not applicable (one study only)**	

3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
Depression	*Burden*	A	**Very large**
		B	**Moderate**
B	C	C	**Slight**
		D	**Restricted**
4. Generalisability			
Depression	*Burden*	A	**Evidence directly generalisable to target population**
		B	**Evidence directly generalisable to target population with some caveats**
A	A	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
		D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability			
Depression	*Burden*	A	**Evidence directly applicable to Australian healthcare context**
		B	**Evidence applicable to Australian healthcare context with few caveats**
A	A	C	**Evidence probably applicable to Australian healthcare context with some caveats**
		D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	*Depression*	*Burden*	**Description**
1. Evidence base	A	A	**Several Level I or II studies with low risk of bias**
2. Consistency	A	B	**All studies consistent/ Most studies consistent and inconsistency can be explained**
3. Clinical impact	B	C	**Moderate/slight**
4. Generalisability	A	A	**Evidence directly generalisable to target population**
5. Applicability	A	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions NONE

RECOMMENDATION Respite care should be routinely available to support family carers of older adults with non specific and advanced life limiting illness, frailty, or extreme old age.	**GRADE OF RECOMMENDATION** A
There is evidence that respite for carers of non specific populations of older adults reduces burden and depression so it is recommended that this strategy should be made available. Flexibility in arrangements and other components of support alongside respite are also recommended as this is likely to enhance the effectiveness of the intervention. In particular, it would be important for respite to be available quickly in the case of an emergency situation, such as carer illness. Respite also needs to be made available at frequent intervals as it is likely that the effect is short lived.	
IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? Yes — respite is not always available and especially not at short notice or at frequent intervals.	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? Yes. The provision of respite care does represent a cost but it should lead to a reduction in carer ill health as a result, which can also be costly in terms of health care provided.	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? Yes — see above.	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? Resource issues	**YES**
	NO

E.4 Disease-specific education for family carers

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does cancer specific education for family carers of older adults with advanced cancer improve family carer confidence, competence, physical, psychological and spiritual health when compared with a lack of this education?		**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*		
B	A	**Several Level I or II studies with low risk of bias**
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
	D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*		
N/A — one study only	A	**All studies consistent**
	B	**Most studies consistent and inconsistency can be explained**
	C	**Some inconsistency, reflecting genuine uncertainty around question**
	D	**Evidence is inconsistent**
	NA	**Not applicable (one study only)**

3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*		
C	A	**Very large**
	B	**Moderate**
	C	**Slight**
	D	**Restricted**
4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
2. Consistency	N/A	
3. Clinical impact	C	
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions

RECOMMENDATION	GRADE OF RECOMMENDATION
Active education in the area of cancer care should be made available for family carers of older adults who have advanced cancer	C

A high quality primary study met the criteria in this field. It is noted that significant effects were found for carer quality of life, burden of patient symptoms, and care giving task burden.

IMPLEMENTATION OF RECOMMENDATION *Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.*	
Will this recommendation result in changes in usual care? Yes as this is not currently widely available.	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? Yes — for the training of staff and for implementation.	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? Yes — see above	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? Yes but there may be overall benefits if the carer needs less health for themselves care as a result of the education	**YES**
	NO

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does dementia specific education for family carers of older adults who have moderate or severe dementia improve family carer confidence, competence, physical, psychological and spiritual health in these carers when compared with a lack of this education?			**Evidence table ref:**
Burden	**Depression**		
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*			
A	A	A	**Several Level I or II studies with low risk of bias**
		B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
		C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
		D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*			
B	B	A	**All studies consistent**
		B	**Most studies consistent and inconsistency can be explained**
		C	**Some inconsistency, reflecting genuine uncertainty around question**
		D	**Evidence is inconsistent**
		NA	**Not applicable (one study only)**

3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*			
B	B	A	**Very large**
		B	**Moderate**
		C	**Slight**
		D	**Restricted**
4. Generalisability			
A	A	A	**Evidence directly generalisable to target population**
		B	**Evidence directly generalisable to target population with some caveats**
		C	**Evidence not directly generalisable to the target population but could be sensibly applied**
		D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability			
A	A	A	**Evidence directly applicable to Australian healthcare context**
		B	**Evidence applicable to Australian healthcare context with few caveats**
		C	**Evidence probably applicable to Australian healthcare context with some caveats**
		D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Burden	Depression	Description
1. Evidence base	A	A	**Several Level I or II studies with low risk of bias**
2. Consistency	B	B	**Most studies consistent and inconsistency can be explained**
3. Clinical impact	B	B	**Moderate Evidence directly generalisable to target population**
4. Generalisability	A	A	**Evidence directly generalisable to target population**
5. Applicability	A	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions

None

RECOMMENDATION: Active education in the area of dementia care should be made available for family carers of older adults with moderate/ severe dementia	**GRADE OF RECOMMENDATION** A

There are two main types of education addressed in this area — the provision of information alone and the provision of information in conjunction with training or advice regarding how this information may be used in the provision of care (active education). Skills training (eg behaviour management or communication training) is generally involved in active education. Other considerations are whether this is group education (generally out of the home) or individualised education (usually provided in the home either face to face or via the phone). There is also variation in the dosage of information.

Active education provided for carers of older adults with dementia has been found to lead to improvements in burden and depression whereas the provision of information alone has been found to have no effect or a negative effect. Active education plus psychosocial support have been found to have the most benefits. Skills training interventions have been seen to have more positive effects when they are delivered over a longer time frame. The use of phone calls for education has been shown to have a limited or no effect. Other outcomes being investigated in this area include well being and quality of life; studies in these areas may provide future sources of rich information.

IMPLEMENTATION OF RECOMMENDATION

Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.

Will this recommendation result in changes in usual care? Yes — this is not routine at present	**YES**
Are there any resource implications associated with implementing this recommendation? Yes — staff time. However, if carer burden and depression are impacted upon there will also be savings.	**YES**
Will the implementation of this recommendation require changes in the way care is currently organised? Yes	**YES**
Are the guideline development group aware of any barriers to the implementation of this recommendation? Resource limitations of service providers and time limitations of family carers	**YES**

NHMRC Evidence Statement (based upon NHMRC standards and procedures for externally developed guidelines updated Sep 2007)

Key question(s): Does stroke related education for family carers of older adults who have an advanced frailty or disability due to stroke improve confidence, competence, physical, psychological and spiritual health in those carers when compared with a lack of this education?		**Evidence table ref:**
1. Evidence base *(number of studies, level of evidence and risk of bias in the included studies)*		
B	A	**Several Level I or II studies with low risk of bias**
	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
	C	**Level III studies with low risk of bias or Level I or II studies with moderate risk of bias**
	D	**Level IV studies or Level I to III studies with high risk of bias**
2. Consistency *(if only one study was available, rank this component as 'not applicable')*		
C	A	**All studies consistent**
	B	**Most studies consistent and inconsistency can be explained**
	C	**Some inconsistency, reflecting genuine uncertainty around question**
	D	**Evidence is inconsistent**
	NA	**Not applicable (one study only)**
3. Clinical impact *(Indicate in the space below if the study results varied according to some <u>unknown</u> factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)*		
C	A	**Very large**
	B	**Moderate**
	C	**Slight**
	D	**Restricted**

4. Generalisability		
A	A	**Evidence directly generalisable to target population**
	B	**Evidence directly generalisable to target population with some caveats**
	C	**Evidence not directly generalisable to the target population but could be sensibly applied**
	D	**Evidence not directly generalisable to target population and hard to judge whether it is sensible to apply**
5. Applicability		
A	A	**Evidence directly applicable to Australian healthcare context**
	B	**Evidence applicable to Australian healthcare context with few caveats**
	C	**Evidence probably applicable to Australian healthcare context with some caveats**
	D	**Evidence not applicable to Australian healthcare context**

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation)*

Fragmented evidence base. Variability in outcomes. Emphasis on care recipient rather than carer outcomes.

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	B	**one or two Level II studies with low risk of bias or SR/multiple Level III studies with low risk of bias**
2. Consistency	C	**Evidence is inconsistent**
3. Clinical impact	C	**Slight**
4. Generalisability	A	**Evidence directly generalisable to target population**
5. Applicability	A	**Evidence directly applicable to Australian healthcare context**

Indicate any dissenting opinions — NONE

RECOMMENDATION	GRADE OF RECOMMENDATION
Active education in the area of post-stroke care should be made available for family carers of older adults who have advanced disability or frailty due to stroke	C

This evidence base for carer education in the area of post-stroke care is fragmented. There is variability in outcomes assessed and a greater emphasis on care recipient outcomes. The evidence is also somewhat inconsistent. On balance, however, benefits are shown for active education.

IMPLEMENTATION OF RECOMMENDATION

Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.

Will this recommendation result in changes in usual care? Yes as this is not usual care at present.	**YES**
	NO
Are there any resource implications associated with implementing this recommendation? Yes, time will be needed to implement the education but is likely to lead to on balance benefits because of improved carer health.	**YES**
	NO
Will the implementation of this recommendation require changes in the way care is currently organised? Yes, routine education programs will need to be developed and implemented.	**YES**
	NO
Are the guideline development group aware of any barriers to the implementation of this recommendation? Yes Resources but these may also be saved if carer health is improved.	**YES**
	NO

E.5 End-of-life care education for family carers

Question: Does education for family carers in end of life care improve their experience of the death of their family member and their post bereavement health as compared with a lack of this education?

Retained articles

None

References

Ali W, Rasmussen P, What is the evidence for the effectiveness of managing the hospital / community interface for older people? A critical appraisal of the literature, New Zealand Health Technology Assessment; 2004.

Clark MS, Rubenach S, Winsor A. A randomized controlled trial of an education and counselling intervention for families after stroke. Clin Rehabil 2003; **17**(7): 703–712.

Hastings SN, Heflin MT. A systematic review of interventions to improve outcomes for elders discharged from the emergency department. Academic Emergency Medicine 2005; **12**(10): 978–986.

Hughes SL, Weaver FM, Giobbie-Hurder A, Manheim L, Henderson W, Kubal JD, Ulasevich A, Cummings J. Effectiveness of team-managed home-based primary care: a randomized multicenter trial. JAMA: The Journal of The American Medical Association 2000; **284**(22): 2877–2885.

Appendix F Processes involved in document development other than systematic reviews

The processes documented here allowed the development of good practice points, these being practice recommendations not underpinned by the findings of systematic reviews of the literature but developed by expert consensus. In many instances, including for Sections 3.1, 3.3, 4.1 and 4.3, nonsystematic review of the literature informed this process. Literature was available for nonsystematic reviews from the extensive search documented in Appendix A.

For the domains of spiritual support, psychosocial care, and advance care planning and advance health care directives, literature reviews (systematic and narrative) were reviewed by our team. These reviews provided a briefer overview than would have been the case had individual studies been utilised, yet allowed for broad topic coverage.

For the domains of a palliative approach to care for Aboriginal and Torres Strait Islander people, older adults from culturally and linguistically diverse groups, and older adults with perspectives or needs requiring special consideration, discussion chapters included relevant literature that was available. This approach was adopted because of the paucity of the literature in the area.

For the domain of symptom assessment and management, clinical practice guidelines were listed for practitioners to access. These guidelines were obtained via a search of relevant databases and via a search of relevant web sites (Table F.1).

Guideline search of databases

All searches were restricted to clinical practice guidelines

CINAHL

1 (Exp Pain/ or Analgesia/ or Pain Measurement/) or (pain manage* or pain assess* or physical suffering)

2 (Exp Fatigue/ or Asthenia/) or debility

3 (Exp Nutrition/ or Geriatric Nutrition/ or exp Diet/ or exp Food/) or hydration

4 (Cachexia/ or exp Weight Loss/) or (wasting syndrome or appetite problem*)

5 Deglutition Disorders/ or (dysphagia or swallowing disorder)

6 (exp Oral Hygiene/ or exp Mouth Care/ or exp Dentistry/ or Candidiasis, Oral/ or Mouth Mucosa/) or (oral care)

7 (Wounds,Chronic/ or exp Wounds and Injuries/ or Pressure Ulcer/) or (skin integrity or wound* or pressure care or pressure sore* or bedsore* or decubitus ulcer*)

8 (Bowel Continence/ or Urinary Continence/ or Bowel Incontinence/ or Bowel Incontinence Care/ or Urinary Incontinence Care/ or Enuresis/ or Bowel Management/ or Bowel care/ or Cathaetics/) or (incontinence or continence or faecal incontinence or laxative* or aperient or constipation or diarrhoea)

9 Delirium/ or exp Confusion/ or Chronic Confusion/ or Delirium Management/ or Hallucinations/

10 (Dyspnea/ or exp Respiration/ or exp Respiration Disorders/) or (respiratory symptom* or dyspnoea or breathlessness or breathing oxygen or breathing problem*)\

11 (Alternative Therapies/) or (complementary therap* or complementary medicine* or alternative medicine)

12 (Exp Depression/) or (depressed or clinical depression)

13 (exp Anxiety/ or exp Anxiety Disorders/) or (anxious or nervous or sad)

14 (Exp Psychosocial Aspects of Illness/ or exp Support, Psychosocial/ or exp Quality of Life/ or Psychological Wellbeing/) or (psychosocial distress or psychological distress or psychiatric distress)

15 Exp Lymphedema/

16 Nausea/ or exp Nausea and Vomiting/

17 (Exp Drugs/ or exp Pharmacy and Pharmacology/) or (medication or medicine* or pharmacist*)

18 Or/ 1-17

19 (Symptom Distress/) or (symptom assess* or symptom measure* or symptom manage*)

20 18 or 19

21 20 and (Publication Type: Practice Guidelines)

22 Limit 21 to (Publication Year from 1997-2007) and (Language: English)

MEDLINE

1 (Exp pain/ or exp Abdominal pain/ or exp Back Pain/ or exp Chest Pain/ or exp Analgesia/) or (pain manage* or pain assess* or pain measure* or physical suffering)

2 (Fatigue/ or Auditory Fatigue/ or Mental Fatigue/ or Muscle Fatigue/ or Asthenia/) or debility

3 (Exp Nutrition Disorders/ or exp Diet/ or exp Food/) or (nutrition or dehydration or hydration)

4 Cachexia/ or exp Weight Loss/ or Wasting Syndrome/

5 (Exp Deglutition disorders/) or (dysphagia or swallowing disorder*)

6 Exp Appetite/

7 (Exp Candidiasis, Oral/ or Oral Health/ or Mouth Mucosa/ or exp Oral Hygiene/ or exp Dentistry/ or Geriatric Dentistry/) or (oral care or mouth care)

8 (Exp Wound Healing/ or exp Wound Infection/ or exp Wounds and Injuries/ or Pressure Ulcer/) or (skin integrity or pressure care or pressure sore* or bedsore* or decubitus ulcer*)

9 (Fecal Incontinence/ or exp Urinary Incontinence/ or exp Enuresis) or (continence or incontinence)

10 (athartics/ or Constipation/ or exp Diarrhea/) or (bowel care or bowel problem* or laxative* or aperient or diarrhoea)

11 Delirium/ or exp Delirium, Dementia, Amnestic, Cognitive Disorders/ or exp Confusion/ or Hallucinations/

12 Accidental Falls/

13 (Exp Signs and Symptoms, Respiratory/ or exp Dyspnea/ or Respiration/ or exp Oxygen/ or exp Oxygen Consumption/ or exp Oxygen Inhalation Therapy/) or (dyspnoea or breathlessness or breathing oxygen)

14 (Exp Complementary Therapies/) or (complementary medicine or alternative therap* or alternative medicine)

15 (Depression/ or exp Dementia/ or exp Delirium, Dementia, Amnestic, Cognitive Disorders/ or exp Aggression/) or (agitation or depressed or clinical depression)

16 (Exp Anxiety/) or (anxious or nervous or sad)

17 (Quality of Life/) or (psychological distress or psychosocial or psychological or psychiatric or personality or distress)

18 (Exp Lymphedema/) or (lymphoedema)

19 (Exp Nausea/ or exp Vomiting/)

20 (Pharmaceutical Preparations/ or Pharmacy/ or Pharmacies/) or (medication* or medicine* or drug*)

21 (Affective Symptoms/ or exp Behavioral Symptoms/ or exp Pathological

Conditions, Signs and Symptoms/ or exp Signs and Symptoms/ or exp Signs and Symptoms, Digestive/ or exp Signs and Symptoms, Respiratory/) or (symptom* distress or symptom* manage* or symptom assess*)

22 Or/1-21

23 Clinical practice guideline* or practice guideline*

24 22 and 23

25 22 and (Publication Type: Practice Guideline)

26 24 or 25

27 Limit 26 to (Date of Publication from: 199701-200712) and (English)

PsycINFO

1 exp Symptoms/ or Positive and Negative Symptoms/ or Symptom Checklists/

2 symptom assessment or symptom measurement or symptom distress or symptom management

3 1 or 2

4 exp Pain/ or Chronic Pain/ or Pain Management/ or Pain Measurement/ or Analgesic Drugs/ or Analgesia /

5 (Fatigue/ or Myasthenia/) or (debility or asthenia)

6 (Nutrition/ or Nutritional Deficiencies/ or Protein Deficiency Disorders/ or Starvation/ or Vitamin Deficiency Disorders/ or Dehydration/ or Diets/ or Food/ or Food Intake/ or Appetite/ or Hunger/) or (hydration or appetite problems)

7 cachexia or weight loss or wasting syndrome

8 (Dysphagia/) or (deglutition disorder* or swallowing disorder*)

9 Dentistry/ or (oral care or mouth care or oral candidiasis or oral mucosa or oral Hygiene)

10 (Wounds/) or (skin integrity or pressure care or pressure ulcer* or pressure sore* or bedsore* or decubitus ulcer*)

11 Falls/

12 (Urinary Incontinence/ or Fecal Incontinence/) or (incontinence or enuresis)

13 (Irritable Bowel Syndrome/ or exp Colon Disorders/ or Constipation/ or Diarrhea/) or (bowel care or laxative* or aperient or diarrhoea)

14 Delirium/ or Mental Confusion/ or Auditory Hallucinations/ or Drug Induced Hallucinations/ or Visual Hallucinations/ or Auditory Hallucinations/

15 (Dyspnea/ or Respiration/ or Respiratory Distress/ or Oxygen/) or (dyspnoea respiratory symptom*or breathlessness or breathing)

16 (Exp Alternative Medicine/) or (complementary therap* or complementary medicine or alternative therap*)

17 (Exp Major Depression/ or Depression (Emotion)/ or Recurrent Depression/) or (depressed or clinical depression)

18 (Anxiety/ or Anxiety Disorders/) or (anxious or nervous or sad)

19 (Distress/ or Psychosocial Readjustment/ or Psychosocial Factors/ or Quality of Life/ or Delirium/ or Dementia/ or Presenile Dementia/ or Senile Dementia/ or Alzheimers Disease/ or Agitation/ or Major Depression/ or Aggressive Behaviour/ or Aggressiveness/) or (psychological distress or aggression)

20 lymphoedema or lymphedema

21 Nausea/ or Vomiting/

22 (Exp Drugs/) or (medication* or medicine*or pharm*)

23 Or/ 1-22

24 Good practice point* or clinical practice guideline* or practice guideline* or treatment Guideline*

25 23 and 24

26 Limit 25 to (Publication Year from: 1997-2007) and (Publication Type:All Journals) and (English) and (Population Group: Humans)

Current Contents

1 pain or pain management or pain assessment or pain measurement or physical suffering or analgesia

2 fatigue or debility or asthenia

3 nutrition or hydration or diet or food

4 cachexia or weight loss or wasting syndrome

5 dysphagia or deglutition disorder* or swallowing disorder or appetite problem*

6 oral care or mouth care or dentistry or oral candidiasis or oral mucosa or oral hygiene

7 skin integrity or wound* or pressure care or pressure ulcer* or pressure sore* or bedsore* or decubitus ulcer*

8 continence or incontinence or urinary incontinence or faecal incontinence or enuresis

9 constipation or diarrhoea or diarrhea or bowel care or laxative or aperient

10 fall* or accident*

11 delirium or confusion or hallucination* or dementia or agitation or aggressi*

12 respiratory symptom*or dyspnoea or breathlessness or breathing or oxygen

13 complementary therap* or complementary medicine or alternat* therap* or alternat* medicine

14 depression or depressed or clinical depression

15 anxiety or anxious or nervous or sad

16 psychological distress or psychosocial or quality of life or psychological or personality or distress

17 lymphoedema or lymphedema

18 nausea or vomit*

19 edication or medicine or drug* or pharmacy

20 Or/ 1-19

21 symptom assessment or symptom measurement or symptom distress or symptom management

22 clinical practice guideline* or good practice point* or practice guideline*

23 20 and 21 and 22

24 community dwelling or home care or home health care or home nursing

25 24 and 22

26 23 or 25

27 Limit 26 to Human and Publication Years: 1998-2007

Cochrane Library

1 Exp Signs and Symptoms/

2 (symptom assessment or symptom measurement or symptom management)

3 Symptom* and (tool* or indicator* or instrument* or assess* or measure* or manage*)

4 1 or 2 or 3

5 Clinical Practice Guideline* or good practice point* or practice guideline*

6 Community Health Nursing/ or Community Health Services/ or Community Medicine/ or exp Home Care Services/ or exp Home Nursing/ or Home Care Agencies/ or Primary Health Care/ or Physicians, Family/ or Activities of Daily Living/ or House Calls/) or (community dwelling or housebound or homebound)

7 (Aged/ or Geriatics/ or Frail Elderly/) or (elder* or gerontology* or old*)

8 4 and 5 and 6 and 7

9 Palliative Care/ or exp Terminal Care/ or Hospice Care/ or exp Death/

10 (Exp Pain/ or Pain Measurement/ or exp Analgesia/) or (pain assessment or pain management)

11 Fatigue/ or Asthenia/

12 Dehydration/ or exp Diet/ or exp Food/ or exp Appetite/ or Cachexia/ or exp Weight Loss/ or Wasting Disease, Chronic/ or exp Deglutition Disorders/

13 exp Candidiasis, Oral/ or exp Mouth/ or Oral Hygiene/) or (oral care or dentistry or oral mucosa)

14 Exp Wounds and Injuries/ or Pressure Ulcer/) or (skin integrity or pressure care or pressure sore* or decubitus ulcer* or bedsore*)

15 (Fecal Incontinence/ or Nocturnal Enuresis/ or exp Urinary Incontinence/ or Constipation/ or exp Diarrhea/) or (incontinence or bowel or laxative* or aperient)

16 Cathartics/

17 Accidental Falls/

18 (Delirium/ or exp Confusion/ or Hallucinations/ or Aggression/ or exp Dementia/ or exp Aggression/) or (agitation or aggressive)

19 (Respiratory Distress Syndrome, Adult/ or exp Dyspnea/ or exp Oxygen/) or (respiratory symptom* or breathlessness or breathing)

20 Exp Complementary Therapies/

21 (Depression/ or exp Anxiety/ or Social Support/ or Quality of Life/) or (psychological distress or psychosocial or psychological or psychiatric or personality or distress or anxious or nervous or sad or depressed)

22 Exp Lymphedema/

23 Exp Nausea/ or exp Vomiting/

24 Medication or pharmacy*

25 Or/ 9-24

26 Clinical Practice Guideline* or good practice point* or practice guideline*

27 25 and 26 and 7

28 8 or 27

29 Limit 28 to years 1997-2007

Informit health databases: (Databases searched simultaneously) **APAIS – Health, ASTIHealth, Drug, H&S- Health & Society Database, Informit E-Library, Rural & Remote Database, Meditext**

1 practice guideline* or clinical practice guideline* or good practice point*

2 aged or elder* or gerontolog* or geriatric* or old* or functionally impaired or frail*

3 community dwelling or domiciliary or home care or home health care or home nursing or hospital in the home or activities of daily living or self care or home visit* or house call* or aging in place or home environment or home hospice or community hospice or homebound or housebound or primary care or general practitioner* or GP* or family physician* or palliative approach

4 palliat* or hospice or end of life or terminal care or terminal illness or dying or death

5 (pain) and (manage* or assess* or measure*)

6 pain management or pain assessment or pain measurement or physical suffering or analgesia

7 fatigue or debility or asthenia

8 nutrition or hydration or dehydration or diet or food or appetite

9 cachexia or weight loss or wasting syndrome

10 dysphagia or deglutition disorder* or swallowing disorder

11 oral care or mouth care or dentistry or oral candidiasis or oral mucosa or oral hygiene

12 skin integrity or wound* or pressure care or pressure sore* or pressure ulcer* or bedsore* or decubitus ulcer*

13 fall*

14 continence or incontinence or urinary incontinence or faecal incontinence or enuresis

15 bowel or laxative* or aperient* or constipation or constipated or diarrhoea or diarrhea or cathartics

16 delirium or confusion or hallucination* or dementia or agitation or aggression or aggressive

17 respiratory or dyspnoea or breathlessness or breathing or oxygen

18 complementary therap* or complementary medicine or alternat* therap* or

19 depression or depressed or clinical depression

20 anxiety or anxious or sad

21 sychological or psychosocial or quality of life or psychiatric or personality or distress

22 lymphoedema or lymphedema

23 nausea or vomit*

24 medication or medicine* or pharmac* or pharmaceutical preparation*

25 Or/ 3 -24

26 1 and 25

27 (symptom*) and (assess* or measure* or distress or manage* or tool* or indicator* or instrument*)

28 symptom assessment or symptom measurement or symptom distress or symptom management

29 27 or 28

30 27 and 1 and 2

31 26 or 30

32 Limit 31 to Years 1997-2007

AARP AgeLine

1 home care/ or home health care/ or primary care/ or activities of daily living/ or self care/ or aging in place/

2 palliative care/ or hospice/ or terminal care/ or dying/ or death/

3 symptoms/

4 (pain*) or (pain assessment for the dementing elderly/ or pain assessment in advanced dementia scale/ or pain management/)

5 fatigue/

6 nutrition/ or nutritional requirements/ or nutritional disorders/ or dehydration/ or diet/ or dietary services/ or foods/ or appetite/ or malnutrition/

7 weight/ or weight change/ or weight control/

8 dysphagia/

9 oral health/ or dentists/ or dentures/

10 falls/

11 skin/ or pressure sores/

12 incontinence/ or constipation/

13 delirium/ or delusions/ or dementia/ or confusion/ or hallucinations/ or agitation/ or aggression/

14 respiratory diseases/ or dyspnea/

15 alternative medicine/

16 depression/ or psychological wellbeing/ or psychosocial needs/ or quality of life/

17 medication management/ or drugs/ or pharmaceutical services/ or pharmacists/

18 OR/ 1- 17

19 Clinical Practice Guidelines/ or Professional Guides/

20 18 and 19

21 Limit 20 to (Publication Year: 1997- 2007) and (Audience Type: Research/ Academic

Table F.1 Relevant websites

Website name	Home URL	Search term(s)
National Guideline Clearinghouse	http://www.guidelinegov/	(older adult* OR elderly OR aged) AND palliative AND symptom*
NHMRC	http://nhmrc.gov.au/index.htm	All the words: palliative symptoms The phrase: older adult Optional words: elderly aged File type: Any Sort by: Relevance
Palliative Care Australia	http://www.pallcare.org.au/	Browsing
Palliative Care Australia	http://www.pallcare.org.au/	Browsing
Aged Care Australia	http://www.agedcareaustralia.gov.au/	Palliative
Help the Aged (UK)	http://policy.helptheaged.org.uk/_policy/default.htm	Palliative
Clinical Information Access Online	http://www.ciao.health.wa.gov.au/	search by topic
The Canadian Medical Association	http://www.cma.ca	search by topic
The Institute of Health Sciences, Oxford University, UK.	http://www.ihs.ox.ac.uk/library/Librarylinks.htm#Guidelines	search by topic
The Joanna Briggs Institute	http://www.joannabriggs.edu.au/	Palliative AND/OR Aged care
Medical Journal Australia	http://www.mja.com.au/public/guides/guides.html	Browsing
British Medical Journal	www.bmj.com	palliative AND aged care AND guidelines
New Zealand Guidelines Group	http://www.nzgg.org.nz	search by topic
The Scottish Intercollegiate Guidelines Network (SIGN)	http://www.sign.au.uk	search by topic
Australian Wound Management Association	http://www.awma.com.au	Palliative AND/OR Aged care
National	www.npuap.org	search by topic

Pressure Advisory Panel		
US Department of Health and Human Services	www.hhs.gov	search by topic
Agency for Health Care Policy and Research	www.ahrq.gov/clinic.cpgsix	search by topic
Wound Continence Nurses Society	www.wcns	search by topic
Royal College of Nursing Australia	www.rcna.org.au	Palliative AND/OR Aged care
Royal College of GPs Australia	www.rcgp.org.au	Palliative AND/OR Aged care
Royal Australasian College of Physicians	www.racp.edu.au	Palliative AND/OR Aged care
Royal College of Nursing, UK	www.rcn.org.uk	Palliative AND/OR Aged care
Royal College of GPs UK	www.cgp.org.uk	Palliative AND/OR Aged care
National Hospice and Palliative Care Organisation	www.nhpo.org.au	Palliative AND/OR Aged care AND guidelines
Congress of Aboriginal and Torres Strait Islander Nurses	www.catsin.org.au	Browsing
CRANA	www.crana.org.au	Browsing
Palliative Care Council South Australia	www.pccsa.org.au	Browsing
Australian Society of Geriatric Medicine	www.asgm.org.au	Browsing
Centre for online Health	www.coh.uq.edu.au	guideline
Dieticians Association Australia	http://www.daa.asn.au/index.asp?pageID = 2145833445	guideline (some guideline on site, but documents secure, population unclear)

Department of Pain Medicine and Palliative Care @ Beth Israel Medical Centre NY	http://www.stoppain.org/	browsing and site search
Curtin Centre for Research on Ageing	http://cra.curtin.edu.au/	browsing publications list, find for guidelines
CareSearch	http://www.caresearch.com.au	guidelines and aged (106)/ guidelines and elderly (106), guidelines and palliative and aged (244)
Health Insite	http://www.healthinsitegov.au/	clinical practice guideline* and palliative
National Institute of Clinical Studies	http://www.nhmrc.gov.au/nics/asp/index.asp	palliative
Australian Medical Association	http://www.ama.com.au/web.nsf/	clinical practice guideline and palliative, CPG and elderly, CPG and aged
BMA online library	http://ex-lo-bma.exlibrisgroup.com/F/7 MVN99FR3NT98JAPJELYS2YQSFBTUKPVRCHDBURMVKJLFY7V39–67896?func = find-b-0	clinical practice guideline and clinical practice guidelines
British Medical Association	http://www.bma.org.uk/ap.nsf/content/home	clinical practice guideline and clinical practice guidelines
National institute for health and clinical excellence	http://www.nice.org.uk/	guideline search for aged (63), elderly (5), older adult (88), palliative (11)
From National institute of Clinical Studies *Where's the evidence* document?		
NHMRC (clinical practice guidelines publications menu)	http://www.nhmrc.gov.au/publications/subjects/clinical.htm	browsing
Immunise Australia Program	http://immunise.health.gov.au/	no clinical practice guidelines, however has best practice information….?
Royal Australian and New Zealand College	http://www.ranzcp.org	anorexia nervosa, bipolar, deliberate self harm, depression, panic disorder,

of Psychiatrists		agoraphobia
Royal Children's Hospital Melbourne	http://www.rch.org.au/clinicalguide/index.cfm?doc_id = 5033	search: older adults, elderly, aged — none applicable to aged care
Palliative Care Victoria	http://www.pallcarevic.asn.au/	clinical practice guidelines — see MJA (document 12), other results webpage of therapeutic guidelines (http://tg.com.au/index.php?sectionid = 47) where palliative guideline can't be accessed without full version
Trip Database — Evidence Based Medicine	http://www.tripdatabase.com/index.html	in evidence based medicine: clinical practice guideline* AND (older adult* OR aged OR elderly) AND palliative
SUMsearch	http://sumsearch.uthscsa.edu/	OLDER ADULT* OR ELDERLY OR AGED AND PALLIATIVE AND SYMPTOM* AND CLINICAL (Focus: TREATMENT, ages: aged, subjects: HUMAN)
Google Scholar	http://scholar.google.com.au/schhp?hl = en&lr =	clinical practice guidelines older adults elderly aged palliative
American Pain Society	http://ampainsoc.org.au	clinical practice guidelines
Institute of clinical systems improvement	htt://icsi.org	clinical practice guidelines-search by topic-all available at guideline clearing house
World Health Organisation	http://who.int	clinical practice guidelines
International Association for the study of pain	http://www.iasp-pain.org/terms-p.html	clinical practice guidelines
National Centre for Complimentary and Alternative Medicine (NCCAM).	http://nccam.nih.gov	clinical practice guidelines
Department of Health and Ageing Australia	www.health.gov.au/internet/main/publishing	clinical practice guidelines + medicine and/or complimentary and alternative medicine

An adapted version of the *Appraisal of Guidelines for Research and Evaluation (AGREE) Instrument* (AGREE Collaboration 2003) was used as a guide to determine which guidelines should be documented for practitioners in Chapter 6. To be included, guidelines were required to address each of the domains in the adapted AGREE instrument, meeting a preset proportion of items within each domain (Table F.2). Decisions about which symptoms should be addressed in Chapter 6, and if suitable guidelines should be available, were made in consultation with the reference group and from the findings of the national consultative process.

Table F.2 The adapted AGREE instrument

Item from the AGREE instrument for rating guidelines	Inclusion: what is required to be in the guidelines
Domain 1: scope and purpose *2 out of 3 items must be addressed*	
Item 1. The overall objective(s) of the guideline is (are) specifically described	The guideline describes its objectives as well as the potential impact clearly and specifically
Item 2. The clinical question(s) covered by the guideline is(are) specifically described	The questions that are covered by the guideline are generally or specifically described
Item 3. The patients to whom the guideline is meant to apply are specifically described	The guideline provides a clear definition of the target population, so that the guideline users know exactly to whom the guideline should be applied.
Domain 2. Stakeholder involvement *3 out of 4 items must be addressed*	
Item 4. The guideline development group includes individuals from all relevant professional groups	The guideline development group consists of relevant disciplines
Item 5. The patients' views and preferences have been sought	The guideline development group includes clients/patients or their representatives. The guideline has been reviewed by clients/patients or representatives.
Item 6. The target users of the guideline are clearly defined.	The guideline provides clear information about the target audience who will use the guideline
Item 7. The guideline has been piloted among target users.	The guideline provides clear information about the pilot testing of the guideline among its target audience in clinical practice
Domain 3. Rigour of development *5 out of 7 items must be addressed*	
Item 8. Systematic methods were used to search for evidence	The guideline provides clear information about the search strategy, including databases or other sources, and may describe the search terms used. Or has been based on a published systematic review or meta-analysis.

Item from the AGREE instrument for rating guidelines	Inclusion: what is required to be in the guidelines
Item 9. The criteria for selecting the evidence are clearly described	Inclusion/exclusion criteria are described
Item 10. The methods used for formulating the recommendations are clearly described	A clear description of the methods used to formulate the recommendations are described and if informal consensus methods were used, the guideline describes how areas of disagreement were resolved.
Item 11. The health benefits, side effects, and risks have been considered in formulating the recommendations	The benefits and harms of applying most/some of the recommendations are discussed
Item 12. There is an explicit link between the recommendations and the supporting evidence	Recommendations are linked with the supporting evidence
Item 13. The guideline has been externally reviewed by experts prior to its publication	The guideline provides clear information on the external review process
Item 14. A procedure for updating the guideline is provided	The guideline provides clear information on the procedure for updating and a timeframe is provided
Domain 4. Clarity and presentation *3 out of 4 items must be addressed*	
Item 15. The recommendations are specific and unambiguous	The recommendations are specific and unambiguous
Item 16. The different options for management of the condition are clearly presented	In answering the questions covered by the guideline, different possible options are discussed for guidelines/ recommendations.
Item 17. The key recommendations are easily identifiable	Recommendations are easily identifiable
Item 18. The guideline is supported with tools for application	The guideline is supported with different tools for application, eg: a summary document, patient leaflets and computer aids
Domain 5. Application *2 out of 3 items need to be addressed*	
Item 19. The potential organisational barriers in applying the recommendations have been discussed.	The guideline discusses the potential organisational barriers and provides suggestions how to address these

Item from the AGREE instrument for rating guidelines	Inclusion: what is required to be in the guidelines
Item 20. The possible cost implications of applying the recommendations have been considered	The guideline discusses the potential cost implications
Item 21. The guideline presents key review criteria for monitoring and/or audit purposes	The guideline addresses the evaluation of the guidelines in practice and may provide review criteria
Domain 6. Editorial independence *1 out 2 items need to be addressed*	
Item 22. The guideline is editorially independent from the funding body	States that the guideline has not been influenced by the views or interests of the funding body or that it was developed without external funding
Item 23. Conflicts of interest of guideline development members have been recorded	The guideline mentions the conflicts of interest of the group members or includes a statement that these have been recorded

Adapted from: The AGREE Collaboration (2003). Appraisal of guidelines for research and evaluation (AGREE): Training manual. Available from http://www.agreecollaboration.org.au

References

AGREE Collaboration, Appraisal of guidelines for research and evaluation: AGREE instrument training manual; 2003.

Appendix G Respondents to public consultation

Thirteen following submissions were received in response to the public consultation draft. Table G.1 shows a list of the respondents.

Table G.1 Respondents to the public consultation draft of the guidelines

Received from	Organisation
Mr Evan Biggs	N/A
Ms Sigrid van Fondern	Regional Information and Advocacy Council Inc.
Ms Leontine Muis	Australian Capital Territory Health
Ms Kim Skett	Silver Chain Hospice Care Service
Ms Sue Salau	Palliative Care Victoria
Ms Carol Quayle	Mercy Hospice, Victoria
Ms Jaklina Michael	Royal District Nursing Service
Dr Kate Grundy	Canterbury District Health Board, New Zealand
Dr Susan Mathers	Calvary Health Care Bethlehem
Ms Donna Daniell	Palliative Care Australia
Ms Margaret Woods	N/A
Mrs B Smethurst	N/A
Jane Mussared & Sandra Obst	ACH Group

Appendix H Pilot testing of a plain English booklet

H.1 Objective

The objective of this pilot testing was to determine refinements required for a brief, plain English booklet developed from the main guideline document. The main target audience for this document was to be older adults receiving care and support, their family carers and care workers.

H.2 Method

Ethical approval for this pilot testing was obtained from the Human Research Ethics Committee of Edith Cowan University. Four focus groups were held in metropolitan and rural areas of Western Australia to respond to questions about the summary document and provision was also made for participants to provide written feedback (ie notes written directly onto the draft document or onto feedback forms). Feedback and input were also requested from the reference group and directly from Alzheimer's Australia, the Australian Government Department of Veterans' Affairs, authors of sections in the main document relating to motor neurone disease and Parkinson's disease, and a representative of the Respecting Patient Choices program. Focus groups were recruited via organisations providing home care and support, including carer support. Participants were asked to consider the drafted 'plain English' version of the guideline document and suggest any changes or inclusions necessary to improve the practicality of the booklet to enhance the usage by older people, families, care workers and volunteers in the Australian community setting.

Questions asked at the focus groups were:

1. What are your feelings about the document overall?
2. Would you use this document?
3. How do you feel about the appropriateness of the language used?
4. Please comment on the usefulness of the scenarios provided. How could these be improved?
5. What do you feel is the most useful section of the document? Why is it so useful?
6. What do you feel is the least useful section of the document? How could this be improved?
7. Is there anything requires changing in this document?
8. Do you have any further comments to make about this version of the guideline document?

H.3 Findings

A total of 37 focus group participants were involved in reviewing and providing feedback on the drafted document:

- five care coordinators
- fourteen care workers
- eight home helps
- two volunteers
- seven older people receiving care or informal carers
- one person who chose not to disclose this information.

Participants had a mean age of 54 years (SD = 15.00, range 25–83 years) and 86% of the participants (n = 31) were female.

From the feedback during the focus groups the main changes that needed to be made to the drafted document were as follows:

- the addition of subheadings to separate sections,
- simplified language
- clarification of definitions and terms
- clarification of the target audience
- reformatting of paragraphs to reduce the denseness of the text,
- the provision of phone directory listings for organisations without appropriate 1800 or 131 numbers so that phone numbers can easily be found (numbers were not provided because they would likely change over time)
- the provision of additional contacts
- improvement of the generalisability of scenarios
- the addition of further prompts for care workers.

These changes were incorporated, as was input received from the other organisations and individuals approached. The document was originally split into two sections, both sections being applicable to care workers and only the first section being applicable to older adults receiving care and their family carers. However, concerns about the section for care workers being too confronting if read by people still coming to terms with a diagnosis led to a decision to provide two separate documents, one for care workers and one for those receiving care and their family carers.

Appendix I Articles reviewed in Section 3.1 ‘Providing care’

Study purpose (1) and design (2)	**Sample and selection method**	**Measurement or reporting method (1) and reliability/ validity/rigour issues (2)**	**Analysis method**	**Major findings**
Addington-Hall, J. and D. Altmann (2000). Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses? Journal Of Advanced Nursing 32(4): 799–806. UK				
1) This study investigates how cancer patients who receive care from community specialist palliative care (CSPC) nurses differ from those who do not. 2) Retrospective study using secondary data analysis of retrospective interview survey of deaths in 1990 in 20 nationally representative health districts.	Stratified random sampling of cancer deaths in UK. Of all district health authorities invited to participate, 20 self-selected and 270 deaths in each district randomly sampled from deaths in last 1/4 1990. Cancer deaths were 54% of sample but 26% of national mortality stats. Exclusions: sudden deaths (n = 2062) with 574 having care from CSPC nurses and maybe admitted to hospice while 1488 had no CSPC but maybe admitted to a hospice. 7 districts = CSPCs part of multidisciplinary team, 8 districts = alone or with other nurses, unknown.	1) Semi-structured interviews with deceased's relatives, median time 10months post death. N = 2074, 71% analysed, only cancer deaths. Tables of socio-demographics of patient groups; primary cancer site; symptoms in last year of life of two groups; number of symptoms in last year of life of two groups; dependency, carers, independent predictors using descriptives, t-tests, and regression co-efficients. 2) Study well designed, using appropriate methods of sample selection, data collection and analysis. Respondents categorised into groups to check for bias or differences across groups. Also gives age groups which is helpful. Ethics addressed. Results easy to read and understand. Validity affected by being retrospective and respondent assuming knowledge of patient views and perhaps not knowing which nurse is CSPC or other service.	Univariate analyses; t-tests and chi-square. Significance set at $p<0.05$. If significant, used logistic regression to investigate best independent predictors for a patient to receive CSPC.	27.8% of patients received CSPC. Patients receiving PC more likely than those who did not to have had living children and siblings and less likely to have lived alone or in a nursing/residential home. More likely to be married and own their own house. 69% aged 74 or less. Patients with lymphoma, leukaemia or myeloma significantly less likely to have received PC (OR 0.37, $p<0.0001$) Brain cancer patients less likely (OR 0.63, $P = 0.002$), patients with digestive or breast cancer more likely to receive PC (OR 1.27, $P = 0.04$ and OR 1.44, $P = 0.0009$). More likely to receive PC where informal carer was primary carer, lived with patient or was spouse. 10 variables found to be associated with patient receiving PC: dependence with dressing/undressing; needing help at night; constipation; vomiting/nausea; mental confusion; breast cancer; under 75yo. Patients with symptoms

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
				>6months less likely to receive PC, suggesting may be seen as chronic rather than palliative.
Addington-Hall, J. M. and S. Karlsen (2005). A national survey of health professionals and volunteers working in voluntary hospice services in the UK. I. Attitudes to current issues affecting hospices and palliative care. Palliative Medicine 19(1): 40–48. UK				
1) This paper reports results from a national survey in 1999 of voluntary hospice service in the UK. It focuses on volunteer and staff views of the purposes of hospice care, and on current debates within palliative care.2) National survey	Stratified random sampling of 25 from 175 independent hospice services, excluding children's hospices. N = 215 volunteers and 289 staff including nurses nursing auxiliaries, doctors and other staff.	1) Data collected by survey.2) Reliability and validity not discussed. Questionnaires piloted. Probability of obtaining significant results from sample size estimated.	Chi-square; Factor analysis for items; ANOVA; Bonferroni test or Kruskal-Wallis.	Four fifths of beds in participating hospices were in hospices which provided home, day and inpatient care. Overall response rate = 70%. Most respondents were women, White. Volunteer staff were more likely to be older than 60 years compared to paid staff. (58% vs 5%); two-thirds of volunteers worked four hours a week or less (65%) with 32% volunteering between 4 and 8 hours a week and 3% volunteering over 8 hours each week. Most common areas for volunteers were reception (29%), day care (25%), fundraising (23%) general patient care (20%) tea/snack bar (20%) and transport (16%). Both volunteers and professionals considered care of the whole person, pain and symptom control, QOL and dying peacefully to be important aspects of hospice care. Doctors most likely to choose care of the

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
				whole person as the most important aspect. Hospice volunteers were less positive than hospice staff in attitudes to extending hospice care to noncancer patients, to restricting care to patients with specialist palliative care needs and less negative about euthanasia.
Benjamin, A. E. and R. E. Matthias (2001). Age, consumer direction, and outcomes of supportive services at home. The Gerontologist 41(5): 632–642. USA				
1) This study examined differences in service experience and outcomes between recipients over and under age 65 who direct their own services in one large Medicaid program.2) cross-sectional study	N = 1095 recipients of In-Home Supportive Services in California. Excluded severely cognitively impaired. Stratified sampling by service model, service intensity and age. Measures: Items on Empowerment from National Home Care Survey; Unmet need assessed from measures used by Allen and More; Service Satisfaction adapted from previously developed on medical outcomes. All alphas above.50.	1) Data collection by telephone interview. Response rate = 77.8%. 2) Used already established instruments.	Multiple regression using Stata Factor analysis.	Age is not a uniform determinant of service experience under consumer direction. Elderly users consistently experience less choice than younger users in decisions about service provision and report a lower preference for self-direction. Elderly recipients report fewer unmet IADL needs than younger recipients. Differences between older and younger elders (75+ and 65–74): Over 75 report lower service choice and satisfaction and fewer unmet IADLs.
Bierlein, C., H. Hadjistavropoulos et al (2006). A Six-Month Profile of Community Case Coordinated Older Adults. CJNR: Canadian Journal of Nursing Research 38(3): 32–50. Canada				

Study purpose (1) and design (2)	**Sample and selection method**	**Measurement or reporting method (1) and reliability/ validity/rigour issues (2)**	**Analysis method**	**Major findings**
1) The purpose of this study was to assess the needs of older case coordinated clients receiving community health services, by examining changes in cognitive status, physical and mental health status, social support, risk for institutionalization, and service use over a 6-month period from initial intake into home. 2) longitudinal study	N = 234 people over the age of 65 who were referred consecutively for community case coordination of health services in the city of Regina, Canada over a period of 8 months. Sample mean age = 80, 65% women, 86% lived at home on entrance with 77% at home by second interview., 84% exhibited stable support.	1) Clients were interviewed in their homes approximately 12 days after commencing home care. Follow up interviews at termination of services or within 6 months for 140/234 clients. Used Mini-Mental State Examination; Short Form-8 for health profile; Duke Social Support Index: Abbreviated; Regina Risk of Institutionalization Tool. All have good reliability and validity. 2) Reliability and validity discussed. Instruments appropriate for study.	Descriptive stats; repeated measures ANOVA; correlations; multiple regression.	After 6 months case coordination physical and mental health improved ((F(1,169) = 19.19, p<.001) and (F(1,169) = 18.95, p<.001) respectively) while cognitive status remained stable (F(1,172) = .17, p = .68). Social interaction and instrumental support decreased but subjective support remained stable ((F(1,177) = 4.53, p<.04) and (F(1,175) = 10.48, p<.001) respectively). Risk of institutionalisation decreased by second interview ((F(1,179) = 4.95, p<.03). Occupational therapy, nursing, and homemaking were the most frequently used services. The best predictor of professional and supportive home care was a risk of institutionalization score.
Cheah, G. M. and K. H. Martens (2003). Coumadin knowledge deficits: do recently hospitalized patients know how to safely manage the medication? Home Healthcare Nurse 21(2): 94–101. USA				
1) This study sought to determine the level of Coumadin therapy knowledge patients and/or their medication managers (caretakers) had 1 week after discharge from an acute care hospital.2) descriptive study over 3 month period.	Sample = 50 inpatients from different units in the participating hospital. 2 tools — demographic and telephone survey based on existing tool to assess a Coumadin teaching	1) Demographic data collected at bedside. Followed up by telephone survey 1 week post-discharge. 2) Content validity discussed. No reliability measures given.	Descriptive analysis, ANOVA.	Study showed overall Coumadin knowledge deficit. 1 way ANOVA showed significantly higher number of correct responses from subjects <65 years of age (F = 6.28, p<.05) and satisfied with

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
	program. Content validity for telephone survey established by review panel and pilot testing.			inpatient instruction (F = 5.28, p<.05)
Clark, M., M. Steinberg et al (1997). Patient readiness for return to home: discord between expectations and reality. Australian Occupational Therapy Journal 44(3): 132–141. Australia				
1) This study examined the interface between acute hospital care and return to home in relation to elderly patients' perceived ability and preparedness to cope at home. 2) Descriptive study over 4 month period	N = 76 elderly patients aged 60 years+. Random sample from large Qld hospital. 52 carers also participated.	1) Interviews prior to discharge and 7–10 days post-discharge. Carer interviews also at patient discharge and 7–10 days post discharge. 2) Validity and reliability mentioned but not discussed. Instruments composed of a combination of standard instruments measuring ADLs and quality of care.	Descriptive analyses.	Mean age patients = 71.4, 51% female, 28% widowed, 55% lived alone, 55% cared for by daughter, 90% on government pension with annual income < $20000. Mean age carers = 57, two-thirds were female, usually spouse, 21% in workforce, 60% on government pension. Patients reported marked deterioration in health between discharge and follow-up. Happiness also declined. ADLs and IADL became more difficult after discharge. Few referred to hospital or community based therapy services.
Cowan, J. D., D. Burns et al (2003). A palliative medicine program in a community setting: 12 points from the first 12 months. The American Journal Of Hospice & Palliative Care 20(6): 415–433. USA				
1) Reports on the 1st year of a newly established palliative care program in a community hospital (US). Purpose of program being to enhance patient well being using an integrated team approach to symptom management.2)	All consults assessed and data entered onto computer database. Data collected over 1 year. Sample consisted of patients with a life-limiting illness or	1) Evaluated on a number of levels, diagnosis, symptoms, medication, spiritual, pain, personal/family, used Eastern Cooperative Oncology Group for performance and Non-pain scales	Mainly descriptive analyses using Filemaker Pro data. Chi-square used for physical symptoms. Addressed loss of	Patient and clinician satisfaction with program — see article for specifics. Pain most frequent reason for referral. As study program progressed, pain

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Program evaluation.	progressive serious illness, and difficult to manage physical symptoms and/or complicated emotional/spiritual/decision making issues. Selected by referral to team. Satisfaction survey mailed after 6 months to families/patients and medical staff.	were modified from suffering scales by Baines and Norlander. 2) Ethical issues addressed. Validity and reliability for scales not given, nor method of deciding upon scale items. Otherwise, appears to be thorough in providing definitions and investigation of each factor influencing care.	participants during study.	became less prominent issue
Davidson, P. M., G. Paull et al (2004). Integrated, collaborative palliative care in heart failure: the St. George heart failure service experience 1999–2002. Journal of Cardiovascular Nursing 19(1): 68–75. Australia				
1) To describe the development of a model of an integrated, consultative, palliative care approach within a comprehensive HF community-focussed disease management program.2) descriptive study	Sample = consecutive case-note analysis of deaths at St G Hospital Dec 1999-Jul 2000 n = 121.	1) lit review and appraisal of existing guidelines; retrospective case-note analysis, consultation with key stakeholders - clinicians2) Reporting by descriptive methods. Methods of data collection suitable for model development.	Case note review and consultations analysed for content. Some descriptive analysis.	56% male median age = 84. Integrated palliative care approach enabled almost 50% to die at home, 20% died in nursing home. Due to the ready availability of consultancy and systematic education activities and resources, only 8.3% required specific palliative care referral. Identifies barriers to models of health care, eg cost of oxygen at home.
Diwan, S., L. R. Shugarman et al (2004). Problem identification and care plan responses in a home and community-based services program. Journal of Applied Gerontology 23(3): 193–211. USA				
1) .examines how case managers identify and respond to home care client needs…	169 randomly selected clients in a home care program in Michigan. Participants came from	1) Case note review by trained coders. 2) Coders trained, assessment	Algorithms compared to case manager response.	Case managers more likely to note functional and mental health problems than clinical health

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
2) Chart review	larger study. Of 196 cases requested 169 (86%) were complete and used in this study.	tools already validated, measures to ensure reliability.		problems.
Evans, C., V. Drennan et al (2005). Practice nurses and older people: a case management approach to care. Journal of Advanced Nursing 51(4): 343–352. UK				
1) Reports on a study to find to what extent practice nurses use the 5 cyclical elements of case management approach for people over 75 and what affects this.2) Survey	500 practice nurses from Royal College of Nursing Practice Nurse Association database in UK. Random sample from areas known to have large over 75 population.	1) 26-item structured postal questionnaire between February and June 20002) Pilot study and expert panel to determine content validity of questionnaire. Ethics addressed. Response rate of 45%	Descriptive. Chi-square; Friedman test; Wilcoxon test. and inferential — SPSS. Level of significance set at.05.	Practice nurses mainly women 98.5% working in large general practices in urban setting. Majority of practices offered over-75 health check. Case management elements of assessment, care planning and care delivery were most frequently used. Evaluation of the care provided and referral to an outside agency were least common. Practice nurses with post registration education in district nursing were significantly (P = 0.016) more likely to refer patients to social care services. Lack of time and the central role of the general practitioner were the main reasons for not incorporating case management into practice.
Evers, M. M., D. E. Meier et al (2002). Assessing differences in care needs and service utilization in geriatric palliative care patients. Journal of Pain & Symptom Management 23(5): 424–432. USA				
1) .to assess the comprehensive needs and service utilization of geriatric	Retrospective data analysis of 1184 palliative care consultations in a major	1) Data collected from consultations: Demographic and clinical including NOR status.;	Descriptive and ANOVA analyses.	Statistically significant differences across age groups in patient demographic and clinical

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
palliative care patients. 2) Retrospective data analysis	teaching hospital in the US.	recommendations/implementation of care planning; outcomes — sites of discharge and services offered. 2) Does not describe who and how data collection carried out and stored and whether patient confidentiality was maintained given their medical records were being accessed. Otherwise gives good outline of sample and analyses.		characteristics, advance care planning, and service utilization. Patients over 80 had a reduced prevalence of cancer, higher prevalence of dementia and incapacity, more frequent decisions to withhold or withdraw life-sustaining treatments, and fewer interventions for symptom management.
Finklestein, M., Penner, L., & Brannick, M. (2005). Motive, role identity, and prosocial personality as predictors of volunteer activity. Social Behaviour Personality, 33(4), 403–418. USA				
1)To test contributions to volunteerism of variables suggested by functional analysis and role identity theory; and to resolve disparities in the literature regarding the role of prosocial personality tendencies. 2)Non-experimental observational study	N = 302 volunteers (N = 230 female and N = 56 male, N = 16 didn't indicate gender), at a hospice. Response rate of 29%. Purposive sampling.	1)Survey mailed volunteers, measuring demographic details; volunteer motives (using Volunteer Functional Inventory (VFI) coefficient alpha 0.69 (values), 0.83 (understanding), 0.81 (social), 0.92 (career), 0.74 (protective) and 0.84 (enhancement); volunteer role identity (coefficient alpha 0.75), prosocial personality (using Prosocial Personality Battery [PSB]) (conbachs alpha for other orientated empathy 0.83; helpfulness 0.76); volunteer satisfaction (coefficient alpha 0.65); perceived expectations	Descriptive stats, correlations and regressions	Finding were supportive of a role identity model of sustained volunteerism. Identify and perceived expectations emerged as the strongest predictors of both time spent volunteering and length of service. Initial motives for volunteering showed weaker than expected relationship with volunteerism. Has implications for volunteer dependent agencies for recruitment and retention strategies.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
		(coefficient alpha 0.82)2)Reliability and validity addressed. Ethics not noted.		
Gibson, D. and S. Mathur (1999). Australian innovations in home-based care: a comparison of community aged care packages, community options projects and hostel care. Australasian Journal on Ageing 18(2): 72–78. Australia				
1) To compare Australian client dependency levels in Community Aged Care Packages, Community Options projects and hostels, and to explore the interplay between client dependency, carer availability and levels of service use in community care services.2) Comparative analysis of data	Purposive stratified sample. N = 3800 clients drawn from 224 Care Package providers in Australia. 92% of clients surveyed.	1) Data collected from Aged Care Packages survey 1996, Community Options Projects Survey 1994 and Dept of Health and Family Services Database on Hostel Residents and compared. Patient characteristics taken from 1996 survey. 2) Validity and reliability of process not discussed. Method of constructing dependency scale was outlined.	Data analysed by comparative analysis on dependency items which were scaled. Carer availability and service use were analysed only for community care clients.	Community Aged Care Package clients found to be less dependent than both Community Options and hostel residents. For both sets of community care clients, service use increased with dependency levels. Presence of co-resident carers was associated with lower levels of service use for given levels of dependency. Conclusion was that CACP serves less dependent sector of frail and disabled aged population rather than providing alternative to hostel admission at personal care level. Most recipients also had informal carer.
Glickman, L. L., K. B. Stocker et al (1997). Self-direction in home care for older people: a consumer's perspective. Home Health Care Services Quarterly 16(1–2): 41–54. USA				
1) Elder home care consumers were surveyed to determine their willingness to assume more responsibility for their home care such as in the hiring, paying, scheduling, supervising and/or firing of their home	N = 883 home care clients in the Massachusetts Home Care Program. (44% of sample). Not representative sample as less severely disabled more likely to	1) Structured survey administered by telephone. 2) Addressed sampling issues, ethics, representation, not validity or reliability of instrument.	Descriptive stats, multiple regression.	Respondents 85% female, white 92%, unmarried 90%, living alone 84%. Low income, mean age 79. 51% in Functional Impairment Level (FIL) 3 category 35% in FIL1 or FIL 2

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
care worker. 2) descriptive study	participate. Participants recruited by mail and invited to participate in telephone interview.			categories and had at least 2 ADL deficits. Nearly 75% described health as fair or poor and same percentage had been receiving services for more than one year with two-thirds receiving 3 hours or less of homemaker services per week. Respondents reported high levels of satisfaction with their home care services and home care worker. Substantial minority were willing to assume more responsibility for supervising home care worker and needed less assistance from a case manager.
Good, P. D., J. Cavenagh et al (2004). Survival after enrolment in an Australian palliative care program. Journal Of Pain And Symptom Management 27(4): 310–315. Australia				
1) This study looked at survival of patients after enrolment in an Australian integrated palliative care service that consists of inpatient beds (hospice), community care and consultation services.2) retrospective cohort study	Sample = N = 1138 patients enrolled in palliative care services in Newcastle palliative care services between Jan1 1998 and 30 June 2000.Mortality Follow Up until 31 June 2001. Mean age 70.1+-12.8. Cancer patients and patients with stroke CCF, dementia, COPD, degenerative neurological conditions. Referred by	1) Data collected from computer database at Hospice — custom designed. Data entered by all members of Palliative Care team. 2) Provides literature background, aims, outline of method of data collection and sample selection, also ethics. Validity discussed. Main problem is that community patients are designated as both living in own homes or in residential care facilities.	STATA 5.0 software to analyse. Descriptive stats.	Median length survival 54 days. Large variation in survival according to diagnosis. Longer survival than in other studies.? Due to earlier referral, intervention, low number of non-malignant patients, education of referrers. Need to look at referrals in context of disease progress when deciding if early or late.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
	specialists and GPs.			
Grande, G. E., A. McKerral et al (2003). Place of death and use of health services in the last year of life. Journal of Palliative Care 19(4): 263–270. UK				
1) To investigate whether health service input in the last year of life differs between cancer patients who die at home versus those dying in inpatient care. 2) Post-hoc exploratory case-control study of 127 home deaths and 200 inpatient deaths.	N = 327 deaths from cancer (127 home deaths and 200 inpatient deaths) over 16 month period. Two samples: n = 121 cancer patients over age 16 referred to Cambridge HAH for palliative care. Cancer recorded as cause of death. Sample 2, 299 patients randomly selected from database but not referred to HAH and died in same period as sample 1.	1) Electronic records accessed for patient demographics and medical. Used Jarman underprivileged area and Townsend Index deprivation scores 2) NA	Univariate analysis to compare groups. Chi-square, Yates' continuity correction and Fisher exact probability tests for 2x2 tables; t-test; Mann-Whitney U; Kaplan-Meier log rank statistic.	39% died at home, 35% hospital, 23% hospice. Patients who died at home began their home nursing care closer to death than those who died as inpatients. Home death patients also had more specialist and district nursing. Mean age of patients dying at home = 71.9, as inpatient, = 74.0. More males died at home 51% and more female in hospital, 56%.
Haydar, Z. R., A. J. Lowe et al (2004). Differences in end-of-life preferences between congestive heart failure and dementia in a medical house calls program. Journal of the American Geriatrics Society 52(5): 736–740. USA				
1) To compare end-of-life preferences in elderly individuals with dementia and congestive heart failure.2) Retrospective case-control study	N = 172 patients who died while under the care of the house-call program from October 1996 to April 2001.	1) Retrospective review of medical records.2) Validity and reliability not discussed. Comparative review of data only.	Analysis of records = descriptive stats; Wilcoxon test for nonparametric continuous variables (two-tailed P-value of less than or equal to.05); nominal logistic regression.	Of 172 patients 29 had CHF, 79 dementia, 34 both, 30 neither. Patients with CHF younger (82.6 vs. 87.0, P = .011) and less functionally dependent (ADL score 9.1 vs. 11.5, P = .001). No real difference between time from enrolment to death between groups DNR order for 62% CHF patients and 91% with dementia (P<.001). Hospice used in 24% CHF and 61% dementia patients (P<.001). 45% of CHF patients

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
				and 18% dementia patients died in acute hospital (P = .006). Involvement in medical planning by patients not significant predictor of EOL preferences, but Caucasian ethnicity independent predictor of having documented DNR and death outside acute hospital.
Hegney, D., A. McCarthy et al (2002). Discharge planning from the acute sector for people over the age of 65. Collegian 9(3): 15–21. Australia				
1) Investigate issues and causes regarding health and support needs of older people in Toowoomba who require further services on discharge from hospital and to look at possible options and solutions. 2) Mixed method design	Purposive sampling of various aged care facilities and community services, including GPs. Very low participation for community groups. N = 71 clients and 54 carers (25.4% participation rate)	1) Quantitative and qualitative methods 2) not discussed. Very low response rates particularly in community. Does not describe how the data was collected or managed.	Not described. Tables of percentages supplied.	Majority believe discharge planning should commence early in acute hospital stay; Clinical Liaison Nurse seen as positive development; advocacy role important in discharge planning; 80% of elderly clients (12/15) perceived they depended upon others to make future care choices for them, leading to anger and sense of powerlessness (53% of these). Major theme was the need for additional support and improvements for transitional/short-term care esp. home visits, community care, contact number, volunteers visits, home help and home nursing services.
Hegney, D., A. McCarthy et al (2003). The interface of acute and aged care: the role of the nurse in a provincial area. Australasian Journal on Ageing 22(2): 85–90. Australia				

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
1) .to investigate issues that arose from pre-admission to post-discharge, for people in Toowoomba, Queensland over the age of 65 admitted to an acute facility. concentrating on the role of the nurse.2) Cohort study using mixed methods	Purposive sampling of various aged care facilities and community services, including GPs. Very low participation for community groups.	1) Quantitative and qualitative methods2) not discussed. Very low response rates particularly in community. Do not describe how the data was collected or managed.	Not described. Table of percentages supplied.	Discharge patients — complaints about lack of communication from hospital staff to carer; greater need for GP involvement in co-ordinated care; nurse case manager is more effective than GP.
Higashi, T., P. G. Shekelle et al (2005). Improving patient care. Quality of care is associated with survival in vulnerable older patients. Annals of Internal Medicine 143(4): 274. USA				
1) To examine the link between the quality of care that patients received and their survival 2) Observational cohort study	Community-dwelling high risk patients 65+ who were continuously enrolled in managed care organizations from 1 July 1998 to 31 July 1999. Randomly selected patients who met criteria and assessed using Vulnerable Elders Survey-13.	1) Data collected from medical records (n = 372, 78% response) by nursing and physician reviewers. Blessed Orientation-Memory-Concentration test for patient characteristics, and mental health score from Medical Outcomes Study Short Form - 36 items during recruitment phone call. Quality indicators selected from Assessing Care of Vulnerable Elders. 2) Inter rater reliability of medical records review = 97% for quality indicator eligibility and 95% for overall quality score. Measures to ensure validity and reliability taken, ethics addressed.	Log-rank test for patient survival/quality score; Cox proportional hazards survival model; correlations.	Mean age = 81, 64% women. Of participants, on average 53% of care processes in quality indicators received. Graded positive relationship between quality score and 3-year survival.
Higginson, I. J., P. Astin et al (1998). Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. Palliative Medicine 12(5): 353–363. UK				

Study purpose (1) and design (2)	**Sample and selection method**	**Measurement or reporting method (1) and reliability/ validity/rigour issues (2)**	**Analysis method**	**Major findings**
1) The aim was to analyse the 10-year trends in place of death of cancer patients, by region and by diagnosis, within England.2) retrospective review	data taken from death registrations for all cancer deaths between the years 1985–94 in England. Taken from Office for National Statistics. ICD codes 140–239	1) Not described2) Mainly descriptive study which appears to have good validity — addresses all issues including changes to coding and reasons for missing data.	Descriptives, trend lines of death in whole of England and by region and diagnosis over 10 years. Chi-square test for trend. Significance level set at $p<0.05$ (two-tailed)	1.3 million deaths from cancer over 10 year period, slightly more men. 75% >65yrs. Mean age increased from 69.9 to 71.3 from 1985 to 1994. Increase in death in non-NHS hospitals or voluntary hospices, remaining stable fro home deaths. Ages 74 and less more likely to die at home than 75–84 and especially 85+. Patients with cancers of lung, colorectum, respiratory organs, bone or connective tissue and lip, oral cavity and pharynx more likely to die at home than patients with cancer of breast, or lymphatic or haematological system. Main change was from hospital to hospice or nursing home. Other factors: growth in provision of PC services during late 1980 s to early 1990 s; changes in hospital bed numbers; treatments to manage difficult symptoms, social and clinical circumstances of populations.
Hoad, P. (2002). Drawing the line: The boundaries of volunteering in the community,. Health and Social Care in the Community, 10(4), 239–246. UK				
1)To explore the variety of roles which volunteers play in the community care of older people, their recruitment,	N = 14 volunteer schemes in England. N = 7 specialist volunteer coordinators and N = 2 chairs of	1)semi-structured interviews 2) Ethics addressed	Thematic analysis	Finding identified problems with volunteer boundaries related to professional staff, paid manual work and informal care.

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training and supervision and boundaries of their roles. 2) Explorative qualitative study	management committees. Purposive sample			Boundaries for many of the volunteers lies between what they are able to offer and work which requires professional skills. Must be recognised that volunteers cannot be deployed in the same way as employed staff. Boundaries with informal care relate to the necessity of volunteers supporting this role, rather than replacing it. Highlights the many constraints on volunteers for legal or insurance reasons.
Jakobsson, E., T. Johnsson et al (2006). End-of-life in a Swedish population: demographics, social conditions and characteristics of places of death. Scandinavian Journal of Caring Sciences 20(1): 10–17. USA				
1) . To identify and describe the demographics and social conditions as well as characteristics of the places of death in a randomly selected sample that died in a county in Sweden during 2001.2) Descriptive study — part of larger study	Stratified proportional random sampling. N = 280, final n = 229 after exclusions.	1) retrospective reviews of death certificates, medical records and nursing records. Results reported by descriptive tables and significance levels in text. Useful cross referenced tables.2) Sample selection and exclusions clearly outlined and appropriate; Differences within sample explored statistically as well as descriptives. Procedure for testing assessment tool clearly stated — inter-rater reliability of >85–95%. Limited by using secondary sources.	descriptive stats; t-tests; one-way ANOVA; Tukey's post-hoc; chi-square.	Mean age at time of death = 76 (IP), 84.5 (residential care) 80.1 (home) $p<0.001$); significant differences between living arrangements and places of death ($p<0.001$) Those who died in hospitals and private homes more likely to live with partner; Significant differences between residence prior to death and place of death ($p<0.001$) with individuals in residential care more likely to die in facility and private home more likely to die in hospital.; Most common place of death = acute care hospitals,

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				then residential care, then homes, hospice, other. Significant differences in mean age of death and living arrangement ($p<0.001$)
Kelley, M. L. and M. J. MacLean (1997). I want to live here for rest of my life. The challenge of case management for rural seniors. Journal Of Case Management 6(4): 174–182. Canada				
1) The purpose of this article is to address the complexity of providing health care and social services for seniors living in small rural communities. 2) Descriptive/qualitative study	460 seniors from 6 communities in a district in Ontario. Purposively chosen to obtain heterogeneous sample.	1) Data collected by telephone survey and focus groups. 2) Reliability and validity not discussed. Questionnaire pilot-tested prior to administration.	Descriptive- cross-tabs and percentages. Content analysis of focus groups. More qualitative study.	4 intervention roles identified: providing direct service, consulting extensively with specialists of other disciplines, constructing and supporting natural helping networks, and resource management. Requires a rural case manager to assume a leadership role at the community level in the development of services for seniors.
Kite, S., K. Jones et al (1999). Specialist palliative care and patients with non-cancer diagnoses: the experience of a service. Palliative Medicine 13(6): 477–484. UK				
1) .to identify the pattern of non-cancer referrals to a specialist palliative care service, comprising a teaching hospital support team, home care, outpatients and inpatient hospice, over a 1-year period.2) retrospective review — descriptive study	N = 287 hospital ward referrals, 196 home care referrals and 130 outpatient referrals analysed over 1 year in 1997. Referrals of non cancer patients (excluding HIV/AIDS) identified using PALCARE database.	1) Retrospective case note review using PALCARE database.2) Validity and reliability not discussed. Validity of database is assumed.	Descriptive analysis	Of 287 hospital ward referrals 29% of patients had non-cancer diagnosis and were referred mainly for symptom control (92%), and pain control (84%). Of 130 outpatient referrals, 23% had non-cancer diagnosis, referred mainly for pain (85%). Of 196 home care referrals, 9% had non-cancer diagnosis, referred for endstage treatment. Of 421 hospice inpatient

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				admissions, 17 were for patients with non-cancer diagnosis (4%) and mainly respite care and accounted for 2% of occupied bed days.
Kodner DL, Kyriacou CK. Fully integrated care for frail elderly: two American models. Int J Integr Care 2000; 1: e08. USA				
1)To explore the concept of fully integrated care, and critically examine two American models for the frail elderly (the social health maintenance organization or Social HMO and the program of all-inclusive care for the elderly or PACE) in organizational, efficiency and quality terms. 2)Descriptive	Existing data about integrated care in general, and the two model programs in particular, were collected and analysed from reports published by governmental and non-governmental organisations, and journal articles and other sources	1) Review and analysis of existing data on the care models. Fifteen factors that were consider most integral to the development and operationalisation of the 3 forms of integrated care were used to assess models. Models were also examined in 6 characteristics: (1) status (operational and legal); (2) targeting; (3) benefit package; (4) financing; (5) delivery system and clinical management; and (6) enrolment. 2) Reliability and validity not addressed.	Some descriptive statistics provided	Analysis strongly suggests that fully integrated models of care, such as the social health maintenance organisation and program of all-inclusive care for the elderly, are not only feasible, but offer significant potential to improve the delivery of health and social care for frail elderly patients. Highlights critical differences between the two programs in terms of their design, implementation, and performance. Findings suggests that differences are closely linked to the relative degree of success achieved by each program.
Kodner DL. Whole-system approaches to health and social care partnerships for the frail elderly: an exploration of North American models and lessons. Health Soc Care Community 2006; 14(5): 384–390. USA				
1)To summarise structure, features and outcomes of the PACE program in the USA and the SIPA program in	Selection strategies not discussed	N/A	N/A	Presents positive patterns in terms of service access, utilisation, cost, care provision,

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
Canada.2) Review/Discussion				quality, health status and client/carer satisfaction. Identifies common characteristics of successful impact of partnership initiatives between system models, services and outcomes in integrated care for older people.
Kovacs, P., & Black, B. (1997). Differentiating recruitment strategies for direct patient care, clerical, and fundraising hospice volunteers. The Hospice Journal, 12(4),43–55. USA				
1)To determine effectiveness of identified recruitment strategies for direct patient care, clerical and fundraising volunteers. 2) Descriptive study	N = 259 surveys completed from Volunteers- 44% response rate (N = 137 direct care volunteers, 55% response rate; N = 122 non-direct care volunteers, 35% response rate). Stratified random sample.	1)Survey instrument of 1. Percentage of time spent in direct care, 2. event trigger to volunteer, 3. time considering, being and expected to be a volunteer, 4. satisfaction with volunteer activities, 5. possible sources of learned about opportunity to volunteer, 6. demographic information. 2) Reliability/validity or ethics not addressed.	Descriptive stats, chi square test, T-test and analysis of variance (ANOVA).	Significantly more direct care volunteers learned about opportunity to volunteer through newspaper feature stories than non direct care volunteers. Friends recruit more fundraising volunteers than direct care or clerical volunteers. Events triggering direct care and clerical volunteers were most often from personal experience. Findings have implications for recruitment of volunteers.
Krout, J. A. (1997). Barriers to providing case management to older rural persons. Journal Of Case Management 6(4): 142–150. USA				
1) To identify the barriers to providing case management to older rural persons.2) descriptive study	N = 356 rural case management providers agencies that identified a primary service area as rural, open country, small town or village, or some combination of those	1) Survey using instrument designed and tested by advisory board from case management providers in 6 states and staff from National Association of Area Agencies on Aging, National Council on Aging, and	Descriptive statistics	Of agencies, slightly more than 3/4 of sample agencies not licensed for case management, one third of licensed agencies report that licensing organization is the state; one quarter of licensing organisations is a

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
	settings.	National Association of State Units on Aging.2) Instrument pretested but no measures of validity or reliability of items. Ethics not discussed.		department of social services or public health. Respondents perceived barriers to providing case management: lack of transportation (46%), money to pay for services (40%) and too many regulations (40%); money to pay for case management (29%); lack of community financial support (25%); lack of services (19%) and lack of other providers (18%) and elderly's awareness of case management (18%) were most difficult. Advantages of case management in rural areas: more informal support (17%), knowing the clients better (14%) more community support and better knowledge of the clients (both 10%), and networking and knowing providers better (both 8%).
Lane, C. J., S. E. Bronskill et al (2004). Potentially inappropriate prescribing in Ontario community-dwelling older adults and nursing home residents. Journal of the American Geriatrics Society 52(6): 861–866. USA				
1) To compare patterns of potentially inappropriate drug therapy prescribing in community-dwelling older adults and nursing home residents in Ontario, Canada.2) Retrospective cohort study	Population sample: All 1275619 older adults aged 66 + in Ontario who were dispensed at least one prescription from the comprehensive provincial drug plan in 2001.	1) Data collected from 3 databases with information on individuals and drug dispensing. To measure comorbidity Deyo adaptation of Charlson index calculated using discharge information from previous	Descriptive stats, chi-square, logistic regression, sensitivity analysis.	Nursing home residents were older, more women and higher comorbidity as measured by drug therapies dispensed and Charlson comorbidity scores. Community dwelling significantly more likely to be dispensed at least one

Study purpose (1) and design (2)	**Sample and selection method**	**Measurement or reporting method (1) and reliability/ validity/rigour issues (2)**	**Analysis method**	**Major findings**
	Community dwelling n = 1216900, and 58719 nursing home residents.	5 years. Categories of inappropriate drug therapies taken from previous study.2) Reliability and validity not clearly addressed		inappropriate category (3.3% vs. 2.3%, P<.001) drug therapy. Nursing home residents nearly half as likely to receive potentially inappropriate drug therapies (OR = .52, 95% CI = 0.49–0.55, P<.001)
Malmberg, B., M. Ernsth et al (2003). Angels of the night: evening and night patrols for homebound elders in Sweden. The Gerontologist 43(5): 761–765. Sweden				
1) The purpose of this study was to describe the work of evening and night home care patrols in Swedish old-age care by examining how staff members view their work and the specific work content. 2) descriptive study/exploratory	Sample = 33 evening and night patrols and 76 individual staff members. Convenience sample. 2 questionnaires: 1 to be answered jointly by patrols, the other for each member of team. 75% of patients visited by teams = 65+. Approximately 200 patients enrolled in Home Help service.	1) Descriptive tables and graphs of number of visits per shift and patrol, tasks types; patient diseases 2) No reliability or validity discussed. Questionnaires may not have been piloted prior to survey though categories were outlined. Also small sample sizes and no comparison to demographics for other municipalities for generalisation purposes. Profile of typical patient based on staff descriptions and choices — may not be accurate reflection of client profile.	73% of team questionnaires returned (n = 24) and 63% individual questionnaires returned (n = 48)	On average, evening patrols made 14.6 visits each shift, 21 for night (evening work 4–10 pm, night work 9 p.m. - 7 am approx) Extra shift 4 p.m.-2 a.m. Average of 4 unplanned acute visits each shift. Typical patients as described by team = median age 69, women (68%) live alone (70%). Length of visits varied 5 mins to 2 hours. Tasks — most frequent = personal care. Medical tasks = medications, assisting with catheters and giving IV infusions (10–20% visits). Terminal care mainly to watch over patients and provide companionship plus give medical treatment. Staff thought they needed: more training due to increase in patients with psychiatric disorders and better communication between home

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
				care staff and patrols.
Mann, W. C., T. Marchant et al (2001). Elder acceptance of health monitoring devices in the home. Care Management Journals: Journal Of Case Management; The Journal Of Long Term Home Health Care 3(2): 91–98. USA				
1) The current study sought to determine the acceptance of the concept of home monitoring devices by frail elders in the US.2) Cohort from 10 year longitudinal study	N = 71 elderly persons who have difficulty with at least one ADL or IADL.	1) Face-to-face interviews conducted by Center on Aging Consumer Assessments Study occupational therapists. Mean age participants = 73.5, 78% female, 56.3% Caucasian, 43.7% African American. Mean of 6.6 chronic illnesses and average of 4.7 doctor visits in the past 6 months. 18% required assistance taking medicine and 45.7% had some difficulty with using phone. CAS battery of instruments used- includes parts of Older Americans Research and Service Center Instrument. Home Care Monitoring Devices questionnaire developed and included in this study.2) Reliability and validity not discussed though used previously tested battery of instruments.	Descriptive stats. SPSS version 10.0 for analysis.	Direct applicability or usefulness relative to health status of 5 prototype home monitoring devices to participants was 93% for pill bottle, 63% for blood pressure monitor, 23.9% for blood glucose monitor, 15.5% for metered dosage inhaler, and 1.4% for thermometer. 89.9% favourable responses to monitoring devices and systems. 88% believed monitoring systems would ensure medication compliance, blood pressure monitoring and other health related activities. 85% felt would relieve personal worry.
McCarthy, E. P., R. S. Phillips et al (2000). Dying with cancer: Patients' function, symptoms, and care preferences as death approaches. Journal of the American Geriatrics Society 48(5): S110-s121. USA				
1) To characterize the dying experience of patients with cancer over the last 6 months of life.2)	N = 316 of 520 patients with metastatic colon cancer and 747 of 939 patients with lung cancer	1) Retrospective collection of data at set times back to patient entry to SUPPORT or 6 months prior to death. Original data	Descriptives; bivariate analyses; chi-square; Kruskal-Wallis and	By 1 year after study enrolment, 61% of patients with colon cancer and 80% with lung cancer had died. As patients progress

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
retrospective time series analysis	enrolled in Study to Understand Patients Prognoses and Preferences for Outcomes and Risks of Treatments Project from June 1989 to June 1991 and January 1992 to January 1994 and who died within 1 year of their index hospitalization. Aged 18+	collected by interview of patients and surrogates with validated instruments.2) Relies on validity of previous study.	ANOVA; logistic and linear regression SAS version 6.12.	toward death, 6 month estimated prognosis decreases significantly and severity of disease worsens as does functional status. Most patients have 4 or more impairments within the 3 days before death. Patients with cancer experience significantly more pain and confusion as death approaches, with severe pain 3 to 6 months before death. Dying patients modestly depressed and anxious during their last 3 days of life and favour comfort measures over life-extension in last 3 days of life, with 2/3 not wanting resuscitation within 3 days of death. Families incurred significant financial burden in last 6 months.
McNamara, B. and L. Rosenwax (2007). Specialist palliative care use for people dying of cancer in Western Australia. Caner Forum 31(1): 18–22. Australia				
1) Use WA Data Linkage system to study patterns of specialist palliative care delivery during the last 12 months of life, comparing use between different socio-demographic groups and causes of death. 2) Descriptive study	Population-based survey using Data Linkage System. Sample taken from ABS Mortality Register for 1 July 2000 to 31 December 2002 in WA with underlying cause of death from either cancer or selected non-cancer conditions. (includes heart failure, renal failure,	1) Data collected from datalinkage database 2) Data linkage provides reliable and accurate information regarding patient status, use of SPC and mortality as links across a number of health databases. Reliability and validity not discussed but assumed.	Descriptive stats, logistic regression.	Patients who died of cancer significantly less likely to receive SPCS if they were single or widowed, aged over 85 years, or lived in a region other than a major city. Most patients in the last year of life had at least one hospital admission. Those receiving SPC community-based services were more likely to die in their own homes. Indigenous

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
	COPD, Parkinsons). N = 7399 cancer and 8007 cancer + non-cancer palliative type condition.			patients more likely to have used SPC with 80% living in rural and remote areas. Of these, 63/98 died in hospital.
Mitchell, S. L., J. N. Morris et al (2004). Terminal care for persons with advanced dementia in the nursing home and home care settings. Journal of Palliative Medicine 7(6): 808–816. USA				
1) To describe and compare the end-of-life experience of persons dying with advanced dementia in the nursing home and home care settings.2) Retrospective cohort study	Persons with age = 65+ with advanced dementia who died within 1 year of admission to either a nursing home in Michigan July1,1998 - Dec 31, 2000. (n = 2730) or the state's publicly funded home and community-based services from Oct 1 1998 to Dec 31 2001 (n = 290). Samples derived using demographic and other criteria taken from Minimum Data Set (MDS) - Nursing home Version 2.0 and MDS — Home Care. Functional status quantified using MDS ADL Long Form Scale (0–28).	1) Retrospective study using data from Minimum Data Set which collects data on end of life care. Used by all nursing homes and publicly funded home care services. Data collected by trained nurses. MDS data collected within 180 days of death. Cognitive Performance Scale to define advanced dementia at time of admission to nursing home or home care program. 2) Comparison of 2 groups problematic due to different time periods of data collection plus large difference in sample sizes. Reliability and validity of instruments confirmed. Variable clearly described. Analyses appropriate for group comparisons.	SAS Version 8.1 for Windows for the analysis. Bivariate analyses comparing subject characteristics and end-of-life outcomes. Chi-square and two-sample t-tests also used ADL score based on terciles. Multivariate analyses — logistic regression for end-of-life outcomes that differed significantly for the two groups	Difference between groups: Nursing home residents older, fewer days between admission and death, total functional dependence, white race, CPS score of 6 (versus 5) and behaviour problems. No gender differences. Health services utilization — Significant differences in hospitalization in previous 90 days and hospice referral ($p<.001$) with nursing home patients having more hospital admissions (43.7%) and home care more hospice referrals (10.7%). NO difference in emergency department visits within previous 90 days. Significant difference in advance care planning ($p<.001$) with more nursing home residents having advance care directives. Significant differences in disease related ($p<.001$) with more home care patients having daily pain, shortness of breath, while

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				nursing home patients had more pressure ulcers, pneumonia, and assistance with feeding tubes, oxygen therapy, Foley catheter. No difference in medication for psychosis, anxiety or depression.
Omoto, A. M., M. Snyder et al (2000). Volunteerism and the life course: Investigating age-related agendas for action. Basic and Applied Social Psychology 22(3): 181–197. USA				
1) , this study investigated the purposes, expectations, and outcomes of adult hospice volunteers of varying ages. 2) cross sectional study	N-144 volunteers from 5 different hospice organizations located in the Midwestern and Western US. Age ranged from 19 to 76 with an average age of 49.86 years. (48% response rate)	1) Data collected by mailed questionnaires at baseline and 6 months after volunteer work. Baseline data collected on demographics and expectations. 6 month questionnaire collected data on relationship with client and perceptions and satisfaction with volunteer work including Relationship Closeness Inventory. 2) Used previously developed inventory of motivations for volunteerism. Internal reliability discussed.	MANOVAs followed by univariate ANOVAs with Student-Newman-Keuls pairwise comparisons. Hierarchical regressions.	Younger volunteers tend to be motivated by and to achieve outcomes related to interpersonal relationships, whereas older volunteers tend to be motivated by service or community obligation concerns. Relationship related variables demonstrated greater and significant predictive power for younger relative to older volunteers. Service oriented variables tended to be inconsistently related to these outcomes.
Payne, S. (2001). The role of volunteers in hospice bereavement support in New Zealand, 15, 107–115. New Zealand				
1)To assess the role of hospice bereavement volunteers in New Zealand. 2)Mixed methodology, descriptive qualitative and quantitative design	N = 34 co-ordinators and N = 121 volunteers from 26 hospices in New Zealand. Response rate 74%. Purposeful sample	1) Semi-structured interviews (n = 19 face to face; N = 7 phone interview)- topics included description of hospice service, bereavement support provided, role of volunteers in bereavement support, recruitment, selection, training and supervision of	Qualitative data-content analysis. Quantitative analysis- SPSS. Descriptive stata, chi-square or Fisher exact tests.	Findings revealed that most volunteers were recruited through personal contact and newspapers. Volunteers reported being strongly motivated to help others (88%) and most had previous bereavements (71%). Volunteers provide a range of

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		volunteers; theoretical models of bereavement used in training and service delivery; cultural and geographical factors in service delivery. 2) Ethics addressed		bereavement support within home and/or hospice. 50% reported work to be emotionally distressing and 28% had problems with 'boundaries'. Many volunteers were largely unaware of the need for specialist training, or supervision.
Peruselli, C., P. Di Giulio et al (1999). Home palliative care for terminal cancer patients: a survey on the final week of life. Palliative Medicine 13(3): 233–241. Italy				
1) .aims were to describe the place, circumstances and quality of death of patients admitted to home palliative care units (PCUs), particularly focusing on symptom control and the patient's situation at death. 2) multicentre survey in Italy between 1 Jan and 30 June 1995.	n = 601 randomly selected patients from 56 PCUs and 2 hospices. Referred to PCU for terminal stage cancer and living in catchment area, ages 18+. Sample: mean age of patients = 68, median = 70 range 23–94. Data entered by patients and multiprofessional team. Follow-up survey on pharmacological sedation carried out by phone.	1) QOL evaluated by Therapy Impact Questionnaire, completed by patient at 1st evaluation and subsequent visits or weekly until death or max 2 months after recruitment. Support Team Assessment Schedule (STAS) completed by the palliative care team following patient death along with 12 item quality of death form.2) Instruments previously validated though no reliability given. Addresses consent, describes items and how missing data dealt with and provided copy of QOD questionnaire. Descriptive tables of results.	Descriptive statistics (percentages).	n = 401 after exclusions, refusals, and patient deaths or completion of study prior to death. 32% patients >75 years. Primary tumours lung and pleura, genitourinary tract and oesophagus/stomach most common diagnosis. 80% cared for by PC team for more than 1 week with 95% contacted pre-death. 30% admitted to hospital in 2 weeks pre-death. 76% died at home with 83% of families willing to care at home. Pain control in final week - 20% with continuous pain and 37% had uncontrolled other symptoms. Pain controlled during final week of life. Invasive procedures on 56% of patients which increased to 75% in hospital. 25% were totally pharmacologically sedated in their final 12 hours

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
				with no symptoms or other factors apparently associated with the decision to sedate.
Potter, J., F. Hami et al (2003). Symptoms in 400 patients referred to palliative care services: prevalence and patterns. Palliative Medicine 17(4): 310–314. UK				
1) To describe the demographics and prevalence of symptoms in patients referred to different components of palliative care services: inpatient unit/hospice; inpatient hospital support team; community team and outpatient clinic. To identify any relationship between the different components of palliative care service provision and type or number of symptoms suffered.2) Retrospective case note review.	n = 400 consecutive referrals to 3 palliative care centres in London — NHS palliative care unit, independent hospice, acute teaching hospital — convenience sample. Males = 55%, mean age = 66 range 12–95. 5% non cancer diagnosis. No difference in age, sex or most common cancer diagnosis distribution between subgroup populations.	1) Data collected retrospectively from patient notes using symptoms recorded from 1st assessment. Patients divided into 4 equal subgroups according to referred destination — hospice, community, hospital, and outpatient. 2) Pilot study to compile symptom groups. Process described. Does not state who collected data and how this was dealt with for entry into SPSS. Does not give patient demographics for each group. Limitations — relies upon accurate recording of symptoms; variation in settings for assessment; perhaps affecting amount and type and manner in which symptoms were recorded. Disease type may be linked to symptom, and authors have conceded this but have not stated how they have dealt with it.	SPSS version 10.01. Chi-square analysis.	5 most prevalent symptoms in all four groups = pain (64%), anorexia (34%), constipation (32%), weakness (32%), and dyspnoea (31%). Statistically significant difference between groups for anorexia, constipation, weakness and dyspnoea ($p<.001$) and top 5 symptoms varied between groups. Community groups most prevalent symptom was weakness with 73% of referrals cf hospice (41%) hospital (5%) and outpatient (10%). Pain and anorexia were the 2nd most common symptoms though there was no significant difference between pain for community and other groups. For anorexia there was a significant difference with 56% of community group suffering anorexia cf hospital (6%) and outpatient (17%) and hospice no real difference (58%). Dyspnoea (41%) was listed lower than weight loss (46%) and tiredness (42%) though only

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
				statistically significant compared to the other groups for dyspneoa — hospital 18% and outpatient 13% while hospice slightly higher at 50%. Constipation showed a signifcant difference between groups with community 35%, less common than hospice (52%), hospital (22%) and outpatient (17%).
Steele, L. L., B. Mills et al (2002). Patient and caregiver satisfaction with end-of-life care: does high satisfaction mean high quality of care? American Journal of Hospice & Palliative Care 19(1): 19–27, 72, 1p. USA				
1) The purpose of this study was to determine patient and caregiver satisfaction with a hospice program of care.2) Retrospective longitudinal study	sample = 321 patients, 443 caregivers. Convenience sample of patients and caregivers enrolled in hospice program.	1) Data collected by survey. Patient questionnaire developed by home care agency and modified for use (alpha = .84) Measured by 4-point scale. Caregiver questionnaire developed by National Hospice and Palliative Care Organisation - 5point scale — alpha coefficient = .77. Mailed to participants one month after death or discharge of patient.2) Not sure that this is rigorous enough, even though the questionnaires had good reliability. Allowing caregivers to read and answer questions for the patient is problematic especially in regard to confidentiality and accuracy of data. Results also don't really say	No section on how analysis was conducted.	Majority of patients and their caregivers were very satisfied with hospice services and the care they received.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
		much as the questionnaire was very general. Majority of patients were very satisfied with hospice services and the care they received.		
Temkin-Greener H, Bajorska A, Mukamel DB. Disenrollment from an acute/long-term managed care program (PACE). Medical Care 2006; 44(1): 31–38. USA				
To examine whether the goals of PACE program have been achieved. That is, to be a comprehensive delivery system, dual capitation, and a focus on the most vulnerable population, with low rates of exit and little selective disenrollment.	Purposiveful selection. N = 14,657 PACE participantsenrolled in 30 of the 34 programs in existence beforeJanuary 2002. Four programs were excluded because ofincomplete or inconsistent data.	Administrative database (dataPACE) containing individual-level records onthe participants' sociodemographics, informal caregiver support,health status and disability, medical history, serviceutilization, and disenrollment. Program-specific measures included interviews and surveys, reportsfrom the National PACE Association; and data from the Area Resource Files and the US Census.2) Reliability and validity addressed	STATA 8.2, Descriptive statistics, Cox Model	Findings show a low level of disenrollment. No increase in disenrollment risk by age, functional or cognitive impairment, Medicaid eligibility, or diagnoses. Certain characteristics (eg nursing treatments) appear to reduce the disenrollment hazard, whereas others (eg hospital admissions, private pay status) significantlyincrease it. The risk of disenrollment also increases with longer nursing home stays, until 80–90 days, where upon it begins to decline.
Thomas, M., B. Woodhouse et al (2007). Use of and satisfaction with Community Aged Care Packages in the eastern suburbs of Sydney. Australasian Journal on Ageing 26(1): 8–14. Australia				
1) . To examine the accessibility and the flexibility of the Community Aged Care Package (CACP) program, and provide recommendations for further improvement. 2) Descriptive using survey	Purposive selection of participants from health records of CACP providers in eastern Sydney. Mod-severe dementia patients excluded. N = 80	1) 3 questionnaires — clients were interviewed using structured open-ended questions; mailed to CACP service providers and coordinators. 2) Ethics addressed.	SPSS 12.0 for descriptive and chi square. Thematic content analysis for open-ended questions.	36.2% living in households of more than one person, 54% women, 87.5% 75+, 53.8% Australian born 61.3% spoke English at home. People who spoke English as main language more likely to rate higher

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
		Questionnaires pilot tested and revised in consultation with key stakeholders, giving validity to instrument. Methods of data collection and analysis adequately explained. There was some discrepancy reported between answers to satisfaction part of survey and clients written comments. Method of administration of questionnaires to clients is problematic.		number of CACP days (*X2 = 10.03, df 2, P<0.01)* and more likely to use other support programs *(X2 = 6.67, df = 2, P<0.05).* Average level of client satisfaction with CACP was high, *>62%* extremely satisfied. Concerns were inflexibility, lack of communication between service providers and other health services, poor continuity and quality of care, inadequate funding, problems with recruitment, retention and support for staff.
Wells, Y., H. Swerissen et al (1999). Client outcomes in case managed care: who benefits most? Australasian Journal on Ageing 18(2): 79–85. Australia				
1) To determine how well outcomes could be predicted by initial circumstances and subsequent deterioration in clients and carers.2) Analysis of longitudinal linkage data collected 1992 and 1994	N = case management files of 632 clients of Community Options database 20 months after initial project.	1) Outcomes and predictor variables specified and accessed from linkage database. Barthel index to measure client dependency.2) Validity and reliability not discussed but measures and analyses well outlined.	Descriptive analyses of client dependency; backward logistic regression to select best predictors of outcomes for clients.	Institutionalisation highly likely when carers lost motivation to care. Placement in nursing homes rather than hostels best predicted by incontinence. Clients most successful in avoiding long-term institutional care were in stable situations with a spouse carer.

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Appendix J Articles reviewed in Section 3.3 ‘Using other tools to improve palliative care’

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Elfrink et al 2002) Netherlands	1) Evaluation of a telephone service for palliative care patients discharged from hospital to home with technical support. 2) Retrospective evaluation of registration forms 1997–1999 to evaluate the telephone service of palliative care. 3) Phone service was available to provide advice 24 hours per day to patients, families, GPs, and nurses.	1) 124 patients transferred from 1997 to 1999. Variation in age of patients was 22–77, mean = 54, cancer patients. 2) N/A 3) N/A.	1) Evaluation of registration forms used during telephone interviews with patients. 2) Evaluation design clear, describes categories within which evaluation carried out; provides copy of assessment telephone tool.	Descriptive tables and graphs.	Pain was main symptom (77%) in patients transferred from hospital. Of 124 patients in home care program, 157 calls received from 64 (52%) of patients out of hours. Pain most frequent reason to call (40%) technical problems 33%. In 97% of calls it was possible to solve problem over the phone. Of these, 38% handled by a palliative care nurse, for 62% specialist consulted by nurse. Mean time for 16 minutes.
(Ferrell et al 1998)	1) Presents an overview of the pilot HOPE training program 2) Pre-test post test 3) Intervention: Training program relating to end of life care	1) Purposive sample 2) N = 52 (76% nurses, 11% home health aides, 13% other professionals) 3) N/A	1) Participants rated own self effectiveness and that of their agency before and first session and 2 months after last session. Likert scale 0–10. 2) Reliability and validity not clearly addressed.	Descriptive and tables	Palliative care education and knowledge of home care professionals is necessary to improve patient care at end of life. Program demonstrated increased overall rating of end of life care for self assessment and agency assessment.
(Gilbar & Stefaniuk 2002)	1) To determine what pharmaceutical services are provided to palliative care sites in Australia and Canada and the pharmacist's role on the interdisciplinary team 2) Survey 3) N/A	1) Purposive sample 2) N = 100 selected sites in Aust and Canada 3) N/A	1) Survey including demographic data and duties performed by pharmacists working in pall care- fixed alternative answers and 5 point scales. 2) Reliability and validity not clearly addressed.	Descriptive and tables	Response rate 76% Aust and 69% Canada. Aust (55.3%) and Canada (85.5%) sites employed palliative care pharmacists, with most Aust (83.3%) and Canadian (69.8%) working less than 20 hours per week on palliative care service. Medication review

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
					was most common duty. Approx. 70% provide specific advice. Finding indicated pharmacist play an important role in pall care team.
(Holland et al 2005) UK	1) To examine the effect of home based medication review for older adults on hospital readmission rates, death, and quality of life. 2) RCT, measures at pre test and 6 m. 3) Intervention: Two home visits for previously hospitalised older adults by pharmacist @ 6 and 8 weeks post discharge. Education for patients and carers, liaison with GP, recommendation for compliance aid. Control: usual care.	1) 872 patients aged over 80 discharged to home from four hospitals. Not having dialysis or involved in intensive discharge program. 2) IG = 437, CG = 435. 3) Similar at baseline.	1) Mainly collection of figures from hospitals and GPs. QOL from mailout. 2) Psychometric properties of quality of life scale not indicated. Powered at 90% to detect a change of 20% in readmissions over 6 m.	Poisson regression and survival analysis adjusting for living alone & confusion. T tests for quality of life,	30% greater rate of readmissions in IG ($p = 0.009$), fewer deaths (NS), poorer quality of life in IG ($p = 0.04$). Suggested reasons: more help seeking behaviour when unwell, more compliance with multiple medications (not assessed) leading to adverse effects, increased complexity of care causing anxiety and confusion. Very similar results for heart failure sub group: (Holland et al 2007) and for frail aged sub-group (aged 80 yrs plus) (Lenaghan et al 2007).
(Hsia Der et al 1997). US	1) To assess possible benefits from pharmacists conducting in home medication evaluations for older adults. 2) Pre-test, post- test evaluation. Measures at first visit and follow up visit 3 to 4 weeks later. 3) Home visit by pharmacist	1) 20 male veterans, mean age 75 years, receiving home care, on #+ medications. 2) N/A. 3) 3. N/A.	1) Counts of medications etc. 2) Small sample evaluation - essentially pilot work.	Paired t tests.	All patients were counselled. Recommendations for change in 60%. Significant decrease in problems and discrepancies by Time 2.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
	with medication review. Interview, comparison of patient & carer reports with physician's instructions, efficacy, adverse reactions, use of over the counter drugs, use of alcohol, use of tobacco, home inspection & offer to remove inappropriate medications. Counselling.				
(Kobza & Scheurich 2000)	1) To investigate the impact of a telemedicine intervention for chronic wound management. 2) Historical control 3) Telemedicine wound consultant visits and monitoring versus retrospective chart data (no telemedicine).	1) All patients agreeing to be included within a certain area and having particular chronic wounds (eg pressure ulcers, venous stasis ulcers. 2) 76 people (mean age 70 years) received intervention, Home visits averaged 60 per patient and 191 wounds overall. Compared with data from 120 charts. 3) N/A	1) Progression of would healing monitored. 2) Usual issues with retrospective comparisons - ie other variables may be implicated.	% comparisons — no testing for statistical significance.	Home visits averaged 60 per patient and 191 wounds were treated. When compared with retrospective chart data, healing rates for all wounds had improved with the exception of Stage II pressure ulcers. Average times to healing decreased in all wound categories. No satisfaction data were presented.
(London et al 2005)	1) Evaluating a Comprehensive, Adaptable, Life-Affirming, Longitudinal (CALL) intervention to patients with life-threatening cancer, cardiac illness,	n = 295 patients and families enrolled over 12 months. Selective sampling according to number of criteria but methods of sampling	1) Baseline demographic and 55 item Modified City of Hope Patient Questionnaire. Physical subscale for questionnaire completed at regular intervals over 18 months and rest of	SPSS version 10.01. Chi-square analysis. Missing data from 1	Participants reported improved pain and symptom management. 29% hospitalised 7% critical care admission during 18 months. 48% of those who died had high use of hospice and

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
	respiratory conditions or dementia. 2) Prospective observational study	differed eg chart reviews compared to GP referral.	questionnaire completed at any time over 18 months. Staff completed list of services each participant received (including terminal) and frequency. Bereaved family members completed 64-item Modified City of Hope Bereaved Questionnaire 6–12 weeks post bereavement. Questionnaire measurement by Likert scale. 2) Main problem with study is that patients were selected by different methods which could lead to sample bias. Instrument for assessment is quantitative and able to provide psychometric testing but reliability and validity issues are not noted. Descriptive results only given. Patient response rate 51%. However, refusals due to illness progression and burden of completing survey. Mean age 71.8. Authors have outlined problems with data collection and how study designed and carried out. Ethics addressed.	service due to computer malfunction. Also 94 deaths during study	38% died at home.
(Maiolo et al 2003)	1) Investigate feasibility of telemonitoring services for patients with severe	1) Randomised 2) n = 45 participants with severe respiratory	1st phase -face-to-face medical visits with arterial blood gas analysis, dynamic spirometry	StatView statistical package.	Number of hospital admission and acute exacerbation during telemonitoring phase decreased.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
	respiratory illness. 2)Feasibility study 3) Intervention: telemonitoring Comparison: traditional patient management	failure 3) -face-to-face medical visits with arterial blood gas analysis, dynamic spirometry parameters-forced vital capacity, forced expiratory volumes and peak expiratory flow	parameters-forced vital capacity, forced expiratory volumes and peak expiratory flow 2nd phase-home monitoring for pulse oximetry data and clinic visit Reliability/validity not discussed	Other analysis not specifically described.	Estimation of hospital costs were approx 17% lower than in the 1st phase. Patients were satisfied with telemonitoring in 96% cases.
(Noel et al 2004)	1) Determine whether home telehealth when integrated with the health facility's electronic medical record system, reduces healthcare costs and improves quality of life outcomes 2) Single blind, single site, randomised 3)Intervention: telemonitoring Comparison: usual care	1)Randomised 2)n = 104 CG = n57, IG = n47. 3)NA	1) subjective and objective quality of life measure, health resource use, costs 2) reliability and validity noted.	SPSS 10.0. t-tests, non-parametric tests, logistic regression	Findings indicted significantly less hospital bed days of care, emergency visits, A1C levels, and patient satisfaction. Functional levels and patient rated health showed no difference for people receiving telemonitoring.
(Peters & Sellick 2006)	1) To compare symptom experience, physical and psychological health status, level of personal control over the illness, and quality of life of patients receiving inpatient and home-based palliative care and identify factors predicting quality of	N = 58 M = 22,F = 36, mean age 67.8, range 40–92.Patients with cancer, from 3 inpatient palliative care centres and 4 home-based palliative care centre services in Melbourne. (38 inpatients and 26	1) Data collection: 1.medical checklist and self-report questionnaire for demographic and medical data, including health status, symptom experience, personal control and quality of life. Various Scales to measure symptom experience, physical health, psychological	Response rate = 71% inpatient, 54% home-based. No reasons given for lower response rate among home-	Results: Health: home care patients had statistically significant higher physical health score for physical status($t = 4.83$, $p<0.001$) and global physical condition ($t = -2.77$, $p<0.01$) and lower depression scores ($t = 2.35$, $p<0.05$). Personal control:

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
	life of terminally ill cancer patients. 2) cross-sectional study 3) N/A	home-based) Sample selected as being representative of both inpatient and home-based palliative care services. Sample: 2 independent samples, Sample criteria: primary diagnosis of cancer, prognosis at least 2 months, 18 years and over, able to speak and understand English. Selected by researchers. Of 93 eligible for study, 58 agreed to participate.	health, personal control and quality of life. A combination of self-report questionnaire and interviews. 2) Scales clearly described and said to be reliable and having validity. No reliability measures given. Personal control scale constructed from previous research on studies by Affleck on patients with Rheumatoid Arthritis. Confounding variables addressed post analysis. Processes well outlined, including ethical considerations.	based participants or how this was addressed. Data analysed on SPSS and methods of analysis clearly outlined. Missing data and participant loss not addressed, Analyses: Chi-square for comparison of groups and symptom experience, t-test for symptom experience, personal control, health status, and quality of life. Multiple regression	Home-based group scored statistically significantly higher on all measures. Daily symptoms ($t = -2.33$, $p<0.05$), Course of illness ($t = -4.13$, $p<0.001$) Medical care and treatment ($t = -2.71$, $p<0.01$), Total control score ($t = -4.05$, $p<0.001$). Quality of life: Home based scores higher in all areas except family life. Pain ($t = 2.07$, $p<0.05$), Social, ($t = 2.13$, $p<0.05$), Financial ($t = 2.19$, $p<0.05$), Global quality of life ($t = -2.88$, $p<0.01$). Limitations: small sample sizes, demographic differences between home based and inpatients, with greater proportion of home based patients being married, of Australian descent and having private health insurance and less likely to live alone. Does not address cultural or spiritual.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
				(stepwise) to determine factors predicting quality of life.	
(Wu et al 2006) Hong Kong	1) To investigate the impact upon mortality of telephone counselling and compliance in patients receiving polypharmacy. 2) RCT, outcome assessed at 2 years. 3) Intervention: 6-8 phone calls by pharmacist over 2 years (clarification, reminders of appointments, reinforcement of compliance. Control: no such phone calls.	1) 502 attending a hospital clinic and taking 5 or more medications. Mean age approximately 70 years. 2) IG = 219, CG = 223. 3) Stratified by compliancy, generally equivalent at baseline overall.	1) Mortality statistics. 2) Intention to treat analysis.	Kaplan Meier analysis and Cox proportional hazard regression.	11% died in IG compared with 19% in CG. At 2 years, fewer surviving people in the IG remained non-compliant ($p<0.001$). An investigation within the control group (n = 61) showed that low adherence and an inability to read prescriptions and medication labels was associated with increased numbers visits to the Emergency Department for cardiovascular complaints ($p<0.001$).

IG = intervention group, CG = comparison group. RCT = Randomised controlled trial. AD = Alzheimer's disease. AD = Alzheimer's disease or related disorder. GHQ = General Health Questionnaire

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Appendix K Articles reviewed in Section 4.1 ‘The context of family care’

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
Almberg B, Grafström M, Winblad B. Caring for a demented elderly person--burden and burnout among caregiving relatives. Journal of Advanced Nursing 1997; 25(1): 109–116. Sweden				
1) To describe family caregivers' experience of burnout in relation to caregiver burden when caring for a demented elderly person. 2) Descriptive	Purposive sample. N = 52 family caregivers for people with dementia. High drop-out rate.	1) Interviews and questionnaires. 2 instruments used to measure burden and burnout. Instrument 1- Structure questionnaire to measured subjective burden over time. 2- Burnout Measure (self-rating scale with 21 items). 2) Reliability and validity addressed.	Minitab. T-tests, one-way ANOVA and multiple regression.	Older wives and daughters were most likely to report burden. Some siblings and daughters-in-law also risked developing burnout. Regression analysis showed limitations in social life, poor health and lack of positive outlook on caring, were most independent variable explaining variance in burnout. No difference in experience for caregivers with relative at home or institutionalised.
Aneshensel, C., Botticello, A., Yamamoto-Mitani, N. (2004) When Caregiving Ends: the course of depressive symptoms after bereavement. Journal of Health and Social Behaviour, 45 (5) 422–440. USA				
1) Describe depressive symptoms among caregivers following bereavement and connect these trajectories to earlier features of caregiving using life course and stress process theory .2) Prospective study, natural history approach.	N = 555 caregivers, 249 followed to end ***Quantitative:*** How was the sample selected? From Local Alzheimer's disease and related disorders associations Is their any justification for the sample size? Yes, self selected Was there any evidence of selection bias? only caregivers of clients with dementia.	1) Interviews were six face to face, annually, one at Wave one (n = (249), the subsequent at Wave 3 (n = 74), Wave 3 (n = 72), Wave 4 (n = 60), wave 5 (n = 47) and Wave 6 (n = 38), interviews continued whether the caregiving was continued, client place in institutional care or died.2) A modified Hopkins Symptom Checklist was used, no discussion about the variations being	A latent class mixture model, a semi parametric group based method for modelling was used. A polynomial relationship was used to link depressive symptoms with the number of interview year since death of the client using a censored normal distribution. The customised SAD Procedure TRAJ was use and the Bayesian	About one in five caregivers belong to a trajectory characterized by improved emotional well-being as time since bereavement lengthens. Socioemotional support influences the course of post bereavement depressive symptoms directly and by helping to lessen the experience of grief. Five trajectories were found. The caregivers are not uniform in their responses to bereavement but instead follow several distinct trajectories with regard to their subsequent emotional wellbeing. There are multiple trajectories which bereaved persons can follow. Male caregivers are unlikely to respond with

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
		validated or reliable.	Information Criteria.	depressive symptoms to the loss of their spouse, but may be equally affected. A strong sense of self, social ties are important protectors against distress in bereavement.
Banerjee, S., J. Murray et al (2003). Predictors of institutionalisation in people with dementia. Journal Of Neurology, Neurosurgery, And Psychiatry 74(9): 1315–1316. UK				
1) To identify what patient and carer characteristics influence transition into residential care for people with dementia 2) longitudinal study	179 dyads approached 100 people (56%)with dementia and their main family carer were recruited. (South London)	1) simultaneous detailed assessment of the carer as well as the person with dementia. At 6mth follow up 22 were in residential care, 63 in the community, 8 had died and for 7 there were missing data. Between 6 and 12mths, 7 of the 63 in the community went into residential care,4 died and 12 were lost to follow up.2) Valid instrument used.	dementia patients/family carer assessed at baseline: sociodemographic data and measurement of carer burden, carer mental disorder, carer QOL, cognitive impairment in the person with dementia and behaviour disturbance in dementia. Reassessed at 6 & 12mts to ascertain place of residence.	The most striking finding is the 20-fold protective effect of having a co-resident carer (odds ratio 0.05, 95% confidence intervals. 0.01 to 0.42, p = 0.006). Higher ratings of behavioural problems in the person with dementia were also statistically significantly associated with transition into residential care as was the psychological domain of quality of life of the carer. These findings powerfully illustrate the pivotal role carried out by carers of people with dementia; interventions directly targeted at helping them to maintain this role would be supported by these data. These data also suggest that strategies directed at improving carer QOL at the resolution of behavioural disorder in the person with dementia may also have particular value.
Benzein, E. G. and A. C. Berg (2005). The level of and relation between hope, hopelessness and fatigue in patients and family members in palliative care. Palliat Med 19(3): 234–40. Sweden				
1) to describe the levels of	85 Adults, 40 patients with	1) Herth Hope Index —	The Mann-Whitney U-	As patients sometimes take the

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
and relationships between hope, hopelessness and fatigue in patients and family members in palliative care. 2) quant	cancer in Pall. Care and 45 family members recruited from 4 in-and outpatient oncology clinics in Sweden. Nurses identified/gave info package and two questionnaires (HHI-S, HS). 95 distributed 86 returned. 1 packet was excluded /incomplete. 85 packets incl. in analysis.	Swedish version (HHI-S). 12 items with a four-point Likert scale. The Hopelessness Scale (HS). The Hopelessness Scale consist of 20 items and is based on a one-dimensional perspective of hopelessness, ie Negative expectations. The internal consistency reliability in this study was measure by Cronbach's alpha and calculated as 0.90.2) high concurrent and construct validity	test was used to compare the scores of the patients and the family members. Cronbach's Alpha was calculated to test the internal consistency of the measures. Spearmen's rank-order test was used to test correlation between the variables under study. Missing values were dealt by imputing the most common value in the series. The sample size was small and some of the correlations weak.	responsibility for family members' wellbeing, nurses would benefit from adopting a family focused perspective, eg talking to the patient and family members/s at the same time. Efforts to increase the experience of hope and decrease hopelessness and fatigue must include not only the patient but also the family members. Then, patients and family members can support each other and share good moments in their vulnerable situation in the midst of dying.
Beery, L et al, (1997). Traumatic Grief, Depression and Caregiving in elderly spouses of the terminally ill. Omega, 35 (3), 261–279. USA				
1) To examine the effects of changes in role function, caregiving tasks, caregiver burden and satisfaction on symptoms of traumatic grief. 2) Prospective longitudinal study	N = 60Quantitative: How was the sample selected? Not described, but were spouses of terminally ill in Pittsburgh. Is their any justification for the sample size? No. Was there any evidence of selection bias? Not described.	1) Interviews prior to death of husband and then at 3, 6 and 13 months post death. Semi structured interviews. Instruments included Hamilton Rating Scale Depression (proven internal consistency and reliability), Inventory of Traumatic Grief (unpublished prior use), Caregiver Difficulties Rater, Inventory of complicated Grief. Pearsons correlation coefficient were used to	Pearson correlation coefficients were used followed by regression and stepwise regression models.	Depression was significantly associated with IADL ($r = -0.31$ and $p < 0.05$); caregiver burden ($r = 0.31$, $p < 0.05$) and caregiver change in role function (r-0.34, $p<0.01$). traumatic grief was not associated with caregiving burden or caregiver change in role function. No significant association between ADL tasks performed for spouse, caregiver gratification, duration of caregiving and time spent caregiving each week were not associated with either of the mental health outcomes. Caregiver burden significantly

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
		examine relationships between variables2) Instrument were shown to be valid and reliable. Confounding variables were not addressed		predicted severity of both depression (beta = 0.14, p = 0.006) and traumatic grief (beta = 0.36, p = 0.02). IADLs were negatively associated with caregiver depression. Changes in caring for self including eating habits, household chores, working on hobbies and going to work were shown to significantly influence caregiver's depression but none of these were associated with traumatic grief. Caregiver burden was a significant predictor of traumatic grief. Caregivers restriction in sports and recreational activities were the most significant predictors of depression. Caregiver gratification had no significant association with either health problem. A shorter duration of caregiving predicted a higher traumatic grief score, suggesting that traumatic grief in caregivers is most intense shortly after the diagnosis of the spouse's terminal condition.
Bookwala, J., B. Zdaniuk et al (2004). Concurrent and long-term predictors of older adults' use of community-based long-term care services: the Caregiver Health Effects Study. Journal of Aging & Health 16(1): 88–115. USA				
1) This study examined concurrent and long-term assocs. between caregiver-related characteristics and the use of community long-	1,300 in 4 sites. Inclusion-shared a household and indicated they were married and living with their spouse (n = 3.185). Patient: at least	1) Caregiver-related need variables as predictors of service use were of primary interest and included caregiving demands,	Caregivers in the attrition group reported significantly more depressive symptoms at T1 than caregivers in the	A significant finding in the current study was the consistent link between caregivers' mental health and the use of formal services. At T1, more caregiver depressive symptoms predicted greater

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
term care services in a sample of 186 older adults caring for a disables spouse. 2) cross-sectional/longitudinal	one ADL or IADL. 548 individuals in the caregiving pool were consecutively approached to achieve the target sample size of approx. 400 caregivers, yielding a refusal rate of 28%. 248 were eligible, completed data at T1. At T2 the number of eligible caregivers declined by 62, yielding an attrition rate from T1 to T2 of 25%. Reasons included the demise of the care recipient (n = 26), missing data on at least one relevant study variable (n = 15), refusal to continue participation (n = 12), demise of the caregiver (n = 6) and other (n = 3) Final sample 186 65>. 47.3% women (n = 88) and 52.7% men (n = 98)	caregiver mental and physical health and mastery. The IADL and ADL subscales of the Older Americans Resource and Services Scale (OARS) 2) valid instruments	final sample, $t(246) = 1.99$, $p<.05$. Functional limitations, Cronbach's alpha values were.77 at T1 and.84 at T2; similar estimates for ADL limitations were.72 at Ta and.79 at TS. On average, caregivers reported 3.56 (SD = 2.27) IADL limitations at T1 and 3.50 (SD = 2.47) IADL limitations at T2 for their spouse. On ADL limitations, caregivers reported an average of 1.51 (SD = 1.65) and 1.75 (SD = 1.85) difficulties for their spouse at T1 and T2, respectively. Memory and behaviour problems, 30-item Caregiver Supplement of the Problem Behaviour Inventory. Memory and Problem Behaviour based on Zarit & Zarit checklist. Caregiver-related variables-used expanded component Andersen behavioural model. Caregiving	service use; at T 2, more caregiver activity restriction and depressive symptoms predicted greater formal service use; increases in caregiver activity restriction and depressive symptomatology over time predicted increase in service use. Clearly, the caregiver's mental health can be an important risk factor for increased service use.

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			demands, caregiver health and caregiver mastery were also measured.	
Braithwaite, V. (1998). Institutional respite care: breaking chores or breaking social bonds? Gerontologist 38(5): 610–7. Australia				
1) Research question: why respite care is evaluated positively by caregivers, yet is often not used by those considered to be in need of the service. 2) Descriptive	144 caregivers in Canberra, Australia are the basis for examining the relationship between five appraisal dimensions and respite care usage, both in the past and in the future. Face to face interviews + questionnaire	1) measures included — two respite care outcome measures 1st related to whether respite had been used already in the course of caregiving. 2nd related to whether respite care would be used in the future. + ADL dependency — relationship to care recipient — age of caregiver 2) valid instruments	Descriptive Statistics and Correlations + Logistic Regression Analyses	This data show that use of respite care is higher when the task demands of caregiving are high and when caregivers and care receivers are bound together in dysfunctional caregiving relationships. The factor that is most likely to reduce the likelihood that respite care will be used in the future when past use is controlled is the caregiver's appraisal of an intimate and loving relationship between caregiver and care receiver.
Brazil, K. Bedard, M. & Willison, K. 2003. Bereavement Adjustment and Support Among Caregivers. Journal of Mental health and Aging, 9 (3) 193–204.Canada				
1) To examine the influence of health status, demographics, duration of bereavement, caregiving experience and the use of formal services on bereavement adjustment for caregivers. 2) Systematic study.	N = 151 family carers ***Quantitative:*** How was the sample selected? Caregivers that had provided care to a client over 50 (mean was 71 years) and had died within the previous year. Excluded if client had dementia and death was not due to malignancy or medication. Is their any justification for the sample	1) A telephone survey by researchers with relevant undergraduate degrees2) Instruments included Caregiver Reaction Assessment, SF-12	Detailed description of previous verification of tools used. Statistical Analysis was undertaken using SPSS version 9 for Windows. Data may not be generalisable, sample was convenience sample only.	Mean age of respondents was 71 years. 89% felt that things were going reasonable well, and 60% felt they had come to terms with their loved one's death. 51% did not look forward to things in the same way and 57% reported loneliness as a problem, however 77% of these felt that this was Something they would get over soon. Younger caregivers with poorer mental health status that were spouses of

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	size? Yes Was there any evidence of selection bias? Yes, all family carers had been recipients of palliative care via community nursing agencies.			clients had more depressive symptoms in bereavement. Family members (74%) were the most common source of support followed by friends and neighbours (63.8%). Formal care providers were used by 49.7% of the family carers to talk about the death. Most often this care was provided by GPs (34%), priests or ministers (22%), nurses (9.3%), and other physicians (7.3%). Reaction to grief was characterised by sleep disturbance, loss of appetite and general distress.
Brazil, K., D. Howell et al (2005). Preferences for place of care and place of death among informal caregivers of the terminally ill. Palliative Medicine 19(6): 492–499.Canada				
1) 2 aims - 1.To determine informal caregivers perceptions about place of care and place of death; and 2- to identify variables associated with a home death among terminally ill individuals who received in-home support services in a publicly funded home care system. 2) Part of a longitudinal study.	648 convenience sample. 530 consented (82%). 309 informal caregivers had a care recipient die while enrolled in the study of which 216 consented to participate in a bereavement interview. (70%) Recruited over a 24mth period. (Jan 2000-Jan 2002) informal caregivers who had a care recipient die in the study (longitudinal — Care of the Seriously Ill in the Community (CSIC)), were invited to participate in a telephone bereavement interview. Inclusion criteria -care	1) Phone bereavement interview- care recipient characteristics + informal caregiver characteristics — the use of a family physician and community services and perceptions of service delivery and satisfaction with services received. Preference for place of death was examined using a set of six questions: 1. Where did (he/she) die? (home, hospital, nursing home, other). 2. Did (he/she) ever say that there was place where (he/she) would have	Means, standard deviations, frequencies and percentages were used to describe care recipient/caregiver characteristics, place of death and preferences for place of death. Chi-square analysis used to assess for differences-died in an institutional or home setting. A two-sided Fisher's exact test used to determine significance. Differences in coding by the researchers were	Most caregivers reported that they and the care recipient had a preferred place of death (77 and 68%, respectively) with over 63% reporting home as the preferred place of death. Caregivers had a greater preference for an institutional death (14%) than care recipients (4.7%). While 30% of care recipients did not die in their preferred location, most caregivers (92%) felt, in retrospect, that where the care recipients died was the appropriate place of death. Most caregivers reported being satisfied with the care that was provided. The odd of dying at home were greater when the care recipient stated a preference for place

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	recipient incl.50yo> reside in the study catchment area (Ontario, Canada); was not a resident of a nursing home or assisted living facility; received in-home services delivered through a Community Care Access Centre (CCAC) and was designated as palliative by the CCAC. Inclusion criteria for the informal caregiver-included. residing in the study catchment area and able to communicate in English.	wanted to die? (yes, no, don't know). 3. Where was this place? (home, hospital, nursing home, other). 4. (Ask if any discrepancy between Q 1 & 3) What would have been needed to be different so that….could have died at (his/her) preferred place? (please explain) 5. Do you feel that where (he/she) did was the right place for him/her? (yes, no, [please explain], don't know). 6. Did you have a preference for where (he/she) died? (yes [home, hospital, nursing home, other, please explain], no, don't know). 2) Relevant instruments	examined and resolved through clarifying and redefining the definition of the codes.	of death)OR: 2.92; 95% CI; 1.25, 6.85), and the family physician made home visits during the care recipients last month of life (Univariate odds ratios (OR): 4.42; 95% CI: 1.46, 13.36).
Brazil, K., M. Bedard et al (2003). Caregiving and its impact on families of the terminally ill. Aging & Mental Health 7(5): 376–382.Canada				
1) to describe the type of assistance that patients need in the home and identify factors associated with significant family caregiver burden. 2) retrospective over two year period	Recruited through one of two community nursing practices providing palliative care services in homes. Retrospective reports used. Most caregivers in this study were the female spouse of the patient. Lived with the patient	1) interview procedure/Addington-Hall & McCarthy (1995b) Caregiver Reaction Assessment tool used (CRA) 24-item scale measuring the reaction of family caregivers, caring for older adults with physical	Analysis of the CRA showed that Cronbach's alphas varied between 0.62 and 0.83 for the separate subscales, indicating sufficient internal consistency. Means (standard	Reveal that the physical demands of caregiving and their cumulative effect are associated with caregiver burden. Caregiver needs — education, support, psychotherapy and respite, place a strong emphasis on reducing the amount of physical care provided by family caregivers. Exhausted caregivers

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	and not employed outside the home while caregiving. Inclusion criteria-deceased patients >50/english communication/informed consent. Caregivers excluded if-patient had dementia.	and mental impairments. 5-point Likert scale score 2) valid instruments used	deviations) and frequencies were used to describe patient and caregiver characteristics. Univariate odds ratios (OR) used to determine patient and caregiver variables associated with high caregiver burden. Assessed by a multivariate logistic regression.	could potentially become future care recipients, an outcome that may be preventable when the appropriate supports are provided. Main limitation was uncertain generalisability of the findings: 51% revealed 41% caregivers reported that the patient did not receive a home visit from their family physician. (Other reports note that family physician identified as a key element in supporting the terminally ill to die at home).
Brazil, K., M. Bedard et al (2005). Service preferences among family caregivers of the terminally ill. Journal Of Palliative Medicine 8(1): 69–78.Canada				
1) describe service preferences among informal caregivers of the terminally ill. 2) 373 caregiver-telephone interviews at two points in time: when designated as palliative and 5 months subsequent to the first interview/or 3mths after the death.	A convenience sample of 648 potential participants. 535 consented (82% consent rate) Inclusion criteria incl. the care recipient >50 years, residing in the study location, receiving formal services from a Community Care Access Centre (CCAC) and designated as palliative by the community care agency. The caregiver had to be a resident of the study loc. able to communicate in English.	1) Caregivers recruited over a 2 y period. Letter/phone then 4wks after recipient designated as palliative. Recording service use was modelled after the interview protocol used in the Canadian Study of Health and Aging.2) valid instruments used	Means (standard deviations) and frequencies used to describe caregiver and care recipient characteristics. Univariate unadjusted odds ratios (OR) were used to determine which caregiver and recipient variable sere associated with service needs. Then regression analysis. Services classified as being primarily oriented toward either care recipients or caregivers.	The 5 services caregivers reported a most valuable included: in-home nursing care, (90.7%), family physicians (45.6%) medical specialists (46.4% housekeeping 23.6%) and religious support (11.3%). The 5 most frequently reported services that family caregiver would have liked to have received or had more available included: housekeeping (13.1%) caregiver respite (10.2%), in-home nursing care (8.0%) personal support workers (4.6%) and self-help/support groups (3.8%). Analyses revealed that most (64.8%) received service needs were of a supportive nature for caregivers. Caregiver perception of the value and perceived need of services were consistent over time and into

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				bereavement. Regressional analysis suggested that younger caregivers who were not employed, reported higher levels of burden and cared for someone with a diagnosis of cancer had greater perceived service needs.
Burton, A, Haley, W & Small, B. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. Aging and Mental Health, 10 (3), 319–326.USA				
1) To determine if there is variation in bereavement response between expected and unexpected deaths of spouses 2) Prospective study	N = 193 ***Quantitative:*** How was the sample selected? Obituaries, death record tapes and the National Death Index to determine when the client died, then follow up of the spouses. Spouses had previously been interviewed as part of CLOC study. Is their any justification for the sample size? Ill health, death and refusal. Was there any evidence of selection bias? No	1) Interviews pre loss; 6 moths after death of spouse and then 18 months post loss. Instruments included Bradburn Affects Balance Scale and the Epidemiological Studies — Depression (CES-D).2) Both tools were previously validated a	Mixed Models analyses	Unexpected death was associated with depression at six month and increase by 18th moths. Spouse with lower stress showed significant increase in contact with children and grandchildren, although those spouse with higher stress levels also did not change the way they were socialising. Worsening depression was evident in the unexpected death groups. Difficulties that family carers have in retaining their social roles may impact on their bereavement, particular if they have become socially disengaged. Highly stressed carers have experienced a lack of, or negative support.
Carr, D., House, J., Wortman, C., Nesse, R. & Kessler, R. (2001) Psychological Adjustment to Sudden and Anticipated Spousal Loss Among Older Widowed Persons. Journal of Gerontology: Social Sciences. 56B (4) S237-S248.USA				
1) To examine if older adults psychological adjustment to widowhood varies based on whether the death was sudden or anticipated and if	N = 1532; data from 155 were used (see below) ***Quantitative:*** How was the sample selected? English speaking married couples where the husband	1) Interviews conducted at 6, 18 and 48 months after spouse's death. Instruments included Epidemiologic Studies Depression,	Descriptive statistics and t-tests	The average warning time for participants that their spouse was going to die was 5–6 months. Regression results indicate that the forewarning on survivor well being was far weaker

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these effects are mediated by death context characteristics. Sudden death effects only, linear effects of warning time and curvilinear effects of warning time. To evaluate whether particular parameterization of forewarning better predicts widowed persons' psychological adjustments. 2) prospective study	was 65 years or older, non-institutionalised and capable of participating in a 2 hour long Interview. from parent study (CLOC). Although some of the spouses were caregivers, the sample was all inclusive for deaths types eg sudden deaths, violent deaths. Is their any justification for the sample size? Response rate was 68%, there were 335 respondents known to have lost a spouse, 6% died. 263 participated in at least one follow up interview. Was there any evidence of selection bias? Correction for drop out rate described. After correction not one variable was a significant predictor.	Symptom Checklist 90 revised, Bereavement Index, Present Feelings about Loss and Grief.2) Instruments were validated. Confounding factors were acknowledged and measured.		than past research indicated. There was very limited effects of forewarning on reactions to widowhood among older adults and warning time was not a significant predictor of the outcomes ie depression, grief shock and anger at 8 or 18 month. Sudden death was associated with slightly higher yearning scores among women at 6 and 18 months. Few death context variables had direct effects on intrusive thought although having been with one's spouse at the moment of death protected against high levels of intrusive thoughts ($p <= 0.001$). Persons who discussed death with their spouse and those whose spouses resided in nursing homes had significantly lower levels of intrusive thoughts. Individuals whose spouses resided in a nursing home prior to death had significantly lower anxiety levels at Wave 1 and Wave 2 and for this group communicating about death with their spouse was unrelated to anxiety levels at 6 and 18 months. Gender differences in the effect of forewarning remained significant at the $P <= 0.05$ level. Grief among elderly widowed persons has shown that the protective effects of death forewarning on survivors' mental health found in earlier research may be overstated. Prolonged forewarning increases

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				survivors' anxiety levels both 6 and 18 months after death.
Casarett, D. J., K. B. Hirschman et al (2003). Caregivers' satisfaction with hospice care in the last 24 hours of life. American Journal of Hospice & Palliative Care 20(3): 205–210. USA				
1) To identify elements of care that contributed to positive and negative perceptions of hospice care in the last 24 hours of life and to define patient and family characteristics that are associated with satisfaction with care during this difficult period. 2) Descriptive	Surveys sent to 207 primary caregivers and 112 were returned. patients primary caregiver were identified prospectively in the hospice's database and sent a survey between 2 and 6 weeks after death.	1) Measurement included patient age, patient gender, location of death, and diagnosis. Also, satisfaction with care during the last 24 hours. Caregivers' descriptions of the last 24 hours. Symptoms. Continuity of hospice personnel. Anticipatory guidance. Accessibility of hospice personnel. 2) n/a	Nonparametric texts (eg Rank sum test and Spearman correlation coefficients) and the Chi-square test were used for all analyses.	This study reports four findings that elucidate the factors that make family members more or less satisfied with the care that their loved one received during the last day of life, and how satisfaction with this period of care should be measured. a) 4 dimensions of care — accessibility of hospice staff, continuity of hospice personnel, anticipatory guidance and symptom management. b) it is noteworthy that families' perceptions of the efficacy of symptom management, whether or not they were accurate, were strongly associated with satisfaction.
Chentsova-Dutton, Y., Shucter, S., Hutchin, S., Strause, L., Burns, K., Dunn, L., Miller, M. & Zissok, S. (2002). Depression and grief reaction in hospice caregivers: from pre-death to 1 year afterwards. Journal of Affective Disorders 69, 53–60.USA				
1) To examine emotional adjustment and grief intensity among hospice caregivers from the pre-bereavement baseline through the first year after death. 2) Longitudinal study. Pre	N = 112 caregivers of clients in a community based hospice program. ***Quantitative:*** How was the sample selected? Family carers of all clients accepted into hospice program were invited. Controls were selected if they had not	1) Data collection included semi structured interviews and self completion of tools including self report questionnaire. Instruments included Hamilton Depression Rating Scale, Self Related Brief Symptom	Repeated measures analysis of covariance was used in comparing groups. The assumptions of ANCOVA including normality, homogeneity of variance, linearity between covariates,	Overall caregivers reported higher level of depression than did controls 2 weeks before the death and 2 months after the death, but not at 7 and 13 months after the death. Caregiver depression did not change significantly between first and second time, but reduced at 7and 13 months. 23% of caregivers had at

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and Post bereavement. Small sample. High reliance on self — report measurements. Carers that remained in the study for its duration may have been healthier and less depressed than those that dropped out.	experienced the death of a relative or friend in previous 2 months and were recruited by word of mouth, friends and neighbours of staff and researcher and notices at the hospice and medical centre. Is their any justification for the sample size? Small sample size and high attrition rate. 47 controls dropped out at time 4. 56% of carers dropped out before Time 4. Although these persons were not demographically different. Was there any evidence of selection bias? All caregivers were receiving hospice care which is inclusive of pre and post bereavement counselling, this sample may be at lower risk of complications of grief than most population. Sample was mostly Caucasians and representative of users of the Hospice program in Diego.	Inventory and Texas Revised Inventory of Grief.2) Instruments not discussed, but referenced from previous studies.	homogeneity of regression slopes, absence of multicolinearity between covariates and reliability of covariates were adequately met.	least mild depression as compared with none in the control group 2 weeks prior to the death of the client. ANCOVA analyses, caregivers mean scores were significantly higher than those of the controls over time on the subscales of anxiety ($P<0.01$), hostility ($P<0.01$) and depression ($P<0.01$). Caregivers anxiety and hostility diminished over time whereas controls level of anxiety remained relatively stable and low. In respect to grief there were no differences between adult children and spouse nor male and female caregivers. By 7 months after death levels of depression subsided in caregivers and were equal to population controls. The death of family member were not associated with increased depressive symptomotology. The illnesses were chronic, the deaths anticipated and most carers felt good about their effort in providing care in terminal phases of the illness. The sample may be at lower risk of untoward or complicated grief. Distress may persist for some individuals during the first year of bereavement. Children that are caregivers of parents are every bit as distressed as spouses that provide care for their partners.
Covinsky, K. E., C. Eng et al (2001). Reduced employment in caregivers of frail elders: Impact of ethnicity, patient clinical characteristics, and caregiver				

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characteristics. Journals of Gerontology Series a-Biological Sciences and Medical Sciences 56(11): M707-M713.USA				
1) …to determine the patient and caregiver characteristics associated with the reduction of employment hours in caregivers of frail elders. 2) cross-sectional	2806 patients (mean age 78, 73% women, 29% African American, 12% Hispanic, 54% with dementia) with at least one potentially working caregiver (defined as one who is either currently employed or who would have been employed if they had not been providing care) and their 4592 potentially working caregivers.	1) Patients were enrolled at 11 sites of the Program of All-Inclusive Care for the Elderly (PACE). Social workers interviewed Patients and caregivers at time of PACE enrolment. Caregiver were asked if they had reduced the hours they worked or had stopped working to care for the patient. Nurses interviewed Patients and caregivers to assess independence in activities of daily living (ADLs.) The presence of behavioural disturbances/cognitive function Short Portable Mental Status Examination (SPNSQ; 19). Co morbid conditions were assessed by physicians during enrolment examinations. 2) valid instruments	Patient characteristics independently associated with a caregiver reducing hours or quitting work were ethnicity (odds ratio [OR] = 1.42, 95% confidence interval [CI] 1.14–1.78 for African American; OR - 1.90, 95% CI 1.43–2.52 for Hispanic), ADL function below the median (OR = 1.76, 95% CI 1.44–2.15), a diagnosis of dementia (OR = 1.68, 95% CI = 1.31–2.17 if associated with a behavioural disturbance; OR = 1.31, 95% CI 1.06–1.63 if not associated with a behavioural disturbance), or a history of stroke (OR = 1.42, 95% CI 1.16–1.73). After controlling for these patient characteristics caregiver characteristics associated with reducing work hours included being the daughter or daughter-in-	A total of 604 (22%) of the 2806 patients had at least one caregiver who either reduced the number of hours they worked or quit working to care for the patient. The burden of reduced employment is more likely to be incurred by the families of ethnic minorities and of patients with specific clinical characteristics. Daughters and caregivers who live with the patient are more likely to reduce work hours than other caregivers. It is important for providers and policy makers to fully recognise the economical and personal contributions of unpaid family caregivers. Most elders eligible to live in nursing homes continue to live in the community, in large part because of the unpaid efforts of their caregivers. However, almost no data are available on the economic consequences of caregiving, and the costs of caregiving are rarely considered in policy discussions of healthcare costs. The failure to consider these cost parallels the anecdotal reports that the health care system is not responsive to the needs of caregivers.

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			law of the patient (OR = 1.69, 95% CI 1.37–2.08) and living with the patient (OR = 4.66, 95% CI 3.65–5.95 if no other caregiver lived at home, OR = 2.53, 95% CI 2.03–3.14 if another caregiver lived at home).	
Covinsky, K. E., R. Newcomer et al (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. Journal of General Internal Medicine 18(12): 1006–1014.USA				
1) The goal was to determine the patient and caregiver characteristics associated with depression among caregivers of patients with dementia. 2) Cross-sectional.	5,627 patients (mean age 79yrs) with moderate to advanced dementia (59% women, 88% white & 44% had less than a high school education) and their primary caregivers (unpaid, mean age 64yrs, 72%women enrolled in the Medicare Alzheimer's Disease Demonstration (MADDE) at 8 locations in the United States.	1) Caregiver depression was defined as 6 or more symptoms on the (15-item) Geriatric Depression Scale (GDS). Patient characteristics measured included ethnicity and other demographic information, income, activities of daily living (ADL) function (5 activities), Mini-Mental Status Exam (MMSE) score (30-point),and behavioural problems. Caregiver characteristics measured included demographic characteristics, relationship to the patient, hours spent	We used X2 and t-tests to measure the bivariate relationships between patient and caregiver predictors and caregiver depression. We used logistic regression to determine the independent predictors of caregiver depression.	32% of caregivers reported 6 or more symptoms of depression and were classified as depressed. Independent patient predictors of caregiver depression included: younger age (odds ratio [OR], 1.91; 95% confidence interval [CI], 1.33 to 2.76 in patients less than 65 yrs compared to patients over 85yrs, white (OR, 1.53; 95% CI, 1.18 to 1.99) and Hispanic ethnicity (OR, 2.50; 95% CI, 1.69 to 3.70) compared to black ethnicity, education (OR, 1.16; 95% CI, 1.01 to 1.33 for those with less than a high school education), ADL dependence (OR, 1.55; 95% CI, 1.26 to 1.90 for patients dependent in 2 or more ADL compared to patients dependent in no ADL), and

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		caregiving and ADL and Instrumental Activities of Daily Living (IADL) function. Caregiver functional dependence-Katz ADL scale. Lawton Instrumental Activities of Daily Living (IADL) scale.2) Valid instruments		behavioral disturbance, particularly angry or aggressive behavior (OR, 1.47; 95% CI, 1.27 to 1.69 for patients with angry or aggressive behavior). Independent caregiver predictors of depression included: low income (OR, 1.45; 95% CI, 1.18 to 1.77 for less than $10,000/per year, compared to >$20,000 per year), the relationship to the patient (OR, 2.73; 95% CI, 1.31 to 5.72 for wife, compared to son of male patient), hours spent caregiving (OR, 1.89; 95% CI, 1.51 to 2.38 for 40 to 79 hrs/week compared to less than 40hrs/week), and functional dependence (Or, 2.53; 95% CI, 2.13 to 3.01 for ADL dependent compared to IADL independent).
Cravens, D. D., D. R. Mehr et al (2005). Home-based comprehensive assessment of rural elderly persons: The CARE project. Journal of Rural Health 21(4): 322–328.USA				
1) To design an effective model for rural home-based CGA (Comprehensive Geriatric Assessment)2) developmental demonstration project	51 volunteers 75> who did not have a terminal diagnosis or immediate plans to enter a long-term care facility.	1) In-home assessment. CGA involves medical history taking, a physical exam, and evaluation of functional status, mental status, cognitive status, gait and balance, medications, vision, extent of social supports, and home safety. The following assessment instruments were used. Barthel Activities of Daily Living (ADL) scale,	Means of 1.1 major problems and 4.9 non-major problems were identified per patient. Based on clinical considerations, we diagnosed depression and cognitive problems in this study population more commonly than would be predicted by the standard cutpoints on the geriatric	We identified many patient problems, including a large number of unrecognized major medical problems, mental health problems, functional impairments and environmental hazards. Among the 51 patients undergoing CGA, Instrumental Activities of Daily Living dependency and balance and gait problems were highly prevalent. Recommendations were implemented for 32% of major problems and for 35% of nonmajor

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		Lawton Instrumental Activities of Daily Living (IADL) scale, Folstein Mini-mental Status Exam, 15-item Geriatric Depression Scale. Tinetti Gait and Balance Exam, self-rated health items from the Medical Outcomes Study 36-item Short Form (SF-36), medication inventory, home safety assessment and Mini-Nutritional Assessment-Short Form. Patients followed up by phone 3mths after the initial assessment plus in-home assessment 6mths after the initial assessment. During this period, 3 subjects died, 1 entered a long-term care facility; and 1 withdrew from the program after initial assessment.2) valid instruments	depression scale (more than 5 depressed responses) or the Mini-mental State Examination (score of 24).	problems. Primary physicians found recommendations for vaccination and home safety change helpful but were sceptical of physical examination findings by the nurse. Practitioners noted that this study resulted in several positive outcomes: (1) some subjects initiated regular clinic visits; (2) several visually impaired elders began services for the blind; (3) identification of gait and balance problems resulted in physical therapy treatment; and (4) identification of caregiver stress was addressed by social-work intervention. Potential further refinements of the model for rural home-based CGA were identified.
Diwan, S., G. W. Hougham et al (2004). Strain experienced by caregivers of dementia patients receiving palliative care: findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program. Journal Of Palliative Medicine 7(6): 797–807.USA				
1) …examines predictors of types of strain experienced by caregivers of community-dwelling patients with dementia enrolled in a	150 community-dwelling patient dyads with dementia were recruited sequentially (90% agreed to participate) All were enrolled in a program	1) Established measures — Caregiver Strain Index, - the Revised Memory and Behaviour Problems Checklist and the Katz Index	Factor analysis of the Caregiver Strain Index revealed 3 dimensions of strain (role, personal and emotional) related to	Using the stress process model to understand predictors of caregiver strain within the palliative care framework highlights the type of stressors, both long and short-term, that

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unique demonstration program titled Palliative Excellence in Alzheimer Care Efforts (PEACE) which moved palliative care upstream, integrating palliative care into the primary care of patients with dementia. 2) quant. Structured, face-to-face interviews	titled Palliative Excellence in Alzheimer Care Efforts (PEACE). Interviewed separately each interview 15–40mins.	of Activities of Daily Living2) valid instruments	caregiving. Using a stress process model, regression analyses examined stressors and resources related to patient, caregiver and support system characteristics in predicting these 3 dimensions of strain among caregivers. Patient problem behaviours predicted all types of caregiver strain. Perceived lack of support from the health care team predicted personal and emotional strain, whereas higher income, surprisingly, predicted role strain. Patient functional limitations predicted personal and role strain. Exploratory factor analysis was conducted to determine the dimensionality of the Caregiver Strain Index and reliability of the subscales was assessed through Cronbach's alpha. Ordinary least squares regression was	need to be addressed. Delivering palliative care through an outpatient geriatrics practice offers promise in developing models that can effectively address the needs of both patients and caregivers over a longer term than what is typical of hospice programs. Our study demonstrates the need for collaboration between the hospice, palliative care, and Alzheimer's disease care communities to develop effective programs based on models derived from the social sciences that offer meaningful end-of-life support and care to patients with dementia and their families.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
			used to examine the predictors of various dimensions of caregiver strain.	
Ducharme, F., L. Levesque et al (2007). Older Husbands as Caregivers: Factors Associated With Health and the Intention to End Home Caregiving. Research on Aging 29(1): 3–31.Canada				
1) …was to determine the factors associated with the health of older husband caregivers and with their intention to end home caregiving for their wives. 2) cross-sectional/multisite	The participants were recruited following a multistage sampling strategy (. To maximize the heterogeneity of the sample the participants were recruited through formal resources offering social, health and community services (eg local community services centres, Alzheimer's societies, day centres). Advertisements were distributed in medical clinics and community organisations and during professional conferences and community meetings. A snowball strategy was used. Inclusion criteria- aged 60>, French speaking, living with a functionally or cognitively impaired wife, serving as his wife's primary family caregiver for at least the past 6mths and spending at least	1) Standardized interview, usually a home, 60–90 minutes. Measures included- Background-contextual factors. Bem Sex-Role Inventory (BSRI) short version 20-items. Spousal relationship-100-mm visual analog scale, Primary objective stressors scale, Revised Memory and Behaviour Problems Checklist 7-items, Mini-Mental State Examination, Primary subjective stressors 4-items, Secondary stressors 4-item, Resources- Inventory of Socially Supportive Behaviours 4-items (two subscales). Carers' Assessment of Managing Index 6-items, Bandura Self-efficacy scale, Personal gain scale 4-items. Dependent	To identify factors associated. with psychological distress, a hierarchical ordinary least squares regression analysis was run. Factors were entered in the analysis by blocks in the order proposed by Pearlin et al's (1990) model. Self-perceived health was treated as an ordinal dependent variable with 3 categories; and ordinal logistic regression was performed. Intention to end caregiving at home was dichotomized into 2 categories, namely, husbands with no intention of ceasing home caregiving and husbands who reported some probability; a	The results showed subjective stressors to be assoc. with outcomes. Role overload was linked to psychological distress and to lower self-perceived health, whereas role captivity was associated with psychological distress and the intention to end home caregiving. The likelihood of ceasing home caregiving increased when caregivers reported high relational deprivation. A high percentage of the variance in psychological distress was explained (51%). The quality of prior husband-wife relationships, the frequency of disruptive behaviours, family conflicts and self-efficacy were associated with this variable. Self-efficacy had a mediating effect between subjective stressors and psychological distress, whereas the number of services received had a moderating effect on the intention to end home caregiving among husbands with high role captivity. This study provides

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
	14hrs per week caring for his wife.	variables-Psychological Distress Index 14-items. Self-perceived health was measured through a question taken from the Quebec Health and Social Survey.2) valid instruments	dichotomous logistic regression was performed.	avenues for interventions sensitive to male caregivers.
Dumont, S., J. Turgeon et al (2006). Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. Journal Of Palliative Medicine 9(4): 912–921.Canada				
1) To determine the extent to which the family caregivers' psychological distress is influenced by the patients' performance status while taking into account individual characteristics of caregivers and their unmet needs. 2) Cross-sectional	212 family caregivers assigned to 3 cohorts according to the patient's performance status, as measured by the Eastern Collaborative Oncology Group Functional Scale (ECOGS)	1) Interview information collected on the services and care provided, as well as one the caregivers' characteristics and level of psychological distress, evaluated using the *Indices de detresse psychologique de Sante Quebec* (IDPESQ) this multidimensional index derived from the Psychiatric Symptoms Index. Cronbach's correlation + Symptom Distress Scale (SDS) + Home Caregivers Need Survey (HCNS) was adapted for this study. 2) All valid instruments -	Family caregivers' psychosocial distress is strongly associated with the patient's terminal disease progress and declined functioning. The level of psychological distress varies from 25.2 to 33.5 ($p = 0.0008$) between groups. The percentage of caregivers with a high level of psychological distress varies from 41% to 62%, while this percentage. is estimated at 19.2% in general population.	A high distress index was significantly associated with the caregiver's burden, the patient's young age, the patient's symptoms, the caregiver's young age and gender, a poor perception of his/her health and dissatisfaction with emotional and tangible support.
Ferrario, S. R., V. Cardillo et al (2004). Advanced cancer at home: caregiving and bereavement. Palliative Medicine 18(2): 129–136.Italy				
1) to contribute towards	121 caregivers invited to	1) Cognitive Behavioural	Descriptive	Caregivers predominantly female

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
improving our understanding of the problems experienced by the caregivers of patients with advanced or terminal phase cancer during the period of caregiving and 3, 6 & 12months after the patient's decease. + verifying the feasibility of using general screening instruments as a means of simplifying the assessment procedure. 2) Questionnaire 40mins for caregivers to complete the entire set of the following questionnaires — see box F	participate. 2 refused & 8 patient deceased before 1st appointment. Invited remaining 111 complete/questionnaire (T0)after the death of the patient (T1, T2 & T3) 3, 6 & 12mths after bereavement. 12mth follow-up completed by 93 caregivers, 13 patients followed up elsewhere and 5 withdrew from study (2 @ T3 and 3 @ T2)	Assessment — Primary Scale (CBA 2.0) - State Trait Anxiety Inventory (STAI X1, X2) - Eysenck Personality Questionnaire (EPQ) - Depression Questionnaire (DQ) - Family Strain Questionnaire (FSQ)2) valid instruments used	statistics/Pearson correlations used to examine the significance of their associations. ANOVA used to verify the influence. Of gender and disease duration on the caregivers' FSQ, State Anxiety and Depressive Symptoms scores at T 0. Multiple linear regression modelling used to ascertain the contributions of the caregiver and patient variable identified at T 0 to the prediction of caregiver maladjustment at T3 (12mths after bereavement)	(wives/daughters of patients) 37% still working (35% stopped working temporarily). Majority declared that they assisted the patient because nobody else was available (53%) and 24% felt that they were more suitable than others in taking care of their loved ones. Economic worries reported by 12% of caregivers, 7% stated their income was insufficient. more than 50% had stopped meeting friends and cultivating their hobbies. 17 patients were followed in hospital outpatient departments. 76 rec. home-care treatment (6 because their carer didn't drive.)
Fried, T. R., E. H. Bradley et al (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. Journal Of The American Geriatrics Society 53(1): 59–65.USA				
1) To examine the adequacy of caregiver-patient communication is serious illness and its relationship to caregiver burden 2) cross-sectional cohort study	226 older persons with potentially limited life expectancy identified using objective criteria. Sequential charts of persons aged 60> with a primary diagnosis of cancer, CHF, or COPD were screened for the primary eligibility criterion of limited life expectancy, using	1) Interviews conducted in patients' homes to obtain descriptive variables by self-report. Other measures included; Health related variables; Healthcare utilization; Caregivers' sociodemographic variables; Caregiver burden. Communication concerns,	Of caregivers, 39.9% desired more communication, and 37.3% reported that communication was difficult. Of patients, 20.2% desired more communication, and 22.3% reported that communication was	A large proportion of caregivers and seriously ill older persons had an unmet desire for increased communication, although they frequently disagreed with each other about this desire. Caregivers' desire for increased communication may be a modifiable determinant of caregiver burden.

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	Connecticut Hospice criteria. Exclusion criteria included cognitive impairment, determined by a score on the Short Portable Mental Status Questionnaire of less than 8. Of the 279 eligible patients 2 did before participation and 51 refused participation resulting in 226. Informal caregivers were identified by the patients as providing the greatest assistance with IADLs was asked to participate in the study. A total of 193 persons aged 60> with cancer, congestive heart failure, or chronic obstructive pulmonary disease and their caregivers participated.	measured in terms of agreement with statements regarding desire for and difficulty with communication about the patients' illness. Caregiver burden, measured using a 10-item subset of the Zarit Burden Inventory, with scores ranging from 0 to 40 and higher scores indicating greater burden.2) valid instruments	difficult. Disagreement regarding communication concerns was frequent in caregiver-pt pairs; of caregivers who desired more communication, 83.1% of patients did not, and of patients who desired more communication, 66.7% of caregivers did not. Caregivers who desired more communication had significantly higher caregiver burden scores than did caregivers who did not (9.2 vs. 4.7, P<.001), even after adjusting for patients diagnosis, income and functional status and caregivers' age, sex and relationship to the pt.	
Fromme, E. K., L. L. Drach et al (2005). Men as caregivers at the end of life. Journal Of Palliative Medicine 8(6): 1167–1175. USA				
1) To examine the experiences of men involved in end-of-life caregiving, focusing on caregiver strain. 2) regression model + qualitative analysis	Random sample. Oregon death certificates to phone survey family caregivers of patients who had died 2–5months earlier in private homes, nursing homes, and other	1) Interviews. Incl. single item indicators and embedded scales to measure caregiver strain and perceived decedent symptom distress.	Analysed caregivers' description of the decedent's last few days of life for the 25 husbands, sons, wives and daughters who	The strongest predictor of high end-of-life caregiver strain was the severity of the decedents' symptom distress. Only 15% of men spontaneously mentioned their own struggles.

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	community-based settings.1384 caregiver from a pool of 3048 death certificates. Men 29% of the caregivers, including 15% sons, 9% husbands and 5% others. Linear regression model, male gender was a significant predictor of lower caregiver strain ($p<0.001$)	2) valid instruments used	reported the highest levels of strain.	
Gaugler, J. E., K. A. Anderson et al (2004). The emotional ramifications of unmet need in dementia caregiving. American Journal Of Alzheimer's Disease And Other Dementias 19(6): 369–380.USA				
1) …sought to determine how various dimensions of unmet need influence subjective stress (eg feelings of exhaustion and fatigue, feelings of being trapped in the caregiver role, loss of intimacy and exchange with the care recipient) of dementia caregivers.2) longitudinal	694 responded to brief pilot study then mailed questionnaire about unmet needs, after caregivers had been identified by staff. Attrition from the UK-ADRC pilot phase to the CCS resulted in a sample of 344 caregivers of persons with dementia still in the community.	1) Measures included — Community Care Survey (CCS), Context of care — Primary objective stressors — Resources — Unmet need — Subjective stressors 2) valid instruments	Descriptive analysis and multivariate regression models found that unmet need for either confidante or formal support had key implications for caregivers' emotional distress in each of the care situations.	The findings suggest that conceptual models should incorporate unmet need as a viable predictor of caregiving outcomes and that assessment of unmet need may provide guidance in the development of more refined psychosocial and community-based intervention protocols.
Gaugler, J. E., R. L. Kane et al (2005). Unmet care needs and key outcomes in dementia. Journal Of The American Geriatrics Society 53(12): 2098–2105.USA				
1) To determine how unmet needs for activity of daily living tasks influenced nursing home placement, death, or loss to follow-up in dementia.	5831dementia patients and their primary caregivers were included at baseline.	1) Interviews conducted every 6mths for 18mths. Measures of sociodemographic context of care; functional, cognitive and behavioural status of care recipients; caregiver	The independent variables of interest were unweighted unmet care need scores and unmet need scores weighted by importance and severity in a prior sample of older	The findings have strong implications for the clinical assessment of unmet need during the course of dementia. Cox regression models suggested that greater unmet need was predictive of nursing home placement, death and loss to follow-up. Items that constitute

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
2) longitudinal-18mth		stress and well-being; and formal and informal resources served as covariates. Behaviour problems were assessed using the 19-item Memory and Behaviour Problems Checklist. Case managers administered the 30-item Mini-Mental State Examination at baseline. Caregiver burden was measured using the 7-item version of the Zarit Burden Scale. The 15-item Geriatric Depression Scale measured caregiver depression. Caregivers' ADL and IADL dependencies and single-item self-rating of health were also included.2) valid instruments	consumers of long-term care. Outcomes included nursing home placement and death. Cox proportional hazards models were used to analyse the empirical effects of unmet needs during the 18mth study on exit outcomes. (separate model conducted for each outcome). The main independent variable of interest was the summary score of unmet ADL care needs. Separate Cox models were conducted for the unweighted and weighted ADL and unmet ADL scores	traditional ADL (eg bathing, toileting, dressing), memory impairment, or behavior problems scales likely vary in their importance and severity in the overall progression of dementia, and treating each item as identically important may reduce the ability of these measures to account for key and costly health outcomes over time. Creating study-specific or even universal weights that account for the severity and importance of items that measure functional, cognitive, and behavioral domains may significantly improve the ability of clinicians and researchers to identify and address the multifaceted challenges of care that occur throughout the progression of dementia.
Given, B., G. Wyatt et al (2004). Burden and depression among caregivers of patients with cancer at the end of life. Oncology Nursing Forum 31(6): 1105–1117.USA				
1) To examine the patient and family caregiver variables that predicted caregiver burden and depression for family caregivers of patients with cancer at the end of life.	152 English speaking caregivers of patients diagnosed with breast, colon, lung, or prostate cancer who had died. Selection criteria-family members and their patients had to have received a diagnosis of cancer within	1) Data collection consisted of phone interviews at 6–8 (T1), 12–16 (T2), 24–30 (T3) and 52weeks (T4) after enrolment. Phone interviews collected sociodemographic and disease-related information and measure of	Categorical variables were evaluated and classified to describe the sample of patients and caregivers. Then, a series of univariate correlations was prepared to evaluate multicolinearity among	The results of the study are applicable to healthcare practitioners in two ways. First, study data indicate that specific groups of caregiver are at risk for negative outcomes and that identification of groups at risk requires that practitioners be aware of sociodemographic characteristics of

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
2) prospective, longitudinal study	8wks prior to study enrolment and be receiving chemotherapy. patients and caregivers were accrued from 24 community oncology sites/Midwest USA.	patient symptoms, caregiver burden and caregiver depressive symptoms were obtained. At the end of the study, audits of patients medical records were conducted to verify site and stage of disease, collapsed into early stages (I-II) and late stages (III-IV) as well as treatment data and state death certificates were reviewed to verify the death of patients. Caregiver depressive symptoms using the Centre for Epidemiological Studies-Depression (CES-D) Scale. Caregiver level of burden, two subscales from the Caregiver Reaction Assessment (CRA).2) Valid and reliable instruments	the predictor variables and to determine the uniqueness of each dependent variable. None of the predictor measures was eliminated based on high levels of association with one another. The 3 dependent variable exhibited surprisingly low correlations. The correlations between caregiver burden (impact of caring on caregiver daily schedule and caregiver sense of abandonment) with levels of depressive symptoms were 0.14 and 0.06, respectively. Impact in caregiver schedule and sense of abandonment was correlated at 0.26. These modest levels of association. led to the conclusion that each measure seems to tap into a different component of caregiver reactions to caring for patients approaching the end of life.	caregivers. Interventions designed to improve the emotional health of caregivers of patients with cancer at the end of life should be targeted to employed adult children caregivers, unemployed spouse caregivers and caregivers of patients with lung and later-stage cancers. Furthermore, study findings emphasized the interrelationship of caregiver and patient variables, specifically that patient variables can affect caregiver outcomes. Thus, healthcare practitioners should be aware that intervention aimed a decreasing symptom severity could affect caregiver burden and depression. Practitioners should treat the patient and caregiver as a patient-caregiver dyad, be aware that the caregiver is at risk from negative outcomes from caregiving and patient characteristics and be aware that concern for well-being should be given not only to the patient but also to the caregiver providing care at the end of life.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
Goldstein, N. E., J. Concato et al (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. Journal Of Palliative Care 20(1): 38–43.USA				
1) To identify factors associated with caregiver burden among those caring for terminally ill patients with cancer. 2) cross sectional study of interviews	391 eligible caregivers, of whom 291 agreed to be contacted by the primary research team. Of these caregivers, 51 refused and 6 were too ill or cognitively impaired to participate. Unable to contact 28 caregivers due to incorrect contact information or the potential respondents having moved. Thus, the final study population consisted of 206 caregivers (53% participation rate). 206 consecutive patients with cancer enrolled /hospice. 76 caregivers interviewed prior to the death of the patient and 130 were interviewed with one month following the death of the patient.	1) data collected on the caregivers sociodemographic characteristics, social network index (SNI) (14) and number of restrictions in their own activities due to their caregiving role. 9-item questionnaire adapted from the Zarit Burden Inventory (ZBI). 2) valid instruments	We were interested in the global concept of burden and did not assess individual subscales. We added 3 items from the caregiver gratification scale used by Beery and Prigerson (16) a scale designed to determine feeling of gratification related to caring for patients. The total none-item scale had good internal validity (Cronbach's alpha = 0.75). 1 caregiver did not answer the question relating to the outcome measure so data from this subject were not included in our analysis. We used simple frequency counts and proportions to describe the patient population. Statistical significant bivariate association between independent variables and high caregiver	The highest burden was reported among caregivers with more limited social networks (OR 1.38, CI 1.02–1.87), more restriction in their daily activities (OR 1.35, CI 1.13–1.61),and those who were younger (OR 1.46, CI 1.10–1.93). Variations exist in the intensity of caregiver burden based on subjective experiences and social support, rather than on the amount of assistance provided. Clinicians should consider factors such as these when targeting caregivers for interventions to alleviate burden.

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			burden we used chi-square tests, Fisher's exact tests and chi-square tests for linear trend as appropriate. We used logistic regression to identify factors independently associated with increased feelings of caregiver burden, including all independent variables that emerged from the bivariate analysis as statistically significant. SPSS used to perform calculations.	
Gonzalez-Salvador, M. T., C. Arango et al (1999). The stress and psychological morbidity of the Alzheimer patient caregiver. International Journal Of Geriatric Psychiatry 14(9): 701–710.USA				
1) To compare stress and psychological morbidity between family caregivers of Alzheimer's disease patients and family caregivers of aged non-demented chronically ill patients and to explore the impact of cognitive and non-cognitive patient symptoms on caregivers. 2) Cross-sectional, case-control.	58 Caregivers of Alzheimer's patients (cases) and 32 caregivers of non-demented chronically ill patients (controls) were studied. Semi-structured interview used to assess info.	1) A cross-sectional case-control design was employed using validated scales to assess patient symptomatology and self-report questionnaires to measure stress and psychological morbidity in caregivers. Measurements included: Mini-Mental State Examination (MMSE). Activity Daily Living Index (ADL). Instrumental Activity Daily Living Scale	In order to perform stepwise regression analysis with different stages of AD, subgroups were combined to provide adequate size. The mild and moderate stages (Amaducci criteria), with similar functional symptoms, were analysed as one sub-group and severe patients in another. Variables available to enter in the	Compared to controls, stress and psychological morbidity were higher in caregivers of Alzheimer's patients. Behavioural symptoms and impairment in instrumental activities of daily living were associated with caregiver stress. Length of care was associated with caregiver psychological morbidity. Caregiver stress may be reduced with special attention paid to the treatment and management of behavioural and functional symptoms in the Alzheimer's disease pt. Caregiver education and

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		(IADL). Behaviour Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD). Symptom Check List 90 Revised (SCL-90R). Relatives' Stress Scale (RSS). 2) Valid instruments.	regression analyses were based on those used in previous studies and the initial results of the current study.	coping skills should also be included.
Grasel, E. (2002). When home care ends -- changes in the physical health of informal caregivers caring for dementia patients: a longitudinal study. Journal Of The American Geriatrics Society 50(5): 843–849.USA				
1) To verify the change in health variables and parameters of health service utilization in a group of active caregivers for older persons with dementia in comparison with former caregivers who had ceased to provide home care for at least 6 months (death of the patient or institutionalized care). 2) A prospective longitudinal study with 1-year follow-up. Active and former caregiver groups originated from a sample of active caregivers at baseline.	Adverts placed in 2 magazines with large circulations + contact addresses /German Assoc for Alzheimer's Disease. 720primary caregivers/dementia patients living in the community. Patients/medical diagnosed of dementia-score of 20 or greater on the mental-mental disturbances factor of the Sandoz Clinical Assessment-Geriatric scale. Care covered 1 of 4 daily living activities. 681 caregivers reinterviewed after 12months.	1) 24-item Giessen Symptom List + key variables. Sandoz Clinical Assessment-Geriatric (SCAG) scale 2) 24-item Giessen Symptom List	Although the somatic symptoms of the active caregivers (n = 427) remained stable at a high level, they decreased significantly (24%) in the group of former caregivers (n = 121). Simultaneously, the number of visits former caregivers made to physicians almost doubled. The reason why home care was terminated (death or institutionalization) did not influence health variables or health service utilization.	The physical health of former caregivers improves in the long term once they cease t provide home care. The fact that former caregivers go to the doctor much more frequently is to be interpreted as an indication that they take the time to attend to their own physical and medical needs.
Grov, E. K., S. D. Fossa et al (2006). Primary caregivers of cancer patients in the palliative phase: a path analysis of variables influencing their burden. Soc Sci Med 63(9): 2429–39.Norway				

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
1) To examine the association. of theory-driven variable with the caregivers' burden by means of path analysis. 2) structural equation modelling	96 caregivers of cancer patients in the palliative phase staying at home recruited from a hospital trust in Norway.	1) The dimensions of burden from the Caregiver Reaction Assessment,-self esteem, lack of family support, impact of finances and impact on daily schedule were used as the dependent variable. The following independent variable were tested in the models: the patients' levels of pain, fatigue and nausea: and the caregivers' physical quality of life, anxiety and depression and social support. Hospital Anxiety and Depression Scale (HADS) the MOS Short Form 36 (SF-36) the Caregiver Reaction Assessment (Caregiver Scale) and the Social Provision Scale (Support scale) Physical Component Summary Scale (Physical) New York Heart Assoc. functional status. Carer Strain Index. SF-36 Geriatric Depression Scale/s. FAMCARE - 2) valid instruments used	The Partial Least Squares approach to structural equation modelling was used for the path analysis. Model 1 shows the direct associations between the independent variable and the dependent variable, explaining 16% of the variance in caregiver burden. Model 1 supports the finding that only caregivers' depression has a direct significant association with caregiver burden, and shows further that the effects of the other independent variables on burden are mediated through depression. In Model 2, anxiety and depression are mediating factors between three other independent variables and caregiver burden and 12% of the variance is explained. Model 2 supports none of the independent variables as antecedents of burden. Testing of the models	Our path analysis models showed that the depression level of caregivers was significantly associated with their caregiver burden, while other relevant variable either showed no significance, or were mediated through depression. Health-care personnel should, therefore, pay attention to the depression status of caregivers, and eventually suggest evaluation or intervention.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
			suggested that caregivers' depression was the main factor associated with caregiver burden, but also an important mediator of indirect assoc. of caregivers' anxiety and physical health.	
Grunfeld, E., D. Coyle et al (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. CMAJ: Canadian Medical Association Journal 170(12): 1795–1801.Canada				
1) We prospectively examined the psychosocial, occupational and economic impact of caring for a person with a terminal illness. 2) prospective, longitudinal study	130 prospective eligible patients within 3mths of diagnosis of visceral metastases or hormone refractory uncontrollable local recurrence or bone metastases. Participating patients asked to identify a principal family caregiver, defined as family member or friend who would be most responsible for ongoing caregiving. Of 130 enrolled, 89 identified a caregiver who consented to participate. Consenting patients and their caregivers were followed prospectively until the patients death or study completion, whichever came first. (Oct77-Oct2000) Only 36 caregivers had patients who entered the	1) Assessments were initially made every 3 months, and increased to every 2wks when the patients' functional status deteriorated. (Karnofsky Performance Status [KPS] score <50). Standardized validated instruments were used to measure all domains. Caregiver general health status was measured by means of the Medical Outcomes Study 36-item Short Form (SF-36). Psychological distress was measured by Hospital Anxiety and Depression Scale (HADS). Family caregiver burden by Zarit Burden Inventory. Satisfaction with care using	Stepwise multiple regression analyses used to construct 2 models for the prediction of caregiver anxiety and depression as measured by the HADS subscales at the start of the palliative period. Candidate predictor variable for caregiver anxiety were patient's KPS score, HADS anxiety and depression scores, SF036 physical and mental components scores, caregiver's age, Zarit Burden Inventory score and MOS emotional support subscale. For care giver depression all the same variable were incl.	We have documented substantial psychological occupational and economic burdens associated with caregiving at the outset of life-limiting illness that increase as patients functional status declines and death approaches. Caregiver burden was the most important predictor of both caregiver anxiety and depression. We have reported the positive aspects of caregiving expressed by a subset of these caregivers. The caregiver's commitment to the patient had primacy over his/her own occupational and health concerns. Changes to health care systems/fewer acute care and palliative care in-patient beds will result in an increased dependence on family caregivers to support dying cancer patients.

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	terminal period.	the FAMCARE instrument. The Medical Outcomes Study (MOS) Social Support Survey was used to measure patient's social support. Scores compared using paired *t* tests.2) valid & reliable instruments	except the caregivers SF-36 physical component score was excluded and the caregivers participation in religious or spiritual activities was included. Only variable showing a univariate assoc. with p less than or equal to 0.15 were used in the regression analysis. Financial burden is presented as both a weekly estimate for the palliative and terminal periods and as a cumulative burden over the entire study period.	
Hebert, R & Schulz, R.(2006). Preparedness for the death of a loved one and Mental Health in bereaved caregivers of patients with dementia: findings from the reach study. Journal of Palliative Medicine 9(3): 683–693.USA				
1) To explore the relationship between preparedness for death and bereavement mental health 2) Prospective study	N = 222***Quantitative:*** How was the sample selected? From parent study REACH. Is their any justification for the sample size? Yes. 16% drop out rate after death. Was there any evidence of selection bias? Participants that perceived themselves to have greater mental health morbidity may	1) Trained interviewers administered standardised survey instruments and open ended questions at 6, 12 and 18 month post death. Instruments included Centre for Epidemiologic Studies Depression Scale, some self assessed and perception re religiosity and caregiver	X squared test and wilcoxon rank sum test, multivariate logistic regression, generalised estimating equations and univariables was used. Data was managed with SAS 8e. Loss to follow up was described	23% caregivers were not prepared for death. Those not at all prepared had more depressive, complicated grief and anxiety symptoms. Blacks, caregivers with less education and income and with more depressive symptoms were more likely to not at all prepared. If the client was in pain prior to death, the caregivers were more prepared. Asking bereaved caregivers whether they were

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	also have perceived themselves as being unprepared.	health. Instrument named was validated2) CES-D validated tool and reliable. Confounding variables were addressed		prepared for death could be a simple way to screen for psychiatric morbidity. Open discussion about death, dying and bereavement between caregivers and healthcare providers would likely improve caregiver's well being. When caregivers voice questions and perceive that their question have been answered satisfaction and quality of life are improved and there are fewer depressive symptoms.
Ingleton, C., J. Morgan et al (2004). Carer satisfaction with end-of-life in Powys, Wales: a cross-sectional survey. Health & Social Care In The Community 12(1): 43–52.Wales				
1) To examine levels of satisfaction with services provided for people in their last year of life in the rural country of Powys, Wales, UK.2) Cross-sectional postal survey of bereaved carers	805 out of 815 possible contacted. 407 agreed to questionnaire - 74% returned.	1) Self-complete questionnaire2) Instrument — modified version of the Views of Informal Carers — Evaluation of Services. VOICES questionnaire - 48questions, subdivided, yielding over 160 items. Limitation 6-mth, post-death time period — recall bias.	SPSS Ver. 10. Open coded-broken down into discrete parts, re-examined and compared for similarities and differences.	90% who rec'd help from district nurses or practice nurses said they were excellent or good. 40% reported needing more nursing help + more help from social care services. 103 our of the 301 respondents, known that the deceased wanted to die at home; only 44 did. Only one-fifth had opportunity to talk to someone from health and social services after their bereavement. 4/5ths found this helpful. one-tenth respondents reported untreated pain at home, increasing proportion received good pain relief. Deficits exist — symptom control, nursing help, assistance from social services with transport and bathing, communication and bereavement support.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
Kahana, B., A. Dan et al (2004). The personal and social context of planning for end-of-life care. Journal Of The American Geriatrics Society 52(7): 1163–1167.USA				
1) To examine the potential facilitators of or deterrents to end-of-life planning for community-dwelling older adults, including personal (health-related and socio-demographic) and social (physician and family) influences. 2) longitudinal study	231adult aged 65–99 who were aging in place, 99 of their primary care physicians (66% of those for whom permission to interview was given) and 127 of their family members were interviewed. Of the remaining 104 respondents, 13 did not turn to someone for health concerns. 68 had a caregiver but did not want them to be interviewed and 23 caregivers were not interviewed. 42 physicians refused to be interviewed and 8 could not be located.	1) In-person interviews with older adults (1 hour), telephone interviews (5–10mins) with physicians and family members. Questions assessing older adults' discussions with others about end-of-life plans. Implementation of advance directive and physical (Older American Resources and Services) illness index and mental (Short Portable Mental Status Questionnaire) health status. 2) valid instruments used	How end-of-life discussions and having an AD related to physical health, cognitive functioning and sociodemographic variables was first investigated at the bivariate level. To explore multivariate relationships, logistic regression was employed, because the two outcomes were dichotomous. Whether physicians and caregivers were aware of older adults' end-of-life wishes and which factors influenced their knowledge was then examined.	These findings suggest that many physicians are not talking with their patients about their end-of-life wishes. Furthermore, the propensity to have such discussions may relate more to the personal preferences and level of comfort of patients, physicians and family members than on the health status of the older adult.
Kesselring, A., T. Krulik et al (2001). Emotional and physical demands on caregivers in home care to the elderly in Switzerland and their relationship to nursing home admission. European Journal Of Public Health 11(3): 267–273.Switzerland				
1) Planning the home care of growing numbers of old, dependent people must include the caregivers' burden.	A convenience sample of 129 caregivers of frail and incapacitated elderly patients with multiple diagnoses was interviewed about the caregiving context, burden,	1) Measurements incl. ADL scale. 'OARS' Multidimensional Functional Assessment Questionnaire. Burden scale (10-items). Symptoms and behaviours	Contributors to variance were for burden (35%), impact of care on caregivers' mental health, social relations and leisure time, patient's	Caregivers were mainly spouses (67%) and female 73%, and the mean duration of care was 5.5years. In five activities of daily living (ADL) 50–69% of the patients needed full help. Caregivers reported predominantly negative effects

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2) cohort	caregivers' tolerance of patients' troublesome behaviours and physical symptoms, mutuality and feelings of closeness between caregiver and patient. Inclusion: the caregiver must have been the prime caregiver for a patient at home for at least 4 days a week for at least 3mths, and speak German. Patients had to be 60> suffer from a chronic health condition and be dependent on another person for help in at least three ADL. 129 were interviewed in their own homes separately from the patient.	tolerance scale. Mutuality scale. Continued maintenance of home care was assessed by a follow-up telephone call. 2) valid instruments	gender, accumulation of patient's symptoms and behaviours; for caregivers' tolerance toward patient's symptoms and behaviours (17%) caregivers' physical health, patient's level of confusion, feelings of mutuality; for mutuality (22%) and for closeness (19%) caregivers' mental health, patient's accumulation of symptoms and behaviours. Within 23 months 19% of the patient's had been institutionalized.	of caregiving on their physical and mental health, rest and sleep, leisure time and social life, problems with patients symptoms and behaviours and little or no conversing (51%) or exchanging feelings with patients (71%). Factors giving a higher likelihood of institutionalization were; being male, caregiver was not a partner, and less closeness between caregiver and patient. Caregiving of older persons has bio-psychosocial ramifications for caregivers. Closeness between caregiver and patient seems to be a key factor in determination of the long-term outcome.
Kosloski, K., R. J. V. Montgomery et al (2001). Utilization of respite services: A comparison of users, seekers, and nonseekers. Journal of Applied Gerontology 20(1): 111–132.USA				
1) . To identify factors associated with nonuse of respite services. 2) cross-sectional study	N = 458 family caregiver of Alzheimer's patients in Michigan, US. Recruited by program personnel at service sites. Purposive sampling to recruit participants from user, non-seeker and seeker groups.	1) Face-to face interviews of 176 respite users, 128 seekers who had enquired about the service but not used it and 154 who neither enquired nor used the service. ADLs assessed using 4-item measure based on Wolinsky and Johnson's 1991 basic ADL factor, reliability (Cronbach's	Logistic regression to test 2 separate models 1. if caregiver was a user versus nonuser of the target respite program and 2. if the caregiver was a nonuser, whether the caregiver was a seeker versus nonseeker.	Need for assistance with ADLs, availability of other caregivers, concern with cost, and adherence by the respite program to an established service schedule contributed significantly to the model distinguishing service users from nonusers. Caregiver burden, the presence of other caregivers, and the availability of transportation services made significant, unique contributions to the model distinguishing seekers

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		alpha = .89) Problematic behaviour assessed using 14-item composite asking caregivers about behaviours reliability = .77, burden and health composite, reliability of.83 and.75 respectively. Demographic variables coded, personal responsibility beliefs assessed with two items reliability of composite was.74, liker scale to measure service delivery impact.2) Reliability discussed. Background and design rationale outlined.		from nonseekers.
Kristjanson, L, Cousins K, Smith, J and Lewin, G. (2005). Evaluation of the Bereavement Risk Index (BRI): a community hospice care protocol. International Journal of Palliative Nursing 11 (12) 610–618Aust				
1) To test the validity, reliability and feasibility of using the BRI as a screening tool for offering bereavement support in an Australian home hospice setting2) Prospective descriptive design.	N = 150 ***Quantitative:*** How was the sample selected? Family members of palliative care clients of Silver Chain Hospice care were invited. Is their any justification for the sample size? Yes, 87.2% response rate, 11 indicated they were not interested, 4 could not be contacted (change of address) and 5 too busy to participate and 2 without reason. Was there any	1) Interviews at 3 and 6 months post client deaths. Instruments used were CBI-17, SF-36 and FAD2) the instrument were valid and reliable	Descriptive statistics and Cronbach's alpha coefficient, Pearson's correlation coefficient and t test	Nurses were able to use the instrument with minimal training and were able to adhere to matched bereavement support protocol. The instrument was brief and simple to use. A very small number of individuals were classified in high risk category, this is important because overtreating bereaved persons can have negative effects. All caregivers had poorer health scores at months 3 and 6 compared to normative data. Spousal partners and younger family carers (<45 years) experience greater

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	evidence of selection bias? ***Qualitative:*** Was sampling purposive (if not please describe)? Was saturation reached?			bereavement distress. The health of the family unit may be compromised during bereavement period. The vast majority of family carers did not receive any supportive care during bereavement.
Kristjanson, L. J., S. Nikoletti et al (1998). Congruence between patients' and family caregivers' perceptions of symptom distress in patients with terminal cancer. Journal Of Palliative Care 14(3): 24–32.Australia				
1) …to determine the congruence between advanced cancer patients' and family caregivers' perceptions of symptom distress experienced by patients receiving care in an Australian home care hospice setting, 2) comparative descriptive	78 dyads of patients and caregivers participated in the study. Patients with stage III or IV cancer currently in home hospice service. Family caregiver identified by the patient as being the person primarily involved in the care of the patient in the home setting. Interviews held in patients home, completed separately by patient (20mins) and family caregiver (30–40mins).	1) Measurements incl. McCorkle & Young SDS (12) 13-item questionnaire rated on a 5-point scale. Demographic data/short questionnaire. Patients medical notes/kept in the home. Illness stage-Karnofsky performance status examination (KPSE).2) valid instruments	The reliability of the SDS and the demographic questionnaire were assessed using Cronbach's alpha coefficient. Descriptive statistics were used to summarize the sample according to disease-specific and demographic variables. The Kolmogorov-Smirnov single-sample test was used to determine whether the variables were normally distributed.	3 clinical recommendations: 1. More often than not, health professionals can trust the family caregiver's perceptions of the patient's symptom distress, particularly when the family caregiver has served as a long-term caregiver in a home hospice setting. 2. Use of a symptom assessment tool administered to both patient and family caregiver from the beginning of the caregiving relationship would allow health professionals to determine the degree of congruence that exists in individual situations. This information would be useful in facilitating communication between patients and family caregivers regarding symptom distress and might serve as a starting point for the education of family caregivers regarding symptom assessment and management. 3. Early assessments of patient-family congruence would allow health professionals to know the extent to which the family will be able to offer

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				input as a reliable and valid proxy for the patient when he/she becomes too ill to provide symptom distress information.
Kuzuya, M., Y. Masuda et al (2006). Falls of the elderly are associated with burden of caregivers in the community. International Journal Of Geriatric Psychiatry 21(8): 740–745.Japan				
1) To determine whether falls of care recipients are associated with caregivers' burden.2) cross-sectional study	1874 community-dwelling care recipients and 1478 caregivers (men: 632, women: 1243, age >65) eligible for long-term care insurance, lived in Nagoya City and were provided various home care services. One participant was excluded because of a lack on info. on the falls experienced. Among 1874 elderly, 1569 participants had caregivers. 91 caregivers were excluded from the analysis because of the lack of their demographic characteristics.	1) 328 nurses visited clients' homes and collected data from structured interviews with patients or surrogates, caregivers and care-managing centre records according to the standard instruments…examined the characteristics of care recipients and caregivers, incl. demographic characteristics, depressive mood as assessed by the Geriatric Depression Scale (GDS-15), the basic activities of daily living (bADL), full history in the past 6mths and physician-diagnosed chronic diseased to determine whether there was an association. with caregivers' burden as assessed by the Zarit Burden Interview (ZBI).2) valid	Stepwise multiple linear regression analysis with a forward selection strategy, using an F value with a $p<0.05$ as the selection criterion. Student's t-test, the Mann-Whitney test, and the chi-squared test were used to compare differences between participants who had fallen during the previous 6mths. (fallers) and those who had not fallen (nonfallers). Pearson's linear correlation coefficient (or Spearman's variable, if any) was ordinal and/or not normally distributed for the correlation between the ZBI score and other variable. Partial	A total of 567 care recipients (30.3%) had a history of falls in the past 6mths. The mean ZBI score of caregivers with falls was significantly higher than that of caregivers without falls. There were negative correlations between the ZBI score and recipient bADL score and positive correlations between the ZBI score and GDS-15 scores of the recipient and caregiver, the level of severity of dementia and the Charlson co-morbidity index. Male recipient, fall history, behavioral disturbance and dementia had significantly higher ZBI scores than those of controls. The stepwise multiple regression analyses found that the GDS-15 score of caregivers and recipients, level of severity of dementia, bADL score and fall history were independently assoc. with the ZBI score. Among the community-dwelling frail elderly, falls are assoc. with caregiver burden even when controlling for various possible

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		instruments	rank correlation coefficients adjusted for age and gender were also used to measure the relationships between the ZBI score and variable.	confounding factors.
Lee, C. and H. Gramotnev (2007). Transitions into and out of caregiving: Health and social characteristics of mid-age Australian women. Psychology & Health 22(2): 193–209.Australia				
1) …To examine changes in caregiving status among middle aged women (45–50yrs) over a 3-year period and the correlates and outcomes of these changes. 2) longitudinal	Secondary analysis of data from the Australian Longitudinal Study on Women's Health (ALSWH). 9.555 middle-aged women were categorised according to caregiving status at two surveys 3yrs apart, as Continuing (2.7%); Stopped (4.9%); Started (3.0%) and Never caregivers (89.4%).	1) Measurements included: Sociodemographic variables; Health variables SF-36; Health behaviour BMI, smoking, physical activity; Psychological variables -The Perceived Stress Questionnaire, Life satisfaction, depression 10-item version of the Centre for Epidemiological Studies Depression Scale.2) valid instruments	Univariate analyses was used to determine which of the 20 selected variable showed differences between the groups of women (Continuing, Stopped, Started and Never Caregivers).	Analyses at each time point show poorer physical and emotional health, health service use, health behaviours and lower engagement in the paid workforce among all three caregiver groups, indicating that middle-aged women who are, have been, or will become family caregivers are in poorer health than women who do not have these roles. Middle-aged women in poor health tend to be selected into caregiving, probable because they are less engaged with the paid workforce. Poor health and disengagement from the paid workforce continue even when caregiving stops. Health care providers should be particularly conscious of the needs of middle-aged caregivers, who are likely to be in poor health even before they take on the role.
Lee, H. S., P. F. Brennan et al (2001). Relationship of empathy to appraisal, depression, life satisfaction, and physical health in informal caregivers of older adults. Research In Nursing & Health 24(1): 44–56.South Korea				
1) The purpose of this study	Multiple settings-adult day	1) Measures included;	Descriptive analyses were	Caregivers with high cognitive

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was to examine the role of empathy in informal caregiving by defining the levels of a caregiver's empathy and the relationship of empathy to caregiving appraisal and caregiver outcomes, and to identify predictors of a caregiver's psychological and physical outcomes. 2) descriptive, correlational, cross-sectional design	care, home health care, senior centres, caregiver support groups, Catholic service centres and the Alzheimer's Center of University Hospital. 140 informal caregivers of older adults (>60years of age) Eligibility criteria included; (a) provides care to an older adult who needs assistance or supervision for either activities of daily living (ADL) or instrumental activities of daily living (IADL) (b) identifies him/herself as a primary caregiver of an older adult, (c) is not paid for the care (d) provides care to the older adult on a regular basis (5hrs+) per week, over a period of time exceeding 1mth. The mean age of caregivers was 65years (SD = 11.6). Caregivers were predominantly female (78%) and Caucasian (91%). 81% lived with the care recipients. 55% were taking care of their spouse, 41% their parents or parents-in-law. The care recipient's mean age was 78years (SD = 8.3); 56 of the care recipients were female	questionnaire eliciting demographic data & caregiver activities mailed (response rate 70%); Mebrahian Emotional Empathy Scale (MES). Barrett-Lennard Empathy Scale (BLES). Appraisal of Caregiving Scale (ACS). Centre for Epidemiologic Studies Depression Index (CES-D). Life Satisfaction Index Z (LS-Z). Perceived physical health; Activities of daily living (ADL), Instrumental activities of daily living (IADL).2) valid instruments	done to examine the levels of empathy, appraisal and caregiver outcomes for the caregivers in our study. Pearson product-moment correlation coefficients were computed to examine the relationship of caregiver empathy to caregiving appraisal and caregiver outcomes of depression, life satisfaction, and physical health. Hierarchical multiple regressions were conducted to identify predictors of the caregiver outcomes.	empathy appraised the caregiving situation as less stressful and less threatening, were less depressed, and reported higher life satisfaction than did caregivers with low cognitive empathy. The caregivers' appraisal, along with educational levels and total household income, significantly predicted individual differences in caregiver depression, life satisfaction, and perceived physical health. Emotional empathy was negatively related to life satisfaction. There appeared to be distinct roles for emotional and cognitive empathy in informal caregiving outcomes. The study supported the important role of caregiving appraisal and resources in caregiving outcomes.

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	and 70% suffered from Alzheimer's disease or related diseases of cognitive impairment. 60% of care recipients were unable to stay home alone, according to the caregivers' reports.			
Li, H. (2006). Rural older adults' access barriers to in-home and community-based services. Social Work Research 30(2): 109–118.USA				
1) This study identified specific access barriers to seven commonly used in-home and community-based services (HCBS) and examined factors that were related to barriers to these services. 2) cross-sectional study	The data used in this study were extracted from the 1999 National Long Term Care Survey 3,347 community-dwelling adults 65> with one or more limitations in activities of daily living (ADL) or instrumental activities of daily living (IADL). The caregiver Survey was completed by 1,283 primary caregivers of the older adults who participated in the Community Survey. A combined sample consisted of 1,234 dyads of older adults and their primary caregivers. and incl. 283 dyads of rural older adults and their caregivers. This study focused on older adults living in rural communities. The final study sample incl. 283 dyads of rural older adults and their primary	1) The data were extracted from the Community Survey and the Caregiver Survey in the 1999 NLTCS conducted by the Centre for Demographic Studies at Duke University. The NLTCS was conducted on a nationally representative sample randomly selected from Medicare enrolment files. 2) relevant instruments	Measures — Dependent Variable. Access barriers. Predisposing Factors. Need Factors. Enabling Factors. Univariate analysis was used to examine the characteristics of older adults and to describe access barriers. The logistic regression model was used because the dependent variable and access barriers were measured dichotomously.	The HCBS to which caregivers most frequently reported access barriers were respite care, transportation and homemaker services. Although access barriers varied depending on individual services, the main access barriers were unavailability, unawareness and affordability of HCBS. Findings showed that predisposing, enabling and need factors had differential influence on access barriers to individual services. The older adult's race, educational attainment and Medicaid enrolment were significant predictors of access barriers to homemaker services. The older adult's annual household income was a significant predictor of access barriers to home modification services.

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	caregivers. 89 dyads were excluded because they consisted of the older adults who did not use and expressed no need for any listed services.			
Livingston, G., R. Mahoney et al (2005). The Caregivers for Alzheimer's disease Problems Scale (CAPS): development of a new scale within the LASER-AD study. Age & Ageing 34(3): 287–290.UK				
1) To calculate the sensitivity and specificity of the CAPS (Caregivers for Alzheimer's disease Problems Scale) in order to measure its usefulness in identifying dementia caregivers as risk of anxiety and depression and therefore whether it identifies clinically relevant areas for intervention or highlights the need for support if the problem could not be changed. 2) cohort study	153 family caregivers recruited purposefully to ensure an epidemiologically representative sample in terms of dementia severity, gender and care setting. People with AD and their caregivers approached through a variety of means, local psychiatric services, voluntary sector and through managers of nursing and residential care homes.	1) 153 family caregivers interviewed as part of a larger epidemiologically representative study of people with Alzheimer's disease and their caregivers. Caregiver anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS). Caregivers for Alzheimer's disease Problems Scale (CAPS) developed. Cornell Scale for Depression in Dementia (CSDD). Mini-Mental State Examination (MMSE). Neuropsychiatric Inventory (NPI) 2) Valid instrument used.	scored each carer-CD dyad on the CAPS, and performed logistic regression analyses in the first 50 caregivers to find independent predictors of screening positive for anxiety or depression, incorporating those variable with *P* values of <0.05. This reduced the scale from 10 to 5 items….then calculated sensitivity and specificity for various cutpoints using data from the remaining caregivers.	The CAPS had high sensitivity and specificity in detecting caregivers with screen positive anxiety and depression. Five areas were indicated: neuropsychiatric symptoms and depression in the care-recipient, co-residence and relationships with the care-recipient and physical health of the caregiver. Awareness of these problems can help clinicians identify those carers most likely to be anxious or depressed and indicate appropriate intervention and support. We recommend that this instrument be used as port of routine assessments of people with dementia and their families.
Marwit, S & Meuser, T. (2002) Development and Initial Validation of an Inventory to assess grief in Caregivers of persons with Alzheimer's Disease. The Gerontologist 42 (6) 751–765.USA				
1) To develop an empirically based, psychometrically	N = 166 ***Quantitative:*** How was the sample selected?	1) Questionnaires completed by participants2) The	Varimax, factoring model	The MM-CGI was developed and its three factors show internal consistency,

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sound instrument for the assessment of grief in caregivers of persons with Alzheimer's disease2) Mixed method instrument development	Participants of Memory and Aging Project. Drop out rate 19%, some dropped out after receiving questionnaires others left too many questions unanswered. Is their any justification for the sample size? Yes Was there any evidence of selection bias? Yes, participants needed to be English speaking, educated and able to sustain attention to complete a questionnaire that took some 75 minutes to complete.	questionnaire consisted of validities tools		reliability and preliminary validity.
Meuser, T. & Marwit, S. 2001. A Comprehensive, Stage-Sensitive Model of Grief in Dementia Caregiving. The Gerontologist, 41 (5) p 658–670USA				

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
1) To systematically investigate the grief responses of spouse and adult-child caregivers of dementia patient in mild moderate severe and deceased stages. 2) Systematic cross sectional quantitative and qualitative study.	N = 121 caregiversQuantitative: How was the sample selected? Caregivers were recruited from an Alzheimer's Association clinical research arm of the Alzheimer's Disease research centre and word of mouth, 87 completed the focus groups. Is their any justification for the sample size? No. Was there any evidence of selection bias? Not described. Qualitative: 87. Was sampling purposive (if not please describe)? Yes. Was saturation reached? Yes.	1) Data was collected via questionnaire, informant interview and 16 focus groups. The focus groups were divided into spouse and adult-child group and then divided into 3 stages of dementia and post death groups. The focus groups were videotaped and analysed, one tape was lost due to camera failure. The instruments included Group Assignment questionnaire, Clinical Dementia Rating interview that rated overall function, Anticipatory Grief Scale (AGC) and Many Faces of Grief (MFG) Questionnaire. Measurement bias was not described.2) The AGS had previously been validated. Quantitative analysis included descriptive statistics, mean difference, comparisons (t tests, chi-square) and correlations. The MFG was newly devised. The qualitative data used multiple independent raters to find the themes.	Quantitative data was analysed but no description provided of tools. Qualitative analysis was conducted with assistance of 11 health professionals and 3 undergraduate psychology panels. Summary narrative subset was developed and provide the descriptive model of grief over course of Alzheimer's and the summary narratives for spouse e and adult-child deceased provide the basis for assessing the impact of anticipatory grief.	Quantitative data suggests that grief level declines over dementia progression. Anticipatory grief did not ameliorate postdeath grief. Reliance of retrospective accounts of carers to describe their grief reactions throughout their caregiving results in incompatibilities ie retrospective data does not correlate to the cross-sectional results nor prospective reports of experience. Grief needs to be assessed as it unfolds. Bereavement is far more complex and less tidy, while overall grief patterns for adult-child and spouse were roughly equivalent, the qualitative analyses showed differences across caregiver types and caregiver stages. Eg. grief decreases as dementia progresses according to correlation findings but qualitative data supports this only in the short run, complex patterns were found across time. There are divergent grief trajectories for adult-child and spouse caregivers, Adult-child care givers are more present focused and can be helped by educative and informative interventions in the earlier stages of dementia, and anger management techniques could be helpful in the moderate stages whilst spouses could be helped by support groups and information about how to live alone to ameliorate the intense loneliness many experience.

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Montgomery, R. J. V., J. Marquis et al (2002). Profiles of respite use. Home Health Care Services Quarterly 21(3/4): 33–63.USA				
1) The primary purpose of the analyses reported here was to identify and document long-term profiles of respite use among a diverse sample of families caring for elders with dementia. 2) longitudinal study	N = 2395 client families who used services for more than 2 months and 112 service providers who participated in the Alzheimer's Disease Demonstration Grant to States program in various states in the US. Selected from previous study population and restricted to persons using the services at the time of analysis. Client data collected at time of client enrolment; clients use of services and current status from providers and provider records.	1) Structured survey and record review.2) NO discussion of validity or reliability of instruments. Sampling, variables well outlined.	Descriptives — percentages and tables; hierarchical linear models.	Significant difference in types of services in average intensity of use by clients. Day care clients used twice amount of hours as in-home clients. Client characteristics related to use: relationship to elder; caregiver's gender; ethnicity; income; functional level; and problem behaviours of the elder. Elders in rural areas used in-home respite more continuously. Provider characteristics related to different patterns of use: level of service; fee structure; level of capitation.
Nordberg, G., E. von Strauss et al (2005). The amount of informal and formal care among non-demented and demented elderly persons — Results from a Swedish population-based study. International Journal Of Geriatric Psychiatry 20(9): 862–871.Sweden				
1) To describe the amount of formal and informal care for non-demented and demented persons living at home in a population based sample. 2) longitudinal population-based/rural	Of the 1168 subjects in the original study population, 79% (n = 919) participated in the baseline collection, 13% (n = 147) of the study population had died, 2% (n = 28) had moved from the area or were not reached before examination and 6% (n = 74) rejected participation. 740 inhabitants 75> living at home in a rural community.	1) All participants were examined using the same standardized protocol. Interviews in subjects own home. In addition, an informant interview was carried out for 90% of the participants. Fieldwork 2.5years. Socio-demographic variables. Functional capacity was measured by the Katz index of Activities	Mean values for the number of hours of informal and formal care that the participant received were calculated. Tobit-analyses used to identify different aspects of dementia care, interpreted the same way as an ordinary linear regression.	The amount of informal care was much greater than formal care and also greater among demented than non-demented. There was a relationship between the severity of the cognitive decline and the amount of informal care while this pattern was weaker regarding formal care. Tobit regression analyses showed a clear association between the number of hours of informal and formal care and cognitive decline although this pattern was much stronger for informal

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	Majority were female. 55% lived alone, with significantly more women than men living alone (p<0.001). Clinically examined by physicians and interviewed by nurses.	of Daily Living (ADL). Mental health incl. assessment of cognitive function, dementia diagnosis and evaluation of dementia severity. Dementia severity was measured according to Washington University Clinical Dementia Rating Scale (CDR). Informal and formal care was examined with the RUD (Resource Utilization in Dementia) instrument. Mini Mental State Examination (MMSE) was used as part of the test for cognitive capacity. Physical health + a modification of the Charlsen co morbidity index was used to measure co-morbidity.2) valid instruments		than formal care. There was no gender difference in disability or in dementia prevalence.
Osse, B. H. P., M. J. F. Vernooij-Dassen et al (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. Cancer Nursing 29(5): 378–390.Netherlands				
1) The purpose of this study was to provide a comprehensive picture of the problems that caregivers experience and identify those problems for which they would appreciate more	81 eligible for inclusion: 1 dropped out as patient too tired, 1 patient moved to nursing home, 3 returned blank questionnaires (N = 76). 46 men and 30 women. Mean age was 54yrs. Patients had a poor ultimate prognosis with a	1) Questionnaire - 67items Problems and Needs in Palliative Care -caregiver form (PNPC-c) Caregivers also completed 9items concerning informational needs. Validity of the PNPC-c was confirmed and the	Descriptive statistics used to examine significance of associations. In returned questionnaires, a mean of 3 items (out of 67) was missing per caregiver in the problem aspects and 5.4 in the	The results of this study reveal that the Top 20 list of the problems and needs reported by caregivers includes fears and emotional burdens; for the most part, caregivers did not need any more professional attention than they were already receiving. Many, however, needed support for managing patients'

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professional attention. 2) Cross-sectional design/descriptive study	wide variety of cancer diagnoses: 40% breast, 15% lung, 9% ovarian, 7% prostate, 5% malignant melanoma, 3% variety of solid tumours. There were no significant correlations between patient's age and cancer type.	reliability of its dimensions was acceptable. Checklist in Dutch-a forward-backward procedure was used to ensure the validity of the translation.2) valid instruments used	need aspect of the items. A mean of 1.5 out of 9 information items was missing. Missing values were excluded from analysis.	symptoms and wanted professional attention for the availability and coordination of services. Despite communalities, there was diversity in caregivers' individual needs. Personal needs could be identified with the Problems and Needs in Palliative Care questionnaire-caregiver form checklist. Although only a few caregivers were affected by some issues, such as financial problems, help for them was often needed. In conclusion, most caregivers would like more professional attention for 4 or 5 specific issues, often related to their competence as caregivers for their patients. Using structured needs assessments with the Problems and Needs in Palliative Care questionnaire-caregiver form seems a feasible method to identify the needs of individual caregivers in palliative care.
Papastavrou, E., A. Kalokerinou et al (2007). Caring for a relative with dementia: family caregiver burden. Journal Of Advanced Nursing 58(5): 446–457.Cyprus				
1) To investigate the burden experienced by families giving care to a relative with dementia, consequences of care for mental health of the primary caregiver and strategies families use to cope with the care giving stressors. What is the	A volunteer sample of 172 caregiver/care recipient dyads participated in Cyprus 2004–2005. All patients were suffering from probable Alzheimer's type dementia and were recruited from neurology clinics.	1) Data was collected by the researcher during an interview using the Memory and Behaviour Problem Checklist, Burden Interview, Centre for Epidemiological Studies-Depression scale and Ways of Coping Questionnaire. 2) valid	The data were analysed using independent samples t-tests, correlation analysis and one-way ANOVA followed by post hoc adjustments for multiple comparisons.	Results showed that 68.02% of caregivers were highly burdened and 65% exhibited depressive symptoms. Burden was related to patient psychopathology and caregiver sex, income and level of education. There was no statistically significant difference in level of burden or depression when patients lived in the

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relationship of caregiver burden with the behaviour of the patient and the reaction of the caregiver to the patient's problems? Is there a relationship between the caregiver burden and the caregiver's depressive symptoms? Is caregiver burden related to specific coping strategies? Does institutionalization of the patient reduce caregiver burden? 2) Cross-sectional, descriptive.		instruments		community or in institutions. High scores in the burden scale were associated with use of emotional-focussed coping strategies, while less burdened relatives used more problem-solving approaches to care-giving demands. Caregivers, especially women, need individualized, specific training in how to understand and manage the behaviour of relatives with dementia and how to cope with their own feelings.
Prokos, A & Keene, J. 2005. The Long-Term Effects of Spousal Care Giving on Survivors' Well being in Widowhood. Social Science Quarterly, 86 (3) 664–682USA				
1) To analyse how spousal care giving affects survivor's depressive symptoms 18 and 48 months into widowhood. 2) Longitudinal Study Control	N = 1,532 ***Quantitative:*** How was the sample selected? non institutionalised, English speaking, married couples, husband >65. Is their any justification for the sample size? Gradual decrease in number throughout waves of study due to 38% refusal, and illness or death (42%), and end of funding rather than attrition. Was there any evidence of selection bias? No	1) Data was collected by interviews. Using Centre for Epidemiological Studies — Depression scale. Interviews undertaken during caregiving and then at 18 and 48 months post bereavement.2) Instrument considered reliable, no further description of validity.	Pearson's Correlation, no description of management.	Duration of care has no significant effect, higher levels of care have a positive effect, caregiver stress has expected negative impact on depressive symptoms at 18 months. Marital satisfaction and emotional support are not important predictors of depressive symptoms. More intense care has no benefits but does has a negative impact on survivors well being at 18 months. At 48 months, substandard physical health is a strong negative predictor of lower well-being and greater emotional support has beneficial impacts.

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				Conclusion: Simply having been a caregiver has an ameliorative effect on depressive symptoms compared to non caregivers.
Raveis VH, Karus DG, Siegel K. Correlates of depressive symptomatology among adult daughter caregivers of a parent with cancer. Cancer 1998; 83(8): 1652–1663.USA				
1) …to understand the factors that place familial caregivers at risk of poor psychological outcomes and threaten their ability to provide adequate care is important for maintaining chronically ill patients in the community. 2) cohort design	Dyads comprised of 164 cancer outpatients (ages 60–90 years), (60mins) and their adult caregiving daughter completed structured (80mins) telephone interviews.	1) Measures included; questionnaire eliciting demographic data, disease and patient characteristics. Sociodemographics of the caregiver daughter. Constraints on/facilitators of caregiving. Caregiver burden. Appraisal of caregiving situation. Dependent variable-depressive symptomatology. 2) valid instruments	Hierarchical regression was used to determine the individual and cumulative effect of five domains of potential predictors on the daughters' depressive symptomatology (Center for Epidemiologic Studies Depression Scale) [CES-D]) Where appropriate, the reliability of measures, as assessed by Cronbach's alpha. Independent variables were grouped into conceptual domains.	The domains that were shown to be significantly predictive of a daughter's level of depressive symptomatology were daughter sociodemographics, constraints on/facilitators of caregiving, and caregiver burden. The domains of disease/patient characteristics and the daughter's appraisal of the caregiving situation were not found to be significant. The total model suggests that having a health-limiting condition, a greater sense of filial obligation and greater caregiver burden were correlated with higher CES-D scores, whereas having graduated college, having other social roles, having favourable attitudes regarding her caregiving experience, and providing care in a greater number of domains of care were correlated with lower scores.
Redinbaugh, E. M., A. Baum et al (2003). End-of-life caregiving: what helps family caregivers cope? Journal Of Palliative Medicine 6(6): 901–909.USA				
1) i) To identify caregiver coping strategies and specific social resources that were associated with	31 pairs of home hospice patients and their family caregivers recruited through 2nonprofit hospice org. over	1) Questionnaires, patient & caregivers interviewed separately. Coping was measured -Family Crisis	1st examined the descriptive characteristics of demographic, caregiving stressors,	Psychological symptoms a = 0.94, physical symptom distress a = 0.77, existential well-being a = 0.77, social support a = 0.02. Caregiver strain was

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caregiving strain. ii) to test the attenuating effects of coping and social resources on the caregiving stressor-caregiver strain relationship. Examine the relationships among care-giving stressors, coping and caregiver strain in a sample of 31 family caregivers and their terminally ill loved ones enrolled in home hospice programs. 2) Cross -sectional	and 18mth period. All patients/primary cancer diagnosis, be alert and oriented, spend half the day out of bed, speak English, and have a caregiver. Caregiver inclusion criteria noted. 57 dyads met eligibility criteria, 31 agree to participate.	Personal Evaluation Scale (F-COPES) 5 SCALES2) McGill Quality of Life Scale (MQOL) - demonstrates good reliability and validity. Family Crisis Oriented Personal Scales (F-COPES)	coping and caregiver strain variables. Then bi-variate correlations of the outcome variable. Last series/regression models.	significantly correlated with patient ADL needs (r = 0.51) Patient psychological distress (r = 0.42) and patient existential QOL (r = 0.65). Regression equations indicated that reframing coping lessened caregiver strain. Caregivers who accepted their loved one's illness, redefined illness-related problems in a more manageable way and felt capable of solving illness-related problems had less caregiver strain than caregivers who used less of a reframing coping style. Limitation-small sample size making cross-validation with a similar sample difficult due to shrinkage in R2. More research is needed to understand how anticipatory grief affects caregivers' acceptance of EOL illness as well as their abilities to manage caregiving stressors.
Robertson SM, Zarit SH, Duncan LG, Rovine MJ, Femia EE. Family Caregivers' Patterns of Positive and Negative Affect. Family Relations 2007; 56(1): 12–23USA				
1)To examine stressful and positive family caregiving experiences as predictors of caregivers' patterns ofpositive and negative affect in a sample of families providing care for a relative with dementia. 2)Descriptive correlational	Purposiveful sample. N = 234 caregiver–care receiverdyads recruited through adult day care services,in-home respite programs, and community outreachin two Mid-Atlantic state.	1)Interviews. Measure-Demographics, Caregiver Affect (Centre for Epidemiological Studies Depression Scale, Positive Negative Affect Scale); Behavioural Problems (The weekly record of behaviour), Provision of assistance with activities (personal Activities	SPSS Ver. 13. Pearson's correlations, Multiple direct discriminant functional analysis, one-way ANOVS and chi-square tests.	Four affect pattern groups were identified: (a) Well Adjusted (ie high positive affect, low negative affect); (b) Ambiguous(ie low on both positive and negative affect); (c) Intense (ie high on both positive and negative affect); and (d) Distressed (ie high negative affect, low positive affect). A multivariate model that included demographic characteristics and indicators of

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design		of Daily Living Scale-internatal reliability 0.91), Role Overload, Role Captivity, Caregiving rewards, Sense of Competence (Caregiving Competence Scale).2. Reliability and validity addressed.		stressful and positive experiences of caregiving yielded 2 significant discriminant functions that served to classify caregivers correctly into their known affect groups. Implications for improving intervention efforts targeting family caregivers are discussed.
Rudd et al (1999) The grief experienced by spousal caregivers of dementia patients: the role of place of care of patient and gender of caregiver. Journal aging and human development 48 3 217–240.Aust				
1) To compare the grief responses of spousal caregivers who cared for dementia patients at home with those who provided ongoing care once the patient had been placed in a nursing home 2) Two by two factorial design	Purposive sample. N = 60 Quantitative: Spousal caregivers of dementia patients, equal numbers of home and nursing home caregivers. Divided into four cohorts, husbands and wives providing home care, husbands and wives providing ongoing nursing home care.	1) Data was collected using Clinical Dementia Rating Scale, Cognitive Anxiety Scale, Hostility In Scale, Hostility out Scale, Guilt Anxiety Scale, Affects Balance Scale.2) the instruments were valid and reliable.	Manova used to test the effects of the two factors and their interaction on the dependent variables.	Place of care and gender are most powerful predictors of the four psychological states of grief. Caregivers mourn the loss of relative with dementia before death occurs. Bereavement support is therefore needed pre-death in particular for transition to nursing home.
Salmon, J. R., J. Kwak et al (2005). Validation of the Caregiving at Life's End questionnaire. American Journal of Hospice & Palliative Medicine 22(3): 188–194.USA				
1) …developed and validated a questionnaire to measure the needs of end-of-life (EOL) caregivers. Scales adapted in order to be appropriate to EOL caregivers.	Florida Suncoast staff not assoc. with the research study selected 100 current and 100 bereaved caregivers at random from their client stats. Current caregivers were defined as - family member or friend	1) Current caregivers-mailed questionnaire. Bereaved caregivers-'permission to contact' form. Bereaved caregivers were defined as - lost a family member /friend who was served by hospice	For dependent variable we selected the satisfaction and burden scales of the Revised Caregiving Appraisal Scale to measure gains and burdens. Other	The revised and new scales had good validity, reliability and stability. Concurrent validity was measured by Pearson correlations. The new Caregiver Comfort Scale and Importance of Caregiving Tasks were correlated (r = .60) Burden and gain

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2) pilot study — questionnaire	currently receiving care from hospice for at least 2weeks.	and who died 6mths-1 y prior to the survey. mailed 100 current caregivers and 26 bereaved caregivers. participants = 34current and 17bereaved caregivers completed the questionnaire (44%)2) valid/reliable scales used	existing scales were adapted in order to be appropriate. Subscales developed using confirmatory factor analysis and convergent validity was established through correlations with other measures of meaning including the Life Attitude Profile. - has good internal validity as well as good test/retest stability over time.	were negatively correlated (r = -.13) All seven scales showed good internal consistency as measured by Cronbach's alpha including the three new scales and the four published scales that were revised for this questionnaire. The scales had good test/retest reliability, based on non-significant paired samples t-test.
Schulz, R., K. Boerner et al (2006). Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. The American Journal Of Geriatric Psychiatry: Official Journal Of The American Association For Geriatric Psychiatry 14(8): 650–658.USA				
1) To better understand why some caregivers manifest clinical levels of complicated grief post death. 2) prospective	217 caregivers who experienced the death of their care recipient in the course of the study. Drawn from 1222 family caregivers providing in-home care to their relative with dementia. In-home assessments of caregivers and patients were carried out at baseline and 6mth intervals for a total of 18mths.	1) Measures included: The primary outcome measure was the 19-item Inventory of Complicated Grief. Center for Epidemiologic Studies Depression Scale (CESD). Spielberger State-Trait Personality Inventory. Mini Mental — MMSE. Revised Memory and Behaviour Problem Checklist. 2) valid instruments	20% of dementia caregivers evidenced complicated grief along with high levels of depressive symptomatology post death. Controlling for sociodemographic factors, caregivers who had high levels of preloss depressive symptoms and burden, reported positive features of the caregiving experience and were caring for a more cognitively impaired	This study identifies predictors of complicated grief for which interventions could be developed to not only ease caregiver distress, but also serve as preventive interventions for bereavement. Reducing the burden of active caregiving, treating depression before the death of the loved one and providing supportive psychosocial and skills training caregiver interventions can prevent the emergence of post death psychiatric morbidity.

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			patient were more likely to report clinical levels of complicated grief postloss. In addition, caregivers who were enrolled in a psychosocial caregiver intervention designed to reduce depression and burden reported lower levels of complicated grief. Three logistic regression models are tested to identify pre- and post bereavement predictors of complicated grief, including sociodemographic factors, characteristics of the caregiving experience, including participation in a caregiver intervention, other psychiatric morbidities and medication use.	
Schulz, R., Mendelssohn, A., Haley, W, Mahoney, D. et al (2003). End-of-life and the effects of bereavement on family caregivers of persons with dementia. The New England Journal of Medicine, 349 (20), 1936.USA				
1) To describe experience of family members who provided in home care to	N = 265 Quantitative: How was the sample selected? From parent study REACH Is their	1) Trained interviewers administered standardised survey instruments and open	Wilcoxon matched -pairs. Mixed models used to assess scores of CES-D,	Caregivers provided an median of 3 years of care, Half of the caregivers spent at least 11 hours per week

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people with dementia during the year before death and the caregivers responses to bereavement in the short and long term. 2) Prospective Study	any justification for the sample size? Yes (43)16% drop out rate after death. and 5 were excluded due to the date of death being missing. Was there any evidence of selection bias?	ended questions at 6, 12 and 18 month post death. Instruments included Centre for Epidemiologic Studies Depression Scale, some self assessed and perception re religiosity and caregiver health. Instrument named was validated. Data from interviews undertaken before death were used, these were performed 4–65 weeks beforehand. the median time to assessment after the death of the client was 15 weeks. If the patient was in placed in a residential facility or died in the course of the study the assessment was modified to relevant, ie removing caregiver questions and adding items related to placement or bereavement. Instruments included revised memory and behaviour problem list and the CES-D2) tools were validated and reliable	compound symmetric covariance pattern. Piecewise linear-function approach for the time variable.	assisting with ADLs and 35 hours per week in IADLs, and 59% felt they were on duty 24 hours a day. They were extremely bothered by the behaviour, memory problems and aggression of their AD relative. 56 caregivers were employed outside the home, 27 had reduced their hours and 39 had stopped working in order to provide care. 56% received help from other family members. 90% felt that death was a relief to the patient and 72% were relieved themselves when the patient died. 62.6% perceived that the patient had been in pain often or all of the time. 21.4% of caregivers used bereavement services after the death and 14.4% reported needing such services. The distress of carers when the patient was placed in institutional care was higher than for those carers where the patient had died. One year after placement, the scores remained high and were higher for carers who institutionalised patients than those who had died (P = 0.02). A minority of caregivers reported using or needing bereavement services and a majority reported feeling relieved by death. In contrast, carers of patients that were institutionalised did not show recovery from depressive symptoms. when death was preceded

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				by a protracted and stressful period of caregiving, the negative effects on caregivers are typically ascribed to losing a loved one may be substantially lessened due to the experience of providing care. the need for support after the death is limited to a minority of caregivers which suggests that highly targeted intervention strategies may be the most appropriate. The resources for intervention strategies may have the largest benefit when they are applied to caregivers and patients in the period of caregiving immediately preceding death.
Singer, Y., Y. Bachner et al (2005). Home death -- the caregivers' experiences. Journal Of Pain And Symptom Management 30(1): 70–74.Israel				
1) …objectives of this study were to evaluate caregivers' experiences concerning the care of a terminally ill loved one at home, and to compare the death experiences of caregivers with and without access to homecare programs 2) explorative	The primary caregivers of all the patients who died of cancer 6–18 months before the study period (1999–2001) in the Negev area were contacted. Caregivers of 240 patients who died in the home palliative care program and the caregivers of 404 patients who died with no access to the home palliative program during 1999. Of the 240 patients, 76 of their caregivers were interviewed (32%), 26 refused to participate (11%), and the remaining 138 (57%)	1) Questionnaire - + structured interviews/specific facets of the dying experience, including use of bedroom, use of the bed, recollections regarding the function of the health care team and social support received from family members and friends. Caregivers were asked whether they would have preferred their loved one to have died in a different setting….and the short-term and long-term effects of	Tables (1)- comparison between the sociodemographic characteristics of the two primary caregiver groups — Homecare vs. Non-Homecare. (2) Feelings regarding treatment of the patient (3) Treatment of the patient toward end of life. (4) Satisfaction level with the medical team.	Revealed preferences for home-based end-of-life care despite the fact that the physical, emotional, and financial pressures were greater on the home-care program caregivers and these caregivers were less healthy themselves, and more financially challenged. The most notable limitation of this study is the low response rate in both groups. Similar response rate in both groups is an indication that the comparison is possible and valid. Notwithstanding these limitations, the findings support the growing body of literature that suggests that the provision of comprehensive palliative

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	could not be traced for a variety of reasons. Of the 404 patients who died in the oncology institute 83 caregivers were interviewed (21%), 46 (11%) refused, and the remaining could not be reached for various reasons. Total of 159 caregivers interviewed, 76 from home palliative program and 83 caregivers of patients without having had access to a palliative care program.	home death on themselves, and about their views on the advantages and disadvantages of a home v hospital death. 2) comparisons used — questionable rigour — Q whether the results are generalisable.		care services in the patients home leads to a more positive end-of-life experience.
Strain, L. A. and A. A. Blandford (2002). Community-based services for the taking but few takers: Reasons for nonuse. Journal of Applied Gerontology 21(2): 220–235.Canada				
1) …to examine reasons for not using nine community-based services and characteristics associated with these reasons among a sample of 293 older person-caregiver dyads in a Canadian province. 2) evaluation — post test	237 caregivers in community, 211 (89%) completed interviews in 1996/97, 16 (7%) refused to be interviewed and 10 (4%) were considered ineligible (eg too ill, moved from province). Final sample of 293 older person-caregiver dyads. Interviews were recorded verbatim and coded: older persons' health did not necessitate use, family and/or friends provided assistance, older persons did not want or like services, cost of service, caregivers' perception that the	1) Measurements included: Modified Mini-Mental State Examination. Cognitive status was determined using the established National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Assoc. (NINCDS-ARDA) diagnostic criteria. Burden Interview (Zarit et al) continuous higher scores indicate greater levels of burden. 2) valid	The analyses presented is drawn from 1996/97 data as the questions on reasons for not using services were asked only at that time. Frequencies of the reasons for not using services are presented. Logistic regressions were used to identify associated characteristics with older persons' and caregiver characteristics entered as separate blocks into the regressions. Tests for	The most frequent reasons for non use of services were that the older person's health did not necessitate use, family/friends provided assistance, and the caregiver was unaware of the service. Cognitive impairment was associated with not using homemaker and/or cleaning services, in-home nursing services, and home-delivered meals as family/friends provided this assistance: higher caregiver burden also emerged as significant for these services and personal care services. Male caregivers and caregivers with less education were more likely to be unaware of the availability of day

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	older persons were not eligible for the service, and difficulty using the service.	instruments	multicolinearity revealed no difficulty with independent variables. Unawareness of service availability was considered as a reason for nonuse.	centres, day hospitals, and formal respite services. Services included homemaker and/or cleaning services, personal care services, in-home nursing services, home-delivered meals, day centres, day hospitals, respite services in hospitals, respite services in nursing homes, and in-home respite services. Each service was considered separately.
Teno, J. M., B. R. Clarridge et al (2004). Family perspectives on end-of-life care at the last place of care. JAMA: The Journal Of The American Medical Association 291(1): 88–93.USA				
1) To evaluate the US dying experience at home and in institutional settings.2) follow-back survey	…sampled 3275 death certificates. For 549 (16.7%), and informant could not be located. Of the remaining 2727 cases, 1578 (57.9%) resulted in completed interviews, 3 were ineligible, 66 had not informant listed on the death certificate, 688 listed that informants refused to participate, 40 contacts reached households in which English was not spoken and 12 informants were too ill to be interviewed. 1578 decedents used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the USA in 2000.	1) Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours. Interviews were conducted between 9–15mths after the patient died.2) Valid instrument used.	For 1059 of 1578 decedents (67.1%), the last place of care was an institution. Of 519 (32.9%) patients dying at home represented by this sample, 198 (38.2%) did not receive nursing services; 65 (12.5%) had home nursing services and 256 (49.3%) had home hospice services. The actual survey tool, calculation of scores and information on the psychometrics of the measures are available. Analyses performed sing SUDAAN ver. 8.0 (RTI International, Research	About one quarter of all patients with pain or dyspnoea did not receive adequate treatment and one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotion support, compared with about one fifth of thus receiving home hospice services. Nursing home residents were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% v 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality

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			Triangle Park, NC) to account for the complex sampling design. used the x2 test to examine associations between reported perceptions of care and site of care. Multivariate logistic regression analyses were conducted to examine whether the association of last place of care and reported perceptions of care persisted after adjusting for the decedent's age, years of education, sex, race, the underlying cause of death, respondent perceptions of whether death was unexpected, and whether the decedent had difficulty rising from a chair or bed 90 days prior to death.	of care. 70.7% rated care as excellent compared with less than 50% of those dying in an institutional setting or with home health services (*P*<.001).
Thomas, P., F. Lalloue et al (2006). Dementia patients caregivers quality of life: the PIXEL study. International Journal Of Geriatric Psychiatry 21(1): 50–56.France				
1) This survey tends to determine parameters influencing caregivers' quality of life and its possible link with patient's	100 patients diagnosed with dementia who live at home with their principal caregivers were recruited for this survey.	1) A scale measuring caregivers' QOL, developed from data from previous PIXEL studies was used. 20 items questionnaire. Scale related to the socio-	The caregivers QOL was correlated to the QOL of the patients they cared for, the importance of behavioural disorders and the duration of dementia	The caregiver's QOL is linked to the BSPD, the significance of the length of care and the patients QOL. It is also linked to the caregiver's depression. The patient's depression has repercussions on his QOL. The BSPD

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QOL. 2) Cohort		demographic data of both patients and their main caregiver, to the ADRQL scale (Alzheimer Disease Related Quality Life) of Rabins for the QOL of dementia patients, to the patients' medical and therapeutic data, especially a neuropsychological inventory; Folstein's cognition test, Cornell's depression scale, the fast battery of frontal assessment, Katz's dependence index, Cummings' neuropsychiatric inventory for behavioural and psychological symptoms of dementia.2) Valid instruments.	evolution. t-test, Chi test, ANOVA test which was adjusted to the duration of the disease, the caregiver's age, his/her education level, and his/her living place (urban/rural). The regression method used was the multiple linear regression method as well as a descending step by step analysis.	and the patients QOL score condition the caregivers QOL. The question of the evaluation of the impact of the care program of a possible depression of dementia patient or of the caregiver deserves to be raised. Women caregivers had a worse QOL and were more depressive than men.
Tilden, V. P., S. W. Tolle et al (2004). Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. Journal Of The American Geriatrics Society 52(4): 532–539.USA				
1) To examine the end-of-life experiences of elderly decedents dying out of the hospital and their family caregivers in a state in which the vast majority of Medicare deaths occur in community settings. 2) Telephone survey of	Statewide (Oregon) random sample of death certificates. 1189 family caregivers of decedents aged 65 and older who died of natural deaths in community settings between 2000 and 2002. Respondent eligibility (1 respondent per decedent) 18> somewhat or very involved in the decedent's	1) A 69-item telephone questionnaire with single-item indicators and embedded scales that indexed advance directives, use of life-sustaining treatments, hospice enrolment, decedent symptom experience and perceived distress, family	Quant. The distribution of all variables were examined through inspection of frequencies. Chi-square tests were used to determine relationships between categorical variables, t tests to test differences in means, and correlations	Despite high rates of advance directives and hospice enrolment, perceived symptom distress was high for a subset of decedents, and caregiver strain was common. As location of death increasingly shifts nation-wide from hospital to community, unmet decedent and family needs require new clinical skills and healthcare policies.

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family caregivers 2 to 5 months after decedents' deaths.	care and decision-making in last month of life.	financial hardship, out-of-pocket expenses, and caregiver strain. Robinson's Caregiver Strain Index — Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) - Family Memorial Symptom Assessment Scale Global Distress Index (FMSAS-GDI). 4-item Caregiver Strain Index.2) valid instruments used -	to summarize relationships between continuous variables. Ordinary least squares regressions were used to test the relationship between the independent variables and the dependent variables of perceived symptom distress and caregiver burden. All decedents under age 65 excluded leaving 2571 (1976 white and 595 ethnic minority) death cert. 71.6% completed telephone interview. Interrater reliability was 98.7%.E92E91	
Valdimarsdottir U, Helgason AR, Furst CJ, Adolfsson J, Steineck G. The unrecognised cost of cancer patients' unrelieved symptoms: a nationwide follow-up of their surviving partners. British Journal Of Cancer 2002; 86(10): 1540–1545.Sweden				
1) To investigate if a patient's unrelieved symptoms during the last 3 months of life increased the risk of long term psychological morbidity of the surviving partner. 2) Retrospective Observational Study	N = 379. ***Quantitative:*** How was the sample selected? National Register of Causes of Death, and identified surviving partner in the Swedish Population Register. Randomly selected one married woman for every 2 widows matched for aged and region of residence. Is their	1) Interviews 3 years after the death of the patient. Instruments included Spielberger's Trait measure from the State-Trait Anxiety Inventory and Centre for Epidemiological Studies (CES-D) measure for Depression.2) The tools were previously validated.	Quantitative analysis: descriptive statistics	The patient's mental health status during the last 3 month of life was predictive of the widows' anxiety and depression levels as well as sleep disturbance at the time of follow up. Similar increases in risk of psychological complications were obtained when the client was considered to be very depressed during his last months of life. Poor mental

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	any justification for the sample size? Yes. Was there any evidence of selection bias? No	Mantel- Haenszel method was used for confounding factors.		health of the client in their last month of life may predispose the surviving partner to long term psychological morbidity. Clients had poor access to psychological support and there was good access to pain control.
van Exel, J., M. Moree et al (2006). Respite care: An explorative study of demand and use in Dutch informal caregivers. Health Policy 78(2): 194–208.Netherlands				
1) To investigate demand for and use of the four most common types of respite care, namely in-home respite care, day-care, short-stay and special holiday arrangements. 2) explorative study	N = 273 caregivers from population of 110 informal caregivers who presented to regional support centres throughout the Netherlands. (24.8% response rate). Measures of objective burden; subjective burden using self-rated burden measure, visual analogue scale; well-being measured by visual analogue scale; process utility; and knowledge of respite care.	1) Data collected by mailed self-response questionnaires.2) Reliability of assessment tools discussed.	Descriptive stats; bivariate and multivariate correlation analyses. SPSS 11.0 used for analysis.	Caregivers 75% female, mean age 59, mainly not employed (75%), in reasonable health and fairly happy. Most often carer was partner or parent including in-law(78%) who was part of the same household (50%). Care recipients average age 10 years older than caregivers (68.7 total mean age), with relatively poor health status. Most prevalent conditions: muscular-skeletal (17%), mental handicap (14%), problems with nervous system (14%), stroke (12%) psychological problems (9%), dementia (8%) and geriatric conditions (8%). Caregivers in the study well informed about existing services, especially out-of-home services. Least informed was a subgroup that needs but does not make use of respite. About one-third of caregivers used respite. These caregivers experienced substantial burden and expected burden to increase if respite care would no longer be available general satisfaction with

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
				respite care. Main barrier to use was care recipient resistance (38%). 62% of carers anticipated that respite care could substantially decrease burden.
Walker, R. & Pomeroy, E. (1997) The impact of anticipatory Grief on Caregivers of persons with Alzheimer's Disease. Home health Care Services Quarterly 16 (1/2), 55–74.USA				
1) To examine anticipatory grief on the current functioning of caregivers in Orlando, USA2) Cross sectional study. This was appropriate to show some correlations but was unable to demonstrate the variables over time.	N = 100 carers of persons with Alzheimer's Disease Quantitative: Is their any justification for sample size? No There was selection bias, with 75% carers being female and all carers already receiving support from community services or Alzheimer specific organisations.	1) Data collection not described. Instruments Included: Alzheimer's Disease Knowledge Test, Part A of the Memory and Behaviour Problems Checklist, Despair Scale of the non-death loss version of the Grief Experience Inventory, the Stage of Grief Inventory, part B of the Memory and Behaviour Problems Checklist, the Satisfaction with Life Scale, health and Daily Living medical subscale, and Guttmen-type scale and Interview Protocol. Measurement bias likely with high number of female participants, and to carers that already perceived that they needed assistance and were receiving community care2) Instruments were all previously validated built	Simple and multiple regression analysis and stepwise regression analysis.	Grief affects subjective distress and health problems. Female caregivers who reported intense feelings of grief, and were caring for more impaired clients were most likely to report higher levels of subjective stress, anger and guilt were the best predictors in this scale. Intensity of grief was the best predictor of health problems (acute $r = .483$, $p<.001$; chronic $r = .284$, $p<.01$; total $r = .496$, $p<.001$). Females who reported higher levels of grief and were caring for patients with more severe symptoms were most likely to report higher levels of acute and total health problems, but chronic health problems were not strongly associated with any measure of grief and both acute and chronic health problems were predicted by intensity of grief and increased levels of anger and guilt. Intensity of grief was significantly correlated with life satisfaction, increasing grief is associated with declining life satisfaction. Intensity of feelings of grief was most often found

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
		some data was collected without instruments including length of care giving and participation in social support groups. Length of care giving measured the number of hours of care being provided — rather than length of time (weeks years etc)		to be the best predictor of all the negative effects of caregiving. Assisting carers to grieve their losses and manage feelings of anger and guilt may lower the negative effects of caregivers. This may help to prepare them for death of their loved one and help them to adjust better after the death. In addition, managing symptoms may help the emotional and physical well being of the carer and enable them to continue caregiving for a longer period of time. There may also be some preventative benefits in relationship to acute health problems such as loss of sleep and appetite which are associated with hypertension and ulcers, that is if the negative aspects of grief are ameliorated, more serious long term conditions may be forestalled. Some suggestion that distress over the prospect of placing clients in residential care may be helped by exploring their grief. Recommendation that grief counselling and practical assistance to learn better ways of managing the client's decline and maintain their own physical and emotional health could be helpful to people that are expressing anticipatory grief.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
Weitzner, M. A. and S. C. McMillan (1999). The Caregiver Quality of Life Index-Cancer (CQOLC) Scale: revalidation in a home hospice setting. Journal Of Palliative Care 15(2): 13–20.USA				
1) This study re-evaluates the internal consistency and validity of the Caregiver Quality of Life Index-Cancer (CQOLC). 2) descriptive	239 family caregivers of hospice patients with a variety of cancer diagnoses participated. No missing data. Packet of self-report questionnaires.	1) Measures included: The Caregiver Quality of Life Index-Cancer (CQOLC) Scale. Medical Outcomes Study Short Form -36 (SF-36). Caregiver Quality of Life Index (CQOLI). Eastern Cooperative Oncology Group (ECOG) Performance Status Rating (PSR).2) valid instruments	Internal consistency for the instrument was 0.87. There were moderate correlations with overall mental health (r = 0.68) and low correlations with overall physical health (r = 0.01). Low correlations were observed with patients performance status (r = 0.09).	The CQOLC appears to possess adequate validity and internal consistency in this revalidation sample. Since the patient does not exist in a vacuum, determining the family caregiver's QOL allows us to develop methods of improving the patient's QOL by addressing the family system as a whole.
Whitlatch, C. J. and L. F. Feinberg (2006). Family and friends as respite providers. Journal Of Aging & Social Policy 18(3–4): 127–139.USA				
1) . Describes the in-home respite experience of family caregivers served by California's Caregiver Resource Centers direct-pay program who hire family or friends (n = 39) or service providers (n = 77) to provide in-home respite assistance. 2) Descriptive study	Sample recruited from respite caseload of 9 of 11 Californian CRCs offering both agency-based and direct pay-in-home respite assistance. Sample selected upon caregiver status 216 mail-out questionnaires 168 responses.	1) Mail out survey to caregivers who were receiving respite from either direct-pay program (32%) or hired respite aides from homecare or other agency (66%). Instruments of measurement: care recipient demographics; Memory and Behavioural Problems Checklist; Personal Activities of Daily Living (alpha = .74); Instrumental ADLs (alpha = .73); Cognition (alpha = .78); and	Descriptive stats; t-test; least-squares regression analyses.	Very little difference between demographics of two groups but caregivers who hired family and friends slightly more likely to report worse current health than 5 years previously, to report health problems getting in the way, have slightly higher levels of satisfaction with respite assistance and received more hours of respite care at lower cost.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
		Problem Behaviours (alpha = .79) Caregiver demographics and 12-item checklist identifying major reasons for choosing type of respite care plus satisfaction items and 20-item Center for Epidemiological Studies Depression Scale (CES-D; alpha = .93) 2) Reliability of instruments addressed.		
Williams, B. R., P. S. Baker et al (2005). Nonspousal family loss among community-dwelling older adults. Omega: Journal of Death & Dying 51(2): 125–142.USA				
1) to determine the prevalence of recent (within 6mths) nonspousal family loss among community-dwelling older adults, to identify socio-demographic characteristics of older persons reporting the recent death of a family member, and to define functional and health-related correlates of nonspousal bereavement events. We also examined the prevalence and correlates of nonspousal family loss by widowed status. 2) secondary analysis of baseline data	1000 community dwelling adults age 65> recruited between 1999–2001. a stratified sample of randomly selected Medicare beneficiaries in 5 counties in central Alabama.	1) data collected during in-home interviews were used to determine bereavement status, socio-demographic characteristics, physical and mental health and function, self-reported health status, pain and other somatic symptoms. Persons with spousal loss (n = 7) within the past 6mths were excluded from the analyses.2) valid instruments	We examined socio-demographic characteristics, mental health and physical health and function of participants reporting the recent loss of a nonspousal family member (bereaved) and compared these factors with those for participants who did not report the recent loss of a nonspousal family member (nonbereaved). ANOVA and Chi Square analyses were used to identify factors	Although this research was potentially limited by the structure of the original instrument which did not differentiate subtypes of nonspousal family loss, it is important to note that the use of a relational type category (nonspousal family loss) is consistent with the literature on the association between supportive relationships and health and wellbeing among older adults. In addition, the aggregation of all types of nonspousal family loss into one category gave us sufficient power to identity significant associations between and among variables. The cross-sectional design did not permit identification of causal relationships among variables. In spite of this

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
			significantly associated with recent nonspousal family loss ($p<.05$). Bivariate subgroup analyses were also conducted by widowed status to identify significant correlates of nonspousal family loss among widowed and non-widowed participants. factors associated with incidence.	limitation, this study highlights the common occurrence of nonspousal bereavement events among African American and white community-dwelling older adults and supports the need for geriatric researchers to consider potential risk factors, outcomes and consequences of nonspousal family loss, particularly utilizing longitudinal research designs that focus on widowed status as a key variable.
Wolff, J. L., S. M. Dy et al (2007). End-of-life care — Findings from a national survey of informal caregivers. Archives Of Internal Medicine 167(1): 40–46.USA				
1) Family and friends are thought to be predominant providers of end-of-life care, although nationally representative data on this topic have been lacking…we examine the help study participants were receiving in their last year of life. Among individuals receiving help from family or friends, we investigate the nature and intensity of help provided by primary informal caregivers, use of community-based supportive services and caregivers'	1149 primary informal caregivers, stratified by care recipients' survival or death during the following 12months.	1) This study draws from the 1999 National Long-Term Care Survey and its Informal Caregivers Survey to characterize primary informal caregiver's experiences providing end-of-life care to chronically disabled community dwelling older adults. Medicare enrolment files constituted the sampling frame -detailed interviews - in-person community interviews.2) valid instruments	An estimated 11.2% of chronically disabled community-dwelling older adults died with 1 year of being interviewed. Among persons who died, 72.3% were receiving help from an informal caregiver at the time of the interview. End-of-life primary informal caregivers helped an average of 43hrs per week, 84.4% provided daily assistance and caregiver support services were	End-of-life caregivers provided frequent and intense assistance with few supportive services. These data underscore the relevance of families to end-of-life care, and the potential benefit of better integrating families in patient care.

Study purpose (1) and design (2)	Sample and selection method	Measurement or reporting method (1) and reliability/ validity/rigour issues (2)	Analysis method	Major findings
perceptions of their role, including both related burdens and rewards .2) drawn from longitudinal survey			infrequently used (ie respite and support groups were used by less than 5%). While end-of-life caregivers reported significant emotional (28.9%), physical (18.4%) and financial (14.0%) strains, more 2/3 endorsed personal rewards related to their helping role.	

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Appendix L Articles included in Section 4.3 ‘What else may help family carers?’

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Caserta et al 2004) US	To examine the effectiveness of the Pathfinders project. 11 weekly classes in self care or health education. Pre-test, post test, single group. Pre test after first session, post test after last, also 2 and 4 month follow up. Intervention was 11 weekly classes in self care or health education and resource information aimed at promoting taking on the duties of the deceased spouse and developing new social connections.	Aimed at older adults recently widowed but accepted anyone aged 50+ who was widowed. N = 85 N/A N/A	Caserta's perceived competencies scale & other checklists relevant to content of program Tool showed adequate reliability and had subscales confirmed by factor analysis.	Repeated measures ANOVA	Improvements in active coping, household management, and home safety abilities.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Ducharme et al 2006) Canada	To evaluate implementation and effects of a stress management intervention Action research — social worker delivering intervention elected to join the intervention or comparison group & those carers with whom she was working were automatically assigned to that group. Measures at pre-test, 2 m, and 5 m. Intervention — teaching carers to apply coping strategies to fit stressors – 6 meetings over 2 months. Comparison — usual care.	>81 at risk family carers of older adults with physical or cognitive impairment selected from caseload of case managers in Montreal. At risk status based upon opinion of case managers with consideration of complexity of care, self-perceived health and stress, support received. Also had to meet threshold figure for burden, IG = 42, CG = 49. Only difference was the CG carers had been caring for longer.	Zarit Burden Inventory, Stress Appraisal Measure, Carers' Assessment of Managing index, Psychological Stress Index, Self Assessed Health instrument, Goal Attainment Scale. All had reasonable psychometric properties. Qualitative data from case managers & carers. No indication of numbers required. The 81 carers reported were those who provided data at all three timepoints — we know attrition was 14 between T2 & &T3 but no how many were lost from each group, how many were lost before T2, or how many started.	ANCOVA & thematic analysis.	Interventions all provided as planned except for one — due to misunderstanding. Intervention was well received, considered to be transferable, and its focus on the family was appreciated by social workers. Carers reported numerous benefits. Carers in IG used significantly greater problem solving approaches and perceived more challenges and greater control. There was no effect found on burden

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Eisdorfer et al 2003) US	To examine the efficacy of a family based therapy and technology based intervention on reducing carer depressive symptoms. RCT — part of REACH study. I1 = SET — Family therapy program that identifies carer problems, resources, & capacity to collaborate with family to modify burden. I2 = SET + CTIS — information network using phone & computer to facilitate carer links with family, therapist, & resources. Control = minimal support by phone. Intervention period 12 m	225 family carers (114 Cuban) of people with ADRD (living in and providing care at least 4 hours per day for 6 m plus at least one other family member. Most care recipients had moderate/severe dementia. Mean age 83 years. Recruited via adverts and referrals. IG1 = 75, IG2 = 77, CG = 73. No difference at baseline	CES-D to measure depression & Revised Memory & Behaviour Checklist used to assess upset with behaviours. Both know to be valid & reliable tools.	Appears to be repeated measures ANOVA	SET + CTIS lowered white and Cuban carers' depression @ 6 m & 18 m. SET alone only lowered scores in Cuban wives. Small decreases in depression scores occurred I white spouses but higher scores in Cuban spouses.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Hudson et al 2005) Australia	To examine the effectiveness of a psycho-educational intervention offering education and support to family carers of community based palliative care patients with cancer. RCT. Time points pre intervention, 5 weeks later, & 8 weeks post death. Intervention — nurse delivered — two home visits and pone call. Carer guide book and audiotape re caring for a dying person. Mainly information, including making meaning from the situation, also self care. Control — usual community based palliative care service.	106 family carers, mean age = 61yrs. Offered to all eligible carers in the service. IG = 54, CG = 52. Baseline comparisons made, results not found. NB — not specific to older adults.	Archbold et al's Preparedness for Caregiving Scale & Rewards of Caregiving Scale; Pearlin et al's Caregiver Competence Scale, Zigmond et al's Hospital Anxiety & Depression Scale. High attrition — at T2, n = 40 (IG) & 35 (CG). At T3, n = 20 (IG) & 25 (CG).	Repeated measures ANOVA	An impact on caring rewards was detected between Time 1 and Time 3 ($p = 0.03$).

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Kwak et al 2007) US	To evaluate the Caregiving at Life's End (CGLE) program. Pre-test, post test, single group. Pre test after first session, post test after last. Intervention intended to help carers find meaning, purpose, and value in caring by focussing on emotional, spiritual, and practical aspects of life, and relationship completion and closure. Generally offered over a few weeks. No comparison group.	2,025 family carers were trained in the program, 926 completed both surveys. NB no indication of care recipient age but carers' mean age was 60. N/A N/A	1. Comfort with Caregiving Scale, Caregiver Closure Scale, Caregiving Satisfaction Scale. Adequate reliability reported. 2. Appears not to be relevant to carers of people with advanced dementia as the program involves the carer and care recipient working together to identify what is important to them both.	T tests & ANOVA	Overall significant improvement in all three variables ($p<0.001$), especially when more hours of intervention received.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Mittelman et al 2004) US	To examine the long term effect of counselling and support on symptoms of depression in spouse carers of patients with AD. RCT — followed for 5yrs Intervention involved enhanced individual & family counselling and support tailored to the needs of the carer (eg how to deal with behaviours, how to communicate within the family), support group participation, and ad hoc counselling. Continuity of counsellors. Usual care.	406 spouse carers of people diagnosed with AD most with moderate dementia some with mild, only one with severe. Mean age not shown but for spouses this was 71 years. IG = 203, CG = 203 More wives in CG, higher rates of depression in CG (included as c0variates)	Geriatric Depression Scale (good reliability) No indication of numbers needed. Unclear if ad hoc support available for full 5years.	Intention to treat analysis. Mixed model growth curve analyses.	Very low dropout (followed until 2 years after death) – 6.9% refused to continue, 4.9% because of ill health, 1% because of their own NH placement, and 7.6% died. During first year, gradual decrease in depressive symptoms in IG and increase in CG — significant increase @ 12 m ($p = 0.02$). Modelling indicates that the rate of change in depression gradually decreased over time but differences in the IG from the CG were still seen after more than 3 yrs. Indications that the effect continued even after the death of the person with dementia.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Roberts et al 1999) Canada	To determine the effectiveness of individualised counselling by nurses. RCT, measures at pretest, 6 m, 12 m. Intervention = 3 nurses provided up to 10 individual sessions of problem solving counselling over 6 months.	77 carers of people with AD (mean age 78, most in mid stage). IG = 38, CG = 39. Higher education for IG.	Morrow et al's Psychosocial adjustment to illness scale measured primary outcome variable — good validity and reliability. Study also used the Browne's Health and Social Utilisation Questionnaire, Zarit et al's Caregiver Burden Interview, Broadhead et al's Duke Social Support Questionnaire, & Moos et al's Indices of Coping. Little attrition (N = 73 at 6 m) – Those whose relatives had died also responded at this time point. 80% power to detect a difference of 10 on the primary outcome measure.	ANOVA	Average number of nurse visits in 6 m = 8 & 92% rated their counselling very helpful. No differences at 6 m. At 1 year, more problem solving approaches were used in the IG than in the CG ($p = 0.04$).

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Shear et al 2005) US	To compare the effectiveness of complicated grief treatment with that of standard psychotherapy. RCT with stratified random assignment by manner of death and treatment site. Intervention = complicated grief treatment- addresses adjustment to loss as well as restoration of a satisfying life and addresses trauma like symptoms with revisiting (p 2604). Control = individual psychotherapy — commonly used for depression. Therapists were all qualified, experienced, and trained in the treatment that they administered.	102 adults bereaved for at least 6 m and meeting criteria for complicated grief. IG = 51 CG = 51 No differences at baseline. NB — not specific to our population of interest.	Guy's Inventory of Complicated Grief (ICG) & Beck Depression Inventory (BDI). ICG psychometric properties not addressed BDI known to be satisfactory.	Included all who attended at least one session (N = 95). Cochran-Mantel-Haenszel general association analyses. Kaplan Meier curves. Scores at baseline accounted for when comparing group outcomes.	Treatment completion was equivalent. Mean number of sessions was 16 for each group. When those who attended one session only were compared, no statistical difference was found in ICG or BDI scores. When completers were compared, there were positive outcomes seen in the IG in ICG scores ($p = 0.03$), depression ($p = 0.02$), & Work & Social Adjustment ($p = 0.04$).

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Walsh et al 2007) UK	To evaluate the effectiveness of increased support for distressed carers of palliative care patients. RCT Post test at 4, 9, & 12 weeks including after death Intervention = specialist palliative care plus 6 visits in 6 weeks; needs assesses; information and emotional support provided. Control = specialist palliative care alone.	271 family carers were recruited –they were in the service, met GHQ threshold (indicating need), and agreed to take part. Care recipient age unknown, mean carer age 56, 64% spouses. IG = 137, CG = 134. Carer strain higher and quality of life lower in CG at baseline.	GHQ-28 (known to have good reliability & validity). Attrition meant that the study was underpowered.	Stata modelling — generalised linear latent and mixed models.	No effect.

Reference	Study purpose (1), design (2), intervention versus comparator (3)	Sample and selection method (1). Group numbers (2). Baseline comparisons (3).	Measurement or reporting method (1) and reliability/validity/rigour issues (2)	Analysis method	Major findings
(Winter & Gitlin 2006) US	To evaluate the feasibility and effectiveness of professionally led telephone support groups in female carers of people with Alzheimer's disease or related disorders (ADRD). RCT (details of randomisation not reported). Intervention = phone support group conducted by social worker linking 5 carers for an hour per week for 6 m. Control = no t included in phone support.	N = 103 African American and white females carers (aged 50+) of people with ADRD by mailing adult day centre users and clinical programs polus using newspaper adverts. Caring for at least 6 m and phone access. Care recipients' man age approx 80 years. Hard to assess stage of dementia but would appear to be moderate/severe. IG = 58, CG = 45. 3. IG group participants older than those in CG.	Depression measured using CES-D & Burden measured by Zarit Burden Interview. 2. Both scales known to be valid & reliable. 100 participants overall needed to detect an effect size of 0.70 with 89% power.	ANCOVA	Mean participation in IG = 14.8 sessions of a possible 26. Post test data obtained from 94 carers, 81 still caring @ home. No main effect from the intervention. Race and relationship (spouse/non spouse) did not interact with treatment effect but age did — older women benefiting from the intervention but not younger ones (p = 0.014).

IG = intervention group, CG = comparison group. RCT = Randomised controlled trial. AD = Alzheimer's disease. AD = Alzheimer's disease or related disorder. GHQ = General Health Questionnaire

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Appendix M Articles reviewed in Chapter 5 ‘Advance health care planning and advance health care directives’

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
Allen RS & Shuster JL. (2002). The role of proxies in treatment decisions: evaluating functional capacity to consent to end-of-life treatments within a family context. *Behavioural Sciences and the Law*, 20, 235–252. US					
Discussion of literature and presentation of a model to develop advance care directive. Focus on decision making capacity of clients and their family.	1) Narrative 2) No indication of volume of evidence	Effect size not addressed. Advance care directives typically indicate the treatment an individual does not want. Advance care directives are a means of improving communication between clients, families and health care professionals.	Relevant to health care professionals	Applicable in Australian setting.	1) Breadth of review not described 2) Advance care directives are valid when individuals is giving it knowingly, voluntarily and competently. Clients need to be fully informed about diagnosis, prognosis and disease course and be able to choose between treatment alternatives. Competence is both a legal and medical determination. Written directives clarify some decision making about end of life treatment, but not all. Advance care directive are a means of improving communication between clients, families and health care professionals.
Baker ME. (2002). Economic, political and ethnic influences on end-of-life decision-making: a decade in review. *Journal of Health & Social Policy*, 14(3), 27–39.US					
A review of literature on the factors influencing the policy for advance care directive and the impact on minority groups in US	1) Discussion2) No quantitative indication of volume of evidence or methodological quality. Level QE.	No indication of effect size given.	Consistency of evidence that choices involving end-of-life decisions relate more to ethnicity and culture than to age, education, socioeconomic status or other variables. Poor	Applicable in Australian setting.	1) Breadth of review not described2) Advance care directive assume literacy and visual acuity, current findings regarding low usage are inconclusive. Ethnicity is a variable regardless of socio-economic status, age, gender, religiosity, that affects the willingness to discuss end-of life issues, appropriateness of identifying an individual proxy and relevance of advance care directive. Original intent of ADL was to take effect when person medically declared totally and permanently incapable of expressing choices, and no hope for improvement or recovery. Legal and

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
			uptake of advance care directive (4% to 25% of US)- specifically amongst CALD clients. Minority groups more likely to request life sustaining medical treatment, because they lack trust in medical system, fearing cessation or abstinence of treatments that could improve their condition (license to limit treatment).		economic factors as well as society lobby groups right to die were influential in development of policy in addition to lobbying for the rights of family to influence medical decisions and enabling the cessation of life support treatment. However, family wishes can be disregarded in light of advance care directive made whilst the individual was healthy. Evidence of individuals' distrust of advance care directive and consider it may actually be used to their detriment. Policies need to cognisant of educational level, literacy and visual acuity of population and provide more culturally appropriate processes where needed.
Beer C. (2004). End of life care for older people admitted to hospital. *Australasian Journal on Ageing*, 23(2), 58–62.Australia					
Review of literature regarding end of life wishes about 'not for resuscitation' orders and the affect of these on care in Australia.	1) Narrative2) Medline searched for resuscitation orders and aged, and Internet searched for related Guidelines only. Breadth of results not indicated.	Effect size not addressed. The scarce evidence on which to base approaches to decision about Not for Resuscitation orders. Other data indicated doctors	There appears to be a lack of guidelines and written information to assist clinicians and clients' discussions and understanding	Applicable in Australian setting.	1) Conflicting evidence about elderly persons preferences regarding resuscitation. 2) It appears to more common for doctors to discuss end of life treatment with family members than clients in Australian hospitals. Education materials for health professionals and informational resources for clients and families are needed. There is no uniform approach to using not for resuscitation orders. When end of life wishes are expressed

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
		frequently do not discuss resuscitation with patients and when they do they often misunderstand patient preferences. However the discussion about end of life treatment appears to be comfortable to clients, and an invitation to do so should be considered.	about end of life wishes		there is concern that doctors misunderstand clients preferences and that care which promote comfort might be withdrawn as well as the specific items that were requested by the client. Surrogate decision makers that are relatives often express their own wishes rather than the clients. Many clients prefer the doctor or relative to make decisions for them, rather than develop advance care directive. GPP Expert panels recommend that all vulnerable elders should have advance care directives, an identified surrogate decision maker or documentation stating that no surrogate is available.
Brown BA. (2003). The history of advance directives: a literature review. *Journal of Gerontological Nursing*, 29(9), 4–14.US					
To focus on the context in which older people are encouraged to use advance care directive, how they are informed about decision making, and to identify relevant education and educational material and how older people gain access to it.	1) Narrative2) No indication of types of study, appeared mostly descriptive	No indication of effect size given.	Evidence relates to Australia and Canada	Applicable in Australian setting.	1) Breadth of review not described2) Inconsistency in terminology and definition of advance care directive apparent in both Australia and Canada. Laws are different across states and territories and there is uncertainty that documents would be acceptable across state/territory borders. Education undertaken in SA included the public and health professionals, but little guidance given about what type of decisions and under what conditions the doctor needed to help clients to carry out their wishes. Most documents require/or the client may wish to involve lawyers and doctors in developing documents, which is costly and therefore decreases accessibility for many.

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
					Most information and document availability is via the internet, however many elder persons may have neither access nor skills to this type of resource. One nursing home had advance care directive as part of entry process, concern that decisions contained therein exempted the facility from obtaining day-to-day consent where needed.
Clarnette, R. (2000). Dying with dignity: The role of advance care planning. *Medicine Today*. 1(8), 18–20,23,24. Australia					
Discussion of advance care planning in Australia	1) Discussion/Narrative review 2) No quantitative indication of volume of evidence or methodological quality.	No indication of effect size given.	Relevant to practitioners	Applicable to the Australian Setting.	1) Breadth of review not addressed. 2) Discusses advance care planning in Australia. Presents ethical, legal and practical issues relating to advance care planning.
Ersek M, Kagawa-Singer M, Barnes D, Blackhall L & Koenig BA. (1998). Multicultural considerations in the use of advance directives. Oncology Nursing Forum, 25(10), 1683–1690.US					
Focus on potential difficulties nurses may encounter in applying the principles and practices of ADC to CALD patients	1) Description2) No quantitative indication of volume of evidence or methodological quality. Level QE.	No indication of effect size given.	Relevant to health professionals discussions with CALD clients regarding end of life decision making	Applicable in Australian setting.	1) Breadth of review not described2) Four interrelated values of advance care directives are European American values of health care, individual's autonomy, truth telling — full information about condition and treatment options, belief that people should have control over life and death decisions. Different religious, socioeconomic and otherwise diverse grief do not share these values. For example, full disclosure of condition to the individual is avoided in cultures such as those that leave such details to the family and believe the patient should not be burdened; and truth telling is considered rude, disrespectful and harmful by others. Controlling life and death

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
					is inappropriate where such concepts are considered unnatural. Arab groups may perceive that the need to sign a document to reflect decision is considered a sign of mistrust and dishonours the signee. In addition whilst some Caucasians may feel their physician is collaborative and their written wishes will be followed, other cultures may regard the health care system with suspicion based on their experience and beliefs. End of life care should be approached with sensitivity to the client's cultural background. The individuals cultural values should be assessed. Understanding of basic beliefs regards health, illness, death, and normal decision making strategies is needed to enable health care workers to ascertain who to speak to and how to approach discussions about end of life issues. When clients have delegated decision making to others they need to be made aware that they can still obtain information and discuss aspects of care when they wish.
Haley WE, Allen RS, Reynolds S, Chen H, Burton A & Gallagher-Thompson G. (2002). Family issues in end-of-life decision making and end-of-life care. *American Behavioural Scientist*, 46(2), 284–298.US					
To review family involvement in providing care during chronic and terminal illness, in discussion of, plans for and execution of advance directives, and decision making	1) Narrative review.2) Level QE. No indication of level of evidence reviewed.	No indication of effect size given.	Relevant to target population particularly if have family carers.	Applicable in Australian setting.	1) Inconsistencies not discussed.2) Research and legal standards emphasise autonomy and individual decision making but evidence is that family has a major role in making, influencing and executing end of life decisions. ACP documents must be made known to the patient's family to be meaningful. Physicians more likely to refer to family than AD documents or patient, and patient often prefers family to take over

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
during chronic illness and at end-of-life.					decision making — however, family or surrogate may inaccurately reflect patient's wishes (usually opting for more aggressive or life-prolonging treatment). Cultural factors may influence the extent of family involvement in decision making. Distribution of booklets developed by the Geriatric Research Group to inform individual in aged facility is available in Australia and Canada. Forms vary between areas, some organisations create their own and many are complex. Clarification, accessibility and implementation of Advance care directive need further work before they can reach potential. Empirical evidence that the forms are rarely used. Advance care directive main purpose and value at present is prompting discussion between clients and doctors and within family members about death and dying and providing opportunities for opinion to be stated.
Kwak J & Haley WE. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45(5), 634–641.US					
A review of literature on CALD groups and end-of-life decision makings, to identify key findings and provide recommendations for future research	1) Narrative review, descriptive of findings.2) 33 empirical studies. No indication of level of evidence. 24 quantitative and 5 qualitative Studies. And 4 using both quantitative and qualitative methods. Various methodologies, 22 nonprobability	No indication of effect size given.	Consistent evidence that African American have aversion to end of life care, distinctive cultural features of Native American and Asian groups	Individual, group and extent of acculturation need to be considered when discussing end of life issues with clients	1) Variety of method and small size of studies cautions generalisability. Adaptation of measures deters comparability between studies. Diversity of sampling complicated comparison of studies.2) Race, education level and exposure effects level of knowledge about advance care directive. Misunderstanding about advance care directive evident in all groups — not just CALD. Negative attitude to advance care directive relate to distrust of health system both in relation to wishes being respected, and mistrust because of economic

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
	convenience design and 11 probability samples. Inclusive criteria) examined race or ethnicity as a predictor of treatment preference, compared results on decision making across CALD groups, descriptive of a single minority group. Only American and Canadian studies which were written in English 1992–2003.		demonstrate that a variety of approaches are needed to improve end of life care for CALD groups. Cultural features explain differences and inform clinical practice.		motivation. Discussion of end of life problematic eg some religions Taoist, Buddhists and Confucianists, consider end of life discussion taboo. Some cultures, eg Native Americans consider discussion as violation of cultural values. Present attitude (when well) to treatments, can be unrealistic when faced with end of life events. Presence of ADL did not affect treatment in End of life. Choice of aggressive treatment and do not resuscitate are affected by cultural beliefs, and clearly determine choice. Level of acculturation affects decision making. Culture affect who physicians should discuss end of life issues with eg Chinese designate family, Asians prefer son, and Western people prefer spouses as designated decision makers, and all wanted involvement of family members in decision making process.
Lyness JM. (2004). End-of-life care: issues relevant to the geriatric psychiatrist. *American Journal of Geriatric Psychiatry*, 12(5), 457–472.US					
To provide an overview of end-of-life care with a focus on issues relevant to the geriatric psychiatrist (including advance care planning and informal conversations with patients).	1) Narrative review — based on expert recommendations and clinical experience with empirical support where available.2) 150 papers referenced but no indication of level of evidence. Level QE.	No indication of effect size given.	Review is specific to older adults so relevant to target population. Focus is on palliative care so may be less immediately appropriate to healthy older adults living in the community.	As with previous papers is written in the light of the US Patient Self-Determination Act; however, suggestions still relevant in Australian setting.	1) Inconsistencies not discussed.2) Key points include: discussions on end-of-life care and ACP should begin as early as possible and early in the course of life-threatening illness or dementia; discussion should include open-ended questions to take into consideration patient's values, views on death, should include a consideration of family, cultural and spiritual/religious context, doctor has responsibility to educate patient about their options and what these options entail, ACP should include appointment of a proxy as all possible illnesses and outcomes cannot be foreseen.

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
Mahoney MA, Riley JM, Fry ST & Feild L. (1999). Factors related to providers' decisions for and against withholding or withdrawing nutrition and/or hydration in adult patient care. *The Online Journal of Knowledge Synthesis for Nursing*, 6(4). Document number 4. US					
A Review of literature to determine the factors related to health care providers decision for or against withholding or withdrawing nutrition or hydration for adults in terminal phase of care.	1) Review 2) 17 articles, each descriptive, qualitative and quantitative methods, many had convenience samples. The assessment factors related to Nutrition and Hydration as separate and distinct interventions in situations when the decision had been made to withhold or withdraw Nutrition and hydration.	No effect sizes given. Practitioners differentiate ordinary treatment from extraordinary when considering end-of life wishes. Most practitioners consider nasogastric tube feeding and intravenous hydration extraordinary (more often doctors than nurses).	Relevant to health professionals.	Applicable in Australian setting.	1) No consistent variables were found. Decisions about nutrition and hydration appear distinct from other types of end-of -if treatment decisions. 2) Poor correlation between clients end of life wishes and treatment provided. Hospital object on grounds of conscience not to provide or to withdraw life-sustaining treatments. There is some dissatisfaction of health professionals regarding the way clients are involved in developing advance care directive. There is general agreement that respecting end of life wishes is different from assisting suicide. Cultural differences of the health professionals influence their comfort about meeting client's end of life wishes. Moral uncertainty and concerns of conscience. There are differences in attitudes between doctors and nurses. Length of time in practice and clinical experience influence practitioners ability to provide care in accordance with clients wishes. Concern about liability and lack of guidelines.
Mahoney MA et al 1999, cont'd					
		One study found hydration to be considered necessary in dying comatose patients by (73%)			

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
		physicians. Most clinicians have difficulty ceasing treatment once they are begun. Many health professionals are uncertain about the legal, ethical and professional standards that govern their treatment decisions.			
Nayler D, Respecting patient choices: Advance care planning with Aboriginals and Torres Strait Islanders, Respecting Patient Choices Program and Austin Health; 2006.Australia					
Discussion of key issues relevant to advance care planning with Aboriginal & Torres Strait Islander people.	1) Discussion/Narrative review 2) No quantitative indication of volume of evidence or methodological quality.	No indication of effect size given.	Relevant to practitioners	Applicable to the Australian Setting.	1)Breadth of review not addressed. 2) Presents practical points of developing advance care planning with Australian Indigenous people.
Ott BB. (1999). Advance directives: the emerging body of research. *American Journal of Critical Care*, 8(1), 514–519.US					

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
To review existing research on the use of advance directives	1) Narrative review — studies selected if showed emerging consensus OR conflicting results2) No quantitative indication of volume of evidence or methodological quality. Level QE.	No effect sizes given. Care was consistent with advance care directives 75% of time. Treatment choices are most often stable for one year, but advance care directives are seldom reviewed. The wording of life sustaining interventions influenced the choices people made. Proxy decision makers made correct predictions in 66% of instances. Some difficulties with administrative management of directives, for people who have advance care directives, these are only filed 35% of the time. GPP — education for GP and other health care staff re advance care directive.	Authors comment that most of the subject sin studies reviewed were white, middle class and English-speaking — results may not be representative of groups not covered by these characteristics. Age of subjects not always given.	Study examines new procedures and documents available since introduction of Patient Self-Determination Act and increased awareness of ADs amongst the public in the US. Australian situation likely to vary from this due to different legislation/ awareness.	1) Differing results discussed; consensus amongst studies reviewed with regard to overall trend in areas examined.2) Amongst patients with advance directives, demographic data, completion rates and capacity, preferences, treatment choices, stability of decisions, proxies and cost all examined. Only a small percentage (2–15% in US) adults have formal advance care planning document compared to 57% with a will. A majority of US patients are familiar with ACP and are comfortable discussing them with health care providers, preferably their physician. Obstacles to discussion suggested to be physicians lack of time, discomfort or lack of knowledge regarding ADs. People with higher education levels and socioeconomic status as well as the very sick are more likely to complete ADs, while the cognitively impaired are less likely to have any ACP.

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
Ramsaroop SD, Reid MC & Adelman RD. (2007). Completing an advance directive in the primary care setting: what do we need for success? *Journal of the American Geriatric Society*, 55(2), 277–283.US					
To systematically review studies on interventions aimed at increasing the completion of advance directives in the primary care setting.	1) Systematic review — meta-analysis2) Of 84 retrieved and reviewed articles matching search criteria, 18 (published between 1991 and 2005) met inclusion criteria (eg gave completion rates for intervention and control group) and were used in the meta-analysis (12 RCTs, two quasi-experimental trials, two prospective trials, one observational study, one retrospective cohort study). Level II.	Effect size could be calculated for 15 of the 18 studies; pooled effect size of 0.50 (95% CI = 0.17–0.83), ie a moderate overall effect found in favour of the intervention.	Participants included in the review ranged in age from 18 to over 90, and subjects were 'mostly' female. Authors comment that completion of ADs in community-dwelling older adults is higher than in the rest of the population (37% compare to 5–15%)	As for article (1).	1) Individual and pooled effect sizes given and results compared for effectiveness of various interventions.2) Interventions aimed at increasing advance care directive completion rates are effective. The most successful of the range of interventions were those involving direct patient-HCP professional interaction over several visits, while passive education with written materials is less effective. White, married patients of older age, with a longer time in the practice were more likely to complete an AD. Longer study duration and number of intervention components NOT related to completion rates. Barriers to completion included physician factors: time constraints, lack of privacy, lack of skills, and patient factors: deferring to physician, distressing, religious beliefs, putting off until later.
Riley JM, Mahoney MA, Fry ST & Feild L. (1999). Factors related to adult patient decision making about withholding or withdrawing nutrition and/or hydration. *The Online Journal of Knowledge Synthesis for Nursing*, 6(3). Document number 3.US					
Synthesis of empirical data about client/surrogate decision related to withholding nutritional sustenance at end of life	1) Systematic Review2) 16 Articles reviewed, 14 with findings on nutrition and hydration within a range of life sustaining treatments and two focused solely on nutrition and hydration, published within	Effect size not described. Advance care directives have multidisciplinary impact, and clinical guidelines would benefit their implementation.	Relevant to clinicians including aged care workers.	Applicable in Australian setting.	1) 4 themes: identification of patient preference, stability of patient preferences, factors associated with patient decision and surrogate decision making. Numerous factors were described, but no commonality in regard to patient decision making across studies.2) Cultural experiences affect preferences, and preferences differ with situations, decisions are not generalisable nor stable. Client preferences about nutrition and

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
	20 years, however 14 published since 1990.	Nurses share the responsibility of ensuring patient preferences are formulated, communicated and honoured. Reluctance about discussing end of life preferences is apparent across all players — client, family and health professionals. Caution required to avoid generalisation of decisions made.			hydration evolve over time, and between illness context.
Rutledge DN, Bookbinder M, Donaldson NE & Pravikoff DS. (2001). End-of-life care series. Part III: Learnings beyond the SUPPORT and HELP studies. *The Online Journal of Clinical Innovations*, 4(6), 1–60.USA					
Broad review of end of life care.	1) Comprehensive narrative review of studies in the area.2) Extensive studies, not quantified, both qualitative and quantitative.	Effect size was not addressed and studies tended to be descriptive.	Generalisable to our target population on the whole.	Consideration needs to be given to variations between health care systems as this review was US focussed.	1) Consistent findings on the whole.2) Small section on advance directives indicates that these documents were often not recognised although they did influence health care when they were recognised. Those older adults with living wills were less likely to receive aggressive treatments in the last month of life. In a Canadian study, increasing advanced care directives in nursing homes decreased hospitalisation. Other studies reflect need for good communication to hospital staff about advance care directives.

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
Siegler EL & Wolder Levin B. (2000). Physician-older patient communication at the end of life. *Clinics in Geriatric Medicine*, 16(1), 175–205.US					
Physicians communication with clients about end of life issues	1) Description of literature.2) Review of numerous studies, however search strategy and selection criteria are not described.	Effect size not given. Discrepancy between physician and clients views, decision making outcomes and adherence to advance care directives explored and advice for physicians about communication and discussion points provided.	Appears generalisable.	Applicable to the Australian Setting.	1) Breadth of review not described.2) 30 years ago 90% of Doctors did not disclose diagnosis, in the late 70 s, 97% disclose diagnosis but only half discuss prognosis even though 95/101 patients want as much information as possible, positive or negative. Some research reveal clients are distressed about discussion of end of life issues. However, most (57- 81%) of people want such discussion, and many would choose to have someone else with them, and most do not want to make the decision alone. Clients (80%) want physician to provide information and recommendation and for them to bring up the subject before they (91%) are very ill. Only half the people that want to discuss directors have done so with physicians. When discussions occur, many physicians (94%) may not reveal alternative choices and decisions about treatment reveal most people do not want all possible means, and 38% of older adults do not want CPR, however few (23%) of clients have discussed their wishes with their doctor, more often, people discuss these issues with family members. Choice of active treatment is influenced by the disease and condition of the client, eg whilst 86% of well people want CPR, only 14% would chose CPR if they had had a stroke. Physician and nurse predictions of clients choices have shown to be inaccurate even after many years of relationship between them and the client. Drs and family express concern about upsetting the client. When

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
					advance care directive are complete, only one-third of physicians are aware of it (inpatient setting). Drs want education on breaking bad news.
Song M. (2004). Effects of end-of-life discussions on patients' affective outcomes. *Nursing Outlook*, 52, 118–125.US					
Critical review of research on end of life discussion to explore effect of discussions on end of life care on patients affective outcomes and examine characteristics of discussions including who was involved in them.	1) Systematic Review.2) 29 articles retrieved, only 7 met criterion. Either randomised or non randomised intervention studies to examine the effect of end of life discussions, prospective studies to observe the effect of discussion and at least one of the outcomes in the studies to include affective measure.	No indication of effect size given. No evidence of negative affective outcome of discussion re end of life wishes were found.	Relevant to researchers and practitioners.	Applicable in Australian Hospital setting.	1) Study characteristics, methods, participants, interventions and outcomes were extracted.2) End of life discussions occur with terminally ill patients only 18–35% of the time. 43% of life support discussion occurred after cardiac arrest and cardiopulmonary resuscitation. Only 20% of physician indicate routinely discussion end of life care and 70% stated they rarely or never to talk to patient and families about it. Some studies found that when discussions occur patients have greater satisfactions with the physician, and positive psychological responses however other studies show no improvement in satisfaction particularly when client have or no differences for patients. One study revealed some emotional uncertainty within patients. Most studies indicated discussion were held with the patient only and excluded the family. The discussion that were measured indicated 15 minutes or less, and contained no communications about goals of care, patient wishes or preferences for treatment, but were rather directed at the completion of ACD. No negative impact of discussion was indicated. No capture of effect of intervention. The way the discussion are delivered can influence their affective outcomes. No studies addressed patient belief and values and goals of care. Evidence that

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
					decisions made when the patient is healthy are stable or relevant at end of life is lacking. At end of life and despite advance care directive, most discussion occur with surrogates who are unprepared and uninformed about the patient's wishes.
Street, A. F., & Ottmann, G. (2006). State of the Science Review of Advance Care PlanningModels. La Trobe University, Bundoora.Australia					
Review of international evidence of the efficacy of advance care planning models of care.	1) Literature Review2) 1645 articles were initially retrieved, only 85 papers reviewed that meet criteria. Including 16 qualitative and review articles and 59 quantitative studies.	No indications of effect size but clearly clinical impact is profound.	Relevant to researchers, practitioners and policy makers	Applicable to the Australian Setting.	1) Consistency addressed 2) Key recommendations provided relating to policies, staffing, educational processes, research and community health promotion of advance care planning. Determined that, to ensure implementation of advance care planning, there are five prerequisites:i. Ongoing discussions in this area among health care professionals, clients, and families.ii. Systemic processes to support advance care planning across settings.iii. The normalisation of advance care planning within clinical practice.iv. The involvement of particular cultural groups and of the wider community.v. The guiding of the process with education and research.
Wilkinson, A. (2007). Literature review on advance directives. Office of Disability, Aging and Long-Term Care Policy Office of the Assistant Secretary for Planning and Evaluation U.S. Department of Health and Human Services.US					
Examines the empirical evidence about the degree to which ADs and ACP have met their intended goals. Explores medical literature reports	1) Literature Review2) To update systematic review- searched peer-reviewed journals in the United States between 2004 and 2007. Conducted additional	No indication of effect size given D28	Relevant to researchers, practitioners and policy makers	Consideration needs to be given to variations between health care systems as this review was	1) Consistencies/inconsistencies discussed2)Review demonstrates need for improved end-of-life care and past inadequate attempts to implement improvements, but also indicates directions for renewed interventions. It maps out the need for additional research as well as policy implications.

Topics of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisability of evidence	Applicability of evidence	Degree of consistency (1), and key findings (2) of the results
concerning the use of ADs and ACP, disparities among groups in their use, and interventions to enhance the use and value of ADs and ACP.	search from 2000 to 2007 to identify systematic reviews, randomized or clinical controlled trials, epidemiologic studies, and qualitative studies related to additional topics not addressed in the original review			US based.	

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Riley JM, Mahoney MA, Fry ST, Field L. Factors related to adult patient decision making about withholding or withdrawing nutrition and/or hydration. *Online Journal of Knowledge Synthesis for Nursing* 1999; **6**: Document Number 3.

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Song MK. Effects of end-of-life discussions on patients' affective outcomes. *Nursing Outlook* 2004; **52**(3): 118–125.

Street AF, Ottmann G, *State of the science review of advance care planning models*, Respecting Patient Choices Program and the Palliative Care Branch, Department of Health & Ageing, La Trobe University, Bundoora; 2006.

Wilkinson A, Wenger N, Shugarman LR, *Literature review on advance directives*, Prepared for Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, RAND Corporation, Washington, DC; 2007. Contract #HHS-100–03–0023.

Appendix N Articles reviewed in Chapter 7 ‘Psychosocial care’

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
Alexy, EM (2000). Computers and caregiving: reaching out and redesigning interventions for homebound older adults and caregivers, *Holistic Nursing Practice, 14*(4), 60–66 USA					
To discuss use of computer resources for homebound older adults and facilitating continuing education and skill refinement for nurses.	1) No formal appraisal of evidence, which is scant. Qualitative review and personal opinion. 2) Author stated that little evidence is available.	Main argument in R/T our target group — social support for informal caregivers of Alzheimer patients. Discussion of costs of computer resources with suggestions for access. No formal risk/benefit analysis.	Some relevance, but again little evidence.	Transferable to Aust. Homebound - relates to functional or geographical (eg rural) limitation, and extends to informal caregivers unable to leave the home.	1) Literature cited largely reports of computer resources compiled into argument for use by homebound older adults and implications for nurses. 2) Computer resources could be useful for homebound older adults and caregivers to promote social support and mental health — in terms of information, confidence and support. Also, implications of computer resources for enhancing nursing skills in fields of education, research and practice.
Ayers CR, Sorrell JT, Thorp SR & Wetherell J. (2007). Evidence-based psychological treatments for late-life anxiety. *Psychology and Ageing*, 22(1), 8–17.US					
To conduct a review of psychosocial evidence-based treatments (EBTs) for anxiety disorders in older adults.	1) Systematic review2) 77 studies obtained; 17 of these met the EBT inclusion criteria, included appropriate control conditions and were included in the review. Level II.	Overall moderate effect found for psychosocial interventions in treatment of anxiety; individual effect sizes not given.	Authors report that results from studies of older adults not as strong as for younger samples and suggest existing treatments should be modified to suit older patients; however, all studies reviewed looked at older adults so	Transferable to Australian setting.	1) Most consistent evidence for CBT (9/11 studies supported). Cognitive therapy supported by 1/3 studies, relaxation training supported by 4/5, 2) Evidence found for efficacy of 4 types of EBTs in treating anxiety symptoms and disorders. Strongest support for relaxation training (particularly for subjective anxiety) and CBT (particularly for generalised anxiety disorder). Relaxation training highlighted as efficacious and cost-effective. Imagining muscle tensing/relaxing may be as effective

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
			results applicable to this group.		as actual tensing/relaxing therefore of particular benefit to some groups of older adults (eg with musculoskeletal conditions). Supportive therapy and cognitive therapy are supported by some evidence.
Ballantyne, PJ. (2004). Social contexts and outcomes for the ageing breast cancer patient: considerations for clinical practitioners. *International Journal of Older People Nursing* in association with *Journal of Clinical Nursing*, *13*(3a), 11–21 Canada					
To provide an extensive review of the literature on (i) social and psychological factors influencing adjustment to and survival from breast cancer (ii) social and health status of older women, (iii) medical treatment of older breast cancer patients	1) Narrative review2) No quantitative indication of volume of evidence or methodological quality.	Size of population identified for both US and Canada — ie incidence, mortality of breast cancer and ageing statistics.	Included aged patients, breast cancer patients, and both — unknown samples, therefore limited generalisability. Likely to have similar issues and representation in our target population.	Possibly, different social services available in Australia, but largely applicable to the Australian context.	1) Unknown.2) Breast cancer adjustment and survival can be affected by social and psychological factors that are further influenced by ageing, such as changes in social ties and support, economic security, health status, illness behaviour and help seeking behaviour. HCP implications are to (i) provide optimal care (ii) recognise vulnerabilities of older breast cancer patients, (iii) avoid stereotyping the older patient.
Bohlmeijer E, Roemer M, Cuijpers P & Smit F. (2007). The effects of reminiscence on psychological well-being in older adults: a meta-analysis. *Aging & Mental Health*, 11(3), 291–300.The Netherlands					
To assess the effectiveness of reminiscence on life satisfaction and psychological well-being in older adults across different target groups and treatment modalities.	1) Systematic review — meta-analysis with pooling of individual effect size. 2) 30 studies collected; 15 of these met the inclusion criteria (reporting of test and post-test data, use of control group, sufficient	Overall effect size of 0.54 indicating moderate influence of reminiscence on psychological and emotional well-being. Substantial short-term benefits of reminiscence interventions for older	Reminiscence has significantly greater effect on older adults living in the community (effect size 1.04) than in nursing homes/residential	Applicable to Australian setting.	1) Overall consistency between trials moderate (using Higgins et al, 2003, I squared scale). Individual consistencies: low for reminiscence vs. placebo interventions; moderate to high for all others.2) Several moderators tested: life review vs. simple reminiscence, number of

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
	sample size). 13 of the 15 studies reviewed were RCTS. Evaluated by two researchers. Level I/II.	adults.	care (effect size 0.44), so is particularly relevant to this target group.		sessions, duration of intervention, individual vs. group format, living conditions and age. Structured life review was a more effective form of reminiscence (effect size 1.04), across all age groups of older adults, with no difference across treatment times or modalities. May have a decreased but still worthwhile effect on older adults with dementia.
Cattan M, White M, Bond J & Learmouth A. (2005). Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions. *Ageing & Society*, 25, 41–67.UK					
To determine the effectiveness of health promotion interventions targeting social isolation and loneliness in older people.	1) Systematic review2) 30 quantitative outcome studies (experimental, quasi-experimental, and before-and-after studies) published between 1970 and 2002 met inclusion criteria. 16 of these were RCTs; 10 were non-randomised controlled trials. Level I.	No overall effect size; varied measures of effectiveness used, eg reduction in score on several 'loneliness' scales.	Wide range of ages included as 'older' but applicable to those in target group identified as lonely.	Most of the 30 studies were conducted in the USA and Canada. Transferable for purposes of study to Australian setting.	1) Design, methods, quality and transferability varied considerably across the studies included.2) Nine of the ten effective interventions were group activities with an educational component. Group interventions, with focused educational input or specific social activities, targeting specific groups (women, care-givers, physically inactive etc), are effective for relieving social isolation and loneliness, while one-on-one support and home-visiting was not found to be effective. The methods used in the group interventions included discussion, self-help, exercise and skills training. Programs that enabled participant control — eg in planning and delivering activities, were more effective.

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
Chodosh J, Morton SC, Mojica W, Maglione M, Suttorp MJ, Hilton L, Rhodes S & Shekelle P. (2005). Meta-analysis: chronic disease self-management programs for older adults. *Annals of Internal Medicine*, 143(6), 427–438.US					
To assess the effectiveness and essential components of self-management programs across three chronic disease conditions: hypertension, osteoarthritis and diabetes mellitus.	1) Systematic review — meta-analysis2) RCTs that compared the intervention to either usual care or a control - 53 papers met inclusion criteria (26 on diabetes, 14 osteoarthritis, 13 hypertension). Level I.	Clinical and statistically significant effect of self-management programs on blood glucose levels (pooled decrease of 0.81% in HbA1C, effect size -0.36) and blood pressure control (decrease in systolic bp by 5 mm Hg, effect size -0.39). Statistically significant effect on pain of arthritis is clinically trivial.	Focus was on older adults, not in residential care, so applicable to target population.	Reviewed international studies, appears transferable to Australian setting.	1) Inconsistencies and their effect on pooled results discussed. Authors comment that studies were of variable quality.2) Despite variable study quality and possible publication bias, evidence for success of self-management programs in managing diabetes and hypertension. However, the components of the programs responsible for the effect were not able to be determined, so application of successful elements is limited.
Chow E, Tsao MN, Harth T. (2004.) Does psychosocial intervention improve survival in cancer A meta-analysis. *Palliative Medicine 18, 25–31*Canada					
To determine whether psychosocial intervention prolonged survival in cancer patients, given that some previous reports found improved survival and more recent trials failed to detect a difference in survival.	1) Systematic review — all RCTs = Level I2) 8 studies, total 1062 patients — range from 34 to 136 participants. All RCTs (Level II). Quality assessed: 4 were low (2/5) and 4 were mod (3/5). None were blinded to intervention (as not possible).	Not representative of all cancer population, with 50% of studies relating to breast cancer. No discussion of risks/benefits or resource implications as no recommendations made.	All cancer patients - 4 studies metastatic breast cancer; 1 melanoma; 1 gastrointestinal cancers various stages; 2 various types and stages. Small sample sizes and limited cancer representation — not highly generalisable to the target	Broadly applicable to Aust. Review articles from US, Germany, Aust and Canada.	1) Contradictory. 3 of 8 studies reached significance for increased survival. In breast cancer patients, one study reported significance while another using same intervention did not. Also, authors note that studies spanned nearly two decades — with changes in medical treatment, patients' attitudes and desires for psychosocial support, and availability of support (which may contaminate controls.) 2) No evidence that psychosocial intervention prolongs survival in cancer patients, although cannot rule out small effect sizes

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
			population.		because of the small number of studies and small sample sizes. Authors suggest screening patients for psychological distress for intervention may enhance benefits, and future studies on survival should explore the possible mechanisms underlying improved prognosis.
Cuijpers P, van Straten A & Smit F. (2006). Psychological treatment of late-life depression: a meta-analysis of randomized controlled trials. *International Journal of Geriatric Psychiatry*, 21, 1139–1149. The Netherlands					
To determine whether the finding that the psychological treatment of depression in older adults is effective, remains unchanged when examined via a comprehensive meta-analysis of high quality RCTs.	1) Systematic review — meta-analysis.2) From 129 retrieved papers, 34 papers describing 25 studies met inclusion criteria. Only RCTs included, where subjects had clinically relevant depressive symptoms, with sufficient data available to calculate effect sizes. However only two studies reported randomisation carried out by independent third party. Level I	Mean effect size was 0.72 (95% CI 0.59–0.85).	Inclusion requirement was that studies used subjects aged 50 years or older; however, most subjects were over 60 years therefore applicable to the target population.	Interventions would be applicable in Australian setting.	1) Consistency calculated by I squared. Heterogeneity was very low (1.6%).2) Meta-analysis showed clear evidence that psychological treatments are effective in older adults with depression, and that the effect size is comparable both to the effect of psychological treatments in younger adults with depression, and to the effects of pharmacological treatments on depression. Psychological treatments reviewed included CBT, behaviour therapies, reminiscence and life review, psychotherapy, problem-solving therapy, and other therapies. No indication found that one type of psychological treatment is more effective than another.
Filan SL & Llewellyn-Jones RH. (2006). Animal-assisted therapy for dementia: a review of the literature. *International Psychogeriatrics*, 18(4), 597–611.Australia					
To review literature on the	1) Narrative review.2) 13	Effect size not clear due	Majority of studies	Transferable	1) No indication given.2) Qualitative

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
effect of animal-assisted therapy in reducing behavioural and psychological symptoms of dementia.	papers reviewed. Qualitative review only. Papers included investigated a measurable effect of animal assisted therapy. General descriptions and informal observations excluded. Level QE.	to small number of studies but evidence that animal assisted therapy reduces heart rate, decreases agitated behaviour, decreases verbal aggression and increases social interaction in at least one study each measure.	on adults in nursing homes; possible greater role for pets in private homes.	to Australian setting.	evidence suggests animal assisted therapy may be a useful psychosocial intervention for people with dementia. Positive response independent of dementia severity. Indication that dogs in particular have a calming and socializing effect, stimulation of reminiscence. Systematic controlled studies needed to assess longer term effect and distinguish between effects due to interaction with pet and interaction with handler.
Freudenstein U, Jagger C, Arthur A & Donner-Banzhoff N. (2001). Treatments for late life depression in primary care — a systematic review. *Family Practice*, 18(3), 321–327.UK					
To systematically review treatments for depression in patients over 60 years in primary care or general population.	1) Systematic review; studies evaluated by 2 independent reviewers.2) Studies selected (7) met criteria of publication between 1980 and 1999; met Cochrane Guidelines; and were RCTs. Only 2 of these 7 met methodological quality criteria and were reviewed. Level II.	Improvements given in percentages but apply only to drug treatments; no psychological effect sizes covered.	Appropriate for age group if suffering depression. Psychosocial interventions not covered (authors report no high quality studies of psychological treatment published in the time period covered by the review).	Would be equally applicable to Australian setting.	1) Not stated; only two studies reviewed.2) Only two studies met inclusion criteria; both studies reviewed investigated the effectiveness of psychiatric team care for patients with depression. Found a flexible approach to treatment of depression in the elderly achieved considerable improvement in 40–50% patients (compared with 25–30% improvement with routine primary care treatment). Lack of studies particularly for depression that is not categorised as severe and for psychosocial interventions.
Furr LA. (1998). Psycho-social aspects of serious renal disease and dialysis: a review of the literature. *Social Work in Health Care*, 27(3), 97–118. US					

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
To synthesize research on psychosocial aspects of end-stage renal disease (ESRD), ie the effect of ESRD on psychosocial environment and the effect of psychosocial factors on the course of ESRD. The article focuses in particular on dialysis patients at different stages of the life-cycle (childhood, adolescence and adulthood).	1) Narrative review2) Articles between 1985 and 1998 reviewed. Levels of evidence not given. Author states most research has samples non-random therefore not generalisable to larger population or too small to be of statistical significance. Level QE.	Effect size varies but clear indication overall of impact of psychosocial wellbeing on disease course and life expectancy. Effect of social support dependent partially on type of support and strength of family relationships.	Studies on adults not divided into the elderly and younger adults; ESRD patients higher incidence of depression than other chronic medical conditions.	US setting; dialysis centres required by law to have social workers on staff. Also outcomes of some studies may be affected by variable access of subjects to health care in US (eg one study found different outcomes for African-Americans compared to white Americans.)	1) Some variation in size of effect but reported studies concur on psychosocial impact of and on ESRD. 2) Two-way effect of chronic/terminal illness and psychosocial factors — multiple impacts of illness on social status and interactions and on measures of psychological functioning, which in turn impacts on disease course and life expectancy. Psychosocial intervention dependent on age group: for adults, psychological wellbeing is impaired as disease progresses; depression is a common outcome of renal disease and can impact the course of the disease. Health locus of control and social support were two factors reducing depression, medical complications and non-compliance. Social work intervention improves QOL.
Graves KD. (2003). Social cognitive theory and cancer patients' quality of life: a meta-analysis of psychosocial intervention components. *Health Psychology, 22*(2), 210–219. US					
To evaluate whether Social Cognitive Theory (SCT) based intervention components resulted in greater Quoll outcomes for	1) Systematic review — meta-analysis using procedures of Mullen (1989) and Rosenthal (1984). Level I2) 38	Not given. General statement that increased Quoll for cancer patients would lower costs in r/t financial, social and	RCTs — unstated but limited sample sizes (total N = 3216). Mostly white Caucasian	Likely relevant, although unknown if similar SCT	1) Unknown. 2) Interventions with more SCT components had significance larger effect sizes overall ($Z = 3.72$, $p<0.01$). SCT component inclusion had significance greater

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cancer patients involved in RCTs.	studies (341 hypotheses), N = 3216. All RCTs — Level II. Inclusion criteria: psychosocial interventions with adult cancer patients, published (some databases from 1861–1999!) and unpublished studies using RCTs, using QOL or its determinants (affective, physical, functional, or social well being) outcomes, and data given for effect size, sample size etc. Excluded interventions to reduce anticipatory distress r/t chemotherapy or related medical treatments. No further description.	psychological burdens endured by all cancer patients.	population - 21 studies from US. Ages not given. Limited generalisability.	practices occur in Australia.	effect on affective, social, objective physical outcome and specific Quoll measures, and significance less effect on subjective physical and functional outcomes.
Hill A & Brettle A. (2006). Counselling older people: what can we learn from research evidence? *Journal of Social Work Practice*, 20(3), 281–297.UK					
To provide a comprehensive overview of the effectiveness, appropriateness and feasibility of counselling older people.	1) Systematic review2) 47 papers, published from 1985 onwards, met the inclusion criteria and were included in the review. 20 of these were RCTs, 12 used pre- and post- test measures, 9 were systematic reviews (findings were given extra weight), 1 survey, 1 mixed-	Variety of counselling methods shown to be effective (size not given) in reducing symptoms of depression and anxiety and improving subjective well-being, all in the short-term. Less evidence for long-term effects.	Studies with target population 50 years and over were included in the review. 24 of the 47 studies were undertaken in the community setting with specific recommendations given for this	Funded by British Association for Counselling and Psychotherapy. Most findings applicable to Australian	1) Findings summarised; no indication of inconsistencies.2) Counselling is effective and appropriate for older people. Treatments examined included CBT (15 studies), reminiscence (13), generic counselling (8) and other (11). Good evidence for effectiveness of CBT in treatment of depression (including depression with comorbid physical illness) and anxiety and for

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	method, one case notes analysis and 3 qualitative studies. Educational and advisory interventions were excluded. Quality appraisal carried out by two reviewers from a team of nine. Level II.		group.	healthcare setting and particularly Australian community care setting.	reminiscence in counselling for dementia. Individual counselling is preferred by older people living in the community and may be more effective for this group. Older adults in the community may be more susceptible to untreated psychological problems and require a proactive approach to identify these problems.
Huibers MJH, Beurskens AJHM, Bleijenberg G, Schayck CP van. (2007). Psychosocial interventions by general practitioners. *Cochrane Database of Systematic Reviews*, Issue 3. Art. No.: CD003494. DOI: 10.1002/14651858.CD003494.pub2. Netherlands					
To examine the effectiveness of psychosocial interventions by general practitioners by assessing the clinical outcomes and the methodological quality of selected studies.	1) Systematic (Cochrane) review, including meta analysis2) 10 studies included (sample size range 50–923): 8 RCTs(7 high quality, one low), 2 CCTS (low quality) - level II, III1–2. Meth quality assessed using Maastricht-Amsterdam Criteria List (MACL) - 7 high, 3 low. Inclusion criteria: all RCTs, CCTs and CPPTs (controlled patient preference trials), published before Jan 2002, no restrictions on type of participants, psychosocial intervention delivered by a GP.	No overall conclusion — not comparable data. Authors suggest further research needed.	Limited generalisability. Patients aged 18–70 with 5 disorders/complaints: depression, somatisation, smoking cessation, alcohol reduction, unexplained fatigue. Our target population only small part of patients included here. (Most studies cut off at 65). Focus on GPs in the community — may have some applicability.	Review included international search. Likely translates to Aust healthcare.	1) Although selected studies varied in types of interventions, types of complaints, study population and outcome measures, meta-analyses were performed if at least two studies reported data on a particular outcome of a clinically comparable intervention and a similar follow-up period. Levels of evidence — used Van Tulder (1997) etc. Authors conclude that the available evidence addressed different psychosocial interventions for five distinct disorders or health complaints.2) Despite fairly good methodological quality and positive findings of some studies, evidence for the effectiveness of psychosocial interventions by general practitioners does not exceed (level 3 = limited or

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					conflicting evidence using Van T guidelines), except for good evidence that problem-solving treatment is no less effective than antidepressant treatment for depression.
Jané-Llopis E, Hosman C, Jenkins R & Anderson P. (2003). Predictors of efficacy in depression prevention programmes. *British Journal of Psychiatry*, 183, 384–397. UK & The Netherlands					
To identify predictors of effectiveness of programs to reduce depression or depressive symptoms	1) Systematic review — meta-analysis2) Meta-analysis of 69 programs to reduce depression. 69 studies published between 1985 and 2000 included; required to be either RCT or equivalent comparison group, have pre-post test measures and sufficient statistical information to calculate effect size. Level II.	Overall 11% improvement found in depressive symptoms in intervention compared with control groups.	Review was not specific to older adults and included studies of depression prevention programs across all age groups; however, breakdown of effective programs for each age group considered.	UK review of international studies — very applicable.	1) Weighted mean effect size of 0.22; variations given. Large fluctuations in program effectiveness — this is analysed and discussed.2) Intervention methods categorised into behavioural, cognitive, competence, education and social support. Programs with larger effect sizes were multi-component, included competence techniques, lasted more than 8 sessions and were delivered by HCPs rather than lay personnel. Studies looking at older adults found social support effective at reducing level of depressive symptoms. behavioural techniques least effective in studies on older adults.
Jordan-Marsh, M & Harden, JT. (2005). Fictive kin: friends as family supporting older adults as they age. *Journal of Gerontological Nursing, 31*(2), 24–31. USA					
To advance the concept of fictive kin and provide strategies to promote engagement with them in health care planning for older adults	1) Narrative review 2) Extensive review: 55 journal articles, 10 book chapters, 6 nursing texts, 2 volumes of nursing research annual, 2 studies	Link made to potential impact of social support on cognitive health, mortality, longevity, immunological functioning and older	Implications of article relate to social implications of caring for frail, aging adults with few surviving and	Evidence is comment and recommendations, however, transferable to Aust	1) Inconsistent/ unstated. 2) With limited resources to care for older adults in the community, and increasing understanding of the impact of social environment to healthier living, an expanded view of

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	of families. Level of evidence variable. More literature found in social science (anthropological, sociological) than health. Theoretical perspectives on social capital. Some research on social support.	age. No measurement given. Review of nursing literature noted absence of fictive kin relationships and health impact.	willing caregivers in the community = likel y to mirror our target population, but no indication of sampling methods/populatio ns.	context in broad terms.	family is imperative. Fictive kinships are a legitimate form of social capital throughout the lifespan, and particularly in later years. Such kinships are common across ethnic and socio-economic groups. Traditional genograms limit family assessment to legal/genetic relationships. Strategies for HCP to enhance fictive kin relationships are given.
Kraaij V, Arensman E & Spinhoven P. (2002). Negative life events and depression in elderly persons: a meta-analysis. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences*, 57B(1), p 87-p 94.The Netherlands					
To review the relationship between types and number of negative life events and depression in the elderly.	1) Systematic review (meta-analysis) of 25 studies.2) Articles between 1980 and 1998 reviewed; 26 publications on 25 studies included. Inclusion criteria: depression operationalised in terms of depressive symptoms, depressive disorder or dysthymia; negative life events included a wide array of events; empirical data used; sample of 65 years or older. Study features and effect size independently coded by two clinical psychologists. Level I.	Effect sizes were modest but significant except for unexpected life events (not significant). Elderly people with greater number of major and minor life stressors at risk of depression	Generalisable to population living of people 65 years and older in the community.	Results appear transferable to Australian setting.	1) The set of effect sizes were homogenous for severe illness of self or significant others, negative socioeconomic circumstances, sudden unexpected events and abuse. Effect sizes associated with other negative life events were not homogenous.2) With the exception of sudden unexpected events, all other categories of negative life events were associated with a significant increase in population levels of depression. The biggest predictors of depression in the elderly are total number of recent negative life events and number of daily hassles. Social support and coping strategies may buffer this effect.

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Luskin FM, Newell KA, Griffith M, Holmes M, Telles S, DiNucci E, Marvasti FF, Hill M, Pelletier KR & Haskell WL. (2000). A review of mind/body therapies in the treatment of musculoskeletal disorders with implications for the elderly. *Alternative Therapies in Health and Medicine*, 6(2), 46–56.US					
To provide a comprehensive literature review on the efficacy of mind/body therapies (social support, cognitive-behavioural therapy, meditation, placebo effect, imagery, visualization, spiritual/energy healing, music therapy, hypnosis, yoga, tai chi and qigong) in the treatment of musculoskeletal disease (primarily arthritis) and the promotion of 'successful aging'.	1) Narrative review2) Authors reviewed controlled trials between 1990 and 2000; included pre-1990 controlled trials if of 'high quality design', but no indication number of studies. Authors report a 'dearth' of randomized controlled research.	Effect size varies for different interventions. Treatments described as non-invasive. Several recommendations for further research given.	Some studies reviewed not specific to older adults or to musculoskeletal disorders, however results on chronic pain may be extended to elderly population and several interventions (social support, Cognitive Behavioural Therapy, placebo effect, music therapy, tai chi and qigong) particularly relevant to care of older people in community and residential care settings.	Review of US articles. Mind/body therapies covered would be equally applicable to Australian setting.	1) Unclear; anecdotal evidence included in places.2) The techniques covered showed some efficacy in treatment of chronic pain, musculoskeletal disorders (mainly arthritis) and favourable effects on other outcomes such as depression. Most could be used in addition to current pharmacological interventions. Many studies on mind/body interventions do not use optimal scientific methodology. Future research needs to isolate treatments, include randomized control groups, and specify length of dose/intervention and follow-up time.
Luxford K, Fletcher J. Leading the way — best practice in psychosocial care for cancer patients. Cancer Forum 2006; 30(1): 25–28. Australia					
Presents a evidence based recommendations about the effectiveness of	1)Review2) Levels of evidence in studies reviewed is not given.	No indication of effect size given.	Clients with leading forms of cancer including	Applicable to an Australian setting	1) Not applicable2) Presents strategies that have been used to promote psychosocial guideline use.

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psychosocial interventions for cancer patients.			breast, colorectal, gynaecological, lung, melanoma, prostate, urogenital and non-Hodgkin's lymphoma also, pancreatic and head and neck cancer.		Offers recommendations for future implementation of psychosocial guidelines into cancer care.
Markle-Reid M, Browne G, Weir R, Gafni A, Roberts J & Henderson SR. (2006). The effectiveness and efficiency of home-based nursing health promotion for older people: a review of the literature. *Medical Care Research and Review*, 63, 531–569. US					
To review research on the effectiveness and efficiency of the role of community nurses in the provision of health promotion to older people via preventive/proactive home visitation programs.	1) Meta-analysis deemed inappropriate due to heterogeneity of studies; qualitative review of 13 RCTs performed. 2) 12 publications of 13 randomised controlled trials selected from 344 published studies, based on list of inclusion and exclusion criteria and assessment of methodological quality. Articles limited to age 65 and over. Only studies including measures of cost were used. Level II.	At least one favourable effect (on mortality, health and functional status, and/or caregiver outcomes) reported in all but 2 studies reviewed, with no negative effects reported. Effects greatest when assessment and care are ongoing and with a flexible, interdisciplinary approach.	Applicable to home-based community care for those 65 years and older.	Studies referred to conducted in Western Europe, US and Canada. Applicable to Australian setting.	1) Lack of consensus regarding effectiveness of intervention for high vs low risk of functional decline subgroups. Otherwise, various interventions covered but where intervention was the same, there was a high level of consistency of evidence. 2) A diversity of interventions found to improve health, functional status (including psychosocial function and level of depression) and mortality rates, and to reduce hospitalisation and use of nursing homes and costs (measured in years of disability-free life, days of nursing home care avoided, and US$). Interventions not always adequately described so difficult to isolate individual components, but greater role of

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					community nurse linked to greater effectiveness of program. Areas without sufficient research include mental health, social support, caregiver burden and subgroups of patients who benefit most from different interventions. Suggests interventions work best early in progression to frailty and older groups require more frequent visits.
Marshall MJ & Hutchinson SA. (2001). A critique of research on the use of activities with persons with Alzheimer's disease: a systematic literature review. *Journal of Advanced Nursing*, 35(4), 488–496.US					
To critique research on the use of therapeutic activities with Alzheimer's diseases patients, with an emphasis on methodology.	1) Systematic review Evaluated studies based on accepted nursing research framework (Wilson & Hutchinson 1996, Polit and Hungler 1999).2) Reviewed studies published between 1988 and 2001; critiqued 33 papers meeting inclusion criteria, including 4 case studies, 3 descriptive studies, 22 quasi-experimental studies, 2 RCTs and one qualitative study. Level II.	Effect sizes not given. Findings not pooled or summarised. Interventions and studies described but findings not evaluated.	Individual studies covered would be applicable to those in the target population with Alzheimer's disease/ dementia.	Individual studies reviewed would be applicable to Australian setting.	1) Outcome variables studied are listed but results of studies not always given; no information on consistency or contradictory results. Authors report some methodological problems (eg small sample size; problems with staging/diagnosing Alzheimer's disease; sample selection) in studies used.2) Music as an intervention was looked at in 23 studies (16 of these looked at music alone). The remaining studies looked at a wide range of interventions including art therapy, movement therapy, reminiscence, reading and games. Positive outcomes (of individual studies) included improved self-esteem and social interaction, less agitation and improved expression of feelings.

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					Little in the way of overall/ pooled results given.
May C. (2007). The influence of companion animals on the psychological health of older adults. *Australian Vet Practitioners*, 37, 14–19. Australia					
To assess methodological weaknesses in studies on the effects of companion animals on psychological health in older adults.	1) Narrative review. 2) Levels of evidence in studies reviewed is not given.	Wide range of effects considered in studies reviewed but discussion focuses on methodological flaws.	Applicable to the design of future studies on the target population.	Australian study — applicable to further research in this field.	1) Inconsistencies of results and reasons for these are the main focus of this review. 2) Companion animals may improve psychological functioning in older adults by reducing depression, anxiety, depression and stress, and improving social competence, social interest, life satisfaction and self-interest. Methodological weaknesses in studies in this field include the attitudes of participants towards animals, type of instrument used, and the confounding factor of increased human contact (eg animal handler).
Mohlman J. (2004). Psychosocial treatment of late-life generalized anxiety disorder: current status and future directions. *Clinical Psychological Review*, 24, 149–169. US					
To review research on psychosocial interventions for late-life generalised anxiety disorder (GAD), including group vs. individual treatments and the transfer of benefits across age groups.	1) Systematic and qualitative review2) Systematic summary tables given for three controlled group CBT and five individual CBT studies given; remainder of review is qualitative critique. Level III (?)	Varying measures and scales used to assess changes in GAD. Authors argue for better measurement of outcome and more attention to clinically significant improvement and QOL measures.	Most studies have used samples of 65–74 year old white females. However the results are likely applicable to older adults with GAD falling outside of this subgroup.	Should be applicable to Australian setting	1) Inconsistent results reported; many studies have small sample sizes and limited statistical power2) At least three effective therapies for treating GAD but most studies have looked only at CBT. CBT in group and individual format is 'somewhat effective' in reducing anxiety, worry and depression related to CBT, although less effective than similar treatments in younger adults.

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Murray E, Burns J, See Tai S, Lai R, Nazareth I. (2005) Interactive Health Communication Applications for people with chronic disease. *Cochrane Database of Systematic Reviews* 2005, Issue 4. Art. No.: CD004274. DOI: 10.1002/14651858.CD004274.pub4UK					
The objectives of this systematic review were to determine the effects of Interactive Health Communication Applications (IHCAs)- computer based information packages that combine health information with at least one of social support, decision support, behaviour change support — on patients in terms of: knowledge; social support; self-efficacy; emotional outcomes; behavioural outcomes; clinical outcomes; and to determine the effects of IHCAs on economic outcomes, in terms of resource utilisation.	1) Systematic (Cochrane) review involving meta-analyses2) 24 RCTs (Level II) of 3739 participants.14 studies included in meta-analyses. Inclusion criteria: people of all ages with chronic disease, intervention and outcome measures also stipulated. Methodological quality assessed.	Knowledge IHCAs had a significant positive effect (SMD0.46; 95% CI 0.22 to 0.69). Social support -a significant positive effect (SMD 0.35; 95% CI 0.18 to 0.52). Self-efficacy — more likely than not that IHCAs have a positive effect on self-efficacy (SMD 0.24; 95% CI 0.00 to0.48). Significant positive effect on continuous behavioural outcomes (SMD 0.20; 95% CI 0.01 to 0.40); binary behavioural outcomes also showed a positive effect for IHCAs, although this result was not statistically significant (OR 1.66; 95% CI 0.71 to 3.87). Despite this, IHCAs are most likely to be beneficial in terms of behavioural outcomes. Overall authors suggest more relevance to policy than practice.	Overlap with our target population, but inclusion of all patients with chronic disease (including children) - Alzheimer's disease, asthma, cancer, diabetes, eating disorders, encopresis, obesity, urinary incontinence — makes generalising difficult.	Likely transferable. Articles included were from Aust, USA, France, Italy.	1) Some inconsistencies mentioned. Outcome categories emotional and economic only narrative review — not possible to determine whether IHCAs have an effect on emotional outcomes or on overall resource use/cost.2) IHCAs have a significant positive effect on knowledge, perceived social support, health behaviours and clinical outcomes. Results suggest it is more likely than not that IHCAs have a positive effect on self-efficacy. It was not possible to determine the effects of IHCAs on emotional or economic outcomes

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Opie J, Rosewarne R & O'Connor DW. (1999). The efficacy of psychosocial approaches to behaviour disorders in dementia: a systematic literature review. *Australian and New Zealand Journal of Psychiatry*, 33, 789–799.Australia					
To review research on non-pharmacological strategies to alleviate behavioural disturbances associated with dementia in older adults.	1) Systematic review2) 43 studies met inclusion criteria (including 5 RCTs); published between 1989–1998; studies required to include pre and post test measures of behaviour. All included studies rated for validity. Level II.	Outcomes measured include episodes of agitation and attempted exits. Studies with multiple outcome measures gave most information.	Most studies reviewed focussed on residential rather than community care but many of interventions, eg changes to physical environment, would be equally effective in improving outcomes for people in the community with dementia (and possibly in delaying admission to residential care).	Australian review; directly applicable.	1) No quantitative measure of consistency.2) Evidence to support the efficacy of activity programs (structured and well-planned), music, behaviour therapy (even in patients with advanced confusion), light therapy, carer education and changes to the physical environment in reducing wandering, restiveness, aggression and noisiness. Many of these interventions, eg concealing exits, providing music, are inexpensive to implement and require little staff time. Inconclusive evidence found for efficacy of multidisciplinary teams, massage and aromatherapy — more studies of improved design needed in these areas. Studies focusing on a single behaviour or intervention easier to interpret.
Pachana N. Developments in clinical interventions for older adults: a review. *New Zealand Journal of Psychology*, 28(2), 107–117.NZ					
To highlight areas of recent research in the area of clinical psychology relating to diagnosis and treatment of older adults.	1) Narrative review — selective review of clinical interventions.2) Review is qualitative; methodology not given. Level QE.	No quantitative impact given but much of qualitative information of relevance to carer/ therapist of older patients.	Very applicable: paper summarises literature specific to older adults, conditions common to this group and	New Zealand/inter national healthcare setting — applicable to Australian	1) Some areas of inconsistency in studies reviewed — differences often minor and author attributes some of variation in results to differences in diagnostic criteria or assessment instruments used.2) Psychotherapy must be adapted for older adults, who

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			adaptations of psychological interventions adapted to the target group.	setting.	experience various barriers to treatment; are more likely to suffer co-morbidities; respond well to interactive and integrative treatments; may need longer to learn techniques; and are at increased risk of accidental or deliberate substance abuse (which may be misdiagnosed as, for example, dementia). Dementia, Alzheimer's disease, depression and bereavement require special consideration and psychosocial interventions.
Pinquart M & Sorenson S. (2000). Influences of socioeconomic status, social network, and competence on subjective well-being in later life: a meta-analysis. *Psychology and Ageing, 15*(2), 187–224. Germany (and US)					
To synthesize findings of empirical studies on subjective well being (SWB = life satisfaction, happiness, self esteem) and its association with socio-economic status (including income and education), social network (family and friends, quantity and quality) and competence (mobility, leisure activities, cognitive) in the elderly. 9 hypotheses.	1) Systematic Review (meta-analysis — method suggested by Rosenthal, 1991)2) 286 studies, sample sizes 20 to 5000. Combined n's for correlations range from 300 to 80,000. Levels of evidence not given. Quality assessed for representativeness of sample and quality of instruments. Inclusion criteria: participants included older persons, from developmental and gerontological literature,	Not really discussed. Correlational relationships (and sizes given), not causal.	Nationally and regionally representative samples reported separately from non-representative (convenience), therefore generalisability possible. All studies included aged persons (>60) with sample means at least >55. (Some correlations further divided into mean age < and > 70,	All English or German — only 15 German articles of total 286 articles. Likely applicable to Australian context.	1) High variability of effect sizes noted. Methodological quality issues — representativeness of sample and quality of measures, differences measured and discussed where possible. Articles taken from 1954–1999, therefore variable contexts, however, some cohort effects measured and found not significant.2) SES, Social Network and Competence all correlate +positively with SWB. Income correlates more strongly than education. Quality of social contacts correlates more strongly than quantity. Contact with friends correlates more strongly than with

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	reported statistical associations, in English or German.		and <65, 65–75, and >75). Therefore, applicable to our population age-group.		adult children for SWB overall, however higher for adult children than friends for life satisfaction. Likely moderated by age and gender; few studies, and need more research.
Rehse B, Pukrop R. (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: meta-analysis of 37 published controlled outcome studies. *Patient Education and Counselling 50*,179–186 Germany					
To present a meta-analysis of controlled studies investigating the effectiveness of psychosocial interventions on quality of life — addressing (i) overall effect size (ii) types of interventions (iii) duration of intervention (iv) sociodemographic and clinical parameters (v) different conceptualizations of QOL (vi) methodological quality, and effect size.	1) Systematic review. Meta-analysis (Hunter and Schmidt) 2) 37 studies, N = 3120, sample size range 13 to 271. All controlled studies — assume Level III. Methodological quality assessed.	Overall effect — moderate (correlation equivalent delta 0.31, *d = 0.65)*, with duration of intervention most significant moderator. Suggest that psychosocial interventions yield high benefit with low cost in relation to expected effect on Quoll. Adult cancer patients, average age 54.1 years.	Different experimental designs, treatment conditions, outcome measurement — measures taken to standardise. Published articles from 1970 to July 1999 - wide range, and possibly different focus on psychosocial care over this period. Breast cancer 38.7%, Lung/mediastinum 12.9%,GI 9.9%. Over-representation of breast cancer, although authors state no	Studies included English and German language, from Canada (2), Italy (2), Sweden (2), Germany (3), UK (7), US (21). Transferable to Australian setting.	1) Unknown, although authors refers to non-included studies that show similar trends to meta-analysis, except for intervention type, where they suggest further research is needed. 2) Results support usefulness of psychosocial interventions, of at least 12 weeks duration, for improving Quoll in adult cancer patients. Recommend psychosocial intervention as routine treatment for cancer patients completing conventional medical intervention, particularly males, who showed > treatment effect.

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			significance diff between breast and all other tumour types. Younger age group. Limited generalisability to our population.		
Skultety KM & Zeiss A. (2006). The treatment of depression in older adults in the primary care setting: an evidence- based review. *Health Psychology*, 25(6), 665–674.US					
To conduct an evidence-based review of treatments for major and minor depression in the primary care setting.	1) Systematic review2) 8 studies met inclusion criteria. Studies were RCTs that compared psychosocial interventions within primary care setting, with a control ('usual care') condition, published between 1994 and 2004. Two independent reviewers rated article quality. Level I.	No overall effect size but both models shown to reduce depressive symptoms in the short to long term via a diverse range of treatments.	Studies used had sample populations 55 years and over (mean age 72.7). Appropriate for age of target population. Review concentrated on primary care settings rather than community care specifically.	Applicable to Australian setting.	1) Effect sizes were small, moderate or large with discrepancies given; all effect sizes in same direction (decreasing depressive symptoms).2) Studies divided into two treatment models: geriatric evaluation management and integrated health care models; evidence for both models indicated an improvement in symptoms and outcomes in comparison to 'usual care'. Interdisciplinary teams, with coordinated care plans, suggested to be important. Various combinations and duration of interventions covered, with information on interventions/protocols often limited.
Steed HN, Smith BS. Animal assisted activities for geriatric patients. Activities, Adaptation & Aging 2002; 27(1): 49–61 USA					

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Identify the key elements of animal assisted activities (AAA) that may prove helpful in the aging population.	1) Literature review 2) 14 peer-reviewed journal articles met the criteria of no case studies, at least some participants were 65 years or older, subjects were not institutionalized psychiatric patients, and research with animal- human interaction.	No overall effect size but AAA appear to improve the quality of life of aging individuals.	Older (over 65 years) and not in psychiatric inpatient facilities. Can be applied to older people in community setting.	Studies included from a range of countries. Transferable to the Australian setting.	1) Not applicable 2) Interactions with animals decreased blood pressure and heart rate, decreased depression, and increased life satisfaction. Animal assisted activities appear to improve the quality of life of aging individuals. Future research should focus on outcomes of using different types of animals and the amount of time spent with the animals.
Teri L, McKenzie G, LaFazia D. Psychosocial treatment of depression in older adults with dementia. Clinical Psychology-Science and Practice 2005; 12(3): 303–316. USA					
Overview of the current literature on treatment of depression in demented older adults, with particular emphasis on providing guidelines for evidence-based clinical care.	1) Literature review2) Eleven randomized controlled clinical trials that have investigated the efficacy of psychosocialapproaches to reducing depression in dementia.	Overall moderate effect found for psychosocial interventions for depression in older people with dementia; individual effect sizes not given.	Older adults with dementia. Can be applied to community dwelling older adults.	Studies from a range of countries, mainly US. Transferable to Australian community setting.	1) Not applicable2) Presented methodological issues of RCTs to assist practitioners to use finding in practice. Using multipletechniques, including behavioral skill training, communication, social engagement, and sensory and environmental stimulation in a variety of settings, including long-term care and private homes, 7 of the 11 treatments demonstrated clear improvements in depression.
Torrington JM & Tregenza. (2007). Lighting for people with dementia. *Lighting Research Technology*, 39(1), 81–97. UK					
To review lighting conditions that may	1) Narrative review. 2) Guidelines derived from two multi-disciplinary	Impact on comfort and minimising distress in residential care/nursing	Results most applicable in the design of	Recommendations on winter	1) Greater consistency in research on diurnal cycle and provision of natural external view; elsewhere unstated.

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
enhance the well-being of people with Alzheimer's disease or dementia.	research projects and a narrative review of the literature. Level QE.	home residents. Most important at design stage.	residential care facilities and nursing homes but many findings also applicable to older adults living in the community.	lighting and seasonal affective disorder/ depression less applicable to Australian climate; other recommendations would apply.	2) Lighting is a component of the therapeutic environment for older people and should be adapted to general characteristics of the ageing eye (eg reduction of glare and of areas of darkness, increased illuminance and red-yellow lighting). For people with dementia, ensuring sufficient exposure to environmental lighting and a diurnal lighting pattern may lessen sleep disturbances and depression. External natural views increase psychological well-being and social interaction and provide orientation cues. Lighting should also support maximal physical and social activity and aid with recognition of space.
Vachon, M. (2006). Psychosocial distress and coping after cancer treatment. *American Journal of Nursing, 106,* No.3 Supplement, 26–31. Canada					
To review the current literature on psychosocial distress and coping of cancer survivors, primarily those who have completed initial treatment and are now disease free and give direction for future research.	1) Narrative review.2) No quantitative indication of volume of evidence or methodological quality. Reference to several meta-analyses.	No discussion of specific impact, just recommendations for future study. All studies included cancer survivors — variety of types, time from diagnosis, stage etc.	Little mention of aged patients, and no mention of specific community issues. All related to cancer patients, which may constitute some of our target population. Limited generalisability.	Article emanates from Canada, but no mention of populations in review articles. Likely to transfer to Australian healthcare setting.	1) Some discussion given re conflicting evidence. No quantitative data so degree of consistency unknown.2) At least a third of cancer patients experience distress, but only about 10% receive psychosocial therapy. Yet this therapy can aid coping, improve affect, reduce adverse effects of the disease or its treatment, and positively impact on QOL. Patients in different disease stages may benefit from different treatments. Survivors may also

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
					benefit from treatments. There is evidence of effectiveness, with different therapies addressing different needs (eg CBT for cancer related depression, group therapy for breast cancer related depression.
Verkaik R, van Weert JCN, & Francke AL. (2005). The effects of psychosocial methods on depressed, aggressive and apathetic behaviors of people with dementia: a systematic review. *International Journal of Geriatric Psychiatry 20*, 301–314. Netherlands					
To establish the extent of scientific evidence for the effectiveness of 13 psychosocial methods for reducing depressed, aggressive or apathetic behaviors in people with dementia	1) Systematic review — used Best Evidence Synthesis 2) 19 studies included. Cochrane Collaboration guidelines used. All RCTs or CCTs (controlled clinical trial) = Levels of evidence: II, III1/2. Meth quality assessed. 4 inclusion criteria required (studies, participants, psychosocial methods, outcome measures).	No discussion of size of impact. Patient related — all patients with diagnosis of dementia (of all severities) inpatient and outpatients.	Some generalisability for dementia in community patients. Small sample sizes however, n = 15–151.	Review conducted in Netherlands (?some bias), however, international review — included US, UK, Italy, Canada, Switzerland, Sweden. Likely relevant although unknown if the psychosocial methods are used in Aust, although the three with evidence are recognised by	1) Diversity of psychosocial methods and outcome measures therefore used Best Evidence Synthesis (VanTulder et al 2002) conducted = some scientific evidence and limited scientific evidence. 2) (i) Some evidence MultiSensory Stimulation in a MultiSensory Room reduces apathy in people in later phases of dementia. (ii) Limited evidence Behaviour Therapy-Pleasant Events and Behaviour Therapy-Problem Solving reduce depression in people with probable Alzheimer's disease living at home with PCG. (iii) Limited evidence that Psychomotor Therapy Groups reduce aggression in specific nursing home residents with probable Alzheimer's disease. No or insufficient evidence of other ten methods reducing depression, aggressions or apathy. Conclusion — evidence is modest and further research is required.

Topic of review	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Consistency of evidence (1) and key findings (2)
				American Psychiatric Assoc and likely to be well recognised.	
Wetherell J, Sorrell JT, Thorp SR & Patterson TL. (2005). Psychological interventions for late-life anxiety: a review and early lessons from the CALM study. *Journal of Geriatric Psychiatry and Neurology*, 18, 72–82.US					
To review the literature on psychological treatment of anxiety in older adults and to report on preliminary findings of the CALM (Controlling Anxiety in Later-life Medical Patients) study.	1) Narrative review2) Narrative review of RCTs; 14 reviewed. Methodology for selection of studies not given. Level II.	Effect size not discussed. Improvements measured in state or trait anxiety and measures such as depression, worry, QOL.	Studies had patients with mean age of 66 or over so findings appropriate to older adults suffering from anxiety.	Transferable to Australian setting.	1) Various levels of effects found in the studies reviewed — these are summarised. 2) Various interventions including life review, CBT, problem-solving and assertiveness training used to target a range of conditions under umbrella of 'anxiety'. Review found evidence for relaxation therapy as effective treatment for subjective anxiety symptoms; and for CBT for generalised anxiety disorder, panic disorder and miscellaneous anxiety syndromes. CBT designed for younger adults may not be appropriate or as effective for older people and requires adapting.

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Appendix O Articles reviewed in Chapter 8 ‘Spiritual support’

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
Ano GG, Vasconcelles EB (2005) Religious coping and psychological adjustment to stress: a meta-analysis. Journal of Clinical Psychology, 61(4), 461–80. USA					
To synthesize research on situation-specific religious coping methods. To examine efficacy in people dealing with stressful situations.	1) Review & meta-analysis, 2) Forty-nine studies were included High quality evidence and methodology testing relationships between religious coping & adjustment.	Provides context only as this investigates these relationships across population groups.	Results from this US review are relevant to our target population as older adults requiring a palliative approach to care may well be under stress. However, generalising results should bear in mind the Australian context and possible age specific characteristics.	Can be applied within the Australian context	1) Highly consistent. 2) A moderate positive relationship was found between positive religious coping strategies and positive outcomes to stressful events.
Chi GCL, (2007) The role of hope in patients with cancer. Oncology Nursing Forum, 34(2), 415–24.USA					
To gain an understanding of the role of hope in patients with cancer: level of hope, coping mechanisms, strategies used by patients and interventions by health professionals.	1) Systematic review.2) Eight (8) articles addressed the level of hope in patients with cancer. Six (6) articles addressed how patients cope with a cancer diagnosis. Seven (7) articles addressed the strategies patients used to maintain hope. Five (5) articles addressed	Looking solely at the concept of hope. The review only included studies related to hope and cancer, other diseases excluded.	US review. Only two studies were described as including samples of only older adults. Not all studies were community based. Can only be generalised to	Can be applied within the Australian context	1) High degree of consistency.2) Patients felt moderately hopeful. Strength of religious convictions & performance of family role responsibilities significantly related to hope & coping regardless of setting. Intrinsic religiosity, spiritual well-being, associated with hope & positive mood states. Strategies used by patients — finding meaning, affirming relationships, using inner resources, living in the present & anticipating survival; spiritual beliefs &

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
	interventions to help patients maintain hope. Definitions of hope included. The research included was mainly descriptive but also included the testing of interventions.		people who have cancer given that this disease may be perceived differently to other life limited illnesses.		relationships important to hope. Seven hope-fostering categories: love of family & friends, spirituality or having faith, setting goals, maintaining independence, positive relationships with professionals, humour, personal characteristics & uplifting memories. Hope for not suffering anymore, living life to the fullest in the little time left, peaceful death, for better life for families. Interventions to help patients maintain hope — caring behaviours, being present, taking time to talk, being helpful, showing genuineness. Studies show nursing interventions can impact on hope.
Dalby P (2006) Is there a process of spiritual change or development associated with ageing? A critical review of research. Aging & Mental Health, 10(1), 4–12. UK					
To Identify spiritual tasks, needs and changes in spirituality over time and gerogranscendence, a theory about maturing into old age.	1) Critical review of descriptive research.2) Thirteen (13) articles, quantitative and qualitative, were included, looking solely at spirituality, religiosity and gerotranscendence. (39 references)	Studies linking spirituality and well-being or health were excluded. Studies of cognitively impaired people were excluded.	Studies from different parts of the world (UK review), Sweden, Tel-Aviv, Iran, USA. To the extent that these findings were consistent, cross cultural generalisability is good. The exclusion of cognitively impaired participants is common to many studies but limits	Not directly related to aged-care in the community in Australia but does provide contextual information about spirituality and ageing.	1) High degree of consistency2) Reports some evidence of an increase in spirituality or aspects of gerotranscendence with age. Common themes in the qualitative articles: integrity, humanistic concern, changing relationships with others and concern for younger generations, relationship with a transcendent being or power, self transcendence and coming to terms with death.

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
			generalisability.		
Francke AL (2000) Evaluative research on palliative support teams: a literature review. Patient Education and Counselling, 41(1), 83–91.The Netherlands					
To gain an insight into appropriate methods and instruments for use by palliative support teams and their effectiveness on patients' physical, psychosocial and spiritual problems as well as anxiety.	1) Narrative review.2) Sixteen (16) retrospective and prospective studies, of which seven (7) addressed psychosocial and spiritual issues. Six (6) outpatients studies and with three (3) identifying home care. Seven (7) studies addressed psychosocial and spiritual problems. Studies addressed the effectiveness of palliative support teams but generally with uncontrolled studies.	Clinically useful information	This Dutch review provides findings that may be useful to the care of older adults in the community but that are not targeted specifically at this group	Palliative support teams are described as providing advice & support to patients and care providers within existing services so findings might be applicable in the Australian context	1) Poor consistency. A variety of instruments were used, making outcome comparability difficult.2) Psychosocial and spiritual problems are reduced less after referral to a palliative support team than physical complaints. The authors argue that palliative support teams may be better equipped to deal with physical complaints.
Gaskamp C et al (2006) Evidence-based guideline: promoting spirituality in the older adult. Journal of Gerontological Nursing, 32(11), 8–13. USA					
To provide nursing care providers with guidelines for promoting spirituality in older adults.	1) Described as evidence based guideline, presents as a narrative review. 2) Definitions of spirituality, spiritual well-being, spiritual distress, spiritual pain, prayer, hope, forgiveness, reminiscence, meaning, touch and presence. Presents research findings and practice guidance based upon these -	Provides guidance for the clinician that should have a clinical impact.	Not directly aimed at palliative care in the community. Older adults in any setting. US review.	Applicable.	1) Highly consistent. 2) Provides specific nursing actions to take to care for the spiritual dimension of the human being and expected outcome of providing such interventions. Criteria identifying at risk older adults: self-reported inability to practice spiritual rituals; verbalized longing for spiritual rituals and spiritual support; verbalized questioning or loss of faith; expression of interpersonal or emotional suffering, loss of hope, lack of meaning, or the need to find meaning in suffering; presence of life-threatening, chronic or terminal illness; development of

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
	81 references but no precise number/type of included studies.				cognitive impairment; evidence of disease. Tool suggested is the Brief Assessment of Spiritual Resources and Concerns (Koenig 2002; Meyer 2003) to open the conversation. Practices to promote spirituality include active listening (presence, touch, meaning, reminiscence) and spiritual support (forgiveness, hope, prayer).
Gruenewald DA, White EJ (2006) The illness experience of older adults near the end of life: a systematic review. Anaesthesiology clinics of North America, 24(1), 163–80.USA					
The goal was to develop a model of the lived experience of illness near the end of life that was based on the views of older people.	1) Systematic review2) Forty (40) articles were included in this review, of which seven (7) relate to community care. Articles were included when they reported interview or focus group data relevant to quality of life and related issues at the end of life in older adults.	Spirituality just a small component of the review. Model may have an eventual clinical impact.	The population addressed by this US review is generally consistent with that addressed by our project.	Applicable to Australian health care context.	1) High degree of consistency2) Six (6) overarching elements emerged: suffering, hope, dignity, decision-making, control/autonomy. There were three (3) themes: contextual factors, response to illness, and perceptions and concerns — the latter two including spiritual and existential factors. Participants described spiritual needs near the end of life, including needs for religion, companionship, involvement and control, completion of life tasks, of nature, and a positive outlook. They talked over memories with families, conducted life review, resolving bitter feelings, made practical preparations, addressed legacy issues, lived their lives as fully as possible, & desired to make peace with God. They lived with uncertainty about the future: swinging between hope and despair — needed to consider the meaning of life and possibility of life after death. Faith, religion, & spirituality impacted upon perceptions of dying.
Hearn J, Higginson IJ (1997) Outcome measures in palliative care for advanced cancer patients: a review. Journal of Public Health Medicine, 19(2), 193–9. UK					
To systematically	1) Systematic review 2)	Only two (2)	The two tools	Findings from	1) N/A2) This review identified 12 measures (out

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
identify and examine outcome measures that have been used, or proposed for use in the clinical audit of palliative care of patients with advanced cancer.	Twelve measures (12) satisfied the inclusion criteria in physical, psychological and spiritual domains of life. Their characteristics are included, including reliability and validity testing.	measures had a spiritual component.	were selected for their relevance to advanced (adult) cancer patients but could be used for other older adults — they are quality of life scales not specifically designed for cancer patients.	this UK review are applicable in many Australian contexts but are unlikely to be useful in minority cultural groups.	of 41) for use in palliative care of cancer patients, out of which 2 had a spirituality domain, namely meaning of life or meaningful existence: the McGill Quality of Life Questionnaire (MQOL) and the McMaster Quality of Life Scale (MQLS) Raises particular concerns about use and relevance of outcome measures in palliative care. (A) There is inherent difficulty in self-completion measures that affects validity and could lead to potential bias in results (B) The measure might not include all the domains relevant to the palliative care of that person.
Hillerås PK et al (2001) Factors influencing well-being in the elderly. Current Opinions in Psychiatry, 14, 361–5. Sweden					
To discover the factors that either increase or decrease well-being	1) Narrative review 2) Brief review of research (methodology not specified) and possibly other studies (77 references).	Small relevant section on religion — very limited clinical impact	This Swedish review relates to elderly people as well as to young people but its Swedish perspective may limit generalisability.	Some applicability.	1) Inconsistent. 2) Some authors have found positive links between faith and well-being. Others have found that non-religious individuals with a strong meaning and aim in life also have a high sense of well-being. Others found that religiosity buffers the effects of non-familiar stressors but worsens others. On conclusion, a religious belief can affect well-being in both positive and negative ways.
Koenig HG et al (2001) Religion and coping with serious medical illness. The Annals of pharmacotherapy, 35, (3) 352–9.USA					
To explore the role that religion plays in helping patients cope with serious medical illness.	1) Narrative review.2) Findings from a larger review. Studies included are cross sectional and prospective studies examining relationships between religious belief and activity and adaptation to	Multiple psychological, social, behavioural and physiological mechanisms by which religious involvement	In this US review, most studies addressed Christian and Jewish populations only and in the USA. Not old age	Some applicability.	1) Generally consistent.2) Religion is identified as having a role in adapting to ageing, illness, disability and to a caring role Religious coping is seen to be correlated with reduced depressive symptoms (eg loss of hope) but not with others (eg loss of energy). Religious involvement has a generally consistent association with greater well being & life satisfaction. A few studies indicate an

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
	illness.	might enhance quality and meaning of life.	specific.		association between religious involvement and immune function.
Lindberg A (2005) Integrative review of research related to meditation, spirituality and the elderly. Geriatric Nursing, 26(6), 372–7. USA					
To evaluate the learning potential and enquire into the psychosocial benefits of meditative practice for the elderly: can they be taught meditation-relaxation strategies, does it promote hope, integrity and connectedness, does it promote spiritual growth.	1) Narrative review. 2) Thirty-six (36) articles addressed meditation among the elderly. Three (3) investigated spirituality, relaxation and their impact on health. Studies and other articles were included. Most studies related to elderly patients living in residential care.	Potential benefits from meditation that would be of clinical significance.	Results from this review could be generalised to the target population with some restriction as many studies addressed residential rather than community care.	The evidence in this review could be applied to the Australian community healthcare setting.	1) Highly consistent. 2) Correlation between spiritual experience and positive psychological attitudes following training in relaxation (institutionalized patients). Protective function of private religious activity, including prayer and meditation against physical health decline and death. Spiritual beliefs having positive effect on psychological well-being. Reviewer indicates that meditation or spiritual practices when the participant is self directed and active, rather than following a set routine, promotes emotional, and spiritual well-being.
Luskin et al (2000) A review of mind/body therapies in the treatment of musculoskeletal disorders with implications for the elderly. Alternative Therapies in health and Medicine, 6(2), 46–56.USA					
To examine the efficacy of mind/body therapies in promoting successful aging among sufferers of musculoskeletal diseases.	1) Critical review of research testing interventions2) Articles relating to the elderly in the last 25 years were included in this review. This is the 2nd in a 2-part series on the topic of mind/body therapies including social support, cognitive-behavioural therapy, meditation, the placebo effect, imagery, visualisation,	The spiritual component of the interventions is difficult to determine but the review does indicate the likelihood of a clinical impact from mind body therapies.	Musculo-skeletal problems are highly prevalent in our population of interest so findings are relevant here.	This US review is applicable to the Australian community care context.	1) Many mind/body therapies demonstrate anecdotal evidence of value to the care of older persons. Only the elements of religious belief, spiritual healing, and yoga/tai chi/Qigong are considered for the purposes of the current project. 2) Religious belief & mood might impact on pain but this requires more investigation. Spiritual healing is said to be addressed by therapeutic touch, Reiki, Le Shan healing, intercessory prayer, and transpersonal imagery (p 52). Healing is said to possibly occur via a transfer of energy from the healer. One trial has provided some evidence of an effect on EMG activity in healthy volunteers but

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
	spiritual/energy healing, music therapy, hypnosis, tai chi and qigong. Definition of spiritual healing: including therapeutic touch, Reiki, LeShan healing, intercessory prayer and transpersonal imagery (91 references).				further research is needed. Yoga traditionally has a spiritual basis, some research (one RCT & other studies) indicate benefits for arthritis sufferers. Tai Chi, anecdotally, assists in pain management. Tai Chi may reduce frailty with regular practice; trials support that it reduces falls. Qigong is said to unlock an energy source using movements or breathing. No good evidence of benefits.
MacKinlay EB, Trevitt C. Spiritual care and ageing in a secular society. Medical Journal of Australia 2007; 186(10 Suppl): S74-S76. Australia					
To present an alternative view of ageing and a model of spiritual tasks in ageing.	1)Review 2)Strength and quality of evidence not discussed.	No discussion of effect size. However Provides guidance that should have a clinical impact.	Older adults in any setting.	Applicable to Australian community health care context.	1) Not applicable 2) Presents concept of spiritual searching in older adults when questions of meaning, transcendence and hope becoming important. Thus, one important view of ageing is of a spiritual journey. The spiritual quest does not cease with the onset of frailty or with the diagnosis of dementia. Highlights that older people need support and spiritual care that will include helping them search for meaning and grappling with issues when life is threatened. Suggests that using spiritual reminiscence is one way of offering this care.
Meraviglia M et al (2006) Providing spiritual care to the terminally ill older adult. National Guideline Clearinghouse — AHRQ — University of Iowa Gerontological Nursing interventions Research Center (www.guideline.gov) 1–14. USA					
To provide evidence-based guidelines for spiritual care for at risk (spiritual distress) terminally ill older adults	1) Evidence-based guidelines developed using systematic review methodology 2) References not included but were weighted according to a rating scheme	These US guidelines have the potential to have a strong clinical impact. However, the level of	The guidelines are specifically designed for the terminally ill older adult.	Caution is needed due to differences in health systems USA and Australia, ie mental	1) Highly consistent. 2) Criteria for at-risk older adults may include: inability to engage in spiritual or religious practices; frustration, fear, hurt, doubt; loneliness & isolation; lack of hope or feeling life is not worthwhile; feelings of losing control; verbalising questions about faith or loss of faith; emotional suffering (eg lack of meaning, guilt,

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
	for the strength of the evidence. Definitions of spiritual distress (106 references).	evidence in this area is not high and this is a limiting factor.		health provider (cognitive-behavioural therapy and control-enhancing interventions),	anger, anxiety, depression); desire for death. Tools to effectively assess patients with spiritual distress: Functional Assessment of Chronic Illness Therapy — Spiritual (Cella, 1997), Loneliness Scale (Hughes et al, 2004) Herth Hope Index (Herth, 1992), Short Screen for Depression Symptoms (Robinson & Crawford, 2005). Effective interventions may encourage hope & promote connectedness. Easing loneliness may involve learning coping to promote connectedness & include family. Holistic care from a palliative care team; music, massage, aromatherapy; referral to mental health provider; fostering hope are suggested interventions. O/come indicators are spiritual well being, connectedness, hopefulness, depression.
Moberg DO (2005) Research in spirituality, religion and aging. Journal of Gerontological Social Work, 45(1/2), 11–40.USA					
This review focused on conceptual issues of spirituality and religion, current research and its relevance to applications in clinical and social services.	1) Narrative review2) Included diverse research findings, methodology often not indicated. In-depth analysis of the literature with relevance to clinical and social services including ethics, need for future research including triangulation. Review from a social gerontology perspective. Definitions of spirituality and religiosity (135 references).	US review dealing entirely with spirituality and health in ageing. Potential clinical impact considerable.	As the author acknowledges, little research has been done solely on spirituality and the elderly. There is no focus on palliative community care. However some of the key findings could be generalised to Australian older adults.	Most of the research relates to Euro-Americans with Christian ancestry and traditions. The evidence could be applied with some restrictions due to the pluralism of	1) Very high degree of consistency2) There is a general tendency for individuals to become more interested in spiritual interests and practices as they grow older. Religion and spirituality are among the most significant means for coping with the crises and problems of living and dying. Six categories of spiritual need: to help people clarify their centres of ultimate meanings, respond to those meanings through religious and spiritual actions and symbols, find and reframe memories and experiences linked with final meanings, transcend their losses and suffering, establish intimacy with God and others, and find hope. The most widely used instrument for both research and clinical evaluations of spirituality is the Spiritual

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
				the Australian society.	Well-Being Scale (SWB) (Paloutzian, 2003). Only a few research projects use the SWB in elderly people. Whenever spiritual issues emerge as a part of the diagnostic process, appropriate interventions or referrals ought to be provided or brought to the attention of those who need them. Not all spiritualities and religions, nor all denominations and sects within any specific religion, are equivalent to all others, and the same applies to spiritual interventions, some of which may do more harm than good. Studies with older adults suggest a predominantly positive relationship between well-being and spirituality/religiousness. At the end of life, the only healing possible may be spiritual: a biopsychosocial-spiritual model of healthcare is necessary to accommodate such an approach. Spiritual interventions should be patient-centered rather than caregiver-focused and they should be offered only with permission, respect and sensitivity. Service providers need to be aware of the diversity of concepts and definitions plus possible applications of findings about spirituality.
Musick MA et al (2000) Spirituality in physical health and aging. Journal of Adult Development, 7(2), 73–86.USA					
Discussion of the meanings of the terms religiosity and spirituality. Review of studies focusing on effect on health of religion and spirituality.	1) Narrative review.2) Focused on latest studies examining association between religion/spirituality and mortality, self-rated health, chronic health problems, functional health. Extensive review.	Potential benefits of clinical significance.	This US review relates to a broader age-group population & focuses mainly on Judeo-Christian religious	Some applicability.	1) Some inconsistency2) Most of the research on spirituality tends to employ measures based on traditional religious beliefs and practices. many positive and some negative associations have been found between religiosity and health outcomes such as mortality, self-rated health, cancer, and hypertension. Much research examines association rather than effect.

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
			orientations so it has some limited generalisability.		
Pearce MJ (2005) A critical review of the forms and value of religious coping among informal caregivers. Journal of Religion and Health, 44(1), 81–118. USA					
To review what is known about religious coping among informal carers	1) Systematic review 2) Thirty-two qualitative and quantitative studies included	Highly significant.	This US review relates to a broader age-group population & focuses mainly on Judeo-Christian religious orientation. However, it does discuss sub-groups of relevance in depth.	Highly applicable.	1) A very wide ranging paper that reports consistency in some areas and a lack of this in others. 2) i) Religious coping is the key construct most predictive of outcomes but is poorly measured and explored in existing research. (ii) Indications are that many carers use religious coping strategies (including when the care recipient has Alzheimer's disease and when they have cancer. Prayer is the most commonly reported strategy. Churches do not meet all needs. iii) Little work has tested the effectiveness of religious coping but depression is consistently related to this although church membership etc are not. Some indicators of religiousness are associated with positive psychological well being. iv) Religious coping is most often associated with reduced burden and with greater caregiving satisfaction. V) positive religious coping is associated with positive religious outcome (eg spiritual growth) & negative coping (eg blaming God) is associated with negative religious outcomes. vi) Use of religious coping seems to be related to age, gender, ethnicity, & illness severity. vii) The mechanism by which religious coping provides positive outcomes is largely unexplored.
Phillips I (2003) Infusing spirituality into geriatric health care: practical applications from the literature. Topics in Geriatric rehabilitation, 19(4), 249–56. USA					

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
Role of spirituality in geriatric health care and its practical application for rehabilitation, with examples from nursing, social work, occupational therapy and medicine.	1) Narrative review 2) Articles included in this review looked solely at spirituality and religion and its application into geriatric healthcare, mainly from a professional point of view. The literature search strategy was not identified. Definitions of spirituality and religion. Articles included research and discussion papers (55 references). No details provided about research methodologies.	Studies were looking at spirituality in the rehabilitation setting mainly from a professional point of view, not from the patients' point of view. 'To integrate spirituality into healthcare practice effectively, clinicians must cultivate their own evolving spirituality.'	Primarily literature from the USA. Aimed mainly at a geriatric population in the rehabilitation setting so generalisability is somewhat limited.	Much of this information is applicable in the Australian context.	1) Consistent 2) For effective long-term changes, the author makes suggestions on how to incorporate spirituality into healthcare, from the education curricula of the health care disciplines: 'acknowledging the importance of elderly clients' spirituality to their health and overall well-being; remaining open and attentive to clients' spiritual needs, regardless of our own personal beliefs; taking a spiritual history or performing a spiritual assessment, either as an open-ended discussion or using one of several existing scales when appropriate; engaging in active and reflective listening; enhancing communication through stories; providing environmental resources, especially time, space, and physical facilitation, for clients to engage in meaningful spiritual activities; identifying resources within the healthcare community for support; remaining flexible with regard to visits by family and others of significant relationship to the client.'
Pronk K (2005) Role of the doctor in relieving spiritual distress at the end of life. American Journal of Hospice Palliative Medicine, 22(6), 419–25.Australia					
What constitutes spiritual care, should it be part of palliative care, who should provide this care, what are the anticipated outcomes and how can spiritual distress be relieved?	1) Narrative review.2) Articles included in this review were reports of research studies with a variety of methodologies (not clearly articulated) - texts were also included (58 references).	Clinically useful information	Australian review focusing entirely on palliative care although mainly focuses on articles from the UK and USA. Not old age	Generally applicable.	1) No discussion on degree of consistency in this review.2) Agreement that everyone possesses spirituality — may or may not be expressed in a religious way. Spiritual care should be an integral part of and should focus on the patient dictating the pace and nature of care as everyone is at a different stage in their spirituality. Components of spiritual care include awareness of own spiritual dimension, establishing a trusting relationship, drawing on own life experience. Spiritual distress

Topics/aims of review article	Features of review (1) and volume of evidence (2)	Clinical impact of evidence	Generalisablility of evidence	Applicability of evidence	Degree of consistency (1) and key findings (2)
			specific.		may be relieved by fulfilling aspects of spiritual needs such as: worship, beliefs, rituals, customs, human relationships and life reviews, find meaning in suffering and transcendence.
Van Ness PH, Larson DB (2002) Religion, senescence and mental health. The American Journal of Geriatric Psychiatry, 10(4), 386–97. USA					
Examines the relationship between religiousness/spirituality and mental health in people at end of life, with attention to well-being, religious coping, cognitive dysfunction, anxiety, depression, and suicide. Also reviews the extent to which hope is a mediator of purported salutary effects of religiousness.	1) Narrative review 2) Epidemiological and survey research in the USA looking at elderly populations and mental health outcomes. No search terms listed and no number of studies included in the review. Almost all participants were Americans and from prophetic religions: Judaism, Christianity and Islam, whereby they believe that God intervenes in people's lives to cure illness. Definitions of religion, intrinsic & extrinsic religiosity, positive & negative religious coping (97 references).	In most reports of significant associations, these effect sizes associations were relatively small.	This US review did not target the aged population only and there would be cultural differences.	Some applicability.	1) Good consistency. 2) Religious persons reported generally higher levels of life satisfaction and other subjective measures of well-being. There were consistent inverse associations of religiousness with rates of depression and suicide. Religion's effects on mental health are generally protective in direction but modest in strength. Epidemiological studies portrays generally salutary effects of the impact of religiousness on the health of elderly (Americans). The reviewer asserts that religion contributes to a sense of well being that can help them cope with ill health and other issues in later life.

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Conflict of interest statements

Declaration of interests and potential conflict of interests:

Name	Consultant fees or involvement in evaluation of programs	Honoraria/fees for service	Advisory/ steering committee fees	Investigator initiated grants	Travel assistance	Employment
Associate Professor Christine Toye	Previously involved in the evaluation of services or programs provided by Amana Living, Alzheimer's Australia (WA), McCusker Training and Development, the Aged Care Association of Australia, and Aged Care Services (WA.)	None	None	Funding (in cash or in kind) received from Uniting Church Homes and Churches of Christ Homes and Community Care Inc.	None	Previously employed at: Homes of Peace (Inc)., Agmaroy Aged Care Facility, and a RAAFA aged care facility
Ms Jennifer Tieman	None	None	None	None	None	None
Associate Professor Lynn Oldham	None	None	None	None	None	None
Professor Jenny Abbey	None	Presentation fees received from Pfizer Australia and Mundipharma Pty Ltd. Payment from Alzheimer's Australia for a position paper.	None	Funding received from Eventide and Ashworth House Aged Care Facility, TPCH Foundation, Churches of Christ, Aged Care Queensland, and Kendron Wavell Services Club (for Chair of Nursing, Aged Care)	None	None
Professor David Currow	None	None	None	None	None	None
Ms Meg Hegarty	None	None	None	None	None	None
Professor Linda	None	None	None	None	None	None

Name	Consultant fees or involvement in evaluation of programs	Honoraria/fees for service	Advisory/ steering committee fees	Investigator initiated grants	Travel assistance	Employment
Kristjanson						
Dr Ruth McConigley	None	None	None	None	None	Previously employed by the Silver Chain Organisation
Dr Jeremy Drake	None	None	None	None	None	None.
Ms Kristi Holloway	None	None	None	None	None	Employed by the Hall and Prior Aged Care Organisation
Mr Jeff Fiebig	None	None	None	None	None	Employed by the ACH Group and the Italian Benevolent Foundation
Mr Paul Heath	None	None	None	None	None	None
Ms Billy-Jo Reed	None	None	None	None	None	None
Ms Kate Sullivan	None	None	None	None	None	None
A/Prof Moira Sim	None	None	None	None	None	None
Ms Helen Walker	None	None	None	None	None	None
Mr Grant Martin	None	None	None	None	None	None
Ms Catherine Reid	None	None	None	None	None	None
Mr Gordon Gregory	None	None	None	None	None	None
Dr Gill Lewin	None	None	None	None	None	Employed by the Silver Chain Organisation
Dr Jeff Rowland	None	None	None	None	None	None
Dr Louise Welch	None	None	None	None	None	None
Mr Frank Schaper	None	None	None	None	None	None
Ms Meredith Gresham	None	None	None	None	None	Employed by the Hammond Care Group
Ms Shirley Lennon	None	None	None	None	None	None
Ms Dee Penna	None	None	None	None	None	None

Name	Consultant fees or involvement in evaluation of programs	Honoraria/fees for service	Advisory/ steering committee fees	Investigator initiated grants	Travel assistance	Employment
Dr Kay Sorimachi	None	None	None	None	None	None
Dr Victor Chan	None	None	None	None	None	None
Ms Phyl Crawford	None	None	None	None	None	None