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**Role of domiciliary and family carers in individualised nutrition support for older adults living in the community**

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**Abstract**

Protein-energy malnutrition is common amongst people aged 65 years and older, has a multifactorial aetiology, and numerous negative outcomes. Domiciliary carers (non-clinical paid carers) and family carers (including friends and neighbours) are required to support the increasing demand for in-home assistance with activities of daily living due to the ageing population. This review provides insight into the role of both domiciliary and family carers in providing individualised nutrition support of older, community-dwelling adults with malnutrition. Four electronic databases were searched for intervention studies from database inception to December 2016. Both domiciliary and family carers are well-placed to monitor the dietary intake and nutritional status of older adults; assist with many food-related tasks such as the sourcing and preparation of meals, assisting with feeding when necessary; and to act as a conduit between the care-recipient and formal nutrition professionals such as dietitians. There is moderate evidence to support the role of domiciliary carers in implementing nutrition screening and referral pathways, and emerging evidence suggests they may have a role in malnutrition interventions when supported by health professionals. Moderate evidence also supports the engagement of family carers as part of the nutrition care team for older adults with malnutrition. Interventions such as group education, skill-development workshops and telehealth demonstrate promise and have significantly improved outcomes in older adults with dementia. Further interventional and translational research is required to demonstrate the efficacy of engaging with domiciliary and family carers of older adults in the general community.

**Keywords:** Caregivers, homecare services, aged, independent living, nutritional support, protein-energy malnutrition

**Words:** 2,705

**1.0 Introduction: The ageing landscape is changing**

Between 1970 and 2025, the worldwide population growth of persons ≥60 years is expected to increase by 223%, or 694 million, making it the fastest growing age group [1]. Whilst population ageing is considered a triumph for humanity, it also presents some of the greatest challenges to economic and social systems around the world [1]. According to the World Health Organisation, "active ageing" policies and programmes to enhance the health and independence of older adults are necessary to manage the challenges of an ageing population [1]. Changing patterns of disease, increased service demands and shift in expectations of services provided by social, aged and health sectors has necessitated a move towards utilising non-clinical personnel (domiciliary carers); assisting and supporting family carers in their caring roles [2]; and preventing and managing chronic diseases such as malnutrition in older adults [3].

1.1 The emergence of domiciliary carers as the predominant aged and community care providers

One of the earliest observed changes in the delivery of social and community aged care is the rise in popularity of non-clinical personnel (also known as "personal carers" or "community care assistants", herein referred to as "domiciliary carers") [2, 4, 5]. In 2012, domiciliary carers accounted for 64% of the Australian aged care workforce [2] and 76% of social care positions in the United Kingdom [4]. Domiciliary carers may or may not hold trade certificates in aged care, and there is no requirement for clinical, health or medical training to undertake this role [6]. Emergence of domiciliary carers as the predominant social and community aged care providers is due to: workforce pressures; increasing consumer choice and decision-making; and the lower cost of domiciliary workers compared with health professionals such as community nurses [2, 5, 7, 8].

1.2 Family care networks are a critical source of support for ageing communities

Adult children, in particular daughters aged in their 50s and 60s, are the most common type of family carer (also known as informal carers) to older adults; however, family carers may also be spouses, other family members, friends or neighbours [9]. The ratio of family carers to older adults requiring care has reduced in recent years, particularly in Europe, North America, Oceania, and Japan, due to the increasing age of first time mothers and the greater number of single person households, and this downward trend is projected to continue until the end of this century [10-13]. The proportion of Australians involved in caring for an older adult or person with disability declined from 13% in 2003 to 12% in 2009 [11]. This trend will have

implications for social, community and aged care demand and health discharge support services, especially in regards to the increased costs required to provide services. In Australia, it is estimated that if all hours of informal care were replaced by in-home social and aged care services, it would make up 3.2% of gross domestic product (GDP) [2]. As family carers provide substantial support for their older care-recipient, their influence on the nutrition-related health outcomes must be considered in addition to the care provided by health and aged care services [14].

1.3 Malnutrition in older adults

Protein-energy malnutrition (herein referred to as "malnutrition") in older people is characterised by involuntary weight loss and muscle wasting secondary to inadequate dietary intake of protein and/or energy [15, 16]. The substantial number of malnourished older adults (3 – 9% prevalence in the community setting [17]) reflects its complex and multifactorial aetiology in older adults, attributable to physiological, psychological, sociological and/or economic factors [18, 19]. Malnutrition is associated with significant adverse consequences including depression, increased risk of falls, frequent and prolonged hospital admissions, reduced independence with activities of daily living, decreased quality of life, and increased risk of death [20-22]. Despite this, evidence indicates that malnutrition is under-recognised, under-diagnosed and therefore likely under-managed in the community [23], resulting in a significant strain on health care resources [24].

The role of domiciliary and family carers in supporting malnourished older adults in community settings is of high interest due to their potential influence upon the dietary intake of older adults. Therefore, this narrative review aims to discuss the role that domiciliary and family carers have in the nutritional support of older adults living in the community. PubMed, CINAHL, Web of Science and Embase were searched using keywords from database inception to December 2016 for published English language studies. The search strategy was (carer or caregiver or family or domiciliary or home care* or community care*) AND (aged or ageing or aging or senior or elderly or older or geriatric) AND (malnutrition or malnourished or undernutrition or undernourished).

**2.0 Results: the role and benefits of domiciliary and family carers in providing nutrition support to older adults living at home**

Sixteen intervention studies were identified which engaged with domiciliary or family carers of older adults living at home, of which nine were included in a 2013 systematic literature review [8].

2.1 The role of domiciliary carers in managing malnutrition in the community

Domiciliary carers assist their care-recipients through domestic aid, personal care, and respite for family carers [25]. As directed by care plans, domiciliary carers are frequently responsible for the nutritional management of their care-recipients by monitoring weight, dietary intake, hydration status, and functional ability; may assist with shopping, preparing meals, eating, or actual feeding where necessary; and linking clients to services [26, 27]. Compared with other paid carers (such as community nurses or allied health professionals), domiciliary carers usually spend the largest amount of time with the care-recipients [2]. As they frequently enter the clients' home, domiciliary carers have unique insight into the client's environment, values, traditions and beliefs as well as their unidentified needs that would otherwise be missed in conventional inpatient or outpatient health care. This suggests that domiciliary carers are well placed to conduct nutrition screening, monitoring and assist in developing and delivering individualised nutrition intervention within the larger social and aged care system.

Despite the great opportunity for extending domiciliary carers' scope of practice into nutrition support, interventional research has been limited [8]. This literature review identified four intervention studies focusing on nutrition screening and/or intervention programs delivered by domiciliary carers, nutrition assistants or peer volunteers (Table 1). The Australian study by Leggo et. al. [28] suggests that domiciliary carers may have an important role in implementing nutrition screening tools (determining risk of malnutrition) and making referrals to dietitians. Three studies involved domiciliary carers (or peer volunteers) in the delivery of nutrition intervention [29-33]; however, only Luger et. al. [32, 33] found clinically and statistically significant improvements in the care-recipient outcomes (Mini Nutritional Assessment score). La Forest et al. [31] reported high care-recipient and peer-volunteer satisfaction with the interventions; however, it should be noted that peer-volunteers indicated that they were not comfortable giving the intervention without the assistance of a dietitian.

2.2 The role of family carers in managing malnutrition in the community

The impact that family carers have on the health-related outcomes of their care-recipients has been widely examined [14]. A report by Carers UK states that 60% of family carers worried

about the nutrition of their care-recipient [34]; however, studies suggest that the nutrition knowledge of family carers is often sub-optimal [36,38,39]. Nutritional approaches used by family carers may inappropriately focus on a diet high in fruits and vegetables, as opposed to the evidence-based approach of providing a diet high in protein and energy [35]. Furthermore, a direct causal link has been identified between poor nutrition knowledge of family carers and increased malnutrition risk in their care-recipient [38], highlighting the need to ensure that family carers receive support in relation to food and nutrition.

Like domiciliary carers, it is proposed that family carers may be effective in managing malnutrition in older adults due to not only their increased access and time spent with the care-recipient, but also their greater knowledge of individual preferences and psychological and behavioural processes [15]. This may allow nutritional support strategies to be highly individualised and easily adapted to small changes in the care-recipient, which may not be otherwise noticed or reported to health professionals. Marshall et. al. [35] found that some carers held a belief that rehabilitation support services (rehabilitation dietitian and food service staff) would be unable to assist their care-recipient due to an inadequate knowledge of the individual. This has important implications for practice, and suggests that engaging the family carers as part of the nutrition care team will increase the individualised nature of nutrition interventions and may result in improved patient and carer outcomes.

### 2.2.1 Evidence for family carer nutrition interventions in older adults living at home with dementia

Three studies were identified in which health professionals other than dietitians provided nutrition education and skill development training to family carers of older adults with dementia [36-38]. However, in each of these intervention studies, nutrition was a minor component of a larger intervention and the nutrition-related intervention components were not well described. While these interventions were successful in improving family carer outcomes such as quality of life [36] and nutrition knowledge [38]; nutritional outcomes of the care-recipient was not measured [36-38]. Additionally, these studies found no significant differences between the intervention and control groups for malnutrition-related outcomes, such as functional decline, admission to nursing homes, health care utilisation or mortality [36-38].

There were four studies in which a dietitian or nutritionist designed and delivered a nutrition intervention to family carers of older adults with dementia (Table 2) [39-42]. Although the

intervention was not described in one study [39], most were implemented over a period of 12 months and consisted of comprehensive and broad strategies including small group education, weight monitoring support, telehealth and written education materials. Overall, the interventions were successful in improving nutrition status, dietary protein intake, health-related quality of life and falls incidence of the older care-recipients with dementia at six or 12-months follow-up [39-44]. While the study by Lauque et al. [39] aimed to evaluate the effectiveness of oral nutritional supplementation, the control group involved family carers as part of usual care, and engagement and uptake by the family carers was such that it resulted in improved protein and energy intake in the control group as well as a clinically and statistically significant improvement in the nutrition status of the care recipient (MNA score increased by 2.46±4.21, *P*=0.001).

### 2.2.2 Evidence for family carer nutrition interventions in older adults living at home with cancer

In two RCTs with similar interventions reported by Hendrix et al. in 2011 [45] and 2016 [46], nurses provided family carers of older cancer patients with practical skill training, including addressing nutritional risk, at bedside prior to discharge. The interventions were able to improve the short-term self-efficacy of family carers; however, outcomes were not sustained at 4-weeks post-discharge. Additionally, patient symptoms did not improve [45]. As the care-recipients in the study by Hopkinson et al. [47] were older people with terminal cancer, improvements in clinical outcomes were not expected nor measured; however, the intervention resulted in a large decrease in weight-related carer distress [47] which can be of great importance to the carers.

### 2.2.3 Evidence for family carer nutrition interventions in older adults living at home with no specific disease or condition

Malnutrition intervention studies involving family carers in the general older adult community have not specifically focussed on malnutrition nor measured nutrition status as an outcome in the care-recipients (Table 2). The RCT conducted by Toseland et. al. [48, 49], which demonstrated some benefits in family carer and care-recipients' mental health, was the first to measure and demonstrate the cost-efficacy of family carer education and support. The study reported Masud Rana et. al. [50] was also unique compared to other identified studies by utilising a community-wide approach, including the delivery of health education through theatre productions and community celebrations, in addition to small group education. However, the only nutrition advice included was "healthy eating" through the recommending

the avoidance of foods high in salt, sugar and fat [50]. Although health-related quality of life improved, this nutrition approach is incongruous with an evidence-based approach for managing malnutrition [23].

<u>2.3 Impacts of carer burden upon the health and wellbeing of both the family carer and older adult care-recipient</u>

Carer burden is recognised as a significant problem for family carers and has been linked to their caregiving efficacy and care-recipient outcomes [51]. Despite significant intervention with family carers in studies by Riviere et. al. [41] and Salva et. al. [40], there was no increase in carer burden. Qualitative research has suggested that this phenomenon may be explained by family carers already assuming responsibility for nutrition support and that engaging family carers in formal support did not increase their burden but rather helped their strategies to be more effective [35]. As the availability of family carers decreases, it is important that family carers are supported by formal health, aged and social services so that both the carer themselves and the care-recipient may have improved outcomes, or at least a prevention of decline.

## 3.0 Discussion: Implications for practice and further research

There is moderate evidence to support the role of domiciliary carers in implementing malnutrition screening and referral pathways [28], which may be an effective and cost-efficient strategy to managing malnutrition in community-dwelling older adults. Nutrition screening by domiciliary carers may improve patient outcomes across communities [28], supposing dietetic resources were available to provided training to carers and deliver individualised nutrition intervention to clients identified as at nutritional risk.

Although there are no studies of malnutrition interventions delivered by paid domiciliary carers, the evidence provided by Laforest et al. [31] and Luger et. al. [32] suggests that such interventions may be feasible, acceptable and effective. However, further high quality intervention evidence is needed before social and community aged care agencies can realise an extension in the scope of practice for domiciliary carers to include malnutrition interventions without referral to a dietitian. Additionally, methods of quality control and the care delivery benchmarks will need to be determined, as will the benefits and limitations of such models of care by social and community aged care agencies.

There is moderate evidence that proactive engagement of family carers as part of the nutrition care team is effective in preventing and treating risk of malnutrition in older adults with dementia living at home [39-43]. Interventions for family carers of older adults living at home

with dementia may be more effective when a dietitian is included as key part of the multidisciplinary health care team. Effective interventions were long-term and comprehensive, with a range of support strategies including small group education, written educational materials, telehealth and included practical skill building in food provision and weight monitoring. Studies supporting family carers of older adults with cancer have demonstrated important improvements in carer outcomes; however, studies are needed to determine the effect of such interventions on the outcomes of the care-recipient.

Despite growing interest in engaging family carers to address malnutrition in older adults living in the community, evidence has only demonstrated clinical benefits in older care-recipients with dementia. To support translation to practice and demonstrate feasibility of interventions which engage domiciliary and family carers for community-dwelling older adults in general or with other conditions, intervention studies should evaluate clinical outcomes in the care-recipient and the economic impact these interventions may have across health, social and community aged care sectors.

## 4.0 Conclusions

Domiciliary and family carers are well-placed to conduct weight monitoring and nutrition screening of older adults, sourcing and preparing of meals, offering assistance with feeding, and acting as a conduit between their older care-recipient and formal nutrition support staff such as dietitians. Emerging evidence demonstrates that expanding the knowledge and role of domiciliary and family carers in the nutritional management of community-dwelling older adults may improve health-related outcomes in the care-recipient. However, further interventional and translational research is required to before community care organisations may extend the scope of practice for domiciliary carers, and to demonstrate the efficacy of family carers in older adults in the general community as opposed to high-risk groups only.

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**Table 1:** Details of nutrition interventions involving domiciliary carers, peer volunteers and paid nutrition assistants to improve nutrition-related outcomes in community-dwelling older adults

| Study | Study & sample | Intervention purpose and delivery | Intervention components | Outcomes | |
|---|---|---|---|---|---|
| Hyland, et. al. 2006 [29,30] | · UK<br>· Cluster RCT<br>· n=97 care-recipients: μ76y; 14% male.<br>· n=22 peer nutrition assistants: age not described beyond >60y; 18% male. | · **Aim**: To improve nutrition knowledge in older adults.<br>· **Duration**: Two hours each week for 20 weeks.<br>· **Setting**: Communal area of sheltered accommodation area. | **Control:** Not described.<br>**Peer-Led Food Club intervention**: Designed by dietitian and home economist, implemented by nutrition assistants. Focused on 1) practical food preparation; 2) healthier eating; 3) social engagement centred on food; 4) recipe book. | **Care-recipients**: At 1 y post-baseline:<br>· Carbohydrate (percent of energy intake) increased in the IG (+2.4% of energy).<br>· Vitamin D decreased in IG and increased in CG (no data presented).<br>· No significant results: fruit intake, energy intake, overweight/obesity prevalence, food safety knowledge, nutrition knowledge. | **Peer nutrition assistants:** During and post-training and post-intervention:<br>· Three qualitative interviews found the program a positive experience (n=17 nutrition assistants interviewed). |
| Laforest, et. al. 2007 [31] | · Canada<br>· Pilot case-series: post-test.<br>· n=35 care-recipients: μ82.5±7.5y; 14% male.<br>· n=15 peer volunteers: age not described beyond >65y; 0.1% male. | · **Aim**: To identify and manage malnutrition risk.<br>· **Duration**: Three visits over six weeks.<br>· **Setting**: Home visits. | **Pre-intervention:** Not described.<br>**Nutrition education intervention:** Dietitians provided training to volunteers. Volunteers conducted: 1) malnutrition screening; 2) one-on-one nutrition education; 3) development of nutrition intervention (also involving dietitian and case manager); 4) assistance with eating (if needed); 5) linking with services; 6) follow-up of nutrition intervention. | **Care-recipients**: At 6wks post-baseline:<br>· Satisfaction with the intervention was high (83% found volunteers knowledgeable; 90% appreciated efforts of the volunteers; 86% satisfied with length of contact). | **Peer volunteers**: At 6wks post-baseline:<br>· Satisfaction with the intervention was high (85% had positive perception of intervention; 89% had no difficulty using ENS or giving the intervention).<br>· 73% said they would not feel comfortable offering intervention without dietitian assistance. |

| Leggo, et. al. 2008 [28] | · Australia<br>· Case series: pre-test/post-test<br>· n=1145 care-recipients: μ76.5±9.2y; 31% male.<br>· n=16 HACC[a] agencies (data not provided on individual HACC providers). | · **Aim**: To identify and treat malnourished clients.<br>· **Duration**: Nutrition screening was over a period of 2y (unknown if screening was repeated for individuals). Dietetic interventions were provided for a median of 6 months.<br>· **Setting**: Home visits. | **Pre-intervention**: Home care with no nutrition screening nor dietetic referral. No control group.<br>**Improving Nutrition For Older (INFO) persons in the community intervention**: Dietitian trained HACC providers in undertaking malnutrition screening and dietetic referrals. Dietitians then provided one-on-one malnutrition intervention (individualized MNT). | **Care-recipients**: During the 2y screening program:<br>· 14.8% of care-recipients at risk of malnutrition (MST score≥2); of which 75 (44%) agreed to dietetic referral.<br>· 34 (45% of those referred to the dietitian) malnourished care-recipients were provided with an intervention by the dietitian.<br>· Nutrition status (PG-SGA rating) increased (82% improved rating category following intervention and 50% became well-nourished). | **HACC Providers:** Nil measured. |
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| Luger et. al. 2016 [32,33] | · Austria<br>· RCT<br>· n=80 care-recipients: μ83y. Gender not available.<br>· n=80 peer volunteers termed "Buddies". Age and gender not available. | · **Aim**: To obtain adequate protein, energy and other nutrient intakes, preferably by regular foods and beverages.<br>· **Duration**: One hour bi-weekly visits for 12 weeks.<br>· **Setting**: Home visits (following hospital discharge). | **Control:** Visited twice per week by buddies but do not monitor nutritional status nor perform physical training. Are provided instead with cognitive training activities.<br>**Nutrition and physical activity intervention**: Buddies were trained by a doctor and sports and nutrition scientists, and provided one-on-one individualised intervention: 1) strength exercises; 2) problem-solving nutrition related discussions; 3) written educational material; 4) recipes; 5) nutrition play board with food cards. | **Care-recipients**: Compared with baseline, at 12wks post-baseline:<br>· Nutrition status (MNA score) increased in the IG (μ change 1.54 [95%CI: 0.51-2.56]; P=0.004)<br>· Prevalence of impaired nutritional status (MNA score <24) decreased in IG (-25%) and CG (23%). | **Peer volunteers**: Nil measured. |

CG, control group; ENS, Elderly Nutrition Screening Tool; HACC, Home and Community Care; MNT, medical nutrition therapy; MST, Malnutrition Screening Tool; PG-SGA, Patient-Generated Subjective Global Assessment; RCT, randomised controlled trial; wks, weeks; y, years.

a. HACC was a government-funded low-intensity home care package for eligible home-dwelling older adults (and younger adults with disability) including access to domiciliary carers to assist with basic activities of daily living [52].

**Table 2:** Details and results of nutrition interventions which involved the family carer of community-dwelling older adults at risk of malnutrition or malnourished.

| Study | Study & sample | Intervention purpose and delivery | Intervention components | Outcomes | |
|-------|----------------|-----------------------------------|-------------------------|----------|---|
| **Interventions designed or delivered by dietitians to family carers of community-dwelling older adults with dementia** | | | | | |
| Riviere, et al. 2001 [41] | · France and Spain<br>· Controlled before-and-after study.<br>· n=225 care-recipients; µ75.4-77.3±7.9-8.2y; 29% male.<br>· n=225[a] family carers; µ60.5-64.8±12.9-13.1y; gender not reported. | · **Aim**: To identify older adults at nutritional risk and intervene.<br>· **Duration**: Nine 1hr small group education sessions over12-months. Written materials provided during first session.<br>· **Setting**: Small group education at unknown location. Telehealth access via family carers' homes. | **Control:** Usual care and clinical evaluation routinely provided to families and patients in a normal follow-up at a day hospital.<br>**Nutrition education intervention:** Dietitians & other health professionals (not further described) delivered program to family carers. Program included: 1) small group education presentations (n=9), with a focus on enriching food and how to combat eating behaviour disorders; 2) support in weight monitoring; 3) written education materials; 4) telehealth access. | **Care-recipients:** At 6-months follow-up:<br>· ADL (ADL score) in the IG was improved compared to the CG (µ change -0.3±0.1 versus -0.7±0.1; P<0.05).<br>At 12-months follow-up:<br>· Nutrition status (MNA score) in the IG was improved compared to the CG (µ change 0.3±2.6 versus -1.0±3.4; P<0.005).<br>· Weight was improved in the IG compared to the CG (µ change 0.7±3.6kg versus -0.7±5.4kg; P<0.05)[b]. | **Family carers:** Compared with baseline, at 12-months follow-up:<br>· Nutrition knowledge (questionnaire score) increased significantly in IG compared with CG (µ difference1.7±5.9; P<0.005).<br>· No significant results: caregiver burden. |

| Lauque, et. al. 2004 [39] | · France<br>· RCT<br>· n=91 care-recipients: µ79y (range 65-92y); gender not reported.<br>· Family carers not described. | · **Aim**: To prevent and treat malnutrition.<br>· **Duration**: Usual care not described[c]. Intervention group were supplemented for three months.<br>· **Setting**: Geriatric wards and community day care centres; home visits for dietitian follow-up. | **Control**[c]: Dietitians provided education to family carers regarding nutrition and monitoring. Not further described.<br>**Intervention:** Prescription of oral nutritional supplements (300-500kcal/day). Dietitian provided home visits to control ONS distribution and intake. | **Care-recipients in control group:** Compared with baseline, at 6-months follow-up:<br>· Nutrition status (MNA score) improved (µ change 2.46±4.21; P<0.001).<br>· Energy (kcal/kg) and protein (g/kg) intake improved (µ change 2.93±8.82kcal and µ change 0.19±0.48g/day; P<0.05).<br>· Functional status (Katz ADL score) declined (µ change -0.60±1.24 P<0.05).<br>· No significant results: body weight change, hospitalizations, pressure ulcers, fractures, serum albumin, serum C-reactive protein or fat free mass. | **Family carers:** Nil measured. |
| Salva, et al. 2011 [40] | · Spain<br>· Cluster RCT<br>· n=946 care-recipients: µ79.0±7.3y; 32% male.<br>· n=946a family carers[d]: µ58-62±13-14y; gender not described. | · **Aim**: To improve the functional and nutritional status of patients with dementia living at home.<br>· **Duration**: Unclear. There was 12-month follow-up for outcome assessment, intervention aspects may have been available up until this point.<br>· **Setting**: Physician's rooms, small group | **Control:** usual care, not further described.<br>**NutriAlz Intervention**: Dietitians delivered program to physicians and family carers. Program included1) written educational material, hotline/telehealth access, program newsletter; 2) family and carers to attend small group education presentations (n=4); 3) support in weight monitoring; 4) voluntary register for carers for further information; 5) action protocols and decision trees related to malnutrition for professionals. | **Care-recipients**: Compared with baseline, at 12-months follow-up:<br>· Nutrition status (MNA score) improved in the IG compared with the CG (µ change 0.46, 95% CI: 0.09-0.83 versus µ-0.66, 95% CI: -0.8- -0.21; P<0.028).<br>· No significant results: body weight change, functional status (Katz ADL and IADL Lawton score) and BMI. | **Family carers:** Compared with baseline, at 12-months follow-up:<br>· No significant change in caregiver burden (Zarit score). |

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| | | education at unknown location. Mail and telehealth access via family carers' homes. | | | |
| Suominen et. al. 2015 [42-44] | · Finland<br>· RCT<br>· n=101 care-recipients: μ77.4±5.6y; 69% males.<br>· Family carers: μ75.2±7.0; 31% male. | · **Aim**: To correct possible nutrient inadequacies<br>· **Duration**: Four – eight home visits over 12 months, depending on need.<br>· **Setting**: MNT counselling provided in family carers' homes. Group meeting at unknown location. | **Control:** Written educational material regarding nutrition in older adults and usual community care.<br>**NuAD Intervention:** Nutritionist[c] delivered: 1) individualised MNT based on nutritional deficiencies identified via food diary and MNA. ONS was prescribed 1/day if food intake alone insufficient; 2) written educational materials on eating and exercise; 3) vitamin D supplement; 4) group meeting with family carers to discuss nutrition issues and food examples. | **Care-recipients**: Compared with baseline, at 12-months follow-up:<br>· HRQoL (15D score) improved in the IG compared with the CG (μ change 0.0006 [95%CI: -0.016-0.028] versus μ0.036 [95%CI: -0.059-0.013; P=0.007).<br>· Falls declined in the IG compared with the CG (0.55 falls/person/y [95%CI: 0.34-0.83] versus 1.39/person/y [95%CI: 2.16-6.46]; P<0.001).<br>· Protein (g/kg) intake improved in the IG compared with the CG (μ change 0.05g [95%CI: -0.06-0.15] versus μ-0.06g [95%CI:-0.12-0.02]; P=0.03).<br>· Calcium (mg/day) intake improved in IG compared with CG (μ change 85 [95%CI: -24-194] versus μ-17 [95%CI: -98-65; P<0.03).<br>· No significant results: other nutrient intakes (energy, vitamins, minerals), body weight change, BMI change. | **Family carers**: Nil measured. |
| **Interventions involving family carers of community-dwelling older adults with cancer** | | | | | |

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| Hendrix et al. 2011 [45] | · USA<br>· RCT<br>· n=119 care-recipients: >50y; 23% ≥70y; 71% male.<br>· n=120 family carers: 85% >45y; 17% male. | · **Aim**: To manage cancer symptoms and caregiver self-efficacy.<br>· **Duration**: One or two sessions, totaling 2-3hrs<br>· **Setting**: At bedside, prior to discharge from an oncology unit. | **Control**: Interactive training regarding local community services; delivered by a nurse.<br>**Caregiver-Training intervention:** A nurse delivered training to family carers which involved: 1) interactive and technical skill training in patient symptom management including nutrition (problem assessment, maintaining or increasing caloric intake; oral care, tube feeding, bowel management); 2) written educational material on both symptom and stress management. | **Care-recipient**: At 4wks post-discharge follow-up:<br>· No significant results in: patient symptoms. | **Family carers**: At 4wks post-discharge follow-up:<br>· No significant results in: self-efficacy, depression, anxiety, quality of life. |
| Hopkinson et al. 2013 [47] | · UK<br>· Historically-controlled before-and-after study.<br>· n=34 care-recipients: age and gender not described.<br>· n=26 family carers: µ66y (33-84y); 0.8% male. | · **Aim**: Improving carer experiences and addressing carer emotional needs.<br>· **Duration**: One session of unknown length.<br>· **Setting**: home visit. | **Control:** Variable support offered by nurses; patients and family carers received supportive care for weight, eating and other problems.<br>**Macmillan Approach to Weight and Eating intervention:** A nurse delivered training to patients and family carers which included: 1) discussions regarding weight, food and eating in those who are terminal; 2) written educational material regarding topics discussed. | **Care-recipients**: Nil measured. | **Family carers**: Compared with baseline, at 5d post-intervention:<br>· Weight-related distress (VAS scale) improved in the IG but not in the CG (median change 7.5 [IQR:0-10] versus 0 [IQR:-6.3-22.5]; P=0.02).<br>· No significant change: eating-related distress. |
| Hendrix et al. 2016 [46] | · USA<br>· RCT<br>· n=138 care-recipients: | · **Aim**: To manage cancer symptoms and caregiver stress.<br>· **Duration**: One or two sessions, totaling 1-2hrs. | **Control**: Interactive training regarding local community services; delivered by a social worker or nurse.<br>**Enhanced Caregiver-Training intervention:** A nurse delivered training to family carers which | **Care-recipient**: Nil measured. | **Family carers**: At 4wks post-discharge follow-up:<br>· No significant results in: preparedness for caregiving, anxiety depression, caregiver |

| | | | | Care-recipient | Family carers |
|---|---|---|---|---|---|
| | μ57.0±15.1y; 64% male.<br>· n=138 family carers: μ55.3±13.2y; 17% male. | · **Setting**: At bedside, one week prior to discharge from an oncology unit. | involved: 1) interactive and technical skill training in patient symptom management including nutrition (maintaining or increasing caloric intake; managing constipation and/or diarrhoea); 2) skill training in caregiver stress management using a behavioural rehearsal procedure; 3) written educational material on both symptom and stress management. | | burden, health literacy, self-efficacy, coping with stress. |

**Interventions involving family carers of community-dwelling older adults with no specific disease**

| Toseland, et. al. 2004 [48,49] | · USA<br>· RCT<br>· n=105 care-recipients: μ72.5-72.8y; 66-72% male.<br>· n=104 family carers: μ68.7-69.9y; 29-33% male. | · **Aim**: To support and education spousal caregivers of frail older adults.<br>· **Duration**: Eight 2hr weekly sessions followed by 10 2hr monthly sessions (12-month total intervention).<br>· **Delivery**: Small group education at a health organisation (outpatient). | **Control:** Usual care provided by the health organization, including medical, social or psychological support services.<br>**Health education intervention:** A social worker delivered emotion and problem-focused education to spousal family carers of patients with a chronic disease regarding: 1) coping strategies; 2) education on support services and health; 3) support. The fifth monthly meeting focused on nutrition (focus on sugar and carbohydrate) for both carer and care recipient. | **Care-recipient:** At 12-months post-baseline:<br>· Anxiety of physical symptoms (GHQ-somatic symptoms scale) increased in IG (μ0.12±0.18 versus μ0.14±0.21) to a lesser degree than in the CG (μ0.05±0.11 versus μ0.20±0.25) (P<0.01).<br>· Perceived mental health status (MOS SF-36 scale) declined in the IG (μ-2.7±0.1 versus μ-2.5±0.1) and CG (μ-2.7±0.2 versus μ-2.6±0.2) (P<0.0001).<br>At 2y post-baseline:<br>· Total health costs increased to a lesser extent in the IG compared with CG ($USD4,342 less per care-recipient in IG than care-recipient in CG over two years). | **Family carers**: At 12-months post-baseline,<br>· Mental health (GHQ severe depression scale) decreased in the IG (μ0.08±0.2 versus μ0.05±0.15) but increased in the CG (μ0.02±0.09 versus μ0.06-0.15) (P<0.05).<br>· Caregiver burden (Montgomery-Borgotta Burden scale) had a greater decrease in the IG (μ16.0±4.2 versus μ13.7±4.7) than in the CG (μ16.5±4.1 versus μ15.7±4.1) (P<0.0001).<br>· Stress of problems (PPI scale) had a greater decrease in the IG (μ1.9±0.9 versus μ1.2±0.8) than in the CG |

| | | | | | (µ1.8±0.8 versus µ1.3±0.8) (P<0.0001). At 2y post-baseline: · Total health costs decreased to a greater extent in the IG compared with CG ($USD1,529 less per family carer in IG than carer in CG over two years). · No significant results: carer burden, mental health, self-perceived health status. |
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| Masud Rana, et. al. 2009 [50] | · Bangladesh<br>· Cluster RCT<br>· n=839 care-recipients: µ70.2-71.9±17.1-7.6y; 55% male.<br>· Family carer: sample size, age and gender not described. | · **Aim**: To improve health literacy and enhance health-related quality of life in older adults.<br>· **Duration**: 15-months<br>· **Setting**: Weekly counselling sessions, small group and self-help group meetings in villages, and workshops at offices. Social awareness on display in theatre, posters and leaflets. | **Control:** A district of Bangladesh with no intervention implemented.<br>**Health education intervention:** Education delivered by physicians and stakeholders (not further described) to older adults and their families regarding: 1) health care management; 2) health and social awareness; 3) health care. Education was related to illness and pain management, physical activity and nutrition advice to avoid foods high in salt, sugar or fat. | **Care-recipients:** at 3-months post-intervention:<br>· HRQoL (score) improved in compliant IG compared with both non-compliant IG and CG (µ change 0.6 versus -2.4 [P<0.01] and versus -4.0 [P<0.001]). | **Family carers:** Nil measured. |

ADL, activities of daily living; BMI, body mass index; CG, control group; g, grams; GHQ, General Health Questionnaire; HRQoL, health-related quality of life; hrs, hours; IADL, instrumental activities of daily living; IG, intervention group; kcal, kilocalories; kg, kilogram; MNA, Mini Nutritional Assessment; MNT, medical nutrition therapy; MOS SF-36, Medical Outcomes Study of the Short Form-36; ONS, oral nutrition

supplements; PPI, Pressing Problems Index; RCT, randomised controlled trial; UK, United Kingdom; USA, United States of America; VAS, visual analogue scale; wks, weeks; y, years.

a. Sample size of family carer not reported; assumed one family carer per care-recipient as "patient and their caregivers were recruited".

b. Weight was not significantly different between the control group and the intervention group at six nor 12-months follow-up after adjusting for baseline differences between groups.

c. Family carers only involved in intervention components in the control group; Therefore, results of the control group are of interest.

d. 6-9% of carers were paid carers.

e. Nutrition Scientist (Master of Science), qualified in Finland, but was not an accredited/registered dietitian.