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World Health Organization

Integrated care for older people (ICOPE)
Guidelines on community-level interventions to manage declines in intrinsic capacity

Evidence profile: caregiver support

Scoping question:

Does respite care or psychosocial support produce any benefit or harm for family caregivers of care-dependent older people?

The full ICOPE guidelines and complete set of evidence profiles are available at: who.int/publications/i/item/9789241550109

Painting: “Wet in Wet” by Gusta van der Meer. At 75 years of age, Gusta has an artistic style that is fresh, distinctive and vibrant. A long-time lover of art, she finds that dementia is no barrier to her artistic expression. Appreciated not just for her art but also for the support and encouragement she gives to other artists with dementia, Gusta participates in a weekly art class.

Contents

Background

Worldwide, 349 million people are estimated to be care-dependent, of whom 18 million (5%) are children aged under the age of 15 years, and 101 million (29%) are older people 60 years of age and over. Care-dependence is defined as the need for frequent human help or care beyond that habitually required by a healthy adult. In older people, coexisting chronic diseases (multimorbidity) is frequently associated with the need for health and social care *(1)*. In most countries, care for older people is provided by informal caregivers (including spouses, adult offspring and other relatives or friends), and the majority of primary caregivers are women *(2)*. Evidence shows that caregivers of people with severe declines in capacity are at high risk of experiencing psychological distress and depression *(3)*. In many low- and middle-income countries, formal systems of long-term care are poorly developed; the negative effects of caregiving therefore have a strong impact on the physical, emotional and economic status of family caregivers *(2)*.

In the past two decades, psychosocial interventions to support informal caregivers have been extensively studied. Psychosocial support includes different types of service provision, such as psychoeducational, counselling, skill-building and information or emotional support, which may be provided through agency-based settings or in the carer's home *(4)*. These interventions focus on improving the carer's ability to manage everyday caregiving tasks *(4)*. Furthermore, recent research has explored technology-based interventions, including the use of telephone and computer services, to provide adequate support and education to caregivers, with accessibility being a key advantage *(5)*. Another popular intervention is respite care, defined as the provision of a temporary break in caregiving activities for the informal carer aimed at reducing distress and improving the carer's well-being *(6)*. Respite can be delivered in different ways, including in-home services, adult day care or in institutions, such as care homes or hospices *(7)*. Evidence from earlier reviews suggest that most trials of caregiver interventions were from high-income countries and were largely dominated by a range of programmes and services developed to assist caregivers of people with dementia. Therefore, the effectiveness of these interventions in different social, cultural and geographical contexts is unclear *(2)*. Of all the chronic diseases, dementia is a particularly important contributor to caregiver strain. However, the extent to which these interventions can be administered to informal caregivers of care-dependent older people is unknown.

Part 1: Evidence review

Scoping question in PICO format (population, intervention, comparison, outcome)

Population

- Family caregivers (both male and female) of care-dependent older people of 60 years of age and over

Interventions

- Respite care
- Psychosocial support
- Technology-based interventions

Comparisons

- Usual or standard care
- Waiting list control
- Active control intervention

Outcomes

- *Critical:* Caregiver burden, caregiver depression, care recipients' symptoms
- *Important:* Well-being, ability/knowledge, quality of life, anger, anxiety

Search strategy

The search for studies using combined intervention terms was conducted on October 2015 in Ovid MEDLINE (see Annex 1). The Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Clinical Trials databases were searched, using combinations of the following terms:

("caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "caregiver"[All Fields]) AND support[All Fields]) OR respite[All Fields] OR (psychosocial[All Fields] AND interventions[All Fields])) AND interventions[All Fields] AND ("frail elderly"[MeSH Terms] OR ("frail"[All Fields] AND "elderly"[All Fields]) OR "frail elderly"[All Fields] OR ("frail"[All Fields] AND "older"[All Fields] AND "adults"[All Fields]) OR "frail older adults"[All Fields]) (caregiver support OR respite care OR psychosocial intervention) AND frail*.

List of systematic reviews identified by search

Included in GRADE[1] tables *(8–10)*

— Mason A, Weatherly H, Spilsbury K, Golder S, Arksey H, Adamson J et al. The effectiveness and cost-effectiveness of respite for caregivers of frail older people. J Am Geriatr Soc. 2007;55(2):290–9. doi:10.1111/j.1532-5415.2006.01037.x. [Review was updated by WHO in 2015].

— Shaw C, McNamara R, Abrams K, Cannings-John R, Hood K, Longo M et al. Systematic review of respite care in the frail elderly. Health Technol Assess. 2009;13(20):1–224, iii. doi:10.3310/hta13200. [Review was updated by WHO in 2015].

— Sorensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist. 2002;42(3):356–72. [Review was updated by WHO in 2015].

— Pinquart M, Sorensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? Int Psychogeriatr. 2006;18(4):577–95. doi: 10.1017/S1041610206003462. [Review updated by WHO in 2015].

Excluded from GRADE tables and footnotes *(12, 13)*

— Lopez-Hartmann M, Wens J, Verhoeven V, Remmen R. The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. Int J Integr Care. 2012;12:e133. (Reason: eligible studies included were cited in the included reviews)

— Cassie KM, Sanders S. Familial caregivers of older adults. J Gerontol Soc Work. 2008;50(Suppl 1):293–320. doi:10.1080/01634370802137975. (Reason: eligible studies included were cited in the included reviews)

[1] GRADE: Grading of Recommendations Assessment, Development and Evaluation. More information: http://gradeworkinggroup.org

PICO table

	Intervention/ comparison	Outcomes	Systematic reviews used for GRADE	Explanation
1	Respite care vs usual care or waiting list control	• Reduction in caregiver burden • Caregiver depression	Mason A, Weatherly H, Spilsbury K, Golder S, Arksey H, Adamson J et al. The effectiveness and cost-effectiveness of respite for caregivers of frail older people. J Am Geriatr Soc. 2007;55(2):290–9. *(8)* GRADE table 1	Systematic review relevant to the area
2	Respite care vs usual care or waiting list control	• Reduction in caregiver burden • Caregiver depression • Caregiver anxiety • Caregiver anger	Shaw C, McNamara R, Abrams K, Cannings-John R, Hood K, Longo M et al. Systematic review of respite care in the frail elderly. Health Technol Assess. 2009;13(20): 1–224. *(9)* GRADE table 2	Systematic review relevant to the area
3	Respite care vs no intervention Psychosocial interventions vs no intervention	• Reduction in caregiver burden • Caregiver depression • Subjective well-being • Ability/knowledge • Care recipients' symptoms	Sorensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist. 2002;42(3):356–72. *(10)* GRADE tables 3 to 7	Systematic review relevant to the area

Narrative description of the studies that went into analysis

Respite care and psychosocial interventions

GRADE table 1

Mason et al. conducted a systematic review and meta-analysis to examine the effectiveness and cost-effectiveness of respite care for caregivers of frail older people *(8)*. An extensive literature search was conducted and relevant studies were identified and assessed for methodological quality by two of the authors. A total of 22 studies were included: 10 randomized controlled trials (RCTs), seven quasi-experimental studies and five uncontrolled studies. Noticeably, even though the search was not restricted to a particular disease, most of the studies included older people with cognitive impairment exclusively (n = 13). Although physical impairment was also described as a common condition, it was inconsistently reported. Moreover, different types of respite care were covered across the different trials including adult day care, multidimensional packages, respite packages, in-home respite, host-family respite, institutional respite and video respite.

Caregiver burden and caregiver depression were the two main outcomes measured. Pooled estimates obtained from four RCTs and four quasi-experimental studies (N = 989) assessing respite package (n = 1), in-home respite (n = 2) and adult day care (n = 5) found no statistically significant effect of respite on caregiver burden (SMD: 0.15, 95% CI: -0.36 to 0.05). On the other hand, pooled estimates from one RCT and two quasi-experimental studies (N = 295) examining caregiver depression showed a statistically significant positive effect (SMD: 0.32, 95% CI: -0.62 to -0.02).This overall beneficial effect was attributed mainly to results in one trial on day care, however, which undermines the reliability of the pooled results.

The authors concluded that there is evidence suggesting that respite for caregivers of frail older people may have a small positive effect reducing caregiver depression and burden (although the latter effect was not significant when including RCTs in the analysis). They found no reliable evidence that respite care may delay institutionalization or may be more cost-effective than usual care. However, it should be noted that several limitations have been reported by the authors regarding the methodological quality of the studies and the variability of relative effects based on structural differences in the interventions provided.

GRADE table 2

Shaw et al. conducted a systematic review and meta-analysis to assess the effectiveness of respite care on the well-being of informal carers of frail and disabled older people living in the community *(9)*. An extensive search was conducted, including qualitative studies, and methodological quality was assessed by two authors independently. From a total of 104 quantitative studies selected, 16 were included in the meta-analysis (9 RCTs and quasi-experimental studies and seven longitudinal before-and-after studies). All the studies were conducted in high-income countries, the majority assessing day care and mixed respite care interventions, while some assessed in-home care and institutional care. Overall, care recipients included frail older people or older adults with dementia or experiencing mixed problems. Two RCTs and a quasi-experimental study assessing day care respite showed

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no significant effects of respite care on caregiver burden after a six-month follow-up period (SMD: 0.11, 95% CI: -0.38 to 0.17). However, even though studies were rated as moderate to high quality, sampling characteristics of one of the trials were not generalizable to the carer population and another study presented limitations as the uptake of respite was low in the sample. In addition, caregiver depression was assessed as a primary outcome. Due to significant heterogeneity in the studies, random effect model results were used and these are presented in the GRADE tables. Authors found no significant results in favour of day care respite to address carer depression either at short-term (six months) or long-term follow-up (12 months) (SMD: -0.23, 95% CI: -0.49 to 0.03; and SMD: -0.08, 95% CI: -0.41 to 0.24, respectively). Although the overall quality of studies in this group was moderate, authors remarked that the low level of respite provision in two of the studies might explain the intervention's low impact.

Further analysis revealed no significant benefits of respite in terms of caregiver anxiety (SMD: 0.27, 95% CI: -0.28 to 0.82) and single-group studies indicated that carer's quality of life was worse after respite use. However, pooled estimates derived from one moderate-quality RCT and one quasi-experimental study providing day care showed that anger was significantly lower after three

supportive interventions, psychotherapy, respite care, training of care recipient and multicomponent interventions) and six outcome variables (carer's burden, depression, subjective well-being, ability/knowledge and care recipient's symptoms). The number of sessions of the interventions ranged from 1 to 180 (median = 8 sessions) with follow-up assessments conducted in only 22% of the cases after an average of seven months (SD = 5.1 months). The number of carers receiving interventions ranged from 4 to 2268 (mean = 24) with a mean age of 62.3 years for carers and a mean age of 77.3 years for care recipients. Nearly 60% of the studies explored group treatments, 22% individual interventions, 18% combined (group and individual) and in 1% this was not reported. Attrition rates varied from over 35% for respite care to 11.7% for psychotherapy trials. Moreover, almost 70% of the caregivers were female, near 77% of the carers lived with the care receiver and 50% were spouses. Noticeably, more than 60% of the studies included by the authors focused exclusively on caregivers for people with dementia. Also, most of the other heterogeneous samples included people with dementia along with people with other physical or mental disabilities/disorders. All of the studies were conducted in high-income countries.

When analysing the effect of the different interventions