

What interventions are effective to support home-based carers?

The question and the problem

Many people with disabilities require the assistance of other people in order to go about their daily lives. In high-income countries, home-based carers are professional or para-professional workers who provide assistance to people with disabilities, in their homes. They are often well-trained, and remunerated for their services. However, individuals with disabilities in many low- and middle-income countries (LMIC) predominantly live with their family, and receive home-based care from family members. There are some stresses associated with giving care to others, and these include burnout, compassion fatigue, and an array of emotional and social consequences related to the caring role. The carers, too, need care. This evidence brief summarises what we know about how to support home-based carers, taking into consideration that these people, in LMIC, are often untrained, unpaid family members of the person for whom they are caring.

Recommendations

- **Recommendation #1:** Supporting family members caring for a person with a disability needs to be foregrounded in policy, planning and programming for disability in LMIC.
- **Recommendation #2:** Evidence-based interventions to support home-based carers include psychosocial support such as counselling, but in LMIC, peer support groups and problem-solving interventions may be more feasible.
- **Recommendation #3:** Attention needs to be given to wider ecological interventions which enhance carers' capacity to provide care, including practical respite care services and social support.
- **Recommendation #4:** Enhanced access to training (possibly from community health workers, in LMIC) represents a potentially effective method of increasing carers' confidence in their ability to undertake practical aspects of home-based care.
- **Recommendation #5:** All family caregivers will not benefit from the same types of interventions. Targeting and tailoring are required if interventions are to work for individual families.

“There is clearly a significant impact [of caregiving burden] on caregivers with respect to their physical, psychological, and social wellbeing, and constraints on time and financial resources.”

[Thrush, 2014]

Challenges

Challenge #1: There is clearly a significant impact of caregiving burden on caregivers with respect to their physical, psychological, and social wellbeing, and constraints on time and financial resources.

- Globally, families with a disabled member are poorer than families without a disabled member. The activities of caring for a person with disability may further isolate caregivers, reduce their opportunities for employment, and lead to stress and emotional strain.

Challenge #2: Family carers of people with disabilities in LMIC require psychosocial support, yet the resources for professional counselling and support are limited.

- The literature from high-income settings shows that problem-solving interventions, cognitive restructuring, and other counselling techniques can be effective to improve coping and emotional wellbeing among professional and paraprofessional home-based carers.
- Yet, professional psychological human resources are limited in LMIC, and so alternative solutions for delivering these types of interventions need to be sought.

Challenge #3: Enabling environments need to be created for carers in LMIC, as systemic isolation and other forms of exclusion contribute to carer burden.

- The literature from LMIC is limited in respect to how much, how, and with what kinds of effect, respite care, cash transfers and other types of financial support, and social support interventions might contribute to the wellbeing and caring effectiveness of carers. Yet, it is apparent that the wider ecological environment in which the carer and the person for whom they are situated, plays a large role in coping.

Challenge #4: Family caregivers lack practical information about disability, and training in how to perform the practical aspects of care for their family member.

- Carers want clear, understandable information about their relative's condition and want to develop skills that enable them to manage in difficult situations and provide optimal care.
- Yet, it is unclear to what degree these carers interact with formal healthcare services in LMIC, and whether these services, or community-based resources, can be effectively leveraged to train and educate family carers, and whether this impacts on care quality, and the wellbeing of carers.

Challenge #5: A host of factors influence what supports are effective to improve wellbeing among carers of people with disabilities, and yet it is not clear how targeting of supportive interventions may work in LMIC.

- There are a number of personal and social variables that should be considered in determining the type of stress and the corresponding support needs of carers. Examples include the quality and nature of the relationship between carer and family member with a disability, their socio-economic status, and the extent of their social support network.
- Ideally, then, supportive interventions would take into account the specific needs and vulnerabilities of individual carers, and be targeted to provide different types of supports depending on carers' coping. However, this will require more research in LMIC, about which factors most influence carers coping, and which interventions should be delivered to whom, and on what basis.
- It may be that universally-delivered interventions should be provided to all carers, but that targeted, additional provision could be made for carers identified as more in need of support.

How did we find answers

We conducted a review of reviews, examining systematic, narrative, and other types of review evidence on the topic of supporting home-based carers for people with disabilities (including the frail and people with disabling illnesses). Forty-eight reviews were examined to arrive at the present evidence note. Four

reviews concerned LMIC evidence only, while most of the rest drew entirely on HIC research. All recommendations which are drawn from high-income country literature are based on an assessment that the findings and actionable evidence were transferable to low-resource settings.

Evidence-informed Recommendations and Actions

Key Recommendations	Actions
Supporting family members caring for a person with a disability needs to be foregrounded in policy, planning and programming for disability in LMIC.	<i>Governments and community-based organisations, as well as other stakeholders need to give clear priority to the provision of services for family carers. Multi-sectoral coordination could usefully direct action in this area.</i>
Evidence-based interventions to support home-based carers include psychosocial support such as counselling, but in LMIC, peer support groups and problem-solving interventions may be more feasible.	<i>Peer support groups and community health worker-led psychosocial and problem-solving interventions can be effectively delivered in LMIC. Priority needs to be given to evaluating if these models, and delivering which content, work for carers of people with disability in LMIC.</i>
Attention needs to be given to wider ecological interventions which enhance carers' capacity to provide care, including practical respite care services and social support.	<i>To combat social isolation and the economic consequences of caring on family livelihoods, more research is needed to evaluate structural interventions to create enabling environments for carers in LMIC.</i>
Enhanced access to training (possibly from community health workers, in LMIC) represents a potentially effective method of increasing carers' confidence in their ability to undertake practical aspects of home-based care.	<i>Paraprofessional and community health workers in LMIC could be leveraged to deliver training and psychoeducation interventions for carers, as improved self-efficacy in caring could improve not only carer wellbeing, but also quality of care. However, information alone is insufficient in lieu of psychosocial support.</i>
All family caregivers will not benefit from the same types of interventions. Targeting and tailoring are required if interventions are to work for individual families.	<i>Universally-delivered interventions should be provided to all carers, but that targeted, additional provision could be made for carers identified as more in need of support.</i>

Policy priorities

Multi-sectoral coordination between governmental Departments/Ministries, allied agencies, non-governmental organisations, and community-based partners, will be important for the agenda of 'care for carers' to gain momentum, and become the policy and programming priority which is needs to be. The possibility of government-led structural interventions should be examined, and costed at the national level, as – in LMIC – systematic factors contribute to care burden.

Conclusion

In general, there is a lack of review evidence from low- and middle-income countries specifically dealing with how to support carers of people with disabilities. Yet, the component parts of such a literature exist; we know much about the economic and social state of families affected by disability in LMIC, and about the needs of carers, and even about psychosocial programming for wellbeing using paraprofessional and community health worker cadres. What is required is more systematic and comprehensive bringing-together of these literatures, to make a strong case for investment in specific programming, for carers in LMIC.

Publication details: © Disability Evidence Portal, London School of Hygiene & Tropical Medicine, August 2019.

Suggested citation: Xanthe Hunt. Evidence Brief: What interventions are effective to support home-based carers? Disability Evidence Portal, 2019.

Disclaimer: The views expressed in this publication are those of the author/s and should not be attributed to Disability Evidence Portal and/or its funders.

Included sources:

1. Hudson PL, Remedios C, Thomas K. A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC palliative care*. 2010;9(1):17.
2. Stoltz P, Uden G, Willman A. Support for family carers who care for an elderly person at home—a systematic literature review. *Scandinavian journal of caring sciences*. 2004;18(2):111-9.
3. Allen D. Mediator analysis: an overview of recent research on carers supporting people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*. 1999;43(4):325-39.
4. Pusey H, Richards D. A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging & Mental Health*. 2001;5(2):107-19.
5. Brodaty H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*. 2003;51(5):657-64.
6. Pinquart M, Sörensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International psychogeriatrics*. 2006;18(4):577-95.
7. Thompson CA, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. *BMC geriatrics*. 2007;7(1):18.
8. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of clinical nursing*. 2009;18(10):1379-93.
9. Heller T, Gibbons HM, Fisher D. Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and developmental disabilities*. 2015;53(5):329-45.
10. Williamson HJ, Perkins EA. Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with US services and supports. *Mental Retardation*. 2014;52(2):147-59.
11. Grossman BR, Webb CE. Family support in late life: A review of the literature on aging, disability, and family caregiving. *Journal of Family Social Work*. 2016;19(4):348-95.
12. Neely-Barnes, S. L., & Dia, D. A. (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behavior Intervention*. 5(3), 93-107.
13. Silva AL, Teixeira HJ, Teixeira MJC, Freitas S. The needs of informal caregivers of elderly people living at home: an integrative review. *Scandinavian journal of caring sciences*. 2013;27(4):792-803.
14. Palesy D, Jakimowicz S, Saunders C, Lewis J. Home care in Australia: an integrative review. *Home health care services quarterly*. 2018;37(2):113-39.
15. Cleary J, Doody O. Professional carers' experiences of caring for individuals with intellectual disability and dementia: A review of the literature. *Journal of Intellectual Disabilities*. 2017;21(1):68-86.
16. Lou S, Carstensen K, Jørgensen CR, Nielsen CP. Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disability and rehabilitation*. 2017;39(3):301-13.
17. James N. The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: What do carers say? *Journal of Intellectual Disabilities*. 2013;17(1):6-23.
18. Greenwood N, Pelone F, Hassenkamp A-M. General practice based psychosocial interventions for supporting carers of people with dementia or stroke: a systematic review. *BMC family practice*. 2016;17(1):3.
19. Dalton J, Thomas S, Harden M, Eastwood A, Parker G. Updated meta-review of evidence on support for carers. *Journal of health services research & policy*. 2018;23(3):196-207.
20. Griffith GM, Hastings RP. 'He's hard work, but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: A meta-synthesis of qualitative research. *Journal of Applied Research in Intellectual Disabilities*. 2014;27(5):401-19.
21. Greenwood N, Mackenzie A, Cloud GC, Wilson N. Informal carers of stroke survivors—factors influencing carers: a systematic review of quantitative studies. *Disability and rehabilitation*. 2008;30(18):1329-49.
22. Magnusson D, Sweeney F, Landry M. Provision of rehabilitation services for children with disabilities living in low-and middle-income countries: A scoping review. *Disability and rehabilitation*. 2019;41(7):861-8.
23. Semrau M, Lempp H, Keynejad R, Evans-Lacko S, Mugisha J, Raja S, et al. Service user and caregiver involvement in mental health system strengthening in low-and middle-income countries: systematic review. *BMC health services research*. 2016;16(1):79.
24. Thrusz A, Hyder A. The neglected burden of caregiving in low-and middle-income countries. *Disability and health journal*. 2014;7(3):262-72.
25. Lawang W, Horey D, Blackford J, Sunsem R, Riewpaiboon W. Support interventions for caregivers of physically disabled adults: a systematic review. *Nursing & health sciences*. 2013;15(4):534-45.
26. Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database of Systematic Reviews*. 2011;(6).
27. Boots L, De Vugt M, Van Knippenberg R, Kempen G, Verhey F. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *International journal of geriatric psychiatry*. 2014;29(4):331-44.
28. Dickinson C, Dow J, Gibson G, Hayes L, Robalino S, Robinson L. Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. *International psychogeriatrics*. 2017;29(1):31-43.
29. Chien LY, Chu H, Guo JL, Liao YM, Chang LI, Chen CH, et al. Caregiver support groups in patients with dementia: a meta-analysis. *International journal of geriatric psychiatry*. 2011;26(10):1089-98.
30. Eggenberger E, Heimerl K, Bennett MI. Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*. 2013;25(3):345-58.
31. Scott JL, Dawkins S, Quinn MG, Sanderson K, Elliott K-EJ, Stirling C, et al. Caring for the carer: a systematic review of pure technology-based cognitive behavioral therapy (TB-CBT) interventions for dementia carers. *Aging & mental health*. 2016;20(8):793-803.
32. Godwin KM, Mills WL, Anderson JA, Kunik ME. Technology-driven interventions for caregivers of persons with dementia: a systematic review. *American Journal of Alzheimer's Disease & Other Dementias*. 2014;28(3):216-22.
33. Thompson GN, Roger K. Understanding the needs of family caregivers of older adults dying with dementia. *Palliative & supportive care*. 2014;12(3):223-31.
34. Jensen M, Agbata IN, Canavan M, McCarthy G. Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: systematic review and meta-analysis of randomised controlled trials. *International journal of geriatric psychiatry*. 2015;30(2):130-43.
35. Lins S, Hayder-Beichel D, Rucker G, Motschall E, Antes G, Meyer G, et al. Efficacy and experiences of telephone counselling for informal carers of people with dementia. *Cochrane database of systematic reviews*. 2014;(9).
36. Maayan N, Soares-Weiser K, Lee H. Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews*. 2014;(1).
37. McKechnie V, Barker C, Stott J. The effectiveness of an internet support forum for carers of people with dementia: a pre-post cohort study. *Journal of medical Internet research*. 2014;16(2):e68.
38. Orgetta V, Orrell M, Hounsome B, Woods B, team R. Self and carer perspectives of quality of life in dementia using the QoL-AD. *International journal of geriatric psychiatry*. 2015;30(1):97-104.
39. Schoenmakers B, Buntinx F, Delepeleire J. Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*. 2010;66(2):191-200.
40. Schoenmakers B, Buntinx F, Delepeleire J. Supporting the dementia family caregiver: the effect of home care intervention on general well-being. *Aging and Mental Health*. 2010;14(1):44-56.
41. Smith R, Greenwood N. The impact of volunteer mentoring schemes on carers of people with dementia and volunteer mentors: a systematic review. *American Journal of Alzheimer's Disease & Other Dementias*. 2014;29(1):8-17.
42. Macleod SH, Elliott L, Brown R. What support can community mental health nurses deliver to carers of people diagnosed with schizophrenia? Findings from a review of the literature. *International journal of nursing studies*. 2011;48(1):100-20.
43. Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, Young N, Woodhams P, Shiers D, et al. Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. *The British Journal of Psychiatry*. 2015;206(4):268-74.
44. Cheng HY, Chair SY, Chau JP-C. The effectiveness of psychosocial interventions for stroke family caregivers and stroke survivors: a systematic review and meta-analysis. *Patient education and counseling*. 2014;95(1):30-44.
45. Ellis G, Mant J, Langhorne P, Dennis M, Winner S. Stroke liaison workers for stroke patients and carers: an individual patient data meta-analysis. *Cochrane Database of Systematic Reviews*. 2010;(5).
46. Forster A, Brown L, Smith J, House A, Knapp P, Wright JJ, et al. Information provision for stroke patients and their caregivers. *Cochrane Database of Systematic Reviews*. 2012;(11).
47. Legg LA, Quinn TJ, Mahmood F, Weir CJ, Tierney J, Stott DJ, et al. Non-pharmacological interventions for caregivers of stroke survivors. *Cochrane Database of Systematic Reviews*. 2011;(10).
48. Vermeoni-Dassen M, Draskovic I, McCleery J, Downs M. Cognitive reframing for carers of people with dementia. *Cochrane Database of Systematic Reviews*. 2011;(11).

GAPS & RESEARCH NEEDS

There is an urgent need for more review evidence from low- and middle-income countries specifically dealing with how to support carers of people with disabilities.

There is a need to know which, if any, structural interventions may work to support carers of people with disabilities in LMIC, as well as which evidence-based universal interventions can be delivered by paraprofessional and community health workers.

Finally, there is a need to establish the factors according to which some carers may be identified for targeted support.