

Research-based Recommendations For Effective Caregiver Interventions



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Recommendations for Effective Caregiver Interventions

The Michigan Dementia Coalition finalized a state plan in 2003. Recognizing the immense contribution of family caregivers to the care for persons with dementia, the Coalition identified as its first goal: “Increase support for family members who provide care for persons with dementia at home.” The Coalition formed the Caregiver Support Workgroup to implement strategies to increase support for caregivers of persons with dementia. Workgroup members recognized the need to identify what research studies suggest about effective caregiver interventions. A workgroup subcommittee reviewed two meta-analyses and other research articles, and prepared a summary report from this review. In order to provide useful information to organizations that provide caregiver interventions, a succinct list of recommendations was created from this review.

It is our hope that you will consider these recommendations in your policies, objectives and strategies when offering programs to family caregivers. The research findings indicate that implementation of these recommendations will lead to the greatest impact on caregivers, and thus on the quality of care for the person with dementia. Specific questions and issues for organizations to consider are offered at the end.

The Caregiver Support Workgroup will continue to explore means of sharing information, best practices, and collaborative efforts to support caregivers. Please send related information, experiences, questions, or suggestions to Lorie Massuch, email: lmassuch@mphi.org.

Attached:

1. Research-Based Recommendations for Effective Caregiver Interventions
2. Detailed Information on Recommendations
3. Descriptions of Types of Interventions
4. Linking Type of Intervention and Variables to Specific Outcomes
5. Questions and Issues for Organizations to Consider in Using These Recommendations
6. Sources of Workgroup’s Meta Analyses Review and Examples of Caregiver Assessment Tools
7. Forms to Guide Organization Review
8. Inviting Your Feedback Form

Research-based Recommendations for Effective Caregiver Interventions

WHEREAS...*The Michigan Dementia Coalition has established a Caregiver Support Workgroup with the purpose of increasing effectiveness of dementia caregiver support throughout Michigan by facilitating communication between key service and program providers, and coordinating activities related to identified dementia caregiver support priorities...*

AND WHEREAS...*the Caregiver Support Workgroup priorities include continuing to promote improvements in respite care for persons with dementia, disseminating knowledge of the most effective interventions for dementia caregivers, exploring potential for conducting a caregiver needs assessment, and considering various other current and emerging caregiver support initiatives and addressing those appropriate...*

AND FOLLOWING...*a Meta-analysis report of Caregiver Interventions by work group members...*

THE WORK GROUP RECOMMENDS...*the following research-based recommendations for effective interventions for caregivers of persons with dementia:*

1. ***Conduct Assessments.*** Complete a thorough assessment of the caregiver and the caregiving situation to determine an effective intervention plan that is best suited for the individual circumstance.
2. ***Utilize Multi-Component Interventions.*** Using multiple interventions or techniques simultaneously increases the chances of effectively addressing the variety of caregiver needs.
3. ***Offer Interventions with Higher Intensity.*** The frequency and duration of intervention contacts or events are important considerations. More frequent contacts or events over a longer period of time are more likely to alleviate caregiver depression and care receiver symptoms.
4. ***Promote Consumer-Directed Interventions.*** Caregivers who have more choice, control, and flexibility in their home care options are significantly more satisfied with overall service options which can reduce premature nursing home placement of the care receiver.

Information on Recommendations

1. Assessment

Research indicates that caregiver assessment is a fundamental aspect of determining effective interventions.¹ An accurate and systematic information gathering process is necessary to identify caregiver needs, resources and strengths, to determine appropriate goals, and to match interventions most appropriate for the caregiver in achieving the desired goals.² In addition, a periodic follow-up assessment should be completed to monitor the fluctuating caregiver needs as the care situation changes over time. The caregiver assessment is also instrumental in identifying appropriate system changes that can improve home and community-based health care delivery.³

2. Multi-Component Interventions

Research suggests that using multiple techniques that target multiple stressors at one time is the most effective intervention method. Shulz et al determined that combined interventions that simultaneously target multiple sources of caregiver stress and multiple individuals (caregiver as well as the care-receiver) produce a significant improvement in caregiver burden, depression, subjective well being, perceived satisfaction in ability and knowledge, and sometimes care-recipient symptoms.¹ Multiple intervention options are most able to address a variety of caregiver needs, allow for the different individual caregiver characteristics and preferences, and allow for change in desired services as the care giving circumstances change.²

3. Higher Intensity (frequency and duration) Interventions

Interventions with a higher intensity (increased frequency and longer duration) have a greater positive impact on caregivers than interventions with lower intensity.¹ Sorensen et al found the length of an intervention appeared to be important in alleviating caregiver depression and care receiver symptoms. The higher the intensity of an intervention, the greater its effectiveness for the caregiver.²

4. Promote Consumer-Directed Interventions

Consumer-directed programs give consumers choice and control over their care decisions and allow them to tailor services and supports to meet their individual needs. In Georgia the self-determination program research results demonstrated that the consumer-directed program provided a real safety net, especially for low-income caregivers living in rural areas. Caregivers reported financial, physical and emotional relief; the ability to provide better care; and the ability to keep their older relatives at home. In Minnesota's program "You Decide Your Help," consumer-directed services allowed caregivers to hire the person with whom they felt most comfortable and who best met their needs. In North Carolina, the caregiver voucher program and the restaurant voucher program were easy for family caregivers to use. The program empowered caregivers to make their own decisions, giving them control and independence in their service utilization. It was also cost effective because caregivers were responsible for setting up their own services, which saved administrative costs.³

¹ Schulz, R., Martire, L., Klinger, J. Dec. 2005 "Evidence-Based Caregiver Interventions in Geriatric Psychiatry." *Psychiatric Clinic of North America*. Volume 28 Number 4.

² Sorensen, S., Pinquart, M., Duberstein, P. 2002 "How Effective are Interventions With Caregivers? An Updated Meta-Analysis" *The Gerontologist*. Vol. 42, No. 3, 356-372

³ Feinberg, L., Wolkwitz, K., Goldstein, C., March 2006 "Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support

Descriptions of Types of Interventions

1. Psychoeducation:

Structured program providing information about the disease process, resources, services, and training on how to respond effectively to disease-related behaviors. All caregivers are likely to benefit from enhanced knowledge about the disease, the caregiving role, and resources available. Information is especially effective as an early intervention strategy to delay more expensive supports. Caregivers may also benefit from training in general problem-solving skills as well as interventions that target managing care receiver behaviors or caregivers' emotional response to caregiving, resulting in significant improvements in caregiver depression. Adult children can particularly benefit from disease information and learning to cope with role strain. Psychoeducation along with psychotherapy should be used whenever possible, as research indicates that these two interventions had the most consistent positive effects of caregiver interventions analyzed.

2. Psychotherapy:

Therapeutic relationship between caregiver and trained professional with cognitive-behavioral approach. Goal may be to develop problem-solving abilities and help caregiver re-engage in pleasant and positive activities. Approach may have increased impact because it is based on one-on-one interaction, and therefore discussion is focused on the individual's particular needs.

3. Supportive intervention:

Unstructured support groups focused on building rapport among participants and creating space to discuss problems, successes, and feelings regarding caregiving. Groups may help participants recognize that others have similar problems and provide an opportunity to exchange ideas and strategies for coping with shared difficulties. Members provide mutual emotional support. Spouse caregivers can especially benefit from such interventions that provide emotional support and that build supportive social networks.

4. Respite/day care:

In-home or site-specific supervision, providing assistance with activities of daily living to give caregiver time off. Some include activities for the care receiver. Studies find that respite is only effective if it is the right service at the right time -- in other words if it fits the needs of the consumer (consumer-directed). Spouse caregivers can especially benefit from interventions that free up time. There is a need for low-cost respite care and availability outside regular business hours.

5. Care receiver training:

Activity therapy programs designed to improve competence of person with dementia. Improves care receiver symptoms and caregiver well-being.

Note: Interventions that combine different strategies and provide caregivers with diverse services and supports tend to generate larger effects than narrowly focused interventions. A multi-component strategy utilizes a combination of the types of interventions indicated above. The Reach II study uses a combination of in-home visits, telephone calls, and structured telephone support sessions. This has been shown to be an effective intervention combination for caregivers.

Linking Type of Intervention and Variables to Specific Outcomes

(Primarily noted from article, “How Effective are Interventions with Caregivers? An Updated Meta-Analysis,” Sorensen, Piquart, Duberstein, 2002)

Outcome Measures/Affect on Caregiver:							
<i>Type</i>	<i>Burden</i>	<i>Depression</i>	<i>Well-Being*</i>	<i>Uplifts*</i>	<i>Ability/Knowledge</i>	<i>Social Network</i>	<i>CR Symptoms*</i>
Psychoeducation	X	X	X	X	X		X
Psychotherapy	X	X	X	X	X		X
Supportive	X				X		
Respite	X	X	X				
CR Training*			X				X
<i>Variable</i>							
Multi-component	X		X		X		
Group						X	X
Individual	X		X				
Longer duration	X	X					

*Well-Being = caregiver subjective well-being

*Uplifts = satisfaction from caregiving

*Ability/Know = ability/knowledge

*CR Symptoms = care receiver symptoms (memory and behavior problem checklist, deficits in activities of daily living)

*CR Training = care receiver training

Questions and Issues for Organizations to Consider in Using These Recommendations

We urge organizations to review their programs, policies and strategies in light of this information and these recommendations. This process is also important for those concerned about how their communities are responding to the needs of their citizens.

Questions and Issues to Consider:

1. Recommendation #1, Conduct Assessments

It is imperative that the caregiver is fully assessed for strengths, needs, cultural context, and other situational and environmental aspects in order to provide interventions that produce the highest impact.

- a. How do we currently assess the caregiver and their situation?
- b. Are there tools that already exist that we can use that more adroitly assess the caregiver?
- c. Do we need to re-structure our staff to accommodate thorough assessment? Do we designate one staff member to conduct these or does each care manager/case manager/facilitator conduct his or her own? Do we need to adjust allotted time to conduct these?
- d. What do we do with a thorough assessment? Once identified, do our procedures move clients to the best interventions in the most efficient way?
- e. Does our caregiver assessment take into account the individual and cultural perspectives that impact using the proposed interventions?

2. Recommendation #2, Multi-Component Interventions

If multi-component interventions have more impact than single offerings:

- a. Should we be offering other interventions for our clients along with what we currently offer?
- b. If we expand our offerings, what is the impact on staffing and resources?
- c. If we do not have the resources to offer other interventions, or if our niche or mission does not expand beyond our current offerings, can we partner with other organizations or individuals to ensure multi-component interventions for our mutual clients? If we do so, how do we coordinate our offerings?

3. Recommendation #3, Interventions with Higher Intensity

- a. Should we concentrate limited resources (money, staff, and time) on fewer clients to increase the probability of effectiveness rather than use resources to reach many with less probability of success?
- b. Do we need to re-structure staffing to accommodate more sessions per week?
- c. Do we need to assist caregivers in obtaining extra supports to accommodate increased service provisions (such as respite service for increased number of weekly sessions)?
- d. Do we need to adjust our marketing to convince family caregivers of the importance and impact of taking the extra time for more interventions/week and longer period of time?

4. Recommendation #4, Consumer-Directed Interventions

- a. How effectively do we currently engage the caregivers to elicit their input about specific interests, needs and goals?
- b. How effectively do we work with caregivers to engage the care recipient in decision making?
- c. How effectively do we assist the family in making and attaining their goals?
- d. How effectively do our services provide options to meet the personal preferences of caregivers?

- e. How effectively are we able to help caregivers achieve their goals when they encounter eligibility barriers or other limitations?
- f. Who do we need to bring in and network with outside of our organization to meet caregivers' needs?
- g. If needs and goals are non-traditional (i.e., weekend respite, spending time on a farm), how can we meet them?
- h. What natural supports (neighbors, women's groups, church groups) can be involved in the intervention plan? How can we connect with these supports?
- i. Can our support groups, educational sessions, etc. be configured in a way (such as one for men only, one for grandchildren, etc.) to better serve a wider array of diverse caregivers?
- j. Do our support groups, educational sessions, etc. need to be made smaller to accommodate focus on areas more attuned to participants?
- k. Can we provide more opportunities for individual psychotherapy?
- l. Do we need to review our intake structure and forms to allow time for information-gathering that produces more input from individuals?
- m. Does our staff need training on specifics of person-centered-planning and how to incorporate it into their work and service providing?
- n. Can we incorporate increased staff time for follow-up contact with clients to evaluate if the current interventions are meeting their needs, and to identify changing needs?
- o. Do we acknowledge the wide variety of symptoms that caregivers encounter?

Sources of Workgroup's Meta-Analysis Review

Primary Articles:

- a. "Evidence-Based Caregiver Interventions in Geriatric Psychiatry," Schulz, Martire, Klinger. Examines caregiver intervention studies for Alzheimer's disease, stroke, and mental illness published between 1999 and 2005. N=41.
- b. "How Effective Are Interventions with Caregivers? An Updated Meta-Analysis," Sorensen, Pinquart, Duberstein, 2002. N=78

Further Articles:

- c. "Caregivers Count; A Toolkit to Help Practitioners Assess the Needs of Family Caregivers," Family Caregiver Alliance
- d. "Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support," Feinberg, Wolkwitz, Goldstein, Nat'l Center on Caregiving, Family Caregiver Alliance
- e. "Support for Caregivers of people with Alzheimer's type dementia," Thompson, C., Briggs, M. (2000)
- f. "A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial." Mittelman, Ferris, Shulman, Steinberg, Levin. 1997.
- g. "Taking Care of caregivers." Mittelman. 2005.
- h. "Novel Program Enhances Dementia Caregivers' Quality of Life" (The Reach II study), U.S. Department of Health and Human Services, National Institutes of Health, NIH News. November 20, 2006.

Caregiver Assessment Tools:

The following websites offer samples of caregiver assessment tools. This is not an exhaustive list.

Family Caregiver Alliance has sample assessment tools that are used in several states - http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695

Mount Saint Vincent University has a sample that can be used for reference – <http://www.msvu.ca/Family&Gerontology/CaregiverAssessmentTool/Instruments.asp>

University of Connecticut Health Center has the Zarit Burden Interview available - <http://memoryclinic.uchc.edu/siteindex/site.html>

Tool to Guide Organization Review of Caregiver Interventions

The following is a tool to help organizations review their current service structure and discuss/review potential changes in policy and structure on the basis of these Caregiver Intervention Recommendations.

Given Recommendation #1: “Conduct Assessments.”

Currently we:

Should we consider questions about:

- a. tools

- b. staff structure

- c. assessment outcomes

Next Steps:

What will we do?

By whom:

By when:

What resources are needed?

Given Recommendation #2: “Utilize Multi-component Interventions”

Currently we:

Should we consider questions about:

- a. other interventions to offer

- b. impact on organization

- c. partnerships

Next Steps:

What will we do?

By whom:

By when:

What resources are needed?

Given Recommendation #3: “Offer Interventions with Higher Intensity”

Currently we:

Should we consider questions about:

- a. changing allocation of resources and offerings

- b. assisting consumers

- c. marketing

Next Steps:

What will we do?

By whom:

By when:

What resources are needed?

Given Recommendation #4: “Promote Consumer-Directed Interventions”

Currently we:

Should we consider questions about:

- a. analyzing our interventions for consumer-directed aspects

- b. changing how we provide and direct services

- c. increasing options available to consumers

- d. enlarging supports to meet consumer goals

- e. follow-up

Next Steps:

What will we do?

By whom:

By when:

What resources are needed?

Given Potential Changes, We Need to Review and Consider:

1. Staffing
2. Training
3. Marketing
4. Community collaboration
5. Budgeting
6. Time allotted for assessment, support and follow-up
7. Other

