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Providing Services to Family Caregivers at Home: Challenges and Recommendations for Health and Human Service Professions

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Providing Services to Family Caregivers at Home: Challenges and
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ABSTRACT

The home represents a relatively new arena for practice for most service providers, especially those working with families of persons with dementia. This article describes four key factors to consider when working with caregivers of persons with dementia in their homes. The authors also discuss seven common challenges of service provision in the home and recommend strategies for addressing these challenges.

Introduction

A wide range of programs and services have been developed to support the efforts of families caring for persons with Alzheimer's disease.^{1,2} These programs include respite services, educational and psychosocial support groups, counseling, and skills training. Whereas supportive services are typically offered in medical or community-based settings, more recent models of care including hands-on skills training, environmental modification, and family therapy occur in the home of family caregivers.³ To date, there is no empirical evidence to suggest that the provision of services in the home is more efficacious for caregivers than other service contexts. However, national health care trends suggest that home and community based care will increasingly serve as a setting for the delivery of health and human services.⁴ This may be especially applicable to persons with dementia as well as their family caregivers.

The home represents a different context in which to provide care than a medical or community-based setting. While providing services in the home offers multiple benefits for both caregivers and health and human service professionals, it also presents challenges that are unique to that setting. This article discusses the specific challenges of providing supportive services to family caregivers in their homes and provides recommendations for handling common dilemmas that professionals may encounter. The material presented in this article draws on the research and clinical experiences of the authors and specifically on a home environmental skills-training intervention currently being tested as part of the Philadelphia REACH (Resources for Enhancing Alzheimer's Caregivers Health) project. REACH is a multi-site study funded by the National Institutes of Health that seeks to test the feasibility of innovative interventions for family caregivers. The Philadelphia intervention, labeled the Environmental Skill-Building Program

(ESP), is designed to help families identify and modify factors in the physical and social environment of the home that may contribute to problem behaviors or caregiver concerns.³

Benefits of Providing Services in the Home to Family Caregivers

Providing services in the actual context where families conduct caregiving offers multiple benefits for both caregivers and health professionals (see Table 1).

Insert Table 1 about here

Foremost for caregivers is the convenience of meeting with a health professional in the home without having to arrange for the safety and well-being of the person with dementia. This saves caregivers time and energy, which is particularly important for families caring for persons at the moderate to severe stages of the disease process. At these stages, it is often difficult or impossible to leave the person with dementia unattended for significant amounts of time. Another benefit of home delivered care is the potential for caregivers to control the encounter with health professionals. The provider enters the home much like an invited guest and thus, the interactions are typically guided by the caregiver who can more easily direct the type of services and information he or she wishes to receive.

For the provider, the benefits of the home include the opportunity to gain an in-depth understanding of the multiple issues that caregivers confront and the unique situations of each household. This understanding enables providers to derive recommendations that are tailored or customized to the specific concerns and contexts of care provision. Customization is particularly important because the course of dementia and the resources and supportive needs of families vary considerably. A provider's approach to working with a family caregiver may vary based on the

caregiver's educational background, personal values and caregiving style. Being in the homes of families affords a more realistic appraisal of how these factors may impact on service delivery. Another important benefit of home delivered care is the opportunity for service providers to observe directly both the caregiver and the person with dementia in the natural context in which caregiving and personal daily tasks occur.

Factors to Consider in Providing Services at Home

There are four key factors to consider in providing services to caregivers in their homes (see Table 2).

Insert Table 2 about here

Understand the Personal Meaning of Home for the Family

A primary consideration is that homes reflect personal meanings and historical events of significance to families. The meaning of home encompasses many facets including personal control, comfort, protection, development, and independence.⁵ For example, the home may be filled with memories of marriage and family development, thereby representing a safe, comfortable place. Moreover, older people in particular are invested in maintaining their autonomy and view the ability to live in their own home as an important symbol of control and independence.

The arrangement of space and objects reflects and embodies those who live there. Thus, the meaning of space and objects must be taken into account when delivering an intervention. With the progression of dementia, the home may become a "sickroom" filled with medical equipment

such as medications, a hospital bed, commode, and other special equipment. For some family caregivers, the medicalization of their home environment may become in itself a source of distress. Some families prefer to conceal medical objects in an effort to maintain a sense of normalcy in the home environment.⁶ Understanding the meaning of objects and their placement is particularly important when recommending home modifications to help the caregiver achieve a safe and functional environment. Safety recommendations typically require environmental modifications such that potentially dangerous objects are removed, furniture is rearranged, or objects that alter the meaning of home (e.g., safety locks, signs on doors that say “stop”) are strategically placed.⁷

View Caregivers as “Lay Practitioners”

A second key factor in providing a home intervention is to understand the role shift that occurs for providers. The provider role shifts from one of “expert” to one of a partnership that facilitates mutual respect and collaborative problem-solving. In the home, caregivers reflect “lay practitioners,”⁸ a term that refers to the unique expertise and knowledge families obtain from providing daily care to a person with dementia and which he or she brings to the interaction with a health practitioner. Viewing the caregiver as a practitioner fosters a provider-caregiver partnership in which each participant contributes his/her particular expertise and knowledge. Caregivers bring in-depth knowledge about the role history and daily behaviors of their family member and what may work or not work in providing care. Providers, in turn, offer specialized and technical knowledge from their respective disciplines.⁶ Viewing the caregiver as a lay practitioner facilitates collaborative problem solving to address caregiver concerns.

Identify the Caregiver’s Beliefs and Values

A third factor that influences the provision of home care is the caregiver's beliefs and values about disease and disability that guide decision-making and care practices. It is thus important for providers to identify the caregiver point of view regarding what approaches they consider to be best for managing dementia. Caregiver perspectives on their role and best practices may be influenced by many factors including race, ethnicity, education, socio-economic status, family relationships, gender, and religion.

Providers may possess an "outsider's view" of the caregiver's situation and recommend care strategies that are inconsistent with the family's values and beliefs.⁹ Discordance in perspectives may be stressful to the caregiver or lead the provider to make recommendations that are not perceived as helpful by the caregiver. Conversely, when providers have a clear understanding of the caregiver's beliefs and values, they are able to work more effectively with the caregiver to create strategies that fit the family's perspective.

Recognize the Demand Characteristics of the Intervention

A fourth factor to consider in providing home services is the potential impact of that service on caregiver well-being, or the "demand characteristics" of the intervention. Home-based services typically require active participation and involvement of a caregiver. This necessitates a level of commitment and investment of time and energy on the part of caregivers. For example, skills training at home may require a caregiver to learn and practice new approaches to communicating or setting up the environment to support the person with dementia. These new skills place demands for behavioral change that may overwhelm caregivers, especially those who are stressed or fatigued. Furthermore, caregivers who are clinically depressed may find behavioral change interventions particularly overwhelming and have difficulty complying with such recommendations.¹⁰ In such cases, providing only one strategy at a time and working with the

caregiver to help incorporate such changes into daily routines become important approaches to effectively intervene in the home.

Common Challenges and Potential Solutions for Working with Families at Home

Health and human service providers confront many different challenges as they work with caregivers in their homes regardless of the type of service or intervention that is being provided. We present seven such challenges and potential solutions (Table 3).

Insert Table 3 about here

Building Rapport

One of the first challenges health and human service providers confront in the home is the need to build rapport with a caregiver. Rapport involves establishing a level of trust and open communication such that caregivers feel comfortable discussing their central and intimate concerns. Although providers and caregivers sometimes form an instant rapport, the therapeutic relationship is typically established over time, through a number of contacts. The evolution of this process may be thought of as a “courtship period” in which the provider and caregiver gradually become familiar with each other and gain a sense of each other’s values and priorities. Ideally, the relationship between provider and caregiver is transformed through this process so that the provider, who was formerly a guest in the caregiver’s home, becomes a trusted partner and adviser.

There are numerous strategies that can be used to enhance rapport building (Table 4).

Insert Table 4 about here

Foremost is initiating a relationship with a caregiver by using open-ended questions such as “How are things going? Tell me about a typical day. What are things like for you now compared to before?” Such questions enable caregivers to tell their story while providing important insights as to their personal beliefs about dementia and how they are providing care. Insights gained from listening to the caregiver’s story can then guide recommendations and best approaches to working with the caregiver. Strategies that are framed by using the caregiver’s own language also facilitates rapport building and understanding.

Meeting the Needs of Both the Caregiver and the Person with Dementia

Many health and human service providers are accustomed to working directly with “patients” and providing direct intervention for persons with an identified diagnosis. Working with caregivers in the home is especially challenging, because it requires providers to consider the needs of both the caregiver and the person with dementia.

In order to meet the needs of both the caregiver and the person with dementia, the provider must use a holistic approach. Interventions for the caregiver must be designed to address caregiver issues while incorporating the needs of the person with dementia. This is especially important because the problems that caregivers face are so intimately related to those of the person with dementia. For example, the agitated behaviors of a person with dementia frequently influence the caregiver’s level of distress. Conversely, when the caregiver experiences high levels of distress, the person with dementia may become more agitated. One way to address both sets of

needs is to involve the person with dementia in a meaningful activity that (s)he enjoys. This activity may be performed jointly or separately from the caregiver, depending on the caregiver's need. For example, if the person with dementia enjoys homemaking activities, (s)he could fold towels while the caregiver takes care of washing and drying the laundry, or set the table in preparation for a meal. Performance of a purposeful activity together enables the person with dementia and caregiver to maintain a connection and supports the dignity of the person with dementia as someone who can contribute to the family.¹¹ At the same time, it enables the caregiver to perform essential tasks with less disruption.

Other strategies that may meet the needs of the caregiver and the person with dementia simultaneously are caregiver education and home modification. For example, instructing the caregiver in safe transfer techniques helps to prevent injury to both the caregiver and the person with dementia. Providing adaptive equipment, such as a grab bars in the tub, can make performance of personal care tasks easier for the caregiver while enhancing the care receiver's comfort and mobility.

Obtaining Assessment Data

In order to provide effective intervention, health and human service providers must gather information about the family situation and about specific behaviors of the person with dementia. In some instances, it may be difficult to obtain this type of information in a manner that is respectful of the person with dementia. This is especially challenging when the person with dementia is aware of but has difficulty acknowledging his or her limitations. (S)he may also feel embarrassed or self-conscious when emerging limitations are discussed with the provider. Thus, the provider must assess the response of the person with dementia to his or her limitations, use direct observation, and collaborate with the caregiver to determine what kind of approach may be

best. Some persons with dementia may be capable of and wish to participate in a home-based intervention by actively problem-solving with the provider and caregiver. In these instances, the provider can work jointly with the caregiver and person with dementia to develop strategies that address the family's issues. However, other persons may not be able to participate or they may not be able to recognize their limitations.

There are several strategies that the provider can use to address the challenge of working with a person with dementia who is unaware of his/her limitations or does not wish to have them discussed in the presence of others. One approach is to "reframe" the purpose of assessment so that it is more acceptable and supports the dignity of the person with dementia. For example, persons with dementia who deny their limitations may react very negatively when the provider asks the caregiver to describe their problem behaviors. However, asking questions in a more neutral way can help alleviate the awkwardness of this situation. One helpful approach is to use the preferred language of the caregiver and person with dementia to describe problem areas. For example, phrases such as "not feeling yourself", "difficulty", or "disorganized" may be preferable to words that suggest a limitation, like "confusion", "dementia," or "Alzheimer's." Providers may also find it helpful to ask the person with dementia if it's okay to discuss with the caregiver "how (s)he is doing" with caregiving tasks.

If it is not feasible to involve the person with dementia in the discussion, other strategies can be employed to obtain assessment data. One approach is to schedule phone conversations to discuss topics that cannot be initiated when the person with dementia is present. An alternative is for the provider to discuss this information while the person with dementia is otherwise occupied, such as when (s)he takes a nap, watches television, or attends adult day care.

Ensuring Optimal Fit between the Intervention and the Family

Because rapport building occurs throughout the intervention process, the first encounter may be particularly challenging. Once a level of trust has been established the provider must continue to build the relationship by developing and refining recommendations and strategies that fit with the caregiver's values, beliefs and household structure.

One approach to customizing recommendations is to identify the differences in perspectives between the provider and caregiver. Differences that arise between the perspective of the provider and caregiver may be due to several reasons. Chief among these reasons are differences that emerge in interpretations or beliefs about dementia and basic values as to what constitutes good care. Different values can be reflected in individual behaviors such as one's style of communication. For example, one person might place the highest value on polite, respectful communication whereas another might feel that the highest priority is to be direct and adopt a "straight from the hip" communication style.

Providers and caregivers may have different interpretations of behaviors, problem areas and how to proceed. For example, a caregiver's beliefs about the causes of their family member's problem behaviors (such as incontinence) may be inconsistent with a provider's formal knowledge. The caregiver may believe that the family member is incontinent "for spite" whereas the provider may view this as a problem with caregiver communication, and scheduling liquids and bathroom trips. In this case, helping the caregiver reframe the causes of the incontinence and educating about the disease process might be a starting point for an intervention prior to introducing scheduling and communication strategies. Thus, it is important to understand the underlying belief system of a caregiver in order to determine an appropriate intervention.

Self-reflection is a clinical reasoning technique that is helpful in evaluating the household situation and why differences in perspectives exist. Practitioners might consider asking themselves questions such as “What is important to this caregiver? What do I see as the major issues? What does the caregiver see as the major issues?” as a way to uncover the rules and beliefs that guide caregiver actions.

For example, the provider may find him/herself working with a caregiver who treats her spouse in the same manner as she would a small child. The provider may be offended by this approach, seeing it as an affront to the dignity of the person with dementia. However, using the reflective questioning strategy described above could enable the provider to reframe his or her view of the situation. Thus, the provider may realize that the caregiver is anxious to take control of her home situation and is using the only way she knows to modify her spouse’s problem behaviors—those the caregiver previously used when raising her children. This insight could then stimulate the provider to think of ways (s)he could help the caregiver consider alternate approaches, such as relying on adaptive equipment (i.e., safety locks) to control or prevent problem behaviors.

Self-reflective questions can also help providers determine whether family actions or attitudes represent a high risk issue. Several questions can help the provider evaluate the situation more objectively, such as “What are the actual safety issues? Is the caregiver or person with dementia in any real danger? Are my values and beliefs interfering with my ability to look at the situation objectively?” .

Another strategy to ensure optimal fit between the intervention and the family is to review with the caregiver the actual techniques he or she uses. The provider can then build on these strategies and lay the groundwork for further discussion. Additionally, the provider can recommend alternate approaches when the strategies used by the caregiver are ineffective. To assure an

optimal fit between an intervention strategy and family values and culture, it is important to discuss the potential outcomes, both negative and positive, of a currently used or considered strategy. This is particularly true when introducing changes to the environment or adaptive equipment. Even when caregivers agree to a physical adaptation (e.g., a ramp, railing, or hand-held shower), they might not recognize how they will feel about it or whether the adaptation will actually be effective in addressing the problem(s). For example, even a simple adaptation such as installing locks to prevent wandering can be difficult for a caregiver to use. It may have the effect of making a caregiver feel “locked in,” further emphasizing a sense of isolation. This unintended consequence can be avoided to some extent if the issue is explored with the caregiver prior to installing a physical modification.

Involving the person with dementia in such discussions is also important when feasible and valued by the caregiver. Showing pictures of an adaptation, and describing or simulating how it will be used may be helpful techniques. By involving the caregiver and when possible, the person with dementia in each step of decision-making, a recommendation may be more easily accepted and integrated into the family’s routine.

Matching the Intervention to Caregiver Expertise and Knowledge of Dementia

Caregivers vary considerably in their levels of expertise in the caregiving role and their knowledge of dementia. They may also have feelings of being overwhelmed and may be clinically depressed. Providers must adjust their approach to the caregiver’s level of expertise, knowledge of dementia, and the caregiver's emotional response to the caregiving role. Adapting the approach to the caregiver in this way ensures that the intervention will address the caregiver's unique needs and abilities. In this section, we will discuss challenges that occur when working

with caregivers who are primarily overwhelmed, depressed, or who demonstrate such proficiency in the caregiving role that intervention does not seem necessary.

The Overwhelmed Caregiver

Caregivers may become overwhelmed at any stage of the caregiving process. High levels of caregiver burden and nursing home placement are associated with increased cognitive decline, behavioral problems, and functional impairments, particularly incontinence, at the moderate and late stages of dementia.¹² However, caregivers may experience significant stress at the early stages of caregiving, particularly if the diagnosis is not fully understood or accepted by the family. This can create a lack of awareness about the problems of the person with dementia or make it difficult for the family to recognize the effects of intervention.

Some caregivers may not understand or acknowledge the gravity of the disease process and have difficulty recognizing potential safety issues. For example, when caregivers initially encounter a family member's wandering behavior, they may not view it as a serious concern. In these situations, providers must be careful to address potential safety risks for the person with dementia while respecting the caregiver's abilities as a lay practitioner.

There are several strategies that health and human service providers can use to address a caregiver's lack of understanding about dementia-related behaviors. First, it is important to recognize that caregivers may need more time to understand the effects of dementia and the ways in which the intervention can help them. This does not mean that the provider cannot make suggestions; however, he or she should present the suggestion in a way that supports the caregiver's confidence and fits the caregiver's beliefs and values.

Second, providers must consider how a caregiver's gender, educational level, previous roles and responsibilities influence caregiver ability to address a problem behavior. It may be difficult

for example, for some men to discuss toileting issues of their spouses, or assume new roles such as preparing meals, doing the housework and laundry. Conversely, older female spouses may have difficulty telling a previously dominant husband what to do or assuming responsibility for finances, including managing investments and filing tax returns.

Third, providers may need to help caregivers recognize the impact of an intervention. For example, a provider might work with a caregiver to adapt the home environment by putting up “stop signs” to limit rummaging behaviors. It is important to emphasize the relationship between this strategy and a decrease in rummaging to enable the caregiver to apply similar strategies to address other problem behaviors. By following up with a caregiver as to how a strategy is working and reinforcing the strategy’s effectiveness when it works well, the provider reinforces and validates the caregiver knowledge. Also, labeling the strategy, giving it a name, reinforces the technique. Another useful approach may be to photograph an adaptation, since it provides caregivers with concrete evidence of the strategy. Sharing stories of how strategies worked for other caregivers may also be helpful, especially if the caregiver is skeptical about the effectiveness of a strategy.

The Depressed Caregiver

More than 60% of families caring for persons with dementia show signs of clinical depression, particularly at the moderate stage of the disease process.¹³ Caregivers who are depressed may have difficulty participating in supportive home-based services that involve behavioral skills training or changes to the home environment. Signs of clinical depression include suicidal ideation, feelings of worthlessness, self-reproach, or excessive guilt, difficulty in thinking or concentrating, and loss of interest or pleasure in usual activities.¹⁴ While most caregivers will have feelings of being blue, overwhelmed and upset, depression is a clinical condition for which

treatment can be effective. Caregivers who are clinically depressed may view their condition as a natural consequence of providing care to a person with dementia and reason that all caregivers feel the way they do. Depressed caregivers may not understand that their feelings can be effectively addressed through counseling or medication. Thus, it is important to distinguish upset from depression and to explain to the depressed caregiver that depression can be treated.

The Master Caregiver

Providers may sometimes meet caregivers who demonstrate such a high level of expertise that it appears nothing more can be done to help them. However, although master caregivers may have developed effective ways of handling their responsibilities in some areas, it is still important to determine possible ways to improve life quality for the family. One area that may be overlooked by families is the importance of providing meaningful activities that engage or occupy the person with dementia. Providers can address this area by exploring with the caregiver the activities that were previously enjoyed and meaningful to the person with dementia. The provider can then show the caregiver techniques to simplify an activity so that it is appropriate for the person. For example, a person who had enjoyed working with their hands or performing craft activities may find bead sorting an engaging activity.

Even if no specific strategies appear helpful to a master caregiver, it is beneficial for the provider to validate and name and frame the caregiver's management techniques. Also, it is helpful to explore with master caregivers the types of strategies they find effective, since their suggestions may then be useful for other caregivers with whom providers work. This may also help to enhance the caregiver's feelings of skill, control, and efficacy.

Working within the Family System of Roles and Relationships

When health and human service providers enter a caregiver's home, they often enter a complex set of relationships that have historical significance. Family members typically provide care for the majority of persons with Alzheimer's, and their previous relationships with the person with dementia can impact the approach to caregiving. One major challenge is to help caregivers manage behaviors that may appear to be manipulative, controlling or spiteful. For example, resistance to care, refusal to eat, agitation during bathing or toileting may be interpreted by a caregiver as spiteful, willful behavior reflecting long-standing patterns in the history of the relationship between the caregiver and the person with dementia. Providing education about the disease is critical. Role playing these difficult situations with the caregiver allows him or her to explore alternate ways of communicating. Most importantly, this type of experiential training teaches caregivers to communicate in a way that validates the feelings of the person with dementia while maintaining an assertive stance in directing behaviors.

Multiple Caregivers

Providers working with caregivers at home may encounter situations in which more than one caregiver is involved in making decisions about and providing care. For example, a husband and wife may both care for the husband's parent. Depending on established roles and interpersonal relationships in the family, the couple may have an equal role in taking responsibility for the parent's care, or one partner may assume the primary leadership role. Specific tasks performed by the caregivers may also differ. For example, one caregiver may assume the majority of personal care tasks, while the other is responsible for making major decisions such as arranging for other family members to share caregiving tasks, choosing the parent's primary physician, and using community resources such as adult day care and respite services. Thus, it is important for

the care provider to identify and reflect upon the roles of each family member. This process can help providers work within the family's perspective and lifestyle and develop more suitable intervention.

Helping Caregivers Access and Use Resources

Caregivers differ considerably in their knowledge of the healthcare and social service systems and other available resources. Lack of knowledge in this area can be critical especially when the caregiver faces an acute medical problem, requiring additional support. Potential problems in these situations include lack of instruction about proper home care (e.g., how to treat a diabetic wound) and need to coordinate additional home care or medical services. Caregivers may lack knowledge about what services are available under these circumstances or how to access them. One strategy to help caregivers in these situations is to provide education about specific ways to access services and, in some cases, making initial contacts for them. Another key point is that other health and human service providers who have worked with the caregiver and/or person with dementia may not recognize or understand how to use healthcare and social services effectively. Therefore, it is important that providers conduct a comprehensive assessment at point of contact and not assume that another provider has already taken care of the presenting problem. Providers may also need to educate themselves as to what services are available so they can refer caregivers to the services they need.

The caregiver's willingness to accept help from service providers, family members, and the community is a key issue in accessing and using resources. Caregivers may be reluctant to accept help for several reasons. First, the idea of accepting help from others may be seen by the caregiver as a personal failure, an indication that he or she is not a good caregiver because (s)he cannot meet all the needs of the person with dementia all the time. Additionally, the caregiver

may feel no one else can provide adequate care for the person with dementia and thus, (s)he must provide all the care. In these situations, it may be helpful to assist the caregiver in identifying specific tasks that (s)he might allow another person to perform. One approach is to first review or make up a list of the daily care tasks with the caregiver. Then, the provider can assist the caregiver in identifying tasks for which (s)he might consider asking for help. The caregiver and provider can then discuss persons in the family or community who might be able to assist with the identified tasks. This approach enables the caregiver to remain in control of the overall caregiving process while shifting some of the care to others.

Another impediment to obtaining help is that the caregiver may feel that he or she has already asked for, but not received assistance, when in fact his or her needs have not been articulated clearly. For example, the caregiver may express frustration to a family member or friend that (s)he never has time away from the person with dementia, but does not explicitly ask them to take care of the person for a day. Role playing situations with the caregiver in which (s)he asks for specific help enables him or her to become more comfortable with the process and learn how to communicate clearly and directly.

Summary

The home represents a relatively new arena for practice for most service providers, especially those working with families caring for persons with dementia. Providing intervention in the home is very different from delivering services in clinical settings where providers enact a traditional expert role and are clearly “in charge.” It is important to recognize the factors that influence service provision in the home and the specific challenges that providers may confront. Understanding the parameters of intervening in a home can enhance service delivery in that setting. We identified four key factors that influence service provision in the home. These factors

are to understand the meaning of home to the family; view the caregiver as a “lay practitioner” with whom to develop a collaborative partnership; identify the caregiver’s beliefs, values, and care practices; and recognize the demand characteristics of the intervention. Providers must also be prepared for seven common challenges. These include the need to build rapport, incorporate the needs of both the caregiver and the person with dementia, and obtain assessment data while respecting the dignity of the person with dementia. Additionally, providers must ensure optimal fit of the intervention to the family situation, match the intervention to the caregiver's expertise and knowledge of dementia, identify and work within the family system of roles and relationships, and help caregivers access and use resources. Providers may encounter these challenges in the provision of any type of intervention. Moreover, the provider's ability to meet these challenges may impact a caregiver’s response to the intervention, and acceptance of recommendations and strategies. Awareness of these challenges and potential solutions provides a framework from which providers can effectively work with families in their homes.

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Table 1 Caregiver-Provider Benefits of Providing Services at Home

| Caregiver Benefits | Provider Benefits |
|---|---|
| Saves time, mental and physical energy | In-depth understanding |
| Remains in control and can guide interactions with the provider | Recommendations tailored to specific home situations |
| More comfortable and can be more at ease | Identification of safety issues that caregivers may be unaware of |
| Can practice newly learned skills in the context in which they are used | Observation of performance in context in which it occurs |

Table 2 Key Factors to Consider in Providing Services at Home

- Understand the personal meaning of home for the family
- View the caregiver as a “lay practitioner”
- Identify the caregiver’s beliefs and values
- Recognize the demand characteristics of the services provided

Table 3
Summary of Challenges and Recommendations for Providing Services in the Home

| CHALLENGE | RECOMMENDATIONS |
|---|---|
| Building Rapport | <ul style="list-style-type: none"> • Identify caregiver’s goals for intervention • Use and respect caregiver’s language • Validate caregiver’s existing strategies • Involve and collaborate with family members and other supportive persons |
| Incorporating Needs of Both Caregiver and Person with Dementia into Intervention | <ul style="list-style-type: none"> • Use holistic approach that addresses needs of both caregiver and person with dementia <ul style="list-style-type: none"> - Involve person with dementia in meaningful activities - Consider effects of education and home modification on both caregiver and person with dementia |
| Obtaining Assessment Data | <ul style="list-style-type: none"> • Actively involve care receiver in intervention when feasible • Ask permission of care receiver to discuss ways of helping caregiver • Schedule telephone contacts to discuss sensitive issues • Obtain assessment data when person with dementia is not present |
| Developing Optimal Fit Between Intervention and Family | <ul style="list-style-type: none"> • Reflect on possible differences between self and caregiver • Review caregiver’s management practices step by step • Refocus on the caregiver’s needs and priorities • Discuss and try out possible strategies |
| Matching the Intervention to Caregiver Expertise and Knowledge of Dementia | <ul style="list-style-type: none"> • Recognize that caregiver may need more time to accept family member’s condition and use provider’s strategies • Ensure that recommendations fit the caregiver’s perspective and priorities • Address quality of life issues in master caregivers • Obtain information on specific strategies from master caregivers that may be helpful for other caregivers • Follow up on how recommended strategies are working, if necessary modify strategies • Reinforce value of strategies • Photograph physical adaptations or develop pre-post photos to reinforce positive changes |
| Working within the Family System of Roles and Relationships | <ul style="list-style-type: none"> • Role play using simple language and validation of care receiver’s feelings • Recognize roles of multiple caregivers and reflect on how they fit into the caregiving situation • Facilitate communication and collaborative problem solving between caregivers |
| Helping Caregivers Access and Use Resources | <ul style="list-style-type: none"> • Be aware of existing resources available to caregiver • Educate caregiver about appropriate resources • Help caregiver to identify tasks (s)he can allow others to perform • Role play ways of asking for help with caregiver |

Table 4 Strategies for Building Rapport

- Establish a tone of respect
- Use empathetic listening
- Use language of the caregiver rather than medical terminology to describe a problem area
- Obtain in-depth understanding of caregiver concerns
- Validate strategies caregivers have in place

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