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THE FAMILY’S ROLE IN PERSON-CENTERED CARE

Practice Considerations

Family has an important place in the person-centered care paradigm. However, with the emphasis of person-centered care on the resident’s perceptions, it is necessary to consider both the positive and negative aspects of family members’ involvement within the long-term care setting. In this article, we consider the roles family members play in providing person-centered care (both as facilitators and impediments) and ways to successfully achieve family participation in this model of long-term care.

BACKGROUND

Person-centered care is an approach to caregiving known to improve care outcomes for older adults residing in long-term care facilities (Beck, 1997; Kitwood, 1997; Rader & Tornquist, 1995). One way to think of person-centered care is as the type of care one would expect in a home environment. This approach seeks to make the institutional environment more comfortable and home-like. Person-centered care also means truly individualizing care based on the personal needs,
experiences, and routines that are meaningful to each resident. With this approach, residents wake up and go to bed when they like; eat what and when they like; bathe in a manner that provides comfort and nurturing, as well as cleanliness; celebrate life events according to lifelong traditions and values; and interact with their family members and friends in ways that are important and meaningful to them.

As described by Talerico, O’Brien, and Swafford (2003), the concept of person-centered care has a long history and tradition in nursing, although the terminology and emphasis have varied. Most recently, Zenul (2003) defined the concept (using the term “resident-centered care”) as:

a systematic approach to improving both quality of care and quality of life in nursing homes through organizational policies and practices that create supportive social, spiritual, and physical environments and that stem from residents’ value systems. (p. 7)

This approach represents a move away from a care model in which caregivers are interchangeable and care is organized by institutional routine, rather than residents’ needs and preferences. According to Swafford (2003), key elements of person-centered care include:

- Providing care that is meaningful to people with dementia.
- Facilitating freedom of choice.
- Maximizing control of one’s environment.
- Nurturing relationships between people with dementia and their caregivers (both family and professional).

Person-centered care applies equally to people who are cognitively intact and those with dementia. Although residents with severe dementia may be unable to participate actively in their care, attention to their individual needs and preferences is still a goal of care.

THE FAMILY’S ROLE

The family’s role in providing person-centered care has at least five dimensions. Residents’ family members serve as:

- Sources of information for staff, helping them understand the residents’ unique preferences and needs.
- Members of the residents’ social network, linking residents to the larger community.
- Direct care providers (e.g., helping residents eat, participating in activities with them).
- Caregiving team members (e.g., helping identify ways to address residents’ behavioral symptoms, planning person-centered care services, managing care, and developing personal relationships with staff).
- Advocates to ensure their loved ones receive the kind of care they desire.

Sources of Information

To provide care that is meaningful to residents, a key element of person-centered care, it is necessary for staff to understand something about resi-

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dents’ likes and dislikes, personality, history, and values. However, this information may be difficult to obtain when residents have dementia. Residents’ family members can provide insight, photographs, stories, and facts. Knowing something of residents’ pasts can deepen staff’s understanding of who the residents are—not just frail, bedridden, or incompetent older adults, but people with interesting lives and histories.

Information about residents’ previous occupations can clarify their current behavior. For example, knowing that a resident worked nights and made building rounds may suggest a history consistent with current nightly wandering behaviors. Sometimes understanding residents’ unique histories is critical to current care, such as when staff consider a male resident with moderate dementia incapable of escaping a facility, but the family reminds staff that this man once scaled mountains.

Although family members often serve as informants, or as proxies in research to gather data, about residents in long-term care, caution should be used in relying on them for such information. In a study by Neumann, Araki, and Gutterman (2000), proxies (usually family members) tended to report greater impairment or problems than the older adults, especially for those with dementia. However, residents and proxies were similar in reports about preferences for type or setting of care.

Kane et al. (2003) argued that nursing home residents, including those with mild to moderate cognitive impairment, can reliably report directly about their quality of life. This argument is increasingly supported by other researchers, who indicate that people with dementia can speak for themselves and staff and caregivers need to listen to them (Schnelle, 2003; Snyder, 2001).

Besides the issue of simple respect and the validity of residents’ own opinions about their situations and quality of life, reliance on family reports runs the risk that family members lack insight into their loved ones’ current views and needs. As individuals’ physical and mental states change, so may their values and preferences. For example, a person who was a gourmet cook may no longer have any desire to heat a pot, and a once dapper gentleman may find it painful to be shaved and develop a preference for sweat clothes. Developing person-centered activities for residents based on past values or habits may pressure residents to perform activities that were once meaningful but no longer are. Therefore, the people receiving care should be the primary informants, with their family members serving as supplements, regarding the individuals’ needs, preferences, and values.

**Members of Residents’ Social Network**

Research has clearly shown that family members remain an integral and important part of long-term care residents’ lives (e.g., Duncan & Morgan, 1994; Keefe & Fancy, 2000; Kelley, Buckwalter, & Maas, 1999; Levesque, Ducharme, & Lachance, 2000). For most older adults who live in long-term care settings, a meaningful living environment will include contact with family members who socialize, visit, and converse with them. Regular visiting is an appreciated and welcome part of life. In addition, family members help connect residents with friends in the community and bring residents to holiday celebrations away from the facility.

Although family relationships continue in long-term care settings and may be meaningful to both residents and their family members, family life still has the same complexities it did outside this setting. Social networks may provide positive or negative experiences for their members (Ingersoll-Dayton, Morgan, & Antonucci, 1997). Family members often have multiple viewpoints, and many family researchers (e.g., Lyons, Zarit, Sayer, & Whitlach, 2002; Marshall, Matthews, & Rosenthal, 1993) argue that input from many family members is needed to understand how families make decisions, define issues, and experience life transitions. Therefore, family members who are involved in the residents’ care or who are a part of the residents’ social network may have different perceptions about what is meaningful for their loved ones with dementia, how the residents should be cared for, and how well the facility staff provide care.

Some families have a history of long-term abuse or conflict-laden, adversarial relationships. These disparate views and the difficult family relationships that may exist can create a challenge in forming a cohesive process for planning and providing care. Intrafamily conflicts are often stressful for staff, as well as for residents, and may hinder quality of care (Kramer, 2003).

**Direct Care Providers**

Family members frequently perform essential tasks for their loved ones, ranging from helping with meals and doing laundry to taking them to medical appointments or participating in activities with them, both within and outside the facility. Family involvement in these activities, by its very nature, ensures personalization of these services, and by performing these tasks, family members offer another, individualized hand in care delivery.

However, with family involvement in direct care comes the...
potential for tension between staff and family members. In 1981, Litwak warned of tension that can arise when family members engage in “technical” care, rather than emotional and social support. Litwak (1981) advocated a division of tasks between family members and staff. Today, we may take a different view, given the great demands on paid caregivers and increased understanding about family roles and involvement. Yet, Tornatore and Grant (2002) found that family members who provided direct care generally experienced greater burden than those who did not. In addition, family members who provide direct care were more likely to have lower expectations for care. In other words, these family members felt compelled to provide care not as a way to be involved but because they found care provided in the nursing home deficient.

Caregiving Team Members

Family members’ feelings of burden may decrease if they perceive their involvement in their loved ones’ care as being part of a team with staff, rather than as making up for the lack of services provided by staff. Family members often participate with nursing and social services staff in planning services, managing care, and identifying ways to address residents’ behavioral symptoms (Logsdon, 2000). The opportunity for family members to engage in joint problem solving with nursing home staff was a key family value identified by Gladstone and Wexler (2000). Lustbader (2001), Noelker and Harel (2001), among other researchers, stressed the importance of including family as part of the caregiving team precisely because of their unique knowledge of the residents receiving care and their role in personalizing that care. This is particularly important when communication with the residents is difficult due to Alzheimer’s disease and other dementias. In a qualitative study, Ericson, Hellstrom, Lundh, and Nolan (2001) found that family members and professionals defined “best care” for individuals with dementia differently, suggesting that family members and paid staff may complement each other in the attention they give to different aspects of care.

If residents’ family members support the concept of person-centered care, their involvement in planning will enhance successful implementation of that care. Research suggests that, in general, family members do endorse the basic concepts of this approach (Duncan & Morgan, 1994; Gladstone & Wexler, 2000; Lustbader, 2001; Noelker & Harel, 2001). However, this may not always be the case. For example, what happens when a resident falls out of bed and, based on current standards of practice, facility staff refuse to restrain the resident? Some family members, concerned about their loved ones’ physical safety, may feel the facility is being irresponsible. Similarly, what if a family member focuses on their loved one’s appearance, insisting on regular showers, hair styling, and their wearing specific types of clothing, although showers have become frightening, hair combing painful, and dressing in certain clothes a battle for that resident? Thus, it is important for staff not to assume that family members’ perspectives are always consistent with person-centered care. However, if the idea of family members as members of the caregiving team is embraced, then the team will provide education and guidance to family members, as well as staff, and more effectively come to a consensus about care.

Advocates for Quality Care

Common wisdom suggests that family involvement in long-term care is essential to ensure residents receive the quality, personalized care they desire. Many family members consider their roles as advocates, rather than as direct care providers or caregiving team members. They observe care and intervene with administration or staff as they feel it necessary to ensure standards of care. Family members are often used in research and practice (e.g., regulatory monitoring) as a key source to help evaluate quality of care. Ejaz, Straker, Fox, and Swami (2003) pointed out that assessing family members’ views on the quality of care provided gives a human face to care, which complements data obtained from statistical, quantitative measures.

Although the literature generally endorses the idea that family involvement in care and monitoring of the quality of care are typical and beneficial to residents, it is important to recognize the potential for overreliance on family members as information sources and spokespeople. As indicated above regarding family members as sources of information, such overreliance may actually undermine staff efforts to provide person-centered care. Therefore, when working with family members, it is important to consider:

- Whether the family members’ perspectives always represent the residents’ views.
- The need to acknowledge that family members often have divergent opinions and responsibilities.
- That relationships among family members may often be ambivalent.

These issues influence family members’ perceptions of and contributions to person-centered care.
STRATEGIES FOR ENGAGING FAMILY MEMBERS IN PERSON-CENTERED CARE

Just as strategies for working with staff are needed to ensure person-centered care is provided effectively, specific steps are needed to ensure family members become actively engaged in this care. Here we offer some ideas for enhancing family involvement in care in ways that further the goals of person-centered care.

Provide a Welcoming Facility Environment

This is the foundation for engaging family members in person-centered care. To support frequent visitation, family members need to feel they are welcome in the facility. Facility characteristics such as restricted visiting hours, lack of quiet space for family gatherings or private conversations, inaccessibility of visiting accoutrements (e.g., beverages), or uncomfortable seating may limit family members’ comfort. Such a lack of accommodation may reduce family members’ desire to visit and ultimately negatively affect the residents (Chapman & Carder, 2003).

Conversely, providing opportunities for family members to get to know the facility and its staff, particularly in relaxed, friendly ways (e.g., monthly, informal or educational events) can enhance family members’ enjoyment in visiting their loved ones. Tornatore and Grant (2004) found that the more often family members visited, the more satisfied they were with the nursing home. The researchers suggested that frequent visits allowed family members the opportunity to meet and interact with staff and feel comfortable with the care being provided.

Facilitate Family Involvement in Care Planning, Care Meetings, and Problem Solving

For care to be truly person-centered, the care plan and care provided need to reflect the residents’ desires and preferences. Ideally, as described above, the residents’ own voices will be apparent in case planning and written care plans. In addition to this information, residents’ family members can describe people and events from residents’ past. Inviting family members to help develop a “personhood profile,” as part of the residents’ permanent records, is one way staff can encourage family members to participate in this process. The residents’ work identity, events before marriage, and children can be described, as well as other, less-tangible information, such as missed opportunities or unfulfilled dreams. Perhaps long-forgotten hobbies or activities may emerge. Developing such a personal history with the residents and family members can be included as a component of the intake process. This approach has been used successfully in the developmental disabled population (Smull, 2002).

In addition to providing intake information, many facilities invite family members to attend monthly or quarterly care meetings. Welcoming family members as part of the caregiving team can enhance care and tap into residents’ personal histories and preferences. Unfortunately, direct care workers, those who have the most contact with residents and know them best, are rarely included in these team meetings.

Involving family members in problem solving about staff’s health and behavior concerns about the residents may offer insights and, thus, help find solutions. For example, if a resident is losing weight and becomes agitated at dinner time, information from family members about the resident’s past habits, food preferences, and eating style may provide clues to resolve the issue. Perhaps the resident was a vegetarian and dinners featuring meat are distressing. Because residents’ current health conditions may affect their food preferences, balancing family input with staff knowledge provides an excellent opportunity to arrive at joint solutions for care.

Provide Education, Training, and Support

It is very important for nurses to be proactive in training staff and family members about the importance of cooperation and teamwork in providing care; to discuss roles; and to promote team cooperation, which includes residents’ families. Brainstorming ways to engage family members in the care process can be a component of staff training. It is essential for all participants in care delivery to be educated about the underlying principles of person-centered care and to have an opportunity to consider the rationale for, as well as the risks of, applying these principles. Given the generally high staff turnover in long-term care facilities, it is important there be a process for introducing new staff to not only the residents but also their family members.

Family members’ understanding of the principles and practices of person-centered care will facilitate their active participation in it. For example, Bond and Fiedler (1998) found little correlation between staff’s and family members’ views of the organizational culture of the facility they were studying. Orienting family members to the principles of person-centered care, care processes, and the many ways family members, as well as residents, can participate in care should be included when new residents join a facility.
Several models of family education have been described in the literature. Pillemer, Hegeman, Albright, and Henderson (1998) described a successful education program, Partners in Caregiving, in which parallel workshops were provided for staff and for families. Content emphasized communication and listening skills, saying what you mean clearly and respectfully, understanding cultural and ethnic differences, and understanding different values. Both staff and family members experienced high satisfaction with the process, each describing new insights, changed behavior, and a reduction in interpersonal conflict.

Peak (2000) described a family support project that emphasized education on many topics, accurate information, support group services, and suggestions for successful visits with their loved ones with dementia. Despite residents’ declining capacity and increased behavioral symptoms, family members reported greater enjoyment visiting their loved ones at the end of the program. The Caregiver Helpbook: Powerful Tools for Caregiving (Schmall, Cleland, & Sturdevant, 2000) and Living a Healthy Life with Chronic Conditions (Lorig et al., 2000) are additional resources for both family members and staff to increase their understanding of dementia and how to communicate successfully with one another about their own needs, as well as the residents’ needs.

Make Positive Use of Family Input

Actively and routinely seeking input from residents’ family members and engaging them as caregiving team members are consistent with person-centered care. It is important that family members feel comfortable in bringing their concerns to staff. Family input can be gathered through periodic written surveys, individual meetings with facility administration, or focus groups. It is critical that facility line-staff understand it is important and positive for family members to be considered part of the process to ensure quality of care and enhance residents’ quality of life. Developing creative ways to receive and share this valuable input is important to sustaining the positive interactions between staff, residents, and family members.

Set Boundaries When Needed

As noted above, the centerpiece of person-centered care is the resident. It is paramount for staff to validate the residents’ views of expressed needs, relevance, and meaning. It is possible that residents, their family members, direct care staff, and administrative personnel may view situations through different lenses. As long as all participants in planning are focused on the principles of person-centered care, such differences can be negotiated, with this approach to care as the guiding principle. Of course, this requires that all participants fully understand the philosophy of person-centered care. Although research suggests that family members generally hold values consistent with this approach, there are times when they may become concerned that actions taken with or on behalf of their loved ones may jeopardize the residents’ safety or health (e.g., not stopping a resident with diabetes from eating sugary donuts for breakfast).

Establish Policies and Procedures to Support Family Engagement in Care

Policies and protocols that reflect person-centered care may help staff and families navigate issues that arise in developing, implementing, and modifying care plans. Written documents can facilitate consistency and commu-
nication among all individuals involved in care (e.g., residents, staff, family members). Policies can guide care planning to ensure inclusiveness and may serve as a resource to alleviate staff feelings of being in no-win situations. For example, there may be times when a resident’s desires override those of their family members. This can be a very delicate situation, and there must be a process for addressing such issues. Staff may need to advocate for residents when there is family conflict. For communication to be successful and not conflict laden, established procedures must ensure that everyone is heard. It is necessary to develop processes in advance for addressing issues of conflict between residents and their families or between family members and staff. Examples of policies to include are those that:

- Ensure family members have access to staff at all levels of the facility (e.g., direct care providers, nurses, administrative personnel).
- Establish an understanding at all levels of staffing that family members are welcome in the facility and should be treated both as a part of the residents’ social network and as members of the caregiving team.
- Seek input from family members who problems arise, but not to the exclusion of the residents’ input. Discussing differences in perspectives between residents, family members, and/or staff, using the principles of person-centered care as the focal point, can help resolve these differences.
- Ensure all family members who visit and communicate with residents and staff understand the principles of person-centered care (e.g., regarding the risks of restraint use and violations of diet or medication guidelines).

**SUMMARY**

Effective implementation of person-centered care requires a shared understanding and commitment to make it a reality by administrative personnel, direct care providers, and residents and their family members. Long-term care facilities must seek ways to engage residents’ families in person-centered care through its training, policies, care planning, and documentation. Doing so may require revisions to policies and work practices, and ongoing leadership efforts to maintain this care framework within the realities of staff turnover and regulatory requirements. Developing protocols and procedures that facilitate family members’ communication with staff and build consensus and shared values will result in a system that represents and honors the unique perspectives, values, and needs of each resident receiving care.

It is important for facility leadership to set the tone for acknowledging the importance of family involvement in person-centered care by modeling acceptance of concerns and criticisms as valid and by acknowledging that direct care providers, residents, and their family members have a voice in care decisions. Such an approach has the greatest chance of success in promoting person-centered care and the shared values necessary to ensure its successful implementation.

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