

## Moving Toward Person- and Family-Centered Care

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**Person- and family-centered care (PFCC) is an orientation to the delivery of health care and supportive services that addresses an individual's needs, goals, preferences, cultural traditions, family situation, and values. PFCC can improve care and quality of life by its focus on how services are delivered from the perspective of the older adult and, when appropriate, his or her family. PFCC both recognizes and supports the role of family caregivers, who often are critical sources of support for older adults with chronic or disabling conditions.**

Person- and family-centered care (PFCC) has gained attention in recent years as a mechanism for transforming health care and long-term services and supports (LTSS). PFCC promotes choice, purpose, and meaning in daily life, and supports well-being for individuals and their families.

Although the concept of PFCC is gaining prominence, it is not fully understood by many practitioners. In everyday practice, PFCC has not yet been fully integrated across the health care and LTSS systems as an essential part of all care and support. However, the current shift in payment reform and service delivery away from disease or provider-focused models and toward providing incentives that reward better coordination, communication, and continuity of care is likely to promote wider adoption and effective implementation of PFCC.

While PFCC can be applied to people of all ages, this paper focuses on older adults with chronic or disabling conditions. It defines PFCC, explains the rationale for using the term “person” rather than “patient,” and underscores the importance of the family in a PFCC approach. The paper also describes the key elements of PFCC.

### What is Person- and Family-Centered Care?

PFCC generally refers to an orientation to the delivery of health care and supportive services that considers an older adult's needs, goals, preferences, cultural traditions, family situation, and values. It includes the person and the family<sup>1</sup> at the center of the care team, along with health and social service professionals and direct care workers. It also evaluates the person's experience of care. Services and supports are delivered from the perspective of the individual receiving the care, and, when appropriate, his or her family.

The PFCC approach respects and meaningfully involves the older adult's family caregivers,<sup>2</sup> as appropriate, in the planning and delivery of supportive services. It also recognizes and addresses family needs and preferences, and integrates family caregivers as partners in care.

### Person versus Patient

Traditionally, the term “person” is used in LTSS, and the term “patient” is used in a medical and health context. The term “person” rather than “patient” or

“patient-centered care”<sup>3</sup> is preferred because it reflects the “whole person,” including family, when appropriate, and emphasizes continuity of care and support, and quality of life. In contrast, the conventional medical model in health care is organized around providers, specific diseases, episodes of care, and office visits to clinicians. Person-centeredness looks beyond the medical and physical health needs of the older adult.

The concept of person-centeredness and person-centered planning can be traced to changes that took place in the early 1970s as part of the independent living movement, led by people with disabilities. The movement—part of the broader movement for disability rights—focused on the development of a social system in which all people with disabilities have the opportunity to lead productive, meaningful lives as integrated and valued members of their communities.<sup>4</sup> The attributes of a person-centered approach can be found as far back as the 1940s and the 1950s in the work of psychologist Carl Rogers, who pioneered “client-centered” counseling.<sup>5</sup>

### Importance of the Family

The term “person-centered care” alone may not adequately capture the importance of family in the lives of older people. In 2009, family caregivers of adults with chronic or disabling conditions provided an estimated 40.3 billion hours of unpaid care at an estimated value of \$450 billion.<sup>6</sup> Without family caregivers, the health care and LTSS systems would be unable to meet the needs of older adults.

Family-centered care amplifies person-centered care by recognizing and supporting the vital role of family caregivers. It also addresses factors that are essential to good care for older

people with chronic or disabling conditions, building on the strengths of family connections.

- The family is the main source of help for older people with functional limitations in daily life. Researchers estimate that two out of three (66 percent) older people with disabilities who receive LTSS at home get *all* their care exclusively from family members, mostly wives and adult daughters. Another quarter (26 percent) receives some combination of family care and paid help; only 9 percent receive paid help alone.<sup>7</sup>
- Frail older adults often rely on family to help them negotiate interactions with health care and social service professionals. While some older adults want full control over decision making, others may need or prefer to delegate decisions to their family caregivers.<sup>8</sup>
- Family members and close friends often both provide and coordinate care. Family involvement can improve outcomes for older adults needing care and supportive services. For example, recent research shows that family caregivers can help explain clinician comments and instructions to the older adult during medical visits, and they can communicate information about their loved one’s health conditions and functioning to health and social service professionals.<sup>9</sup>
- Family caregivers are often the main source for managing continuity of care. A consistent family caregiver—across all transitions of care and care settings—will recognize his or her loved one as a whole person, not focusing exclusively on a specific disease, disorder, or episode of hospital care. Family caregivers often are the older person’s “eyes and ears,”

recognizing changes in symptoms and function than may necessitate different care or supports.<sup>10</sup>

- Family caregivers typically need information and support to function effectively in their caregiving role. They may benefit from education, training, and access to other caregiver support services, such as respite care. Unless family caregivers are involved in assessment and care planning, they may not understand what is expected of them in their caregiving role.
- Social isolation—for both the family caregiver and the older adult—is considered a risk factor in today’s society.<sup>11</sup> Caregivers who experience social isolation also experience high levels of caregiver stress.<sup>12</sup> Recent findings from the *Stress in America* survey show that family caregivers to aging relatives report higher levels of stress and poorer health than the population at large.<sup>13</sup>
- Family caregivers of older people with complex chronic care needs may be vulnerable and at risk themselves. Ignoring family caregivers’ needs can lead to burnout. When caregivers feel unprepared to carry out caregiving tasks and are overburdened, they may risk their own health and impede their ability to provide care. Reducing caregiver strain can help to prevent unnecessary hospitalizations, and prevent or delay the use of nursing homes.<sup>14</sup>

Family members who provide care typically do not self-identify as “family caregivers.” They often are invisible to health professionals and excluded from the care process. In PFCC, health and social service professionals play a central role in helping family members and friends of older adults—be they daughters, sons, partners, wives, nephews, or neighbors—to acknowledge

their caregiving situation. This explicit recognition is often family caregivers’ initial step in identifying and accessing supportive services for their loved one and maintaining their own well-being.<sup>15</sup>

In some instances, providing good care may necessitate choosing among conflicting responsibilities, values, and principles. In bioethics, with its emphasis on individual autonomy and confidentiality, there is increasing recognition of the need for a family-centered approach in health care and LTSS to enhance mutually supportive relationships among clinicians, service providers, older adults, and their family caregivers.<sup>16</sup>

The interests and decisions made by older adults and their family caregivers may not always be the same. Differences in the wishes, preferences, and capacity of older adults and family caregivers can present ethical challenges to health care and social service professionals. Conflicts may also arise among family members of an individual older adult. Providers can use skills in listening, empathy, conflict resolution, and mediation to help families cope and plan effectively.<sup>17</sup> Holding a family meeting with a neutral facilitator or professional can mitigate disagreements, for example.

### Key Elements of Person- and Family-Centered Care in Practice

In practical terms, PFCC takes a holistic approach to the individual and values the person’s stated preferences about what is meaningful in the provision of care and support.<sup>18</sup> For example, it means that older people can have control over when, where, and how they do things; express preferences for the services they receive and who provides the services; are able to wake up and go to bed when they like; celebrate life events important to them and their family’s cultural traditions and rituals; and engage with their family and

friends in ways that provide purpose and meaning to them.<sup>19</sup> The following are key elements of PFCC:

- **Respect and dignity for the older person and family.** Health and social service professionals listen to and honor the person's and family's needs, values, preferences, and goals for care—asking, “What is important to you?” They are aware of the individual's and family's cultural background and the language in which they choose to communicate, so that they can provide culturally and linguistically appropriate services. They recognize the importance to the older adult of having purpose and meaning in daily living and quality of life. For example, a person's goal might be going to a grandson's wedding in six months, or attending weekly religious services in the community. Identified goals and preferences are incorporated into the planning, delivery, and coordination of services and supports across care settings.
- **Recognition of the whole person.** In practical terms, a “whole person” orientation includes care and support that is integrated within and coordinated across the health care and LTSS systems, and acknowledges the individual in the context of relationships, especially with family and friends. It also emphasizes the person's and the family's well-being, taking into account physical and mental health, spiritual and cultural traditions, social supports, and the person's engagement with her or his community.
- **Assessing and addressing both the individual's and the family caregivers' information, care, and support needs and their experience of care.** Based on an assessment of the older adult's and family's needs, a plan of care reflects the goals, values, and preferences of the individual and family. It is based on wants and needs that are meaningful to the individual (such as directing one's own daily schedules) and the support needs of family members or friends (such as education and training, and respite care) to feel better prepared to continue in their caregiving role without becoming overstressed. Recognizing and listening to family needs and concerns are fundamental principles of good care planning, especially when the plan of care depends on a family caregiver, such as when an older adult has Alzheimer's disease.
- **Promotion of communication, shared decision making, and empowerment.** This element is based on the principle that older adults, their families (if or when desired by the individual), and their health care and social service providers communicate together and build trust in ways that support individuals and families and are useful in decision making. It involves having access to timely, complete, and accurate information and tools to make shared and informed decisions and to plan for future needs. Such decisions should respect individual and family goals and cultural needs, involve the person in everyday care choices, help the person and family better manage health and care options, and reduce caregiver strain.<sup>20</sup>
- **Emphasis on coordination and collaboration across care settings.** Good care for older people with complex, chronic care needs and functional limitations requires a team of health and social service professionals, including direct care workers. This collaborative approach integrates family caregivers into the

care team, engaging them as partners in care and providing tools for family caregivers themselves, such as having one telephone number they can always call for help. Care and supportive services for older adults and their family caregivers are accessible, comprehensive, continuous over time, and coordinated among providers and across care settings.

For older people with cognitive impairment, person-centeredness may mean being able to articulate certain preferences and choices for themselves, such as what to wear or what to do during the day. Research has shown that people with early to moderate cognitive impairment may possess the capacity to express daily preferences for care, and should be encouraged to discuss their everyday care wishes with their family caregivers, before they no longer have the capacity to participate in decision making.<sup>21</sup> Including the perspective of people with cognitive impairment can enhance their autonomy and improve their quality of life.<sup>22</sup>

In a PFCC approach, family caregivers are no longer viewed as just a “resource” for their loved ones; rather, they are recognized as individuals who may themselves need information, training, and support. Family caregivers are acknowledged, their needs are assessed and addressed, and they have access to support services, such as respite care, to get a break from caregiving and to

enable them to continue in their caring role. Health and social service professionals can begin to acknowledge family members by asking the family caregiver, “How are *you* doing?”<sup>23</sup>

### Conclusion

Because serious illness and chronic disability affect the family as well as the older individual, researchers view including both the person and the family caregiver as full partners in care and decision making, and improving their care experiences, as important measures of person- and family-centered care.<sup>24</sup> Understanding and paying attention to family caregiver needs and situations, lessening the strain in the daily lives of caregiving families, and better understanding their perspectives are also important aspects of good care for older adults.

In recent years, PFCC has gained increased attention, but it is not yet commonplace in the delivery of health care and LTSS.

To promote greater adoption of PFCC in everyday practice, public policies should support adherence to the key elements of PFCC; sufficient resources and supportive technology to address coordination and continuity of care; a trained interdisciplinary care team with the older adult and family at the center; and the provision of services and supports that matter most to older adults and to their families.

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## Endnotes

- <sup>1</sup> According to the Institute for Patient- and Family-Centered Care, the definition of family and the degree of family involvement in care and support are determined by the person, provided he or she has the capacity to do so. <http://www.ipfcc.org/about/index.html>.
- <sup>2</sup> The term “family caregiver” is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older adult with chronic or disabling conditions.
- <sup>3</sup> The Institute of Medicine (IOM) defines patient-centered care as “health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs and preferences and that patients have the education and support they need to make decisions and participate in their own care.” IOM, *Envisioning the National Health Care Quality Report* (Washington, DC: National Academies Press, 2001).
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- <sup>13</sup> American Psychological Association, *Stress in America* (Washington, DC: American Psychological Association, January 2012).
- <sup>14</sup> Feinberg et al., *Valuing the Invaluable*.
- <sup>15</sup> National Association of Social Workers, *NASW Standards for Social Work Practice with Family Caregivers of Older Adults* (2010), <http://www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf>.
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<sup>20</sup> L. Feinberg and A. M. Reamy, *Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers*, AARP Public Policy Institute Fact Sheet 239 (Washington, DC: AARP, October 2011).

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