

INTERPROFESSIONAL FAMILY CAREGIVING COMPETENCIES

Background

The number of older adults living with chronic disease, functional decline, and serious illness is growing exponentially at a time when availability of both family and professional caregivers is strained. Achieving optimal outcomes for this vulnerable population involves improving the quality of care delivered, both by families and by health professionals and community programs. By 2050, it is projected that for every 100 adults age 15-64 in the United States, there will be 36 older adults age 65+. This dramatic increase in the age dependency support ratio means that an ever-growing number and percentage of working adults in the US will be involved in family care, posing both personal and financial costs, and potential loss of productivity for employers.

In early 2015, AARP conducted a national survey of family caregiving and identified that many family caregivers struggle with tasks that nurses typically perform, referred to as “medical/nursing tasks”.¹ These include management of medications, dressing changes, handling equipment such as oxygen tanks and dealing with incontinence. Family members typically coordinate complex, disconnected and even contradictory clinical oversight from multiple providers and institutions. Taken together, family caregiving spans everything from administering medications, to accurately recognizing clinical deterioration requiring urgent intervention, to managing appointments and billing issues, to providing personal assistance with hygiene and routine functional needs, to discussions of preferences for end-of-life care and spiritual needs. Sometimes the need to provide care begins abruptly, for example immediately following a hospital stay; in other situations, the needs evolve slowly over time, gradually taxing the capacity of families to manage complex care.

The demands of family caregiving have implications for the mental, physical and financial health of those providing this vital service. Both the caregiver and the person receiving care can face psychological and social challenges such as depression, anxiety and isolation. The stress associated with caregiving can have a negative effect on caregiver health. These issues can go unrecognized by clinicians and threaten quality of life and well-being.

¹ Reinhard, S. C., Levine, C., & Samis, S. (2012). *Home alone: Family caregivers providing complex chronic care*. Washington, DC: AARP Public Policy Institute. Retrieved on April 9, 2019 from:
https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

Purpose

Clinical education has an important role in improving health outcomes for caregivers and care recipients by discouraging a health system culture that ignores or excludes family members and moving towards a family-centered approach to care that recognizes caregivers as integral members of the health team. To support this shift, clinicians must be prepared with the skills, knowledge and ability to support caregivers as care recipients' needs evolve in both type and complexity over the trajectory of illness. As a key preliminary step, the following interprofessional caregiving competencies were developed in collaboration with national experts in family caregiving for use in undergraduate, graduate and professional clinical education to define the desired outcomes of learning activities or curricula.

Domain one: The nature of family caregiving

This domain focuses on the competencies needed by health professionals to understand fundamental concepts relevant to family caregiving.

1. Describe the major theoretical perspectives that have been used to explain and explore the complexity of family caregiving (e.g., stress-process model, symbolic interactionism).
2. Describe the negative and positive consequences of family caregiving for individuals (both care recipients and family caregivers), families and society.
3. Recognize the heterogeneity of family caregiving situations based on the characteristics of the care recipient, family caregiver, nature of the relationship between the care recipient and the family caregiver, and caregiving situation (e.g., illness condition and trajectory).
4. Identify the key sociocultural variables that impact family caregiving.

Domain two: Family caregiving identification and assessment

This domain focuses on competencies needed by health professionals to recognize, understand and assess family caregiving situations and the impact of care on care recipients and family caregivers.

1. Incorporate the identification of who is or has a family caregiver (s) into routine health assessments.
2. Assess care recipient and family caregiver preferences and values to determine goals and priorities.
3. Use valid and reliable tools for assessing family caregiver preparedness for assuming the caregiving role as appropriate for the clinical context and population.
4. Use valid and reliable tools to assess the quality of the relationship between the family caregiver and the care recipient and its impact on the provision of care.
5. Use valid and reliable tools to assess the positive and negative consequences of family caregiving for the care recipient and the family caregiver (e.g. caregiving-specific strain/burden, disease-specific quality of life, physical and mental health, social isolation, financial strain).
6. Implement strategies to monitor and respond to changes in the caregiving situation over time.

Domain three: Providing family-centered care

This domain focuses on competencies needed by health professionals to partner effectively with care recipients and family caregivers to enhance the family caregiving experience and reduce or eliminate negative sequelae over the course of the caregiving trajectory.

1. Demonstrate the inclusion of care recipient, family caregiver and others, as appropriate, in a shared decision-making process for family caregiving.
2. Implement evidence-based interventions to support the quality and effectiveness of family caregiving tailored to the needs, preferences, goals and priorities of the care recipient and the family caregiver.

3. Identify how informal and formal support options can be accessed in a comprehensive family caregiving management plan.
4. Explore how health promotion and family caregiver self-care management strategies can be incorporated into the caregiving routine.
5. Explore ways in which enrichment and predictability may be incorporated into the family caregiving routine.
6. Develop a family caregiving support plan based on an assessment of the strengths, limitations, and resources of the family and the family caregiver.

Domain four: The context of family caregiving

This domain focuses on competencies needed by health professionals to provide family-centered care based on an assessment and understanding of how individual, family, sociocultural, health care system and illness-related variables impact specific family caregiving situations.

1. Tailor the assessment of family caregiving situations based on an understanding of how the illness condition (e.g., dementia vs. cancer) impacts the family caregiving situation.
2. Describe patient, provider, and health care system factors that can facilitate or interfere with effective family caregiving assessment and management.
3. Recognize how one's own conscious and unconscious biases may impact the dynamics and interactions when working with diverse families and family caregivers.
4. Tailor the assessment and intervention with families based on a sensitive understanding of how important sociocultural variables (e.g., race, ethnicity, language, sexual orientation, education) impact care.
5. Develop an understanding of the local, state and federal financing of health care that impacts the populations of family caregivers in one's specific area of clinical practice.

Definitions

- *Family Caregiving*: the provision of care to individuals with acute, chronic or terminal illnesses or conditions by people who are related by blood, marriage or affinity (i.e., families of choice)
- *Care Recipient*: an individual of any age who is dependent in one or more Instrumental Activities of Daily Living or Activities of Daily Living (IADLs or ADLs) or who needs assistance with complex care tasks as a result of an acute, chronic or terminal illness or condition
- *Family Caregiver*: the person(s) who provide assistance with IADLs, ADLs or complex care tasks to a care recipient who is related by blood, marriage or affinity (i.e., families of choice)
- *Healthcare Team*: the family caregiver(s), the care recipient, primary care providers, clinical specialists, psychologist(s), allied health professional(s), social worker(s), care coordinator(s), and those providing spiritual guidance who work collaboratively to assist the care recipient.

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