

Chapter 3

Patient-Client and Family Caregiver Considerations



Gilaine Nettles, Mary-Anne Joseph, and Jared Rehm

Learning Objectives

1. Understand historical perspectives pertaining to the value of patient- and family-centered care.
2. Describe ways to improve the home care experience for patients who are older.
3. Articulate the characteristics and responsibilities of family caregivers.
4. Identify challenges faced by family caregivers in home care settings.
5. Articulate quality of life and wellness strategies for patients and family caregivers.
6. Provide examples of patient autonomy and choice making in the home care setting.

Historical Perspectives on Person-Centered Care, Family Caregiving, and Interprofessional Collaboration

Essential to the interprofessional team (IP) approach to quality healthcare is the concept of *patient-centeredness*. The significance of the patient being at the *center* of care delivery has been recognized for many decades. In 2001, the Institute of Medicine released a paper called “Crossing the Quality Chasm: A New Health System for the 21st Century” [1]. The paper underscored the importance of patient-centeredness in improving healthcare systems. Similarly, a few years later, the

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/978-3-031-40889-2_3.

G. Nettles (✉) · J. Rehm
Department of Physical Therapy, College of Health Sciences, Alabama State University,
Montgomery, AL, USA
e-mail: gnettles@alasu.edu; jrehm@alasu.edu

M.-A. Joseph
Department of Rehabilitation Studies, College of Health Sciences, Alabama State University,
Montgomery, AL, USA
e-mail: majoseph@alasu.edu

Triple Aim framework refocused healthcare providers' attention on the significance of patient-centered care [2].

The Interprofessional Education Collaborative (IPEC) was established in the USA in 2009. Its mission is to prepare healthcare professionals to become collaborative practitioners by implementing interprofessional education in all professional programs. The ultimate goal of interprofessional education and collaboration is to assure patient-centered care. In 2010, the World Health Organization (WHO) released a framework for collaborative practice and interprofessional education. The framework provided guidelines for healthcare professionals to learn from one another, to collaborate in clinical practice, and to effectively develop and implement patient care plans. By cooperating with patients and their families and caregivers, collaborative practitioners build teams that are founded on mutual respect, shared values, and positive communication [3].

In 2011, the interprofessional collaborative panel, composed of six participating professional organizations, united to create the core competency domains for interprofessional collaboration and healthcare delivery. These six professional organizations included the American Association of Colleges of Nursing, the American Association of Colleges of Osteopathic Medicine, the American Association of Colleges of Pharmacy, the American Dental Education Association, the Association of American Medical Colleges, and the Association of Schools and Programs of Public Health. The core competency domains included (1) teams and teamwork, (2) communication, (3) roles and responsibilities, and (4) values and ethics [4]. In 2016, nine new disciplines joined IPEC [5]. The new professions included podiatry, physical therapy, occupational therapy, psychology, veterinary medicine, social work, and physician's assistant education. This new group (the Health Professionals Accreditor Collaborative) further developed the core competencies and expanded the shared vision of achieving quality outcomes in healthcare and improving health equity in population health through collaborative educational learning experiences and practices [5]. This was a positive development for those strongly advocating for more patient-centered healthcare systems.

The Quadruple Aim, published in 2014, evidenced that when IP teams worked collaboratively with patients and families, both patient and provider satisfaction with care increased. Patients reported feeling a part of the team and better connected with healthcare providers. Patients also reported better disease management and better health outcomes [6]. The Quadruple Aim addressed the effects of provider stress, fatigue, and burnout and highlighted the need to enhance providers' healthcare experiences. These improved experiences would impact patients' quality of care and safety, but they would also enhance the care experiences of each IP team member [7].

Additional Federal Reports on Family Caregiving

In 2016, the National Academy of Sciences, Engineering, and Medicine (NASEM) developed an ad hoc committee on family caregiving for older adults. The committee was tasked with the following: (1) investigating the prevalence of family caregiving and the consequences of caregiving on caregivers, (2) exploring existing programs designed to meet the needs of caregivers, and (3) providing recommendations for policies to support caregivers. Similarly, the 2016 NASEM report entitled “Families Caring for an Aging America” provided recommendations for policy changes to better support caregivers’ health, economic, and social needs through agencies such as the Centers for Medicare and Medicaid Services, Social Security, and the Department of Veterans Affairs. Such policy changes would propel an awareness of the tremendous demand for caregivers due to the growing older adult population and the diminished supply of trained caregivers.

According to the NASEM report, 72.8 million US residents will be over the age of 65 by 2030. Furthermore, those in their 80s and older are expected to increase to approximately 37% of the population by 2050 [8]. Without an adequate supply of trained caregivers, this responsibility is increasingly falling on family members. Many family caregivers assume the role by default because no one else is available or willing to provide continuous care for the patient. This special report also revealed that spouses and daughters are likely to be primary caregivers and spend the most time providing care and making caregiving decisions. Secondary caregivers tend to be men who provide intermittent care and often support the primary caregiver.

The Committee of Family Caregiving was established to study trends in caregiving. The committee utilized data and findings from the National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) to aid them in compiling a report with recommendations for federal and state agencies. The study surveyed Medicare beneficiaries who were over the age of 65 and needed caregiver assistance with activities of daily living (e.g., toileting, transferring, bathing, dressing, grooming, or continence). More than half of the caregivers in the study were employed and needed the benefit of time off to assist family members. The study exposed the need for more policies and programs to support caregivers and the need for more research to identify strategies for lessening the stress and strain of family caregivers [9]. The COVID-19 pandemic resulted in large numbers of patients requiring medical treatment [10]. With the shelter-in-place requirement and limited hospital access, caregiver burden during the pandemic was exacerbated.

Improving the Home Care Experience of Older Patients

One of the authors of this chapter is particularly grateful for the IP team’s role in maximizing her father’s home care experience:

My father said that he never wanted to go to a nursing home and he wanted to stay in his home and age in place. Working with the interprofessional team helped me to grant his wishes. In doing so, we had many challenges on a daily basis and it was not always the best situation. But, being at home was better for him than being anywhere else. I am grateful for all of the healthcare providers who guided his home health care. (Gilaine Nettles)

Transforming a home environment into a healthcare environment can be a daunting task. However, members of the IP team are experts at suggesting ways to create a safe and therapeutic environment. For example, physical and occupational therapists can provide low-cost suggestions to increase safety in the home such as installing grab bars, removing throw rugs and clutter, replacing doorknobs with handles, and promoting the use of adaptive equipment. However, some changes can be expensive and more complicated (e.g., adding a fully accessible first-floor bathroom) [11]. In these instances, the IP team should work conjointly with the family to locate trustworthy and affordable contractors. Similarly, home maintenance may become more difficult for older patients, and the cost for maintaining a safe home environment can be quite expensive. Unrepaired floors, steps, and bathroom structures can become safety hazards [12]. The IP team should continuously evaluate the home environment and make necessary recommendations. Team members should link families with appropriate community resources that will promote patient safety and accessibility within the home setting [13].

To maximize the patient's home care experience, IP teams may solicit the support of family members, friends, and other caregivers. Having an established support system can enhance the older patient's level of motivation, compliance, confidence, and satisfaction. A support system is also important when creating opportunities for continuity of care. IP team members can conduct informational sessions with family members and caregivers to facilitate caregiving skill development and appropriate engagement with all healthcare tasks [14].

Health Literacy

As people age, they become more susceptible to health conditions that impact their levels of functioning and their ability to find meaning and purpose in life. For many older adults, this is a period of adjustment. Many older patients struggle to fully understand their health conditions and their new reality as it relates to diminished capacities. Health literacy is useful in helping patients adapt to the biopsychosocial effects of illness and disease. Health literacy is equally beneficial for caregivers. According to the Centers for Disease Control and Prevention (CDC), "personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" [15]. Approximately 88% of adults in the USA have inadequate levels of health literacy that prevent them from navigating the healthcare system and enhancing their well-being [16]. Only 12% of people living in the USA were found to be proficient in health literacy. The lack of health-related knowledge

or skills may present obstacles to engaging in healthy behaviors, taking advantage of preventative services, and managing acute and chronic diseases [17]. Health literacy positively correlates with making better health-related decisions. Therefore, it is imperative that IP team members make health literacy a priority for patients and caregivers.

Health literacy can be accomplished through health classes, health groups, phone consultations, one-on-one meetings with health providers, and informational materials such as pamphlets. Whichever method is decided upon, giving attention to patient and caregiver learning styles can increase the effectiveness of health literacy. It is essential that both the patient and the caregiver absorb health-related information via their preferred learning style [18]. Learning styles include visual (watching the task performed), auditory (listening to an audio recording), kinesthetic (hands-on activities), and reading and writing. Teaching styles, which include explanation, verification, and demonstration, may also need to be tailored to the patient or the caregiver's intellectual and cognitive ability. Healthcare literacy can positively influence communication, patient compliance with treatment, and the patient's overall health status, all of which can result in cost savings to healthcare systems and improved patient-provider satisfaction [17]. Health literacy interventions have been linked to patients and caregivers being able to solve health problems more independently, thus resulting in fewer visits to emergency rooms [19].

Support Systems for Family Caregivers in Home Care Settings

According to a report by the American Association of Retired Persons (AARP) and the National Alliance of Caregiving (NAC), nearly 53 million (21.3% of US adults) serve as caregivers, providing \$600 billion in unpaid care across the USA [20]. With this in mind, healthcare providers must show high regard for caregivers and be mindful of *caregiver burden*. Caregiver burden can be defined as the strain or load experienced by a person who is responsible for the care of another individual who is chronically ill, disabled, or older. This burden impacts both the caregiver and the patient and is reported to affect emotional wellness, physical health, social life and relationships, finances, and overall well-being [21]. To reduce the burden of care, external support systems and resources should be offered to assist the caregiver. Additionally, IP team members must avoid being rigid about care appointments or becoming impatient when providing instruction on caregiving tasks. Team members must avoid overwhelming caregivers with medical jargon, negative feedback, predictions about prognoses, or the cost of services [20]. Table 3.1 provides resources for family caregivers. These resources are supported federally, thus magnifying the importance of caregiver resources and supports. Federal subsidies also assure continuity of these essential resources as well as equity of access [22].

Table 3.1 Resources for family caregivers [22]

Resource	Description
National Family Caregiver Support Program (NFCSP)	Established in 2000 under Section 371 of the older Americans Act of 1965 (as amended, title IIIIE), the NFCSP provides grants to states and territories to fund a range of supports that assist family and informal caregivers in caring for their loved ones at home for as long as possible
Eldercare locator	The eldercare locator is a public service of the US Administration on aging that helps caregivers locate resources for older adults in any US community
National Center on caregiving	The NCC serves as a central source of information on caregiving and long-term care issues for policymakers, service providers, media, funders, and family caregivers throughout the country
Caregiver Action Network (CAN)	The CAN is a nonprofit organization providing education, peer support, and resources to family caregivers nationwide free of charge
eXtension	eXtension is a website developed by the US Department of Agriculture (USDA) cooperative extension system that allows caregivers and advocates to access a wide range of information and materials related to disaster preparedness, housing, and nutrition

Characteristics and Responsibilities of Family Caregivers in the Home Care Milieu

The IP collaborative practice model places the position of the caregiver at its heart, connecting the domains of shared responsibility and values, communication, and teamwork. Assuming the role of a caregiver can be rewarding, but it can also be highly demanding. While the patient is the team captain, caregivers must be coaches and leaders. Active listening is essential to effective communication with the patient and the IP team. This skill helps the caregiver to understand the patient's wishes in order to accomplish care fruition [23]. Caregivers must possess the core values of altruism, caring, and compassion for the patient. They should also demonstrate respect for the patient and all members of the IP team. Caregivers should strive to understand the varied roles and functions of IP team members. They must be receptive to spending time with each provider, asking questions, and gaining knowledge about their responsibilities on the team. Communication with physicians, physician assistants, social workers, case managers, pharmacists, etc. is routine caregiver tasks [8].

Caregivers quickly learn to become care managers (e.g., retaining medical records in a designated location, maintaining a schedule of prescribed in-home activities, and keeping an up-to-date list of medications, appointments, and important contact numbers). Caregivers should keep at the ready a list of pertinent questions for IP team members so they can be easily accessed during provider visits. It is also recommended that caregivers maintain relevant notes pertaining to the patient's day-to-day progress and care. Caregivers can readily relay needed care information when notes are organized and dated. Additionally, caregivers must commit to being available to meet with team members as often as necessary. They

may be required to participate in provider treatments, coordinate times for future home visits, and execute the patient's prescribed care program between visits [23].

Challenges Faced by Family Caregivers in Home Healthcare

Family caregivers must strive to balance their personal needs and the demands of caregiving. This can be done by soliciting support from other family members or the patient's significant others. Some caregivers tend to take on more responsibility than they can effectively handle. Thus, these caregivers benefit from delegating caregiving tasks to others. IP team members must actively listen to caregivers and anticipate their needs. They should support caregivers in their efforts to delegate caregiving tasks to others who are equally capable of caring for the patient. Caregivers need time for self-care, rest, and rejuvenation. Respite episodes are particularly important for employed caregivers and for those who are responsible for the care of minor children or other family members. Under these circumstances, the demands of caregiving can be challenging and overwhelming [24].

It is important that caregivers be supported in maintaining realistic goals (expectations) for themselves and their patients. Research findings have shown that caregiving has a significant impact on quality of life [8, 25–29]. Family caregivers may experience depression, anxiety, psychosomatic symptoms, restriction of roles and activities, strained marital relationships, and diminished physical health [30]. Other challenges encountered by caregivers may include the loss of identity or identity or role confusion. These experiences have the ability to impact patients and caregiver's quality of life.

Quality of Life and Wellness Considerations for Patients and Caregivers

Social isolation and loneliness are often experienced by older adults and those living with severe chronic illnesses. These individuals are often limited in their efforts to independently engage in activities of daily living [31]. While older adults do not have a higher rate of depression than the general population, this group is at a significantly higher risk for the development of depression [15]. Similarly, between 40% and 70% of caregivers exhibit symptoms of depression [32]. Research findings indicate that social isolation and loneliness are related to higher rates of major mental and physical illnesses (e.g., cardiovascular and cerebrovascular risks, depression, anxiety, increased risk of dementia), which poses possible health threats for both patient and caregiver [32]. Signs of depression may be manifested in the following manner [32]:

- Persistent sad, anxious, or “empty” mood.
- Feelings of hopelessness, guilt, worthlessness, or helplessness.

- Irritability, restlessness, or having trouble sitting still.
- Loss of interest in once pleasurable activities.
- Decreased energy or fatigue.
- Moving or talking more slowly.
- Difficulty concentrating, remembering, or making decisions.
- Difficulty sleeping, waking up too early in the morning, or oversleeping.
- Eating more or less than usual, usually with unplanned weight gain or loss.
- Thoughts of death or suicide or suicide attempts.

Loneliness and social isolation can also be experienced by caregivers when care demands hinder their ability to live a balanced life. Caregivers may have altered their formal routines, lifestyle, and social activities in order to focus on the patient, resulting in reduced time to connect with friends and social groups [32]. Regular communication among IP team members about the mood and affect of the patient and caregiver is important. When an IP team member suspects that the patient or caregiver is depressed or exhibiting severe anxiety, a referral should be made to the appropriate mental health authority. It is imperative to remember that the well-being of the caregiver directly impacts the well-being of the patient. The caregiver's ability or inability to adequately perform caregiving tasks can directly impact the quality of care rendered to the patient. Quality of care can significantly impact the patient care outcomes [33].

Client and Family Autonomy and Choice Making

To assure quality care and positive outcomes for home care patients, the basic principle of patient autonomy must be respected. Patient autonomy is formally defined as:

The right of patients to make decisions about their medical care without their healthcare provider trying to influence the decision. Patient autonomy does allow for healthcare providers to educate the patient but does not allow the healthcare provider to make the decision for the patient [34].

Autonomy encompasses patients' freedoms to self-govern and make decisions that they believe are in their best interest. When providing healthcare in the home, IP team members must show their respect and appreciation for patient autonomy. This can be done by respecting requests and decisions relating to home modifications, adhering to the day and time of prescheduled home visits, and deciding what procedure or equipment is acceptable or necessary. The IP member can also demonstrate reverence for autonomy by respecting religious beliefs, religious holidays, and cultural and family norms. Desires to terminate services or change providers should also be respected. The necessity for patient autonomy is further emphasized during the establishment of the advanced directives, living will, medical power of attorney,

and other estate planning activities. IP team members should not assert their opinions, beliefs, or biases when it comes to these very private matters.

Multicultural Considerations

When working in the home care milieu, it is imperative that providers understand the cultural perspectives of the patient and family. Understanding patient and family choices and lived experiences is important. Studies show that ethnic minority caregivers provide more caregiving support than their White counterparts [35]. Additionally, Asian American caregivers' use of professional support is significantly less than their White counterparts [36]. Research findings reveal that African American caregivers experience lower levels of caregiver burden and depression than White caregivers [36]. Hispanic and Asian American caregivers were more depressed than White caregivers [36]. The main reason for these divergences is that cultural perspectives differ across ethnic groups and impact caregivers' perceptions of the caregiving role, their utilization of support services, and clinical presentations and interactions [36]. While ethnicity is a dominant multicultural component, other factors such as sexual orientation, religion, gender, socioeconomic status, environment, and geographic location should be taken into consideration as well.

Home service providers, while not expected to know everything about a person's culture, are expected to acquire minimum competencies that would permit them to be mindful and respectful of patients and caregivers' cultural practices. Becoming culturally competent can promote insight into interventions that may or may not be desirable for the patient or family. Having this knowledge assures that interventions are tailored to fit the needs of patients and caregivers.

Chapter Summary

Now, more than ever, IP home healthcare teams are essential to providing high-quality and cost-effective services that improve health equity and healthcare outcomes. To that end, patient-centered care (coupled with IP team members' support and respect for family caregivers) is an essential function in achieving favorable patient outcomes. Caregiving is a rewarding yet tremendous responsibility. IP healthcare teams can reduce caregiver burden by being available and supportive of caregivers' needs. It is important to remember that the caregiver's ability or inability to adequately perform caregiving functions can directly impact care quality and patient health and wellness outcomes.

Case Study: Jeralean

The case study profiles the health status of Jeralean, a candidate for home healthcare services.

Jeralean is a 75-year-old African American woman with a right lower limb amputation distal to the knee, hypertension, type 2 diabetes, glaucoma, sleep apnea, constipation, painful neuropathy, and osteoarthritis. She complains of pain and stiffness in her fingers and wrists. She is not always compliant with her medications, frequently forgetting to take them. She reports having too many doctors and being on “too much medication.” Jeralean was diagnosed with pneumonia twice in recent years. She presents with a poor appetite, weight loss (20 pounds in 6 months), anxiety, and sadness. Jeralean lost her husband of 45 years less than a year ago.

Jeralean spends a significant amount of time alone and does not desire to be around people. She spends most of her day sitting on the couch in her living room. She consumes large amounts of processed food that contains copious amounts of sodium, sugars, and fats which causes her glucose and blood pressure levels to be higher than normal. She reports “losing strength and energy.” She sleeps very little at night and has difficulty falling asleep and remaining asleep.

Before her husband’s death, the couple took daily walks, shared housekeeping tasks, and cooked most of their meals together. Her current medications include aspirin 81 mg daily, Lopressor 25 mg twice daily, metformin 500 mg twice daily, Lantus 7.5 units BID, NovoLog pen, Combigan 1 gtt os twice daily, Miralax 17 g/day, Neurontin 600 mg TID, Lyrica 100 mg TID, Tylenol #3-tab q 4 h as needed, and nortriptyline 50 mg daily. Jeralean has begun to have difficulty measuring her insulin correctly and giving her insulin shots during the day when her daughter is unavailable. She repeatedly has cuts on her left foot and her hands. She is often unaware of when the injuries occur and unable to gauge the severity of the injuries due to the already existing pain and numbness in the areas. Jeralean has been dropping things lately and has broken several glasses and plates because they slipped out of her hand.

Jeralean resides in a small rural southern county in the USA. Her 48-year-old daughter Alice resides with her and would love to see her remain at home for as long as possible. Alice states that until recently, her mother was meticulous about grooming and self-care and maintained a neat and orderly home. According to Alice, Jeralean has fallen three times recently: once in the bathroom, once in the kitchen, and once in the living room. She believes that her mother is experiencing some balance issues and vision loss. Jeralean no longer wears her prosthesis. She does not like for Alice to worry about her or to give her advice. She becomes angry when Alice attempts to provide physical assistance. While previously being quite social, Jeralean’s current social interactions consist mostly of speaking with her siblings and staff at her doctors’ offices.

Alice is an only child and works full-time as an accountant. Her place of employment is close to her mother’s home. Therefore, she can “check on” Jeralean throughout the day on most days. Alice is in good health. She is divorced (for less than a

year) and has no children. Her life priority at this point is to care for her mother. She worries about her once vibrant mother wasting away and giving up on life. Other than her daughter and sibling who reside out of state, Jeralean does not have a support system. At this time, she does not use a wheelchair or walker, or any other special or adaptive equipment. There are no handrails in the shower or anywhere else in the home. Currently, Jeralean travels over 60 miles to receive healthcare services.

Discussion Question

1. When considering the case of Jeralean, in what areas could she and her family be assisted with health literacy services and how might that service positively and/or negatively impact them?

Multiple Choice Questions

1. Which of the following best describes the term patient-centeredness?
 - (a) The interprofessional team approach to healthcare that places the patient at the center of care delivery and ensures that the patient's needs and values drive and guide clinical decisions.
 - (b) The interprofessional healthcare team meets with the patient and the caregiver in the patient's home to instruct the caregiver on techniques to provide quality care and assess the caregiver's ability to care for the patient.
 - (c) The team of healthcare providers meets with patients and families in a home environment to ensure that the caregiver is providing quality care to the patient.
 - (d) Interprofessional healthcare teams work collaboratively to decide what is best for the patient, based on their knowledge, expertise, and clinical judgment.
2. In 2010, the World Health Organization released a framework for interprofessional education and collaborative practice. Which of the following statements is *true* about the WHO framework for IPECP?
 - (a) The framework provides guidelines for healthcare professionals to learn from one another in academic settings.
 - (b) The framework provides guidelines for healthcare professionals to work collaboratively in clinical practice settings to develop and implement healthcare plans as a team.
 - (c) The framework promotes teams that are founded on mutual respect, shared values, and positive communication.

- (d) All of these statements are true regarding the WHO framework for interprofessional education and collaborative practices.
3. Health literacy is best defined as
- (a) The degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others
 - (b) A patient who has achieved the highest level of difficulty in reading and understanding medical information related to his or her health condition
 - (c) The capacity of a patient to determine the best course of care for themselves or their family members based on their reading comprehension
 - (d) The ability of the person to gather health information from the Internet and social media sources to learn about health conditions
4. Which of the following *best* defines caregiver burden?
- (a) Caregiver burden is best defined as the strain or load of the person who is responsible for caring for a chronically ill, disabled, or older person that can impact the well-being and quality of life of both the patient and the caregiver.
 - (b) Caregiver burden is best defined as the cross the caregiver must bear for the blessing they have received in life or the blessing they hope to receive in the future.
 - (c) Caregiver burden refers to the cost of providing quality healthcare in the home environment related to the modifications and adaptations that the caregiver is required to make.
 - (d) Caregiver burden refers to the physical lifting required by caregivers to assist patients who can't move from one surface to another or transition into different positions.
5. What is the primary role of the caregiver on the interprofessional health-care team?
- (a) The primary role of the caregiver is to provide continuous support in a healing relationship for the patient whenever and wherever it is needed.
 - (b) The primary role of the caregiver is to follow the instructions of the health-care professionals and communicate them to the patient.
 - (c) The primary role of the caregiver is to ensure that the healthcare providers show respect for the patient, keep their scheduled appointments, and report to the physician or home health agency about the quality of each healthcare provider.
 - (d) All of the above.
6. Who are the caregivers?
- (a) Caregivers tend to be spouses, partners, family members, or neighbors who often assume the role without much training and preparation.
 - (b) Caregivers are individuals from a home health agency whose sole purpose is to assist with daily activities and chores.

- (c) Caregivers are typically the men of the family who can provide the most financial support for the patient.
- (d) Caregivers are the individuals and family members who volunteer to care for patients because they have the most time and energy to support the patient.

References

1. Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. The National Academies Press. <https://doi.org/10.17226/10027>
2. Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: Care, health, and cost. *Health Affairs*, 27(3), 759–769. <https://doi.org/10.1377/hlthaff.27.3.759>
3. World Health Organization. (2010, September 10). *Framework for Action on Interprofessional Education & Collaborative Practice*. World Health Organization. Retrieved May 7, 2023, from <https://www.who.int/publications-detail-redirect/framework-for-action-on-interprofessional-education-collaborative-practice>.
4. Interprofessional Education Collaborative Expert Panel. (2011). *Core competencies for interprofessional collaborative practice: Report of an expert panel*. Interprofessional Education Collaborative.
5. Interprofessional Education Collaborative. (2016). *Core competencies for interprofessional collaborative practice: 2016 update*. Interprofessional Education Collaborative.
6. Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: Care of the patient requires care of the provider. *The Annals of Family Medicine*, 12(6), 573–576. <https://doi.org/10.1370/afm.1713>
7. Arnetz, B. B., Goetz, C. M., Arnetz, J. E., Sudan, S., vanSchagen, J., Piersma, K., & Reyelts, F. (2020). Enhancing healthcare efficiency to achieve the QUADRUPLE AIM: An exploratory study. *BMC Research Notes*, 13(1). <https://doi.org/10.1186/s13104-020-05199-8>
8. NASEM, Family Caregivers Alliance. (2016). *Caregiver statistics: Demographics*. <https://www.caregiver.org/resource/caregiver-statistics-demographics/> I guess it was deleted. It was under challenges faced by caregivers—delete this.
9. National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. The National Academies Press. <https://doi.org/10.17226/23606>
10. Sinsky, C. A., Brown, R. L., Stillman, M. J., & Linzer, M. (2021). COVID-related stress and work intentions in a sample of US health care workers. *Mayo Clinic Proceedings: Innovations, Quality & Outcomes*, 5(6), 1165–1173. <https://doi.org/10.1016/j.mayocpiqo.2021.08.007>
11. Chandrasekhar, P., Moodley, S., & Jain, S. H. (2019). 5 Obstacles to home-based healthcare, and how to overcome them. *Harvard Business Review*. <https://hbr.org/2019/10/5-obstacles-to-home-based-health-care-and-how-to-overcome-them#:~:text=These%20include%3A%20environmental%20hazards%20such,needs%20of%20patients%20receiving%20home>
12. Herbert, C., & Molinsky, J. (2019). What can be done to better support older adults to age successfully in their homes and communities? *Health Affairs*, 38(5), 860–864. <https://doi.org/10.1377/hlthaff.2019.00203>
13. Jayson, S. (2021, November 19). *How to make your home safe for aging parents*. AARP. Retrieved May 7, 2023, from <https://www.aarp.org/caregiving/home-care/info-2019/safety-tips.html>.
14. Prado, P., Norman, R. S., Vasquez, L., Glassner, A., Osuoha, P., Meyer, K., Brackett, J. R., & White, C. L. (2022). An interprofessional skills workshop to teach family caregivers of people living with dementia to provide complex care. *Journal of Interprofessional Education & Practice*, 26. <https://doi.org/10.1016/j.xjep.2021.100481>
15. Centers for Disease Control & Prevention. (2022). *What is health literacy?* <https://www.cdc.gov/healthliteracy/learn/index.html>

16. Lopez, C., Kim, B., & Sacks, K. (2022). *Health literacy in the United States: Enhancing assessments and reducing disparities*. https://milkeninstitute.org/sites/default/files/2022-05/Health_Literacy_United_States_Final_Report.pdf
17. Phaneuf, M. (2013). *Teaching in caregiving*. <http://www.prendresoin.org/wp-content/uploads/2013/11/Teaching-in-caregiving.pdf>
18. Chesser, A., Woods, N., Smothers, K., & Rogers, N. (2015). Healthy literacy and older adults: A systematic review. *Gerontology & Geriatric Medicine*, 2, 1–13.
19. Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, 7(4), 438–445. <https://doi.org/10.1016/j.ijnss.2020.07.012>
20. Caldera, S., Houser, A., & Choula, R. (2023). *Valuing the invaluable 2023: Strengthening support for caregivers*. AARP Public Policy Institute. <https://doi.org/10.26419/ppi.00082.008>
21. Zolbin, M., Huvila, I., & Nikou, S. (2022). Health literacy, health literacy interventions and decision making: A systematic literature review. *Journal of Documentation*, 78(7), 405–428.
22. USDHHS. (2023).
23. Underwood, A., Watson, S., & Booth, B. (2015). *Caregiver's handbook: A guide to caring for the ill, elderly, or disabled-and yourself*. Harvard Medical School.
24. Akçoban, S., & Eskimez, Z. (2023). Homecare patients' quality of life and the burden of family caregivers: A descriptive cross-sectional study. *Home Health Care Services Quarterly*, 1–14. <https://doi.org/10.1080/01621424.2023.2177224>
25. Sales, E. (1991). Psychosocial impact of the phase of cancer on the family. *Journal of Psychosocial Oncology*, 9, 1–9.
26. Ell, K., Nishimoto, R., Mantell, J., & Hamovitch, M. (1988). Longitudinal analysis of psychosocial adaptation among family members of patients with cancer. *Journal of Psychosomatic Research*, 32, 429–438.
27. Johnson, J. (1988). Cancer. *Recent Result Cancer Research*, 108, 306–310.
28. Pederson, L. M., & Valanis, B. G. (1988). The effects of breast cancer on the family. *Journal Psychosocial Oncology*, 6, 95–118.
29. Toseland, R. W., Blanchard, C. G., & McCallion, P. (1998). A problem-solving intervention for caregivers of cancer patients. *Social Science Medicine*, 40, 517–528.
30. Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R., Eden, J. editors. *Families Caring for an Aging America*. Washington (DC). National Academies Press (US); 2016 Nov 8. 3, Family Caregiving Roles and Impacts.
31. Townsend, E. (2020). *Home health care can help seniors with loneliness and social isolation*. Retrieved from <https://www.heartsforhospiceandhomehealth.com/home-health-care-can-help-seniors-with-loneliness-and-social-isolation/>
32. Wellness Everyday. (2023). *Caregiver stress*. Retrieved from <https://www.wellnesseveryday.org/caregiver-loneliness>
33. Alonazi, W., & Thomas, S. (2014). Quality of care and quality of life: Convergence or divergence? *Health Service Insights.*, 10(7), 1–12.
34. Marks, J. (2021). *Medical definition of patient autonomy*. MedicineNet. https://www.medicinenet.com/patient_autonomy/definition.htm
35. McCann, J., Hebert, L., Beckett, M., Scherr, P., & Evans, D. (2000). Comparison of informal caregiving by black and white older adults in a community population. *Journal of the American Geriatrics Society*, 48, 1612–1617.
36. American Psychological Association. (2011). *Cultural diversity and caregiving*. American Psychological Association.