Role of the Infusion Nurse

Caring for the Family/Lay Caregiver of Older Adults

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ABSTRACT

Approximately 43 500 000 family caregivers provide unpaid care to an adult or child. Most caregivers provide care to older adults, most often parents. Caregivers are often ill-prepared to assist their loved ones, creating or increasing caregiving burden and/or risk of compassion fatigue, potentially leading to critical "caregiving tipping points." Identifying families who are experiencing increased burden or risk of compassion fatigue is a skill that nurses, including infusion nurses, who have unique entrée into the caregiving situation, should develop. The purpose of this article is to describe "impending" tipping points before they occur and to offer solutions for how nurses can help caregiving families identify them and access additional supportive services.

Key words: caregiving burden, compassion fatigue, family caregiving, infusion nursing, older adults, rewards of caregiving, tipping point

According to the Family Caregiving Alliance and AARP, approximately 43.5 million caregivers have provided unpaid care to an adult or child in the last 12 months.[1] Informal or unpaid caregivers, family and friends, are often untrained and ill-prepared to provide the required level of assistance with activities of daily living (ADLs; eg, bathing, toileting, dressing, transferring, cooking, and feeding); assisting with instrumental ADLs (IADLs; eg, shopping and transportation); and/or managing medications, including administering infusion medications and solutions. Although a majority of caregivers of older adults are daughters and are employed full-time outside the home, all caregivers, including sons, spouses, and a variety of demographics representing the general population,[2] are the focus of this paper.

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Family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems can arise from complex caregiving situations and the burden of caring for frail or disabled relatives, which in turn can affect the whole "caregiving family." Stress and burden may also be related to caregivers not being well-matched with their loved ones. For example, in 1 study, many mothers reported that they would have preferred that one of their other adult children were their caregiver rather than the one that is in that role.[2] This paper provides a synthesis of the impact of chronic illness on caregivers, how to identify impending caregiving tipping points, and offers resources, tools, and strategies to support the caregiving family.

It is important to be aware of possible precursors to caregiving burden and other changes in caregivers' situations leading up to "caregiving tipping points." A *caregiving tipping point* is defined as "a seemingly abrupt, severe, and absolute change event involving either the older adult, their caregiver(s), or both, and indicates a breakdown in the status quo of the caregiving system."[3p585] For example, a tipping point could be a juncture at which the physical condition of an older adult has deteriorated, resulting in his/her receiving an injury from a fall, or the caregiver injuring her back in catching the older adult during a fall.

Usually changes that can avert a tipping point are accomplished through nursing intervention, including introducing resources that can support the caregiving family. For example,

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if it is increasingly difficult for the older adult to transfer from bed to chair, and the caregiver is becoming more unable to manage transfers, a home health nurse or physical therapist could suggest the use of assistive devices and perform other mobility assessments. In this scenario, if supportive services are not brought in, a "tipping point" is likely to occur, which could result in a more extreme, yet preventable, change for the whole family, such as a transition to a more intense level of care (eg, placement in a nursing home).

CAREGIVING BURDEN AND COMPASSION FATIGUE

Caregiving burden has also been studied in the clinical setting. When related to nurses and other professional care providers, instead of family caregivers, the term often used is *compassion fatigue*. Some of the characteristics of compassion fatigue are similar to those of caregiving burden and can provide additional insight and sensitivity about caregiving burden. Compassion fatigue was first introduced in the literature in 1992.[4] *Compassion fatigue* was defined as the acute onset of the negative emotional effects experienced by professional health care workers when providing patient care.[4,5] Researchers have varied in their opinions about the onset of compassion fatigue. Some have contended that compassion fatigue is a progressive and cumulative result of internalizing emotions of others or continually giving of one's self when caring for others[6]; however, others have described the onset of compassion fatigue as sudden, unexpected, or acute.[7]

Overall, compassion fatigue is described as emotionally devastating. Compassion fatigue differs from depression as it involves exposure to someone who is suffering, leading to feelings of helplessness, hopelessness, and the inability to be empathetic. One study did apply the concept of compassion fatigue to family caregivers, with interviews and statements by their participants suggesting that family caregivers might be at risk for increasing caregiving burden and compassion fatigue.[8] It is important for nurses to be cognizant that family caregivers may be at risk for caregiving burden, compassion fatigue, and a caregiving tipping point. Nurses have the opportunity to learn how to intervene with tools and resources aimed to alleviate contributing factors.[8] Awareness of the symptoms is necessary for proper intervention.[4]

DETECTING IMPENDING CAREGIVING TIPPING POINTS

Research has included descriptive and intervention studies about deciding to use services that can help prevent caregiving tipping points. Studies have included testing strategies for normalizing the use of supportive services by caregiving families reluctant to bring in others to help them and how to access such services.[9] Research has also focused on professional nurses as caregivers being overwhelmed as a result of providing care to older adults in skilled nursing facilities. Findings were that registered nurses (RNs) caring for older adults in a skilled nursing facility reported both "compassion satisfaction" (similar to "rewards of caregiving") and compassion fatigue,[10,11] similar to caregiving burden and feeling emotionally overwhelmed.[12] When compassion fatigue was unresolved by RNs providing care to older adults, physical and emotional manifestations emerged.[10,13] Participants described positive feelings when they were able to help make a difference in the lives of the older adult but reported negative feelings when they could not: "All we do is give, give, give, give, give, give, give."[(10p94)] As a result of this, many participants described the daily care they provided as "draining, exhausting, taxing and demanding physically and emotionally."[(10p93)] The manifestations of negative feelings as they approached a nursing tipping point were physical depletion, sleep and gastrointestinal issues, overall fatigue, frustration, sadness, depression, and anger.[11,13] Nurses may both detect impending tipping points and support families through their expertise while providing care in home health and hospice settings, assisted living facilities, skilled nursing facilities, and outpatient infusion centers, as well as during acute care hospitalizations.

Knowing how to identify caregivers who are experiencing increased burden or compassion fatigue before a critical caregiving tipping point occurs is a skill that all nurses should have. Nurses can be instrumental in helping caregiving families identify the issues causing burden and compassion fatigue and provide valuable support and resource information to assist caregiving families.[14-16]

CONCEPTUAL FRAMEWORK

The *caregiving family*, that is, the older adult and the caregiver, is conceptualized as situated in the center of a larger system, described within the Ecological Model.[17] In this model, concentric circles, proximal and distal, surround and affect the health and function of the caregiving family. When tipping points are impending, nurses should be aware of the proximal and distal factors that may be affected by and/or may affect the health of the caregiving family. Proximal factors, such as extended family and *fictive kin*, individuals who are considered as part of the family but not related by blood,[18] as well as distal factors, such as community resources, including long-term support services (LTSSs), all interact with the caregiving family. LTSSs can support the caregiving family and help prevent the impending tipping point. Nurses can consider talking with families about various LTSSs, making referrals, and/or contacting case managers or social workers to help families access the appropriate LTSS. Even more distal factors, such as local, regional, and national policy, in the outer concentric circles also affect caregiving families.[3] Grounded in their clinical practice, infusion nurses as clinical experts can take leadership in

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representing and advocating for caregiving families by making necessary changes in practice policies in their place of employment, as well as in regional and national policy.

ASSESSMENT

Caregiving burden for caregivers of older adults with both physical and cognitive impairments has been studied and measured for decades.[19,20] Caregiving burden is often categorized as objective and/or subjective. Caregivers may enumerate all the tasks that are required (objective burden). They may also indicate how tiring, difficult, or upsetting the tasks and care are (subjective burden).[19] *Primary* and *secondary stress* of caregiving has also been recognized.[21] Examples of primary stress are similar to Poulshock and Deimling's[19] categories of caregiving burden: the objective tasks and work of caregiving and the subjective psychological and emotional responses to the tasks.

Secondary stress is related to the non-primary care valued activities. This type of stress may be related to career issues, social issues, or stress proliferation manifested in problems with health, sleep, illness, and negative relationships. Similarly, research has revealed that *increased* caregiver depression was associated with stress; but also that *decreased* depression was associated with "mutuality," the positive relationship between the caregiver and the loved one for whom they provide care.[22,23] Then, secondary stress, parallel to compassion fatigue, may decrease when the caregiving is rewarding or with higher "compassion satisfaction."

Nurses can assess for primary stress (objective and subjective caregiving burden), as well as for secondary stress (risk for compassion fatigue), by recognizing patterns and changes in patterns of caregiving families as systems. Some indications may be, for both the older adult and caregiver: worsening physical health, emotional distress, noticeable restriction of activity or diminishing social activities, negative caregiving relationships, and family disagreements. Also, changes such as impediments to the older adult's or caregiver's career or financial limitations are important to notice. As well, caregivers may be burdened by *role overload*, that is, having to act in the role of case manager or *system navigator*.[24] Sometimes when the health care system is not systematic in delivering continuity of care, the caregiver must be the person to provide information between health care facilities or even within the same hospital[25] or to find resources without assistance.[24]

RESOURCES, STRATEGIES, AND TOOLS TO SUPPORT CAREGIVING FAMILIES

Resources: LTSSs

Of options to reduce the threat of impending tipping points, the focus in this paper is accessing and using LTSSs. For older adults, the use of LTSSs decreases re-hospitalizations, emergency visits, and older adult functional impairment and, for caregivers, illness, burden, depression, involuntary separation, and mortality.[23,25,26] Therefore, these are critical services for supporting the family caregiving system. LTSSs can be addressed in the various contexts where impending caregiving tipping points are detected. The contexts may be in the acute care setting, outpatient facility, or the community. For example, a home infusion nurse may notice that a caregiver leaves work each day to provide her loved one with lunch. The infusion nurse may facilitate accessing and using home-delivered meals 5 days a week through a local Area Agency on Aging.[27]

STRATEGIES

Two specific strategies can be used by nurses in helping families address impending tipping points; these strategies are treating caregivers as a system and with cultural competence. Treating caregiving families as a system entails being cognizant of both the older adult's and the caregiver's needs, changing patterns, and problems. It is important to investigate how changes for each part of the system may affect the other part of the system, as demonstrated in the model cases below. Nurses also need to be open to possible differences in how caregiving families view the family caregiving situation vis-à-vis their particular ethnic/racial/cultural perspectives.[28] Culture influences how families perceive older adult family care.[29-31] Cultural competence is essential for nurses to use when assessing the caregiving family system. Being aware of one's own culturally based beliefs and values is an initial step, because people may approach families and make judgment based on one's own beliefs and values.[32] It is also important to skillfully ask about preferences. This approach is more effective than memorizing and assuming generalizations about specific cultures.[33]

For example, Mexican American individuals have more disabilities at younger ages than other Latino subgroups and non-Latino white individuals.[34] However, the cultural norm of *familismo* or familism, stresses the responsibility of family members to take care of their ill loved ones.[35] In some cultures, caregivers do not even identify themselves as being "a caregiver" but gradually take on more responsibilities in helping their loved one age in place. However, this cultural norm may be changing, and there is evidence that caregivers do not have support from other family members in their role, in contrast to certain families' values.[36] Also, ethnically diverse families often do not know about or understand that home health care is available, how to access these services, or trust that the services will be safe and as good as the caregiver can provide.[37] Strategies are needed to address cultural barriers to use needed resources.

TOOLS

The nurse is in a perfect position, in whichever context he/she provides care, to observe the caregiving family system

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and hear confidences through exposure to the caregiver, as well as the older adult. As part of the health care system, the infusion nurse also can affect care management that is provided in any setting by sharing insights about individualized family needs with case managers. Nurses can connect caregivers and older adults with discharge planners during "hand offs," which are information exchanges between nurses during transfers of patients from one room to another, one department to another, or between health care facilities.[25] Nursing's expertise is both technical with the rigorous training that nurses receive but also psychosocial with listening skills. Thus, the nurse, aware of resources in the form of LTSSs, can strategize using his/her personal and professional tools to prevent caregiving tipping points by helping match the right LTSS with the caregiving family at the right time.

DISCUSSION

Application and Implications

When caring for older adults receiving infusion therapy, for example, assessment of older adult and caregiver needs may vary depending on where they are on the health care continuum. For example, when providing infusion therapy treatment in an acute care setting, nurses may be involved with older adult and caregiver/family assessment when the caregiver visits the older adult. Objective and subjective data collected while caregivers or family members visit the older adult may provide cues that a tipping point is near. Nurses can be advocates for older adults and families when the hospital's case management team is determining the appropriate health care setting for the older adult to continue infusion therapy treatment. By combining infusion therapy expertise with acute assessment of the older adult's support system, the infusion nurse demonstrates a comprehensive, holistic approach to patient care in various health care settings. The principles outlined above may seem theoretical and abstract. It can help to illustrate concepts by portraying them with model cases. The following cases specific to infusion nurses are set in various health care delivery contexts, including community, emergency department (ED) units, hospitals, and outpatient infusion clinics.

MODEL CASE #1

In the Community, ED, Hospital, and Back to the Community

Ms Arevalo, a 93-year-old widow, who lived alone with a small, energetic terrier, was able to manage her ADLs. Ms Arevalo had a 57-year-old daughter who lived nearby. The daughter helped with some IADLs, for example, overseeing her mother's financial books and shopping for her groceries. Ms Arevalo was independent in preparing her own meals and taking her medications, including 1 antihypertensive per day. One day, Ms Arevalo tripped over the rambunctious dog. She was immediately taken to the ED with a fractured wrist and hip (a seemingly abrupt tipping point). Ms Arevalo was admitted into the hospital. While hospitalized, she contracted *Clostridium difficile*. She was prescribed intravenous antibiotics for several weeks (*the infusion nurse now enters into the story*). Ms Arevalo told the infusion nurse that she had been experiencing dizziness but had not wanted to tell her daughter or the primary care provider. When the daughter checked Ms Arevalo's home medications, she discovered that her mother had not been taking the correct dosage.

When Ms Arevalo went home, she was afraid of falling and subsequently curtailed her activity by not getting out of her chair or bed or walking as much. The daughter felt obligated to increase her caregiving duties (eg, stay at her mother's house to be sure she was safe, to encourage her to get up more) and to monitor her medications (ie, increasing objective caregiving burden). She also hired a daytime caregiver to assist with ADLs and cook meals. Ms Arevalo reluctantly gave away her companion dog on her daughter's insistence based on safety concerns. Outcomes of these events included the diminishing of Ms Arevalo's independence; life had permanently and dramatically changed at the point of the broken hip: a tipping point. Another outcome was her daughter's worry about her mother and feelings of guilt about her mother's loss of her pet, her mother's discomfort, having a hired assistant in the home, and that she was unable to sleep well at her mother's house, that is, a symptom of compassion fatigue.

Implications

Although home infusion therapy treatment can be safely administered, some older adults have invasive devices and are receiving high-risk infusion therapies.[16] When determining if the home setting is appropriate for an older adult to receive infusion therapy, consideration of a caregiver's availability may be critical to successful and safe treatment and reduce the risk for complications. Effective education may not only include the older adult but also a competent and available caregiver to administer infusion therapy. Infusion nurses must use critical thinking, assessment skills, and professional judgment when deciding what infusion therapy–related skills to teach an older adult or caregiver.[16] The infusion nurse becomes the advocate for the older adult or caregiver when working with insurance payors and providing the necessary data to support older adult and caregiver educational needs with future home visits. Meticulous care of the older adult and comprehensive assessment are performed by use of excellent assessment skills to determine older adult or caregiver functional and cognitive abilities.[16]

Infusion nurses not only focus on tasks associated with specific infusion treatments but have a holistic approach, which includes economic, psychosocial, emotional, and cultural assessment and monitoring.[16] The final aspect

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essential to safe and successful discharge to home, including at times home infusion therapy treatment, is interprofessional communication and collaboration with the older adult, caregiver, and all other members of the health care team. This includes the infusion nurse's responsibility to be knowledgeable of community resources, such as LTSSs, described previously. The infusion nurse in this model case can support the family's use of LTSS and help discern whether additional or different LTSSs are needed.

MODEL CASE #2

Outpatient Infusion Center

An infusion nurse at an outpatient center encountered Ms Baker, with cancer, who was receiving hydration. She confided to the nurse, while her husband was in the waiting room, that she was afraid to go home. She told the story that her husband was juggling his work, as well as providing her ADL and IADL care without her being able to contribute (caregiving burden), while feeling worried and concerned about his wife's illness (compassion fatigue). She realized that her husband was angry, and he would either be late with or even withhold her pain medications. This was a sign of an approaching caregiving tipping point. The infusion nurse was privileged to have been trusted enough for the wife to confide her concerns. With the resources, strategies, and tools to defer the impending tipping point, the infusion nurse could contact the agency's or insurance carrier's case management department, for assessment and referral, or provide information and assistance in accessing home care services directly.

Implications

Nurses may become aware of negative caregiving practices, such as withholding pain medication, or other indications of abuse or neglect, which can be caused by both interpersonal interactions (eg, the older adult not contributing to household responsibilities) and externally driven situations (eg, employer demands).[38,39] Conversely, older adults have also been found to abuse their caregivers.[40] Caregivers may also confide this type of negative caregiving situation to nurses that they trust. Nurses need to be aware of supportive services within their organizations and community LTSS to which they may refer caregivers for their protection and safety. As older adults' complexities and needs relative to their diagnoses increase, the care needs may be transferred to caregivers. Then caregiving burden and risk of compassion fatigue may increase with the older adult's disease progression and increasing care needed, despite the caregiver's willingness to provide this care. Although it is natural for the nurse to focus on the tasks involved with specific treatments, it is also the role of nurses to assist the older adult and caregiver in understanding the impact that family caregiving may have on their daily lives and offer resources to help support the older adult and caregiver.[16]

MODEL CASE #3

Caregivers of Older Adults in the Hospital

Ms Carter knew that her mother, a stroke survivor, was stronger on her right side and transferred more easily to a bedside commode on the right side. It seemed to Ms Carter like a battle to get nurses and technical associates to keep the commode on the correct side of the bed. Caregivers reported experiencing uncertainty and miscommunication during hand offs between in-hospital departments in a recent qualitative study.[25] For example, in a recent study of caregivers of hospitalized older adults who were interviewed about their experiences, caregivers reported feeling uninformed and uncertain, often beginning in the ED, not receiving information from staff about their older loved ones' status, exacerbated by the long waiting room times. Caregivers often undertook new caregiving tasks. These included insuring that important information was passed on between various departments' health care professionals who were caring for their loved one. Caregivers often felt ignored and not asked for their unique information. They reported that this caused increased stress. Other than providing information, caregivers found themselves in the role of care and quality control coordinators. Caregivers experienced role conflict between their observed need to constantly oversee their loved one's care, which often seemed inconsistent, and wanting to be in the role of family member able to trust the care being provided.

Implications

Nurses may be key team members to become aware of personal details that are so very important to the older adult and caregiver. The nurse may to need to advocate for the family with the direct care team to acknowledge and act on these specific needs. Evidence shows that stress, or burden, can escalate toward a tipping point when the caregiver is not recognized as part of the team. With relocation comes new caregiving burden, going to the hospital, giving up the primary caregiving role,[23,25,26] yet worrying about the loved one, potentially intensifying the risk of compassion fatigue. Acknowledging the caregiver as a contributor to the older adult's well-being improves outcomes for the older adult, prevents a caregiving tipping point, and even promotes rewards of caregiving.[41]

Nurses are familiar with caregivers who regularly assist their older loved ones in ADLs and/or IADLs. These caregivers are usually active in helping their older loved ones "age in place" in the community and are present when the older loved ones seek outpatient or ED care or are admitted into the hospital or alternative residence. Sometimes in the ED or other parts of the hospital, case managers do not make referrals to LTSS. Decisions about whether to approach the older adult or caregiver about the possibility of using LTSS, for example, home health care services, are often based on whether the family has health insurance, regardless of the older adult's health care needs.[42] Nurses may need to

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advocate with case managers to investigate further into local funders for LTSS, such as Area Agencies on Aging.[27]

AVOIDING CAREGIVING TIPPING POINTS

Success stories are helpful to illustrate what is possible. In the following section, tipping points were avoided before they occurred. In the first example, Ms Delgado, a 60-year old, doctorally prepared nurse practitioner, living alone with her 2 cats, with chronic health issues post-cancer, had rapidly occurring flu-like symptoms with vomiting and diarrhea, on a weekend. Realizing that she had developed dehydration, she went to the ED. In the ED, staff would not listen to her self-diagnosis, and they delayed treatment. A fictive kin, who was a knowledgeable nurse practitioner and concerned about her friend advocated for intravenous hydration in the ED and for continuation when Ms Delgado was discharged home. A very responsive infusion company's director of nurses, on call for the weekend, recognized Ms Delgado's frustration and panic and the caregiver's concern. The director of nurses was able to decrease Ms Delgado's discomfort, the caregiver's burden, and compassion fatigue risk by use of proper interventions. Interventions included listening, considering their assessment of increasing dehydration and the need for immediate hydration, streamlining the administrative process of the referral, delivering the prescribed infusion as quickly as possible, checking in with them throughout the weekend, and providing follow-up documentation to the primary care provider. Potential exacerbation of the symptoms and resulting dehydration, caregiving burden and compassion fatigue, and a subsequent impending caregiving tipping point were averted, with Ms Delgado's return to a comfortable rapid recovery in her own home with her pets.

A second way tipping points may be avoided is that some caregivers have better self-rated health, decreased mortality risk, and experience gain (ie, "rewards of caregiving")[43,44] or other positive feelings that result from providing care such as *compassion satisfaction* and resiliency rather than caregiving burden or compassion fatigue. Such rewards may be embedded in some cultures more than others.[45] Other various causes of rewards of caregiving may be that caregivers are selected into the caregiving role secondary to their own personal well-being or may vary by whether the older adult has physical or cognitive needs, by gender or race; or whether the caregiver is providing care to one person or multiple older adults at the same time.[46]

CONCLUSION AND CHALLENGE

One of the outcomes of caregiving families reaching caregiving tipping points is re-hospitalization, costing billions of dollars annually. If a caregiving tipping point is reached, one potential outcome could be caregiving crisis, in which the caregiver is no longer available. This is similar to the consequences of nurses reaching a point of compassion fatigue that affects their personal and professional lives and is a cause for nurses to leave the profession.[10,13] A caregiver reaching the point of "*I am at the end of my rope*" can cause involuntary separation, most recently noted for spouse caregivers.[26] The increased burden, guilt, and heartache (ie, compassion fatigue) when the loved one requires more care than the caregiver can or will provide can be very difficult.

Research and clinical cases presented enable health care professionals to identify family caregivers who are at particular risk for reaching a caregiving tipping point. With this knowledge, researchers might develop screening tools to help identify this vulnerable group of caregivers and track the outcomes of interventions designed to help family members cope more effectively with caregiving burden and risk for compassion fatigue before a tipping point is reached.

Nurses who are able to understand and recognize mounting signs and symptoms can work with families and their social service personnel to alleviate selected contributing factors, thereby protecting the caregiving family from the sequelae of caregiving tipping points. Nurses can support family caregivers through interventions directed at using LTSS to help decrease uncertainty and provide caregivers with increased feelings of control and ability. The National Family Caregiver Support Program can be contacted for local resources or for referrals at their website.[47] In addition, however, readers are challenged to ask for staff development to obtain the skills to identify needs, when and how to intervene, to understand the LTSS resources that are available, and for protocols for making referrals to LTSS. Organizations employing nurses, and specifically infusion nurses, need to work these topics into their orientation and continuing educational sessions.

All nurses are challenged to engage in assessment and intervening practices that not only keep their older patients receiving treatments, including infusion therapy, safe but also assist the whole family, including caregivers, in continuing their unique and challenging roles. Readers are challenged to continue working with their interdisciplinary colleagues to advance practice and policy to assist older adults to age in place, care for the caregiver, and make health care truly accessible and equitable for all caregiving families.

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