Chapter 14. Supporting Family Caregivers in Providing Care

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Background

Most patients have families that are providing some level of care and support. In the case of older adults and people with chronic disabilities of all ages, this “informal care” can be substantial in scope, intensity, and duration. Family caregiving raises safety issues in two ways that should concern nurses in all settings. First, caregivers are sometimes referred to as “secondary patients,” who need and deserve protection and guidance. Research supporting this caregiver-as-client perspective focuses on ways to protect family caregivers’ health and safety, because their caregiving demands place them at high risk for injury and adverse events. Second, family caregivers are unpaid providers who often need help to learn how to become competent, safe volunteer workers who can better protect their family members (i.e., the care recipients) from harm.

This chapter summarizes patient safety and quality evidence from both of these perspectives. The focus is on the adult caregiver who provides care and support primarily for adults with chronic illnesses and chronic health problems. The focus is not on those with developmental disabilities. In the first section, we discuss the evidence for protecting the caregiver from harm. The second section addresses research aimed at protecting the care recipient from an ill-prepared family caregiver.

Caregivers as Clients

For centuries, family members have provided care and support to each other during times of illness. What makes a family member a “family caregiver”? Who are these family caregivers, what do they do, and what harm do they face? What does the research tell us about ways to assess the needs of these hidden patients and evidence-based interventions to prevent or reduce potential injury and harm? This section answers these questions and highlights the need for nurses to proactively approach family caregivers as clients who need their support in their own right.

Description of Caregiver Population

The terms *family caregiver* and *informal caregiver* refer to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care. Recent surveys estimate there are 44 million caregivers over the age of 18 years (approximately one in every five adults).[1] The economic value of their unpaid work has been estimated at $257 billion in 2000 dollars.[2] Most caregivers are women who handle time-consuming and difficult tasks like personal care.[3] But at least 40 percent of caregivers are men,[3] a growing trend demonstrated by a 50 percent increase in male caregivers between 1984 and 1994.[4] These male caregivers are becoming more involved in complex tasks like managing finances and arranging care, as well as direct assistance with more personal care.[5] Nurses are likely to see many of these caregivers, although many of them will not identify themselves as a caregiver.

Those caring for someone 50 years or older are 47 years old—on average—and working at least part-time.[1] If they are providing care to an elder who is 65 years or older, they are, on average, 63 years old themselves and caring for a spouse; one-third of these caregivers are in fair to poor health themselves.[6] In many cases, they are alone in this work. About two out of three older care recipients get help from only one unpaid caregiver.[7] In the last decade, the proportion of older persons with disabilities who rely solely on family care has increased dramatically—nearly two-thirds of older adults who need help get no help from formal sources.[4]

Caregiver Responsibilities

Caregivers spend a substantial amount of time interacting with their care recipients, while providing care in a wide range of activities. Nurses have a limited view of this interaction. Caregiving can last for a short period of postacute care, especially after a hospitalization, to more than 40 years of ongoing care for a person with chronic care needs. On average, informal caregivers devote 4.3 years to this work.[8] Four out of 10 caregivers spend 5 or more years providing support, and 2 out of 10 have spent a decade or more of their lives caring for their family member.[9] This is a day-in, day-out responsibility. More than half of family caregivers provide 8 hours of care or more every week, and one in five provides more than 40 hours per week.[1]

Most researchers in the caregiving field conceptualize the care that family members give as assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). But those concepts do not adequately capture the complexity and stressfulness of caregiving.[9] Assistance with bathing does not capture bathing a person who is resisting a bath.[10, 11] Helping with medications does not adequately capture the hassles of medication administration,[12] especially when the care recipient is receiving multiple medications several times a day, including injections, inhalers, eye drops, and crushed tablets. The need to make decisions on behalf of family members who are unable to do so is stressful, as this is contrary to the caregivers' normal role, and they are concerned that the decisions are correct. Supervising people with dementia and observing for early signs of problems, such as medication side effects, are serious responsibilities as family members are often unable to interpret the meaning or the urgency. The medical technology that is now part of home care and the frustrations of navigating the health care system for help of any kind is not even part of the ADL/IADL measures.[13] Being responsible for medical and nursing procedures like managing urinary catheters, skin care around a central line, gastrostomy tube feedings, and ventilators is anxiety provoking for the novice nursing student, but is becoming routine family care of persons with chronic illnesses living at home.

Family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, and receive little guidance from the formal health care providers.[14-16] Nurses and family caregivers rarely agree about specific needs or problems during hospital admission or discharge,[17] in part because nurses are often unaware of the strengths and weaknesses of both the patient and caregiver. Due to inadequate knowledge and skill, family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed. Family caregivers may not know when they need community resources, and then may not know how to access and best utilize available resources.[18] As a result, caregivers often neglect their own health care needs in order to assist their family member, causing deterioration in the caregiver's health and well-being.[19-21]

Caregivers get very little help from health care professionals in managing their tasks and the emotional demands of caregiving. Among the greatest challenges for family caregivers is interacting with nurses and other professionals in the hospital setting, and a rough crossing back home, as the patient is "discharged to family."[22] Naylor's review[23] of nearly 100 studies published between 1985 and 2001 confirms that breakdowns in care during the transition from hospital to home result in negative outcomes. Health professionals in emergency departments and inpatient hospital settings do not adequately determine the after-care needs of older patients when they are being discharged.

Effective discharge planning is impeded by gaps in communication between the hospital and community interface, such as illegible discharge summaries and delays in sending information to the physician.[24] Focus groups of caregivers found that they experience their family member's discharge from the hospital as an abrupt and upsetting event because the hospital staff did not prepare them for the technical and emotional challenges ahead of them. Many caregivers felt abandoned at a critical time, and none of the focus group participants had been referred by any health care professional in the hospital to community-based organizations for emotional support—or any other kind of support.[22]

Hazards of Caregiving

Health professionals' lack of explicit attention to caregivers is a serious gap in health care in light of the more than two decades of research that documents the potential hazards of family caregiving. Caregivers are hidden patients themselves, with serious adverse physical and mental health consequences from their physically and emotionally demanding work as caregivers and reduced attention to their own health and health care.

Declines in physical health and premature death among caregivers in general have been reported.[21, 25] Given and colleagues[18, 19] and Kurtz and colleagues[26] found that family caregivers experience significant negative physical consequences as the patient's illness progresses. Elderly spouses who experience stressful caregiving demands have a 63 percent higher mortality rate than their noncaregiver age-peers.[21] Most recently, research documents that elderly husbands and wives caring for spouses who have been hospitalized for serious illnesses face an increased risk of dying prematurely themselves.[27]

Declines in caregiver health have been particularly associated with caregivers who perceive themselves as burdened.[21] Caregiver burden and strain have been related to the caregiver's own poor health status, increased health-risk behaviors (such as smoking), and higher use of prescription drugs.[28] Researchers have reported that caregivers are at risk for fatigue and sleep disturbances,[29] lower immune functioning,[30, 31] altered response to influenza shots,[32] slower wound healing,[33] increased insulin levels and blood pressure,[34, 35] altered lipid profiles,[36] and higher risks for cardiovascular disease.[37]

Burton and colleagues[38] examined the relationships between provision of care by family members and their health behaviors and health maintenance. These researchers found that, with a high level of caregiving activities, the odds of the caregiver not getting rest, not having time to exercise, and actually not recuperating from illness were also high. In addition, caregivers were more likely to forget to take their prescriptions for their own chronic illnesses. Providing care poses a threat to the overall health of caregivers, which can compromise their ability to continue to be caregivers. If caregivers are to continue to be able to provide care, relief from the distress and demands of maintaining the required care must be considered.

Both highly negative and highly positive consequences of providing care may exist simultaneously.[39] It is plausible that positive consequences, such as rewards and satisfaction, may buffer the negative effects of caregiving. Positive aspects of caregiving are important,[40-42] some researchers are now using a caregiver rewards scale to better understand caregivers' experiences.[41, 42] Other researchers are exploring the positive aspects of care as the mutuality between the patient and caregiver develops.[40] Archbold and colleagues[40] demonstrated that mutuality and preparedness did reduce some of the strain on the caregiver. Picot and colleagues[41, 42] worked primarily with African American caregivers and found that the rewards perceived by caregivers were more important than coping. A specific Picot Caregiver Reward Scale of 25 items exists and has been widely used to show that both rewards and costs can exist in the same care situation.

Caregivers who attempt to balance caregiving with their other activities, such as work, family, and leisure, may find it difficult to focus on the positive aspects of caregiving and often experience more negative reactions, such as an increased sense of burden.[43-45] Regardless of amount of care provided, caregivers may become increasingly more distressed if they are unable to participate in valued activities and interests.[46] More than half of adult children who provide parent care are employed.[7] Caregiving responsibilities can have a negative effect on work roles as caregivers adapt employment obligations to manage and meet care demands.[47, 48] Caregivers who are employed report missed days, interruptions at work, leaves of absence, and reduced productivity because of their caregiving obligations. They have difficulty maintaining work roles while assisting family members.[46] On the other hand, employment provides some caregivers respite from ongoing care activities and serves as a buffer to distress.[49-51]

Low personal and household incomes and limited financial resources can result in increased caregiver risk for negative outcomes, particularly if there are substantial out-of-pocket costs for care recipient needs.[45] Caregivers who are unemployed or have low incomes may experience more distress because they may have fewer resources to meet care demands. Overall, financial concerns cause particular distress for caregivers during long treatment periods,[52, 53] as resources become depleted. Higher-income families, with greater financial resources to purchase needed care, might not become as distressed or burdened as those with limited resources.[54]

Caregiver burden and depressive symptoms are the most common negative outcomes of providing care for the elderly and chronically ill.[20, 55, 56] Caregiver burden is defined as the negative reaction to the impact of providing care on the caregiver's social, occupational, and personal roles[57] and appears to be a precursor to depressive symptoms.[58] Whether the caregiver develops negative outcomes seems to be directly related to the care recipient's inability to perform ADLs, either due to physical limitations or cognitive status.[51] If the care recipient wanders (associated with Alzheimer's disease) or displays unsafe behavior, the caregiver has to be alert and on call for supervision 24 hours per day. The constant concern for managing disruptive behaviors (such as turning on stoves, walking into the street, taking too many pills, yelling, screaming, or cursing) also affects the caregivers negatively.

Care recipients' functional, cognitive, and emotional status predicts caregiver burden and depression,[58-62] which may be manifested in feelings of loneliness and isolation, fearfulness, and being easily bothered, as the demands of caregiving limit their personal time.[58] Care recipient behavior such as screaming, yelling, swearing, and threatening are associated with increased caregiver clinical depression.[63] Caregiver depression may also have a somatic component, such as anorexia, fatigue, exhaustion, and insomnia.[64]

Caregivers may suffer severe fluctuations in sleep patterns over time, which may affect depression[65] and exacerbate symptoms of chronic illnesses. Pain management is an intractable problem for caregivers that results in substantial caregiver distress, as caregivers assist with both nonpharmacologic and pharmacologic pain-management strategies.[66-68]

Research Evidence: Interventions for Caregivers as Clients

The literature provides substantial evidence that caregivers are hidden patients in need of protection from physical and emotional harm. Interventions directed to the family caregiver should serve two purposes (see Evidence Table). First, interventions can support the caregiver as client, directly reducing caregiver distress and the overall impact on their health and well-being. In this intervention approach, the caregiver is the recipient of the direct benefit and the patient benefits only secondarily. Second, interventions can be aimed to help make the caregiver become more competent and confident, providing safe and effective care to the patient, which can indirectly reduce caregiver distress by reducing their load or increasing their sense of certainty and control. In this section, we focus on the research evidence supporting caregivers as clients.

Despite the importance of information and support to help family caregivers, studies on interventions to increase support for family caregivers have lagged far behind those provided for patients. A focus on the family as a part of the patient's therapeutic plan of care is largely absent from interventional research and from general clinical practice as well. Few randomized clinical trials of educational interventions directed toward family caregivers have been conducted or published, and there is limited research to inform us about skills training for caregivers to prevent back injuries, infection, and other potential risks inherent in the caregiver situation.

Interventions To Reduce Burden and Distress

Recent meta-analyses of caregiver interventions found mixed results, which are important to note. Multicomponent interventions, rather than single interventions like support groups or education, significantly reduced burden.[69, 70] Other interventions found no reductions in burden, but significant improvements in caregiver knowledge and delayed nursing home admission for care recipients.[71] Sorenson and colleagues[72] found that interventions aimed at individual caregivers were more effective in improving caregiver well-being than group interventions, although group interventions were more effective in improving care-recipient symptoms. Reasons for this are unclear. The effectiveness of caregiver interventions lasts approximately 7 months. Few studies are funded for long-term followup.

Comprehensive counseling sessions for spouses caring for a person with dementia help reduce depression.[73] Counseling appeared to be effective in improving the quality of life for caregivers of stroke survivors.[74] However, even a simple one-to-one telephone call may be effective in helping the caregiver as client. An automated, interactive voice-response telephone support system for caregivers reduced burden for those caregivers with a lower sense of control over their situation.[75] Davis and colleagues[76] found an unexpected reduction in burden and distress for caregivers receiving friendly, socially supportive phone calls that provided some respite from caregiving, even without in-home caregiver skills training. Home visits and enhanced social support also can help reduce caregiver depression.[77, 78]

Zarit and colleagues[79] used a quasi-experimental design to demonstrate that caregivers who used adult day care services for their relatives with dementia had significantly lower levels of caregiver stress, anger, and depression after 3 months of this respite care than a control group of similar caregivers who did not obtain this intervention. Sorenson and colleagues[72] also found that respite/day care interventions effectively reduced caregiver depression and increased well-being.

Interventions To Improve Competence and Confidence

Smeenk and colleagues[80] investigated the quality of life of family caregivers who received a home care intervention that consisted of a specialist nurse coordinator, a 24-hour nurse telephone service with access to a home care team, a collaborative home care dossier and case file, and care protocols. The care dossier was used to assist with communication and coordination between caregivers and health professionals. The dossier included the lists of the patient's caregivers, discharge reports, nursing home case transfer reports, medication lists, and multidisciplinary reports. From these reports, specific patient intervention approaches were developed. The intervention significantly improved caregiver quality of life at 1 week and 4 weeks after discharge from the hospital.

Houts and colleagues[81] describe a prescriptive program that is based on research on problem-solving training and therapy. Designed to empower family members to moderate caregiver stress, the Prepared Family Caregiver model is summarized in the acronym COPE (Creativity, Optimism, Planning, and Expert information). COPE teaches caregivers how to design and carry out plans that focus on medical and psychosocial problems that are coordinated with care plans of health professionals. Although proponents of this program assert it has positive outcomes for caregivers, a formal evaluation of COPE was not found.

Teaching caregivers how to manage specific patient problems can improve the caregiver's well-being. For example, not being able to sleep at night is a serious problem for caregivers of people with Alzheimer's disease, as the caregivers become fatigued and exhausted, which can have an adverse effect on both the physical and emotional health of the caregiver. Teaching them how to improve their family members' nighttime insomnia through daily walks and exposure to light can improve sleep time for both the caregiver and care recipient.[82] Even caregivers providing end-of-life care can benefit from structured interventions. McMillan and colleagues[83] found that a skills and coping training intervention with family caregivers of hospice patients improved the caregivers' quality of life.

Caregivers as Providers

Twenty-five years of research have documented that the work of family caregiving can be stressful. That stress can adversely harm both the caregiver and the care recipient. This section addresses research aimed at protecting the care recipient from an ill-prepared or emotionally stressed family caregiver. It describes the link between the work of caregiving and patient harm, and examines interventions that aim to make the caregiver a better worker and less likely to harm the patient.

The Potential for Harm

Caregivers can place their family members at risk in two ways, and both situations are preventable. First, despite their good intentions and hard work, if caregivers do not have the knowledge and skills to perform their work, they may unintentionally harm their loved one. This risk for injury is directly related to lack of knowledge and competence, which can be improved through caregiver education and support. For example, a recent study confirmed that patients had many negative outcomes when untrained informal caregivers managed their home enteral nutrition or tube feeding.[84] Problems included tube displacement, tube clogging, infection, and dehydration—all of which can lead to a stressful caregiving situation and hospital readmission.

A second concern is that the demanding work of caregiving can put caregivers at risk of engaging in harmful behaviors toward their care recipients, particularly among caregivers of persons with cognitive impairments.[85] Depressed caregivers are more likely to harm their spouses. Caregivers who are at risk of depression while caring for spouses with significant cognitive or physical impairments are more likely to engage in neglect or abusive behaviors, such as screaming and yelling, threatening to abandon or use physical force, withholding food, hitting, or handling roughly.[63]

In general, family members may be challenged to find the capacity or ability to provide care, but Fulmer[86] found that caregivers who were in poor health or from low-income or dysfunctional situations might have the most limited capacity to provide needed care. They also might not understand the standard for quality and might not provide the level of care that is needed.

The risk of elder abuse. The presence of dementia and cognitive behavioral problems put the care recipient at risk for abusive behaviors by the caregiver.[86, 87] Neglect may also occur, including neglect of nutrition and access to food, unmanaged pain, urinary incontinence, and falls. Caregiver neglect may occur because the dementia patient is unable to communicate and the caregiver is unable to understand or know how to deal with nutritional intake and pain management. Mittelman and colleagues[88, 89] found that counseling and support for caregivers who face disruptive behaviors from their ill family members will decrease their stress over their multiyear caregiving responsibility.

Medication errors. With regard to caregiver knowledge and skills, an important example of the potential to harm the patient is caregivers' administration of medications. A substantial number of community-dwelling elders do not recall receiving any instructions on taking their medications.[90] They often rely on family members for help in taking them. Travis and colleagues[12] found that caregivers manage between one and 14 medications on a daily basis, have difficulty keeping so many prescriptions filled, and often miss doses due to their work schedules. Their responsibility to monitor for adverse or toxic effects in family members who are not capable of reporting problems themselves is important in preventing dehydration brought on by vomiting and diarrhea, and even more serious emergency situations. Caregivers need education to recognize both classic and atypical adverse drug effects they may see as their family member's condition changes, and help in developing the critical thinking skills that would enable them to manage these potential problems.

Neglect and family conflict. The caregiver's perception of the care situation is crucial in understanding the potential for harm. The amount of "bother" the caregiver perceives in relation to the patient's symptoms affects the caregiving context. Caregivers bothered by symptoms tend to inaccurately assess patients' symptoms, particularly patients' pain and patients' ability to care for self.[91-93]

Neglect is more common when the caregiver is depressed or distressed. It interferes with the person's ability to make observations and to identify needs or provide social stimulation for their ill family member. When caregivers themselves are distressed, burdened, or depressed, they might leave elders alone for long periods of time, ignore them, or fail to provide any companionship or interaction.[86] Annerstedt and colleagues report on the breaking point of caregivers providing care for patients with dementia.[59] When caregivers have a high level of burden, care becomes inadequate. The amount of care demands and time per week, impaired sense of own identity, clinical fluctuations in the patient, and nocturnal deterioration in the patient predict the caregiver breaking point.

When there is family conflict, there is less assistance to the patient. Bourgeois and colleagues[94] looked at the consequences of disagreement between primary and secondary caregivers and found divergence in perceptions. There was, however, more agreement on patient behaviors and caregiver strain. Primary caregivers with pessimistic secondary caregivers were less distressed than those with optimistic ones. Given and Given[18] found that secondary caregivers left the care situation over time and only returned with increased physical care needs. Caregivers may also relinquish caregiving when they are unsuccessful in maintaining a relationship or when the care becomes difficult, such as when the care recipient loses cognitive function. Conflicts can also occur with unfulfilled or mismatched aid. Negative interactions with kin include despairing comments on caregiving, caregiver health status, and criticisms of care decisions.[95, 96]

Research Evidence: Interventions for Caregivers as Providers

Interventions designed to help the caregiver become a more competent and confident provider are important to ensure that the patient receives safe and effective care. These interventions are aimed at: preventing abuse and neglect, and improving the caregiver's knowledge and skills; supporting caregivers with early identification of patient problems and managing patient care; developing psychomotor skills training for the safe administration of medications and use of equipment; and enhancing emotional and coping skills to deal with the caregiver's anger and frustration. In these situations, interventions, such as role playing and rehearsal, are designed to help the caregiver better understand how to communicate with the care recipient and manage negative reactions, or remove the care recipient from a dangerous caregiving situation. A focus on the former may help prevent the latter. All of these interventions can strengthen caregivers' competence and reduce harm to the patients under their care.

Strengthening Caregiver Competence

Strengthening caregivers' competence and confidence improves their *mastery*, defined as the amount of control that a person feels over the forces that are impinging upon him or her.[97] Caregivers with higher levels of mastery of the care situation have more positive responses to providing care[98, 99] because they perceive themselves as able to meet care demands.[100, 101] Caregiver mastery can reduce caregiver distress by influencing the availability of healthy problem-coping strategies to meet care demands.[102, 103] The control associated with caregiver mastery is also associated with a lower stress response and more positive health-related behaviors among caregivers.[104]

Caregivers require knowledge, skills, and judgment to carry out the tasks of care for patients, and research has shown that caregivers who feel prepared to deliver care (i.e., have the knowledge and skills needed) have less burden.[15] Providing care takes into account the following dimensions: (a) the nature of the tasks; (b) the frequency with which tasks are performed; (c) the hours of care provided each day; (d) the skills, knowledge, and abilities of caregivers to perform tasks; (e) the extent to which tasks can be made routine, and thus incorporated into daily schedules; and (f) the support received from other family members. Caring for patients ranges from providing direct care, performing complex monitoring tasks (e.g., monitoring blood sugar, titrating narcotic dosages for pain), interpreting patient symptoms (e.g., determining the fever level to report to a health care provider), assisting with decisionmaking, and providing emotional support and comfort. Each type of involvement demands different skills and knowledge, organizational capacities (e.g., obtaining needed community services or ordering the best wheelchair), role demands, and social and psychological strengths from family members.[16, 104, 105] Each of these is a potential area of concern for patient safety and caregiver distress.

Developing Task-Specific and Problem-Solving Skills

Despite the overall lack of interventional research with caregivers, there is some evidence that interventions designed to improve specific caregiving tasks are helpful. For example, Ferrell and colleagues[106] examined the impact of pain education on family caregivers who were providing care to elderly patients with cancer. The pain education program included pain assessment, pharmacologic interventions, and nonpharmacologic interventions. The pain education program helped improve caregivers' knowledge and attitudes about managing their family members' pain. Other researchers have found that interventions to build skills and problem-solving abilities help caregivers of persons with Alzheimer's disease by decreasing negative behavior in those they care for.[107] Weekly telephone interventions to help caregivers of stroke survivors problem-solve led to reduced depression.[108]

Another example of specific training found nurse-initiated interventions to teach older adults and their caregivers about safe medication administration resulted in significant improvements in the ability to name prescribed medications and their administration schedules correctly.[109] This knowledge base is essential for caregiver competence and patient safety.

Several interventions have been aimed at assisting caregivers to develop problem-solving skills. For example, Toseland and colleagues[110] and Blanchard and colleagues[111] implemented a randomized trial (Coping with Cancer) using a psychosocial intervention aimed at spouses of cancer patients. A six-session problem-solving intervention was designed to help spouses cope with the stress of caring for their partners. Intervention components included support, problem-solving, and coping skills. There was little change over time with respect to caregivers' levels of depression, perhaps because the level of caregiving activities was low. This kind of problem-solving training may be more critical for caregivers who spend more time providing care.

Psycho-Educational Interventions

The majority of intervention studies for caregivers have utilized a psycho-educational intervention. That is, the intervention emphasizes both the provision of information and a psychological/counseling approach to decrease caregiver distress. Although not explicated as such, these interventions aim to address caregivers as both clients and providers.

A randomized clinical trial designed to test the effects of a psycho-educational intervention for caregivers and patients with newly diagnosed cancer who had recently initiated chemotherapy had a positive effect on reducing caregiver depression.[112] Four months after attending a psycho-educational caregiver cancer education program that addressed symptom management, psychosocial support, and resource identification, the number of caregivers who reported being well informed and confident about caregiving increased.[113]

Training caregivers in a multiracial primary care setting about specific ways to manage behavioral disturbances appears promising.[114] Anger and depression management interventions decreased anger, hostility, and depression and improved the caregiver's sense of control.[115] Caregivers received moderate support from an AlzOnline's Positive Caregiving classes, in part because they felt an increased sense of control over their caregiving situation.[116] An intervention to teach management of behavioral problems and basic activities of living left caregivers feeling less upset and more capable of managing difficult behaviors.[100] Similar findings were demonstrated for a portable CD-ROM training program for caregivers of people with dementia.[117]

Navigating the Service Delivery System

Family members must interact with the health care system to obtain information, services, and equipment, as well as to negotiate with family and friends to enlist and mobilize support. Interventions to increase caregivers' knowledge about community services and how to access them can increase their sense of competence and reduce depression.[118] Caregivers' involvement in direct and indirect care changes over time, in response to the stage of illness and treatment, and caregivers must be able to adapt to changes in the amount, level, and intensity of care demands. Given and colleagues[19] describe that it was not the amount of care itself, but the change in care demands (either increased or decreased) that resulted in caregiver distress. Change requires constant adaptation and adjustment by the caregivers, which translates into adapting to different schedules, changing routines, and accommodating other roles for which family caregivers are responsible.

One of the most essential aspects of navigating the system is finding home- and community-based services, and determining what private and public programs might be available. The public sector side is particularly complex. People who are very frail and below or close to the poverty line can receive home care under Medicaid. Much of this care is provided through a home health agency. Through the authority of section 1915(c) of the Social Security Act, States can request Federal permission to provide a range of services, which may include respite service for family caregivers. Benefits vary by State, but research documents an increasing trend in the numbers of people served and dollars spent in Medicaid home- and community-based care. In addition, policymakers are facing pressure to increase these services to address the unmet needs of patients and their families.[119] A study examining the benefits and costs of home- and community-based services in Florida[120] found that people receiving these services had been diagnosed with at least three chronic health conditions and needed help with three or more ADLs and seven IADLs. With services, they were able to avoid institutionalization despite this high level of needs. Other research has shown that the presence of a caregiver can reduce nursing home stay by 3.2 days. These caregivers need help finding services.

Options for arranging flexible services are emerging from Medicaid-funded consumer-directed care programs, which allow people to select and manage paid home care workers, as well as purchase assistive devices or home modifications. The program gives people the flexibility to adjust the frequency and timing of paid and unpaid services. Benjamin and colleagues examined the services of low-income Medicaid beneficiaries under agency-directed and community-directed services. People who directed their own services had positive outcomes. They were more satisfied with services and had fewer unmet needs.[121] Foster and colleagues[122] assessed the impact of consumer direction on caregiver burden in Arkansas and found that caregivers had greater satisfaction with the care recipient's care and were less worried about safety. Caregivers in the study reported less physical, emotional, and financial strain compared to the control group receiving traditional agency services. Primary informal caregivers who became paid caregivers reported substantial benefit compared to the group receiving agency services.

Evidence-Based Practice Implications

A review of the literature found that society depends on family caregivers to continue providing care for their loved ones, but does little to teach them how to do it and support them in this stressful work. At a minimum, nurses can recognize and respect their efforts, assess their needs, provide concrete instructions on the specific care they are giving (e.g., medication administration, dressing changes, and similar tasks), and refer them to potential sources of ongoing help. Nursing interventions in these areas can help reduce harm to caregivers and the patients they serve.

Respecting the Patient–Family–Professional Triad

The most important practice implication of this review of caregiving research evidence is that nurses can meaningfully change the course of caregiving for both the caregiver and care recipient by respecting the role that each has in managing ongoing care beyond the classic boundaries of professional patient care. For example, it is often not easy for the elderly patient in the hospital who is going to need postacute care to accept the need for family help, because they view themselves as independent. Nurses can help shift their views of classic independence as freedom from functional limitations to a context of family care in which giving and receiving assistance does not need to strip away autonomy.[123] It is also important to understand that burdened caregivers can successfully support their family member, but these caregivers may need help to bolster their sense of self-esteem.[124] They want to be part of the decisionmaking team.[125]

Nurses in all practice settings need to partner with patients and their families to move from the traditional nursing context of *doing for* clients in the "expert model of service delivery" to more mutuality in nurse-client relationships.[126] Nurses may need to "enact more empowering partnering approaches" and "reframe their professional image, role, and values"[126] to accomplish this. Listening skills and the ability to interpret body language and verbal communication are essential competencies in all encounters with patients and their family members.[127]

This model is consistent with Dalton's theory of collaborative decisionmaking in nursing practice triads, where the triad comprises the client, the nurse, and the caregiver.[128] In this vision of the caregiving environment, the nurse interacts with and assists not only consumers, but the informal caregiver as well. This kind of collaboration can increase feelings of control over health, the sense of well-being, and compliance with prescribed treatments.

Providing Information

Nurses need to communicate effectively with clients and caregivers to develop cost-effective plans of care and achieve positive client outcomes.[129] Communication is crucial across settings. The emergency room and hospital discharge planning processes, assisted living facility admission process, skilled nursing facility discharge process, and the home health care admission and discharge process are all critical points of interaction where health care professionals, patients, and family caregivers can benefit from respectful, high-quality communication.[130] In the managed care environment, providing concrete care information along with emotional support can help spouses of frail older adults better manage their caregiving situation.[118]

At all points in the patient's disease trajectory, caregivers need information to deal with the patient's care and treatment demands. Nurses and other health care providers should not expect caregivers to be responsible for sorting out relevant information and applying it to the care requirements for their family members. Research documents that caregivers have difficulty obtaining information from health care professionals, particularly physicians and nurses.[131-133] Professionals should be more responsive to patients' and family members' information needs.

It is important to provide information in a clear, understandable way through verbal, written, and electronic methods. Caregivers want concrete information about medications, tests, treatments, and resources. They also want time to have their questions answered. Nurses can provide anticipatory guidance for what the caregiver can expect.[134] This kind of information can relieve caregivers' distress arising from uncertainties about their ill family members' disease and treatment status and the care they may need.[135, 136] For example, teaching caregivers how to manage pain and other symptoms benefits both the patient and the caregiver. Caregivers who report more confidence in managing symptoms report less depression, anxiety, and fatigue.[137]

Caregiver Assessment

Given caregivers' essential role in caring for their family members and the hazards they face in doing so, their needs and capacities to provide care should be carefully assessed.[138] This assessment should focus on the caregiver as both client and provider before health professionals can assume caregivers are able to provide competent care without harming themselves or their family member.

Assessing the home and family care situation is important in identifying risk factors for elder abuse and neglect. Heath and colleagues[87] found that in-home geriatric assessments are needed to determine the risk for and occurrence of elder care recipient mistreatment. Fulmer's research[86] documents the need for interdisciplinary teams in emergency rooms to screen for elder neglect, with attention to risk factors associated with caregiver and elder vulnerability, such as the elder's cognitive and functional status and depression. Health care professionals who conduct detailed assessments of the caregiving situation through separate conversations with the patient and the caregiver are better prepared to provide guidance and collaborate with the family to prevent abuse and neglect.

Assessing the needs of older people living in the community is a prerequisite for helping caregivers find resources and adhere to a comprehensive plan of care. Outpatient geriatric evaluation and management can reduce caregiver burden, particularly for those who are less experienced caregivers.[139]

Linking Caregivers to Resources

Caregivers need adequate resources to assure minimization of risk to the patient.[140] To reduce the rough crossing that family caregivers experience as they navigate the discharge from hospital to home, there is a clear need to develop referral criteria and guidelines, accurate documentation, and prompt referral to continuing care professionals.[24] More case management programs may be useful to help ease this transition, promote safe and effective hospital discharges, and support caregivers in their ongoing, posthospital care. Nurses, preferably those trained in gerontological nursing, have a key role in case management for frail older people.[141]

Linking caregivers to resources throughout the disease trajectory is important because caregivers are often unaware that there are support services available to help them. A recent study of caregivers of people with Alzheimer's disease found that 75 percent had unmet needs, yet only 9 percent had used respite services and only 11 percent had participated in support groups.[142] Extending nursing care beyond the hospital boundary, nurses can help caregivers mobilize supportive resources in their natural network as well as formal services.[143]

Research Implications

Taken as a whole, interventions to improve caregiver outcomes have been varied. Intervention studies have typically been descriptive in nature, used small convenience samples, and have not included comparison groups. In addition, many studies have limited their samples to patients with only a single diagnosis. In the future, randomized trials are needed to substantiate the role of similar programs in enhancing caregiver skills and minimizing caregiver distress.

The majority of studies have focused on a single construct of the care situation (i.e., examining the correlation between the caregiver-patient relationship and caregiver burden). Researchers have given limited attention to the nature of the knowledge and skills of the caregiver, and to personality factors or dispositions of caregivers.[144, 145] Most of the intervention studies did not consider potential confounding or risk variables, such as prior family relationships, cultural variation, caregiver health status, stage of disease, hours of care, or competing caregiver role demands. In addition, little detail was provided about the intervention design. Finally, few studies described the nature of care tasks of the caregiver, so we are unaware whether caregivers were effectively managing symptoms, providing emotional support, providing direct care, monitoring patient status, or performing a combination of these tasks.

Recommendations for Future Research

Since much of the caregiving research remains descriptive, there are many gaps in the evidence-based research to promote patient safety and quality care for caregivers as secondary patients and caregivers as providers to vulnerable patients. To advance our knowledge in this field, we recommend several strategies for future research.

Because caregiving is a day-in, day-out role that fluctuates as the needs of the care recipient change, it is not well understood through cross-sectional research designs. It is essential that descriptive and longitudinal designs be employed to follow the care requirements over the course of the illness trajectory. Longitudinal research to date has uniform intervals between observations such as 3, 6, or 9 months, without concern for treatment protocol or stage of disease or care demands. Further studies should take into consideration other time points that may better reflect the disease trajectory, such as time of initial diagnosis, protocols alterations, and points of disease exacerbation or decline. A special focus on safety, risk for negative outcomes, and adverse effects for both the caregiver and care recipient should be noted.

Key variables to include in these studies are the type and stage of the disease and the treatments because they will be related to the types of continuing therapy. These various therapies will be related to the needs of the patient and assistance with self-care, as well as the patient's ability to perform other customary daily activities. Are the demands on the caregiver such that they jeopardize his or her health? We also need larger population-based studies so we can have heterogeneous samples related to diagnosis, stage of disease, caregiver distress, care provided, patient impairment, and duration of care as they relate to caregivers' ability to provide safe care without jeopardizing their own well-being.

Research that uses carefully selected inception cohorts is needed so that variation in care demands can be understood. We will be in a far better position to describe how the course of the disease and associated treatment influence caregivers' responses if we start with inception cohorts of those caregivers beginning with initial treatment and proceeding through palliative care. Adverse patient care and caregiver situations, such as medication errors, falls, and subsequent hospitalizations, can be noted over time.

We need studies that target caregivers that are from minority and economically disadvantaged groups if we are to better understand their own needs and interventions to support them in providing safe care. Furthermore, focus on variations or adaptations needed to minimize caregiver distress related to ethnic, racial, cultural, or socioeconomic diversity is needed. We know very little about the distress and resource limitations of various vulnerable groups and the acceptability of various types of interventions to ethnically and racially diverse populations.

We need to investigate the interplay between the formal and informal systems of care for the ongoing needs of patients as well as caregivers. More research needs to be conducted that focuses on how family influences care-related decisions and the impact to clinically significant processes of care and/or client outcomes. There is very little research to suggest how variations in caregiver contact with the formal health care system interacts with the amount and types of responsibilities faced by family caregivers. Can prepared caregivers contribute to the quality of patient clinical outcomes as well as patient safety? What does competent and appropriate family care contribute to patient clinical outcomes? How does it affect cost and care utilization?

Future research should identify and test patient- and family-directed interventions and chart their impact upon the quality of care outcomes for patients. In addition, interventions should report the cost of care, as well as the cost of utilization of services. What are the costs of negative outcomes that result when safety and neglect or abuse are involved?

Interventions that can demonstrate improved patient outcomes are particularly essential to building a high-quality system of continuing care. Caregivers who face conflicts in competing demands related to caring for children, spouse, or parent and to maintaining their work roles are particularly threatened by and vulnerable to the demands for continuing home care. More appropriate home care and home care support (resulting in caregivers who are prepared to care and have adequate formal support) may lead to fewer patient or caregiver hospital readmissions, fewer interruptions in treatment cycles, shorter periods of work loss, and better patient and caregiver mental health. Quality of care and patient safety are concerns.

We need to design and test interventions to assist patients and their families to increase their preparedness to deal with the overall care process, to deal with both the direct and indirect care demands. How do we increase their sense of control and mastery of their care situation? Future intervention studies should utilize multidisciplinary, randomized clinical trials (including physicians) to determine the unique contribution of educational programs versus social support versus psychological support on caregiver outcomes and patient outcomes.

Future studies should explore whether health care professionals can assist the caregiver to build effective buffers against being overwhelmed and distressed. Interventions that assist the caregiver to engage in activities that promote their own health should be carried out to identify strategies of health promotion. Research questions should address whether or not caregiver distress (i.e., depression and burden) affects caregiver decisionmaking and judgment about patient care, and to examine caregiver behavior and choices and the subsequent quality of care. Do these have a negative impact on the patient or on themselves?

Examining caregiver distress as it relates to quality of care is absent from the literature. Research is needed to understand the *quality* of care that family members provide and then determine how that care impacts the overall therapeutic plan and patient clinical outcomes.

Longitudinal studies of caregivers are needed to explore the complex interactions of caregiver physical health and mental health, and how self-care and health-promotion practices of the caregiver are altered. Exploration is needed of which self-care practices (i.e., nutrition, exercise, sleep, stress management, preventive and promotive health care) can influence caregiver distress and physical health status so that caregivers can continue to provide quality and positive care.

To better understand the effects of care on family caregivers and on patient outcomes, caregiver roles, responsibilities, knowledge, and skills need to be more rigorously explored and defined. For instance, what do caregivers do well? What do caregivers not do well? In what areas are the patient outcomes most likely to be compromised? In what areas is patient safety most in jeopardy? What areas cause caregivers more distress? Once these questions are answered, we can target interventions at those who are at risk and intervene early in the care situation, rather than late.

Finally, interventions must recognize professional or formal caregivers and family caregivers as partners in health care—partners who offer unique and vital skills and resources—and engage them in the entire plan of care. Such interventions are critical as we increase the focus on outcomes of care and as providers are paid for outcomes performance. Family members as partners are critical.

Conclusion

Family caregivers are critical partners in the plan of care for patients with chronic illnesses. Nurses should be concerned with several issues that affect patient safety and quality of care as the reliance on family caregiving grows. Improvement can be obtained through communication and caregiver support to strengthen caregiver competency and teach caregivers new skills that will enhance patient safety. Previous interventions and studies have shown improved caregiver outcomes when nurses are involved, but more research is needed. There is more to be learned about the effect of family caregivers on patient outcomes and areas of concern for patient safety. Nurses continue to play an important role in helping family caregivers become more confident and competent providers as they engage in the health care process.

Search Strategy

The research cited is a comprehensive but not exhaustive review of the caregiver literature. The literature search for this paper was done in the databases MEDLINE, CINAHL, and PsycINFO using variations of the terms "caregiver" and "long-term care" or "home care services," combined with other terms relating to patient safety and nursing practice. Other terms employed included "case management," "education and training," "medication," and "risk management." The search was limited to articles written in English, but not limited to the United States.

The search terms applied were usually kept very broad, and keyword searches were frequently employed more often than searches that relied upon the use of controlled descriptors, as the topics of patient and caregiver safety, which are often intertwined, are difficult to isolate through clearly defined identifiers. As a result, search results were large, and relevance was frequently determined through the reading and review of abstracts of large sets of retrieved publications. Relevant articles for this review were not always indexed using terms relating to nursing; the *potential* involvement of the nurse as a contributor to *improved* patient and caregiver safety was a determinant for inclusion. Some articles discussed the professional health care team in general terms, while others focused on the specific role of a nurse serving as a factor in *safe family caregiving*. The broad search strategies delivered high retrieval levels and the need to distill relevant evidence.

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Evidence Table: Supporting Family Caregivers in Providing Care

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Acton & Kang 2001[69]	Care burden	Meta-analysis	Various meta-analysis (Level 1) Effect sizes calculated; studies were grouped by intervention category; pooled effect size calculated for each intervention category (Level 3)	24 reports testing 27 treatments for adults with dementia.	Various educational	Multicomponent interventions have a small significant effect on burden. No effect on burden from support group, education, psycho-education, counseling, and respite.
Austrom 2004[114]	Nonpharmacologic methods, such as this collaborative stepped-care management intervention program, are the intervention of choice for behavioral disturbances, which can add to caregiver burden and affect quality of care.	Randomized controlled trial	Randomized controlled trial (Level 2). Questionnaires were periodically administered to evaluate frequency of behavioral disturbances in patients as well as a measure of the caregiver's reaction (Memory and Behavior Problems Checklist), and measure of severity of the caregivers depression (Patient Health Questionaire-9). (Level 3)	Minority Alzheimer's patients, who were less likely to visit specialty clinics, may find interventions more accessible if they were delivered through primary care clinics. Intervention of three basic components: (1) comprehensive screening and diagnosis protocol, (2) multidisciplinary team approach to care coordinated by a geriatric nurse practitioner, and (3) proactive longitudinal tracking system.	All participants receive Alzheimer caregiver guides, educational interventions, and specific protocols for common behavioral disturbances. Treatment group then received treatment recommendations for specific behavioral disturbances from a clinical treatment team of geriatric nurse practitioner, social psychologist, geriatrician, geriatric psychiatrist.	Study is ongoing. Preliminary data indicate that program is well received by patients, caregivers, and primary care physicians. Subjects are attending voluntary meetings more frequently than those not in the program.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Beach 2005[63]	Threatening behavior, verbal abuse	Convenience sample (descriptive)	Structured interviews (Level 5) Care recipients reports of harmful caregiver behavior, screaming, yelling swearing, threatening (Level 3)	265 caregiver/care recipient dyads	None	Harmful caregivers were associated with greater recipient ADL needs; spouse's greater caregiver cognitive physical symptoms; caregiver at risk for clinical depression.
Bowles 2003[146]	Home care referral can lead to better care	Noncomparative	Interviews with content analysis (Level 5) Identify patterns clinicians used when gathering information, determine information essential to discharge referral decisions, and explore why patients in need may not be referred for service (Level 3)	Patients discharged without home care referrals were presented as case studies to nurses, social workers, physicians, and discharge planners. Observations were recorded.	None	Three themes describe why patients may not receive referrals: (1) patient characteristics, (2) workload, and (3) staffing, educational issues.
Brodaty 2003[73]	Psychological distress in caregivers	Meta-analysis	Meta-analysis (Level 1) Various psychological morbidity and benefits (Level 3)	30 studies	34 interventions	Significant improvement in caregiver distress and caregiver knowledge. No improvement in caregiver burden.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Brown 2006[126]	Changing the home care nursing approach from the expert model of service delivery to a more client-centered empowering model can optimize the potential for improved interactions and understandings between the nurse and consumer, and greater professional autonomy for the nurse.	Non-comparative (interpretive phenomeno-logical using hermeneutic analysis)	Holistic interpretation of nurses' experiences through analysis of interviews (Level 5) Identified concepts were noted and categorized until themes and patterns emerged. Participant review and peer review of findings assured authenticity of data. (Level 4)	Purposeful sample consisting of 8 registered nurses who had in-depth experience in the flexible client-driven delivery approach, identified by a key informant within the home care program (Canada). Employed maximum variation sampling regarding age, education, experience in in-home nursing.	None	While interpretive research findings are not generalizable, this study identified pitfalls and suggests potential ways that nurses can implement practice change. Several barriers exist that impede nurses from evolving to a client-centered service model: system level (governmental financial), organizational (centralized allocation and control of service delivery), personal (remuneration, workload, working conditions). Home care nurses revealed a tendency to seek direction of physicians and managers rather than to exert professional autonomy within the scope of professional nursing practice. Empowering partnering approaches in nursing fosters sharing power to optimize the potential for nurse and client. Nurses may have to reframe their professional image, role, and values to enact this interaction.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Burton 1997[38]	High-level caregiving can increase odds of insufficient rest and exercise, and poorer outcomes while recovering from illness or threats to health.	Cross-sectional (descriptive)	Caregivers compared to noncaregivers (Level 4) Structure interviews in their home (Level 3)	Health effects study. 434 caregivers with a control matched 385.	None	Being a high-level caregiver increased odds of not getting rest, not having time to exercise, and not recuperating from illness and forgetting to take prescription meds when compared to noncaregivers.
Cameron 2006[99]	Complex rehabilitation has negative health outcome on caregivers.	Cross-sectional	Survey (Level 4) Identify aspects of the caregiver’s emotional distress and psychological well-being; compare health-related quality of life of informal caregivers. Evaluated outcomes by CESD, postaffect scale SF36 (MO5). (Level 3)	Informal caregivers matched age and gender of ARD survivors.	None	Caregivers had more emotional distress, more lifestyle interference, lower misery. Caring for ARD survivors with more depression, poorer overall health quality compared to age and gender matched group lasted 2 years.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Campbell 2004[137]	Caregiver strain and burden	Cross-sectional (survey description)	Descriptive cross-sectional (Level 4) Quality of life, self-efficacy, mood (Level 3)	Age mean 57.6, intimate partners of patients with prostate cancer.	None	Caregiver self-efficacy was associated with both partner mood and caregiver strain. Caregiver self-efficacy scores were negatively correlated with partner depression, anxiety, and fatigue subscale scores since partners who reported greater overall confidence in assisting patients with symptom control also reported less depression, anxiety, and fatigue. The total self-efficacy score was negatively associated with strain. Increased self-efficacy in the caregiver led to better adjustment to the symptoms and increased mental health of the patient.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Coon 2003[115]	Anger and depression	Cross-sectional	Survey (Level 4) Anger, depression coping intervention (Level 3)	Female caregivers age 50+, older community dwelling, 169 females; psycho-educational and skill building, 2-hour workshops for 8 consecutive weeks followed by two booster sessions at 1-month intervals for 3 months. Two options: anger management or depression management, intervention study, R(2/CT) 3-4 months.	Psycho-educational small group over 3-4 months.	Anger and depression management interventions decreased anger, hostility, and depression and improved self-efficacy at 3 months. Anger management improved coping skills. RCT, effective. Self-efficacy impaired in both groups. Pretreatment depressive symptoms moderated intervention.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Crist 2005[123]	Understanding how care recipients feel about the care they receive and the level of autonomy that they retain while under care may facilitate better understanding between caregivers and recipients, and result in less anxiety and better relationships.	Non-comparative (hermeneutic interpretive phenomenological)	Exploration of shared meanings through multiple, open-ended, in-depth interviews, observation (Level 5) 2-5 interviews were conducted with each elder. A 3-member investigator team co-constructed an emergent interpretation of the narratives within the specific context. (Level 4)	Convenience sample of 9 elders (5 women, 4 men) in urban and rural areas of the Pacific Northwest, recruited from three home health agencies, one adult day center, one neurological clinic. Elders were 65 or older and had an identified family member who provided assistance with at least one ADL.	None	Elders can incorporate family care into their lives while still viewing themselves as autonomous. Gerontological nurses, who traditionally measure independence as the level of a client's functional ability, may shift to understand the recipient's view of autonomy and independence is constructed independently and individually. Positive relationships between elders and caregivers resulted in personal growth; a positive family care context facilitated recipients' willingness to incorporate receiving family care into their lives.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Christakis 2006[27]	The hospitalization of a spouse with a serious illness may be associated with an increase in the risk of death of a partner.	Retrospective cohort	Cohort compiled from data in Medicare claims forms. (Level 4) Two statistical methods were applied (Cox regression and fixed-effects) to estimate the relationship between the hospitalization of a spouse and the subsequent death of the partner, while controlling for all constant characteristics of the spouses and their environment. (Level 1)	518,240 couples who were enrolled in Medicare in 1993, 65 years of age or older	None	Serious spousal illness and spousal death appear to be independently associated with the risk of death of the partner. Hospitalization for various diseases may differentially affect partners. Implications: training and assistance of spouses who serve as caregivers can lower costs and improve the health of patients and partners. Such interventions might decrease mortality among partners. Interventions may be more useful in certain diseases, such as stroke or dementia.
Dalton 2005[129]	Quality of care can be improved when client-caregiver-nurse (triad) communication occurs; caregivers can better understand care plans; coalition decisions within triads may increase the possibility that client interests are maintained.	Non-comparative (ethnographic, content analysis); exploratory	Observation, recording, and transcription of triad interactions. (Level 5) Qualitative and quantitative analysis of frequencies of different types of decisions and decisionmaking situations. (Level 4)	12 client-caregiver-nurse triads admitted for the first time to home health care agencies in suburban New England during 1994	None	Coalitions (two members of a triad acting together) form during triadic interactions; of 157 decisionmaking situations evaluated, coalitions formed in just 8 (5%). Decisions were organized into program decisions, operational decisions, and agenda decisions. Two of the roles (advocate and passive participant) that can be assumed by a third person were evident.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Dalton 2003[128]	An understanding of triad interaction and how coalitions are formed in clinical settings may enhance the effectiveness of clinicians' communication with clients and family caregivers and facilitate positive client, caregiver, and nurse outcomes.	Systematic literature review (theory generation)	Literature review (Level 1) Theory generation (Level 4)	None	None	The theory of collaborative decision-making in nursing practice for a triad provides a framework for studying the effects of collaborative decision-making among nurses, family caregivers, and clients.
Davis 2004[76]	Telephone-based psycho-educational interventions may provide relief from the burden, distress, and depression suffered by caregivers who are not able to, or do not wish to, seek help from sources that require that they leave their home.	Three-group pretest and post-test (repeated measures design with randomization to treatment group)	Each of three groups of caregiver-recipient dyads received 12 weekly sessions of training by in-home contacts; training by telephone contacts; and friendly, socially supportive phone calls. (Level 2) Caregiver self-reported outcome measures: burden, distress, depression, social support, and life satisfaction. (Level 4)	71 caregiver-care recipient dyads were recruited from geriatric clinics and home care agencies in central Alabama, and were randomized into three groups.	Caregivers in telephone and in-home groups were trained in problem-solving, caregiver appraisal of behavior problems, written behavioral programs for managing specific problems, and strategies for handling affective responses to difficult caregiving strategies.	An unexpected reduction in caregiver burden and distress was observed in those receiving only friendly phone calls, possibly because the calls provided caregiver respite. Only the in-home training group experienced significant burden and caregiver distress reduction. Caregiver groups did not differ significantly on caregiver depression. Despite differences in contact time with the three different groups, they were all similar in satisfaction levels.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Dunnion & Kelly 2005[24]	Improvements in planned discharge strategies (a multidisciplinary approach to developing referral guidelines, staff training, and dissemination of information) of elders from emergency room to home can lead to improved quality and continuity of care for the older person.	Cross-sectional (interviews) of 5 groups of health care professionals	Standardized questionnaires (Level 3) Quantitative data were analyzed with SPSS, and qualitative data were content analyzed. (Level 4)	Emergency department in a 320-bed rural general hospital in the Republic of Ireland. Purposeful sample (excluded psychiatric nurses, social workers, physiotherapists) of nursing and medical staff in the emergency room, totaling 222. 135 questionnaires were returned and 131 were analyzed.	None	Findings added support to others that found that in general, health professionals in the emergency department do not adequately determine the aftercare needs of older patients when they are being discharged. Effective discharge planning is impeded by gaps in communication between the hospital and community interface, such as illegible discharge summaries and delays in sending information to the general practice physician. There is a lack of synchrony between hospital and community nurses in relation to the level of communication between the two sectors. The liaison nurse role may help to improve communication links and channels between the primary and secondary interface. There is a clear need to develop referral criteria and guidelines, accurate documentation, and prompt referral to continuing care professionals.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Ferrell 1995[106]	Pain management can affect quality of life and caregiver burden.	Cross-sectional	Quasi-experimental (Level 3) Quality of life and caregiver burden; physical and psychological impact of family caregiving and pain management (Level 3)	50 family caregivers of patients experiencing cancer-related pain from two California medical centers	Pain education program: pain assessment, pharmacologic interventions, and nonpharmacologic interventions	The pain education program was effective in improving knowledge and attitudes regarding pain management. Pain management is a priority for nurses, and use of interventions such as structured pain education improves quality-of-life outcomes for patients and their caregivers.
Fortinsky 2001[130]	The quality of interaction in the health care triad is likely to influence health-related outcomes of family caregivers, persons with dementia, and primary care physicians. The consequences of dementia care communication and practice are most significant when dementia patients are entering or leaving a new health care setting.	Systematic literature review	Literature review (Level 1) Summarization of knowledge base (Level 4)	None	None	Interactions in medical encounters involving dementia care are not optimal from the perspectives of family caregivers or physicians. Physicians are willing to share ongoing management of dementia patients and their families with other organizations in the community. Older persons with dementia, even though physically present during triadic encounters, are unlikely to be involved as active participants in dialogs and decisionmaking regarding diagnosis and management of dementia symptoms.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Fulmer 2005[147]	Elder mistreatment is an enormous social problem, which emergency departments may help identify.	Cross-sectional	Older adults screened and recruited from emergency rooms (Level 3) Elder and caregiver cognitive status, functional status, depression level, health status; demographics; perceived social support; childhood support; personality. Relationship between measured variables and neglect-assessment team's diagnosis of neglect (Level 3)	165 subjects, 70 years or older, English/Spanish speaking, Mini-Mental Status Exam score of 18 or more, using a paid or unpaid caregiver 20 hours per week or more. Recruited from four urban emergency departments in New York and Tampa.	None	Older adults who are diagnosed as neglected are sicker, have fewer financial resources, and have less help in the home. There is a relationship between self-reported childhood trauma and later-life neglect, which may be considered normative by these elders. Personality traits may be indicators of neglect.
Gitlin 2001[100]	Upset family caregivers	Randomized controlled trial	Intervention RCT (Level 2) Behavioral problems, ADL, IADL, caregiver well-being, self-efficacy, and being upset (Level 4)	171 families of dementia patients; five 90-minute home visits by occupational therapists	Focusing on education and environmental modification every other week over 3 months; occupational therapists	Spouses reported reduced upset; women reported improved self-efficacy in managing behaviors; minority women reported improved self-efficacy in managing functional dependency.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Gitlin 2003[70]	Burden among dementia caregiver	Meta-analysis	Meta-analysis (Level 1) Pooled parameter estimates of nine active conditions compared with six control conditions of the Resources for Enhancing Alzheimer's Caregiver Research (REACH) project. Associations of caregiver characteristics and outcomes were examined statistically. (Level 3)	Homes of patients with dementia, multisite study	Consulting education, support, skill building, home visits, problem-solving; 6 months.	Active interventions are superior to control on caregiver burden. Active interventions superior to control for women, those with lower education. Family therapy and computer technology intervention impacted depression. Active better for Hispanics, nonspouses.
Gitlin 2005[107]	Negative behavior in patients with dementia	Randomized controlled trial	Randomized controlled trial (Level 2) Behavior problem checklist, Says ADL, task management affect (Level 4)	127 caregivers, 6 months	Skill building, education, problem-solving, and technical skills. Active—five 90-minute home visits and one phone session over 6 months. Maintenance—one home visit and three phone sessions over the next 6 months.	Decreased days assisting with ADLs at 6 months, no difference at 12 months. Decreased upset with memory-related behaviors at 6 months, no difference at 12 months. Improved affect at 6 months, none at 12 months. Decreased memory behavioral occurrences in patients at 6 and 12 months.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Glueckauf 2004[116]	Caregivers of persons with dementia typically experience emotional, physical, and psychosocial deterioration due to the extreme demands of providing home care without support.	Single-group pretest-post-test	Telephone interviews with caregivers to assess effects of the Positive Caregiving classes (Level 5) Survey instruments for dependent measures were: Steffen et al.'s Caregiver Self-Efficacy scale,[148] Parke et al.'s Stress-Related Growth Scale,[149] Lawton et al.'s Caregiver Appraisal Inventory[150] (Level 3)	21 caregivers of individuals with progressive dementia who had completed the AlzOnline's Positive Caregiving program	Series of six 45-minute interactive (PC- or telephone-based) Positive Caregiving sessions, every 2-3 weeks over a 16-week period	Moderate support was obtained for the effectiveness of AlzOnline's Positive Caregiving classes; significant increases in self-efficacy, concomitant decreases in subjective caregiving burden, little or no change in stress-related growth and positive caregiving appraisals, or perceptions of time burden in providing caregiving assistance.
Grant 2002[108]	Caregiver depression and burden	Randomized controlled trial	Randomized 3-group design (Level 2) Social problem-solving (Level 4)	45 stroke caregivers	Problem-solving: (1) 3-hour home visit with RN, (2) weekly phone calls by RN for 1 month, (3) phone calls by RN every 2 weeks for 1.5 months.	Improved problem-solving skills, preparedness, vitality, social functioning, mental health, and role limitations related to emotional problems. Less depression. No significant difference in burden.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Greenberger & Litwin 2003[124]	Caregiver burden "is liable to diminish the caregiver's ability to provide quality care."	Cross-sectional (interviews)	Structured in-home interview schedule (Level 3) Variables measured: background, personal and social resources, burden measures, feelings of caregiver competence, adherence facilitation, measured with multiple instruments (Level 3)	240 Jewish primary informal caregivers, randomly recruited using records of recently discharged dependent older patients, caring for recipients over the age of 65, who lacked at least one functional ability delineated by ADLs or assessing motor functions necessary for independence in IADLs, and with at least one chronic illness.	None (interaction only)	Operationalizes facilitation of care recipients' adherence to prescribed care regimens in informal caregiving. Shows positive association between caregiver burden and adherence facilitation; burdened caregivers can be successful informal caregivers; and efforts to bolster caregivers' self-esteem and social support may be more effective in assuring quality care than attempts to relieve their sense of burden.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Griffiths 2004[109]	Persons over 65 years old represent a significant percentage of medication-related admissions to hospitals. Community nurses can play a role in managing the administration of medicines and the monitoring of their effects on patients. Community nurses can play a unique role in the "medication team" (i.e., doctors, pharmacists, nurses, consumers) in a multidisciplinary approach to quality use of medicines.	Pretest-post-test with a cross-sectional survey	Survey (Level 3) Participants living at home and receiving community nursing care were assessed for knowledge of and ability to manage medication regimes. A nurse-initiated intervention was developed that included referral pathways to physicians and/or pharmacist medication review. (Level 3)	111 participants over age 65, taking oral medications and having regular community nursing visits, were surveyed. Recruited from case-load of Australian community nurses. A subgroup of 24 participants with diminished knowledge of medications were administered a followup in-depth survey.	Various interventions, including client education, referral paths to physicians and pharmacists, provision of administrative support systems.	After invention, participants showed improvement in their ability to manage medications (alteration in use of compliance aids) and demonstrated increased knowledge about their medications. Clients showed significant improvement in the ability to correctly name their medications and schedules correctly; clients did not experience reduction in the complexity of the regimes. Community nurses can successfully work within the boundaries of a multidisciplinary team to provide interventions within their professional scope of practice.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Hallberg & Kristensson 2004[141]	Preventive case/care management interventions for community-dwelling frail older people may result in better quality of life, fewer emergency medical calls, and a reduction in hospital admissions.	Systematic literature review	Systematic review (Level 1) Three areas of outcome were targeted, though not at the same time: health care consumption, in some cases transformed into costs; quality of care; and patient's health and ability. (Level 4)	A literature review produced 26 papers that related to the topic. Articles discussing a particular group of diseases were excluded, as the focus was on the needs of frail older people with complex needs. Criterion for inclusion of older people in the programs was either having a chronic disease combined with receiving care from at least two professionals or nonprofessional caregivers and living independently in the community.	Case management interventions included traditional tasks (case finding, assessing, planning, implementation, coordination and monitoring, and evaluation of options); comprehensive (outreach, client assessment, advocacy, etc.); extensive (medication and symptom management, caregiver and family supportive counseling).	Case management includes a range of interventions, but the core of the intervention is a task-focused approach, with parallel functions added (interagency coordination, bereavement counseling) depending on the individual's situation. The effect of case management interventions studied showed a range of outcomes. The content of case management needs to be expanded and influenced more by a salutogenic, rehabilitative, and family-oriented health care approach. Nurses, preferably trained in gerontological nursing, have a key role in case management for frail older people. Nurses as case managers, along with a geriatric team, can solve difficult problems. Case management has not been standardized and usually does not take a deliberate preventive and/or rehabilitative approach, using psycho-educative interventions focusing on self-care activities, risk prevention, disease management, community involvement, and functional ability.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Heath 2005[151]	Assessment of prevalence of remediable health conditions from in-home geriatric assessments of referred adult protective services. Elder mistreatment has a significant impact on mortality of victims.	Retrospective cohort study	Assessments were conducted with referred elders by a nurse-practitioner-geriatric physician team, including a detailed medical and functional history, physical exam. (Level 5) Classifications of mistreatment (neglect, financial exploitation, abuse) were employed from the NJ State Dept. of Health and Senior Services as independent variables. Descriptive statistical analysis. (Level 3)	211 adult protective services referred to the Linking Geriatrics With Adult Protective Services program in central New Jersey.	None	The predominance of neglect among the subjects is consistent with the known national distribution of various forms of elder mistreatment. A high level of dementia and depression was also consistent with that found in neglected populations.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Hellstrom 2004[152]	While health problems can reduce quality of life (QoL), dependency on others may also influence how people perceive their QoL. Understanding how living with health-related assistance at home affects peoples' lives can inform what nursing care should focus upon.	Cross-sectional (survey)	Survey (Level 3) Comparison of people 75 years and older, living at home and receiving help with daily living, with those without such help, with regard to sociodemographic data, self-reported illness, health problems, and QoL (Level 3)	1248 subjects (448 receiving help; 793 not receiving help; age stratified randomized sample) responded to a mailed survey in a southern Swedish municipality.	None	Although symptoms of health-related problems did determine QoL, it was specific symptoms and living conditions that predicted low QoL. Therefore, it is especially important to focus on these symptoms in nursing care. The transition from living independently to receiving help from others probably contributes to a change of values and attitudes about what is important in life. This indicates that an assessment of various symptoms and their importance for each individual is vital. There is a need for thorough assessment and monitoring, e.g. by a nurse, of older people who are living at home and who are restricted in their resources in handling daily living.
Heinrich 2003[25]	Support to caregivers of dementia patients; guidance from health personnel.	Non-comparative	Secondary analysis interviews (Level 4) Interview focus groups analysis (Level 3)	Interviews of 20 women who were caregivers and new data from 8 volunteers; 62 interviews total for analyses.	None	Wanted mutuality in decisionmaking with staff and partnership and empowerment. Community resources use was the experience they described. Struggled with personnel.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Hepburn 2003[117]	Caregiver well-being, burden, emotional enmeshment	Changing practice projects	Training program descriptive field study (Level 6) Well-being, burden, goal setting. Burden CESD competence. (Level 4)	140 caregivers, 40% spouses, 47% adult, children	Manual, CD-ROM, workshops for caregivers	Improved reaction to caregiver behavior burden, emotional enmeshment changed, descriptive, increased skill, knowledge, confidence.
Houts 1996[81]	Establishment of a prescriptive problem-solving model for family members who care for patients at home can help caregivers develop and carry out orderly plans that address both medical and psychosocial problems and coordinate with care plans of health professionals.	Published guidelines	Proposal of a model for problem-solving in caregiving (Level 6) No outcome measures (Level 4)	None	None	The role of caregivers needs to be restructured to ensure they become effective members of the health care team. This requires educational materials and training programs.
Jang 2004[73]	Depression diminishes response to helping patient.	Randomized controlled trial	Spouse caregiver, AD patients, RCT (Level 2) Counseling, neuroticism, depression (Level 3)	160 in each group; caregivers, spouses caring for patient with dementia	Enhanced psychosocial care or usual care. Comprehensive, counseling sessions, counseling support and consultation (2), and family (4) sessions, then weekly groups 4 months later with ad hoc individual sessions as needed—usual care group.	Caregivers low in neuroticism responded with declining levels of depression, caregiver's height in neuroticism maintained baseline level of depression.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Kozachik 2001[112]	With a shift to outpatient cancer care and increased responsibilities placed on family members, a greater potential exists for depressive symptoms to arise in a family caregiver.	Randomized controlled trial	Convenience sampling. Control dyads and experimental group that received Cancer Care intervention. (Level 2) Equivalence of groups at baseline; comparison of caregiver depression; impact of patient depression, patient symptoms, caregiver exposure to supportive nursing intervention on caregiver depression (Level 1)	120 caregiver/patient dyads. Caregivers of newly diagnosed cancer patients. Patients were from two Midwestern cancer treatment sites.	Nursing intervention of symptom monitoring/ management, education, emotional support, coordination of services, caregiver preparation to care.	Baseline caregiver depression and the number of patient symptoms at baseline were significant predictors of caregiver depression at 9 and 24 weeks. However, no main effect of the experimental condition existed on caregiver depression; a nonsignificant relationship was found between the number of interventions and depression scores for caregivers.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Kurtz 1994[26]	Depression, health impact.	Cross-sectional studies	Descriptive interviews (Level 4) Issues addressed most frequently occurring symptoms, levels of symptom severity, immobility, dependences in ADLs, and depression variance. (Level 3)	Family caregiver experiences at different stages of patient illness, mean age 55, N = 208. Followed for 12 months.	None	Family caregiver variables of depression, impact on health, impact on schedule, and assistance with ADLs were correlated significantly with all patient variables. Family caregivers of elder patients were less depressed and perceived less impact of their schedules. As stage levels of depression progressed, there was a greater impact on caregivers' health and schedule, and increased involvement in assisting their patients with ADLs, closely mirroring the increasing progression with levels of the patient variables. As increased demands on the family caregiver occurred during the later stage of illness, physical and emotional support for the family caregiver did not occur.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Mahoney 2003[75]	Caregiver bother and depression anxiety	Randomized controlled trial	Multisite randomized trial (Level 2) Bother, anxiety, depression mastery (Level 4)	100 AD caregivers, 50 in usual care and 49 in technology group	Year-long access to an automated interactive voice response system. Provided stress monitoring, counseling system, voice mail links to AD experts, voice mail telephone support group, and a distraction call for care recipients.	Improved caregiver bother and depression for those with lower mastery at baseline. Improved caregiver burden for wives. Affected bother, anxiety, and depression. Benefit from technology.
McCurry 2005[82]	Caregiver sleep	Randomized controlled trials (for caregiver)	Randomized trial (Level 2) 36 Community Developing CESD, Cornell Depression Scale. Problem checklist - Pittsburg Sleep Index (Level 3)	36 dyads who had a sleep problem	Sleep hygiene, daily walking, daily light exposure (over 3 weeks), written materials, principles of sleep hygiene, control group, general instructions	Improve percent sleep time and total sleep time, fewer waking periods per hour at post-test and 6 months, used actigraph. Effective, MR, control patients spent more time in bed.
McMillan 2006[83]	Mastery burden	Randomized controlled trial three-group design	Randomized controlled trial (Level 2) Coping burden mastery (Level 3)	354 family caregivers with patients with terminal cancer. Three interventions: (1) standard hospice care, (2) hospice care plus three supportive visits, (3) hospice care plus problem-solving training	Coping skills	Improved family coping. Improved caregiver QoL, reduced task burden.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Mailey 2002[153]	The nurse's role of educating client's about their health care is an important component of quality care and can be key to successfully coping with a disastrous event.	Changing practice projects/ research	Theory application (Level 6) Neal Theory of Home Health Nursing (Level 4)	None	None	After determining which of Neal's stages (dependence, moderate dependence, autonomy, or collaborator) a nurse occupies, an agency can provide the appropriate resources (training, checklists, supervision, mentoring) the nurse needs (and can communicate to the caregiver) to function effectively in a disaster.
Miller 2006[85]	Caregivers' harmful behavior toward patients	Non-comparative	Descriptive (Level 5). Onetime measures; amount of care provided CO, depression (Level 3)	180 caregiver-care recipient dyads.	None	Compromised cognitive status in 39%; caregiver probably affects the quality of care.
Mittelman 2004[88]	Prevent negative responses to patients' troublesome behaviors	Randomized controlled trial	Randomized controlled trial (Level 2) Problem behavior checklist (Level 3)	406 spouses, caregivers.	Counseling and support and usual care counseling for 4 months, then support groups and ad hoc counseling.	Caregiver distress decreased over time from year 1 to year 4. RCT, effective

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Mittelman 2004[89]	Fewer depressive symptoms	Randomized controlled trial	Randomized controlled trial (Level 2) Geriatric depression scale (Level 3)	406 spouses, caregivers of dementia patients.	Counseling sessions; individual (2) and family (4) sessions, then weekly groups 4 months later with ad hoc individual sessions as needed.	No difference in depression at 4 months, but significant differences at all other points up to 3 years after enrollment.
Metlay 2005[90]	In the outpatient setting, patients and their caregivers play a critical role in ensuring the safe use of medical therapies. Knowledge of the causes of medication errors can inform the design of medication-taking interventions.	Cross-sectional	Prospective cohort study (Level 4) Telephone interviews. Demographic characteristics of survey participants were compared to characteristics of nonparticipants in the PACE program. Five groups were identified for sampling by medication use. Interview responses to specific medication information and medication organization questions were compared across drug categories using chi-square tests (Level 3).	4,955 Pennsylvania Pharmacy Assistance Contract for the Elderly (PACE) members (65 years and older) who were taking warfarin, digoxin, and phenytoin (half of whom lived home alone)	None	Almost one-third of subjects reported not receiving any instructions on the use of their medications. Approximately 40% used no organizational system to adhere to medication regimens. A substantial proportion of older adults on high-risk medications do not recall receiving instructions for the use of their medications and do not take advantage of existing systems for organizing medication regimens.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Naylor 2000[154]	Identification of problems experienced by elders who were hospitalized and discharged to home.	Noncomparative	Content analysis of patient records by advanced practice nurses (Level 5) Problems encountered by discharged elders, interventions used by advanced practice nurses with patients, linkages between patient problems and advanced practice nurse interventions (Level 3)	Sample records obtained from 124 intervention group patients in a large randomized clinical trial.	None	Most problems experienced were either psychological in nature or related to health behaviors. The majority of interventions for both study groups could be linked to problems of circulation and discharge planning.
Naylor 2000[155]	An effective hospital discharge process can contribute to reduced costs and more positive care outcomes for caregivers and their patients at home.	Systematic literature review	Systematic review (Level 1) Development of a transitional care model (Level 6)	None	None	This program of research has increased an understanding of the differential effects of the model on elders with medical versus surgical cardiac conditions, the profile of elders at risk for poor outcomes, predictors of caregiver burden, the unique needs of elders and the contributions of advanced practice nurses in meeting these needs, and decisionmaking regarding home care referrals.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Naylor 2004[156]	Patients and caregivers report substantial numbers of unmet needs resulting from inadequate discharge procedures.	Randomized controlled trial	Two randomized groups (Level 2) Time to first rehospitalization or death, number of rehospitalizations, quality of life, functional status, costs, satisfaction with care (Level 3)	Six Philadelphia academic and community hospitals. 239 patients ages 65 and older and hospitalized with heart failure.	3-month advanced practice nurse-directed discharge planning and home followup protocol.	Time to first readmission or death was longer in intervention patients. For intervention patients, only short-term improvements were demonstrated in overall quality of life, physical dimension of quality of life, and patient satisfaction.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Ohman 2004[127]	Establishment of a close relationship between district nurses and people with serious chronic illness and their close relatives can increase the health personnel's possibility to alleviate and console those suffering illness, and can be useful for reflection of care interventions, in education and supervision of district nurses.	Non-comparative	Phenomenological hermeneutic (Level 5) Interviews with a narrative approach; interpretation of text in three phases: naïve understanding, structural analysis, interpretation of the text as a whole (Level 3)	Sweden. Purposive sample of 10 female district nurses, between ages 50 and 62 with work experience of 2–20 years.	None	The meaning of district nurses' (DNs) experiences of encounters with people with serious chronic illness and their close relatives at home can be understood as DNs being welcomed into the ill person's privacy, to share intimacy and their understanding of illness. This is expressed in three themes: being in a close relationship, sharing an understanding, weaving a web of protection. Listening was a prerequisite for being able to help and support people. A communicative process (interpretation of body language and verbal communication) has the function of establishing a common environment or shared world of meaning. It is difficult for DNs to escape the close relationship after it is established.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Pot 2005[157]	Elders receiving professional long-term care (vs. informal or no care) may experience increased stress and increased risk of depressive symptoms.	Time series (longitudinal)	Part of the Longitudinal Aging Study Amsterdam. Linear regression analysis (generalized estimating equations). (Level 4) Survey data gathered in 3,107 face-to-face interviews in respondents' homes, with followup interviews after 3 and 6 additional years. Independent variables used to evaluate the dependent variable of depression were (a) from no or informal care to professional home care, (b) from no or informal care to institutional care, (c) continuing professional home or institutional care, (d) from institutional or professional home care to no or informal care. (Level 3)	The Netherlands. Random, nationally representative age- and gender-stratified sample of adults 55–85 years old.	None	There was an association between professional care utilization and depressive symptoms over time, and between transitions in professional care and changes in depressive symptoms. Older adults with a transition to professional care reported considerably more depressive symptoms compared with those who did not receive professional care. Older adults who had a backward transition, from professional care to no or informal care only, did not show such change in depressive symptoms.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Rose 2000[17]	Combined knowledge of family caregivers and staff nurses can foster comprehensive and appropriate posthospital care.		Open-ended interviews with content analysis (Level 5) Nurses’ perceptions of patients and family caregivers, family caregiver’s perception of patients and themselves near admission and discharge from hospital (Level 4)	37 caregivers and 37 nurses who were present for discharge but not admission of patient.	None	Suggests a lack of agreement between staff nurses and family caregivers on health issues related to hospitalized older patients.
Roth 2005[77]	Caregiver depression	Randomized controlled trial	Randomized controlled trial (Level 2) Geriatric depression, satisfaction with social support (Level 3)	406 spouses, caregivers of dementia patients	Individual and family counseling; five 90-minute home visits focusing on education and environmental modification every other week over 3 months. Enhanced social support.	Improved number of support persons, satisfaction with support network, and support persons' assistance with caregiving. Increased satisfaction with social support network mediated a significant proportion of the intervention's impact on caregiver depression.
Schulz & Beach 1999[21]	Caregiving as a risk factor for mortality	Perspective population cohort study with 4.5 years of followup	Survey (Level 4) Morbidity, caregiver strain (Level 3)	Population based, community based	None	Caregivers who were providing care and experienced strain had risks 63% higher than noncaregiving controls. Mental or emotional strain is a risk factor for mortality among elderly spousal caregivers.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Schulz & Beach 1999[21]	Death of caregiver spouses	Prospective cohort	Survey. Prospective population-based cohort study with 4–5 year followup. (Level 4) Mortality, caregiver strain (Level 2)	392 caregivers and 427 noncaregivers, ages 66–96 living with spouses	None	Asked if they were experiencing caregiver strain after 4 years of followup, participants providing care who had strain reported mortality 63% higher than noncaregiving controls, and caregivers with no strain did not have elevated mortality rates.
Schumacher 1998[158]	Identification of concepts related to doing family caregiving well.	Systematic literature review	Systematic review (Level 1) Concepts organized into those referring to caregivers perceptions of how well they provide care and those that refer to professional assessment of the quality of care (Level 4)	None	None	Two issues that should be addressed to advance research are the perspective taken on doing caregiving well and change over time in doing caregiving well.
Silver 2004[159]	Core competence and care effectiveness	Noncomparative	Descriptive study (Level 5) Caregiver competence and effectiveness (Level 3)	Interviews of 30 family caregivers during first 3 months	None	Caregivers provided an average of 19 tasks per day. The tasks included functional, care management and technical, nutrition-related tasks. Low caregiver preparedness was associated with unmet training needs and low self-rated caregiver effectiveness.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Sit 2004[143]	Family caregivers of stroke patients often do not have the requisite knowledge and skills to provide the extensive care needs of stroke survivors. The demands and stress of caring for the family member can result in the caregiver becoming a "second patient."	Cross-sectional (descriptive)	Family caregivers participated in face-to-face interviews 12 weeks after starting stroke caregiving role at home (Level 5). Interview guide consisted of four sections: demographics, assessment of stroke survivor's current health status, assessment of social support for the subject, caregiver's general health. Regression analysis applied to responses to open-ended questions (Level 3)	Hong Kong. 102 Mandarin or Cantonese-speaking subjects obtained from four rehabilitation hospitals with established stroke rehab units.	None	After 12 weeks, nearly half of the caregivers reported having somatic symptoms and fatigue to the extent that they needed to see a physician. Unmet social support needs were identified as tangible support, including provision of equipment, transportation, financial, respite; informational support, including guidance in health-related care task at home; structural support, including a network of people supplying support. Social support can have a positive impact on caregiver health, and nurses are in an excellent position to advance their practice by offering this professional support by extending nursing care beyond the hospital boundary. Nurses can mobilize supportive resources in the caregiver's natural network or provide a “created” network to supplement the insufficiency of the family caregiver's existing network during the period of stress and transition.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Smeenk 1998[160]	Patients with complex health care problems being cared for at home are often cared for by numerous professional caregivers. These caregivers may be providing “parallel” vs. “coherent” care, due to communication gaps, which can result in inadequate care for the patient.	Cross-sectional	Direct and professional caregivers of eligible subjects generated reports (Level 3) Costs and time spent providing care was recorded. Professional and direct caregivers completed a questionnaire after patient’s demise, asking opinions on various aspects of intervention. (Level 5)	Terminal cancer patients in the Netherlands. Patients were followed until demise.	Transmural home care intervention program: a specialist nurse coordinator managed discharge from hospital and organized home care; 24-hour phone consultation; dossier maintained at home for various caregivers; specific care protocols established.	Patient, direct and professional caregivers showed that the specialist nurse coordinator and the 24-hour phone service were important components of the intervention. Most of time spent by specialist nurse coordinator was spent in contact with patients and families. Physicians were seen as having a limited role.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Sorensen 2002[72]	Family caregivers of elderly persons with physical ailments and/or dementing illnesses often experience high levels of stress, which can lead to a lowered sense of well-being, feelings of being burdened, depression, compromised physical health, and even premature mortality.	Meta-analysis	A comprehensive literature review and the "ancestry method" (Level 1) Identified 78 eligible studies. Outcome measures were caregiver burden, self-rated depression, subjective well-being, uplifts, ability and knowledge, care receiver outcomes. (Level 4)	For eligible studies: number of intervention sessions ranged from 1 to 180; followups were conducted in 22% of cases; number of participants in the experimental intervention condition ranged from 4–2,268; mean age of caregiver was 62.3; caregivers had been providing care for an average of 4 years with 30 hours/week of care; most studies were conducted with heterogeneous disabilities samples; 60 studies were in North America, 11 in Europe, 7 in Australia.	Psycho-educational, supportive, respite/adult day care, psychotherapy, improvement of care receiver competence, multicomponent	Interventions are, on average, successful in alleviating burden and depression, increasing general subjective well-being, and increasing caregiving ability/knowledge. The majority of these effects persist after an average of 7 months after intervention. Providing psycho-educational interventions, psychotherapy, and a combination of several of these interventions is most effective for improving caregiver well-being in the short term. Individual interventions were more effective at improving caregiver well-being, whereas interventions in groups were more effective at improving care receiver symptoms.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Steffen 2000[57]	Anger and hostility experienced by caregivers can impact psychosocial functioning.	Randomized controlled trial	Interviews of three groups: wait-list comparison, home-based viewing with weekly phone session, class-based viewing (Level 2) Demographics, self-reported anger intensity, depression, caregiving self-efficacy, telephone contacts (Level 3)	33 caregivers of Alzheimer's patients or other dementing disorder. Recruited through various methods. Provide 5 hours weekly of face-to-face direct care.	8-week psycho-educational video series for anger management, workbook.	Family caregivers may benefit from innovative anger management interventions based on cognitive/behavioral principles and techniques.
Teng 2003[162]	Early supported discharge programs may decrease hospital costs without having a negative effect on patient outcomes.	Randomized controlled trial	Two groups randomized to home intervention or usual care (Level 2) Interviews ascertained self-rated physical health; costs estimated for acute-care hospitalization, outpatient care, and in-home care; caregiver stress (Level 3)	Stroke patients who required rehabilitation services and had a caregiver at home.	4-week, tailor-made home program of rehabilitation and nursing services.	Providing care at home was no more (or less) expensive for those with greater functional limitations than for those with less. Caregivers in the early supported discharger group scored lower on the Burden Index than caregivers with usual care.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Toseland 2004[118]	Health education programs can help caregivers reduce depression, increase knowledge of community services and how to access them, change caregivers feelings of competence and how they respond to the caregiver situation.	Randomized controlled trial	Two-level randomized controlled trial (Level 2) General Health Questionnaire, Medical Outcome Short Form Health Survey, Social Provisions Scale, psychological well-being, perceived social support, subjective burden (Level 3)	Caregivers of spouse with chronic illness who was a member of a staff model HMO. Minimum score of 7 on Caregiver Strain Index. Care recipients with at least two impairments in ADLs. Total of 105 caregiver-care recipient dyads.	Multicomponent psycho-educational health education program. Consisted of 8 weekly sessions, followed by 10 monthly sessions.	Caregivers reported that by end of 1 year, they felt the health education program helped them learn about community resources and how to access them.
Travis 2000[12]	Improving understanding of how family caregivers deliver complex care can result in better care.	Noncomparative	Semistructured, face-to-face interviews (Level 5) Content analysis to capture the shared and idiosyncratic experiences of individuals responsible for all aspects of medication administration. Three categories of medication administration hassles were identified: scheduling logistics, administration procedures, and safety issues. (Level 3)	23 family caregivers providing 122 separate accounts.	None	Primary care providers must continually reevaluate and simplify medication regimens for dependent elderly persons in the care of family members, and the family caregivers must be given adequate training and access to ongoing information support systems to help them perform safe and effective medication administration responsibilities.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Visser-Meily 2005[74]	Identification of effectiveness of different types of intervention programs for caregivers of stroke patients.	Systematic literature review	Systematic review (Level 1) Four types of support groups identified: providing specialist services, psycho-educational, counseling, and social support by peers; various outcome measures (reduction of depression and burden, improvement of knowledge, satisfaction with care, family functioning, quality of life) (Level 5)	22 studies, a critical review	None	Could not identify sufficient evidence to confirm the efficacy of interventions, but counseling programs appeared to have the most positive outcome.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Ward-Griffin & McKeever 2000[140]	Quality of care delivered by informal caregiver, contingent upon communication and relationship with nurse	Cross-sectional	Critical ethnography—socialist-feminist perspective (Level 5) 38 in-depth focused interviews (average 75 min. in length) from 23 family caregiver-nurse dyads; data analysis through use of NUD*IST software (Level 3)	Dyads were acquainted 3 months–14 years; sample drawn from three nonprofit, publicly funded community nursing agencies in southwestern Ontario. Average age of nurses was 47 years (one male only); family caregivers' age was 33–82 years (all female); elder care recipients' age was 65–99 years.	None (interaction only)	Relationships between family and professional caregivers appear to be exploitive in nature (economic vs. humanitarian). Family caregivers were contributing more effort toward caring for recipients than nurses, and were not receiving adequate resources to assure minimization of risk to care recipients. Improved communication between formal and informal caregivers may lead to coalition building and collective lobbying for resources, but ultimately a "transformation of the broader political and economic conditions of home care is necessary" for an equitable sharing of caregiving responsibilities.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Weuve 2000[139]	Outpatient geriatric evaluation and management (GEM) may alleviate caregiver burden, e.g., physical, psychological, social, and economic distress.	Randomized controlled study	Randomized controlled trial (Level 2) Assessed caregiver burden by telephone interview survey, using a Likert scale. Statistical analysis used to compare burden scores of control and treatment group. (Level 3)	568 high-risk older adults living in the community who were fee-for-service Medicare beneficiaries age 70 or older living in or near Ramsey County, Minnesota.	Participants in the control group received all health care from their usual providers; GEM participants were assigned to one of three clinical teams, each composed of a geriatrician, a nurse, a social worker, and a gerontological nurse practitioner for 6 months. GEM participants (outpatient) received counseling from the team until it was determined that the participant had attained GEM goals or was adhering to a comprehensive plan of care. Caregivers were assessed for burden at baseline and 1 year later. Caregivers did not receive a standard intervention, although they received resource referrals.	GEM and control caregivers were similar at baseline. During the 1-year observation period, mean burden scores of GEM caregiver group tended to decline, while mean scores of control tended to increase or decline less substantially. Assignment to GEM was associated with a reduction in the amount of time caregivers devoted to assisting recipients in some specific tasks. Caregivers who were less experienced and less closely related to their care recipients tended to benefit more from GEM.

Source	Safety Issue Related to Clinical Practice	Design Type	Study Design and Outcome Measures	Study Setting & Study Population	Study Intervention	Key Finding(s)
Williamson & Shaffer 2001[163]	Potentially harmful behaviors to patients	Non-comparative	Descriptive interviews (Level 5) Caregiver depression (Level 3)	142 caregivers—98 wives, 44 husbands—interviewed	None	Depressed caregivers are more likely to treat spouses in hurtful ways. Premorbid relationships were directly related. If perceived as rewarding, less depression and less harmful behaviors.
Zarit 1998[79]	Family caregivers of dementia patients can suffer overwhelming and uncontrollable stress that can take a toll on emotional health and well-being. Programs can be developed to relieve these negative effects.	Non-randomized trials	Quasi-experimental comparing two groups of primary family caregivers who enrolled relatives in adult day care (Level 3) Caregivers were interviewed at three intervals over 1 year.	Treatment group comprised of caregivers in New Jersey with relatives enrolled in day care; control group was from another state and relatives were not in day care.	Caregivers in treatment group used substantial amounts of day care services.	Use of adult day care by caregivers of dementia patients results in lower levels of caregiving-related stress and better psychological well-being when compared to that of controls.
Zarit 1986[164]	Caregiver burden can affect quality of life and decisions to institutionalize.	Time series	Interviews (Level 5) Caregiver burden, severity of impairment, social support, quality of relationship, placement decision factors (Level 3)	64 caregivers for a spouse with senile dementia, recruited from a clinic offering counseling and support to caregivers, and membership lists from an Alzheimer's disease advocacy group.	None	Severity of the patient's symptoms did not differentiate caregivers who placed relatives from those who did not.

Source	**Safety Issue Related to Clinical Practice**	**Design Type**	**Study Design and Outcome Measures**	**Study Setting & Study Population**	**Study Intervention**	**Key Finding(s)**
Zwygart-Stauffacher 2000[134]	It appears that there is a discrepancy between the perceived needs of stroke survivors and their caregivers and those of health professionals. Stroke survivors' and caregivers' perspectives as to their needs are critical if professionals are to identify unmet needs and deliver health care that is truly high quality and client centered.	Cross-sectional	Phase I: Twelve focus group and individual interviews, with 47 stroke survivors, caregivers, and professionals from the community (Level 5) Asked caregiver to rate importance of needs and degree to which need had been met. Factor analysis done on needs of survivors and caregivers. (Level 3)	281 stroke survivors and 223 caregivers completed the mailed survey.	None	For both caregivers and survivors, the most highly rated domain for importance was the need for information. Both survivors and caregivers identified the importance of clear information about medications, tests, and treatments, as well as wanting time for questions to be answered and resources. The nurse is pivotal in activating discharge services and facilitating smooth transition of care across health care settings. The nurse can provide caregivers more information on what they can expect through written, verbal, and electronic means.