

10 Nursing Interventions for Family Caregivers

Guide to Best Practices in
Adult-Gerontology Patient
Care

Mitzi M. Saunders
Editor

 Springer

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Foreword 1

Rosalynn Carter, the former first lady, was a strong and early advocate for family caregivers, establishing the Rosalynn Carter Institute for Caregivers in 1987 (<https://rosalynncarter.org/>). She would be delighted with the publication of this book as evidenced by the following quote:

There are only four kinds of people in the world—those who have been caregivers, those who are caregivers, those who will be caregivers, and those who will need caregivers.

10 Nursing Interventions for Family Caregivers, by Mitzi Saunders, is a transformational book that heralds new and innovative nursing strategies for assisting family caregivers during the caregiving process. The book makes several important contributions to the literature and clinical practice of caregiving. First, this book expands our knowledge of evidenced-based nursing interventions for family caregivers, an area that is surprisingly not well researched or understood. Second, this book provides a diversity of caregiving situations that range from acute short-term care to long-term care. Although the length and intensity of family caregiving may differ, there is a common thread between these caregiving experiences that nurses can draw on for guidance. Third, this book offers rich examples that provide learning anchors for nurses and facilitates the application of the 10 nursing interventions presented to advance clinical practice. Fourth, this book highlights the unique role of nursing in family caregiving by weaving advocacy, education, inclusiveness, and policy initiatives throughout. Finally, and most importantly, *10 Nursing Interventions for Family Caregivers* focuses on the benefits of family caregiving without minimizing the difficulties. For too long, research has emphasized the “burden” without acknowledging the benefits to both the caregiver and care recipient.

Dr. Saunders and her carefully chosen contributors reflect a strong complement of clinical and academic talent, outstanding nursing professionals whose wealth of clinical knowledge inform the caregiving discussion. The in-depth examination of specific topics (e.g., end-of-life care, burnout) or medical conditions (e.g., Alzheimer’s, mental illness) is enhanced by the presentation of the best available evidence, reflection questions, and resources.

I am confident that *10 Nursing Interventions for Family Caregivers* will make an important contribution to the clinical practice literature on family caregiving. I salute Dr. Saunders, a close colleague and friend for the past 20 years, for undertaking this project and bringing it to fruition.

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Carla J. Groh

Foreword 2

In her book, *10 Nursing Interventions for Family Caregivers*, Mitzi Saunders has filled an important gap in the caregiver science literature by providing a comprehensive and excellent account of the predominant scenarios that face family caregivers and the indispensable role of nurses in critical interventions.

As a country with an increasingly aging population, nearly 12% of the population are taking care of loved ones, predominantly family members. According to the American Association of Retired Persons and other organizations, this translates into over 36 billion hours with hundreds of billion dollars in uncompensated care. Simply put, the long-term care system would not function without the foundation of family caregivers. That care often goes unnoticed and can carry a high price for the family caregiver in their own health (emotional and physical).

Unlike other nursing intervention books, Dr. Saunders, as an experienced clinician and family caregiver researcher, draws on her knowledge, professional expertise, and personal experience in providing the essential interventions needed in this field, from acknowledging and listening to the caregiver to educating, coaching, and role modeling, evaluating the effectiveness of patient outcomes, to family caregiver self-care, and critical advocacy efforts.

The personalized approach of each chapter and scenario draws in the reader to see and experience the actual patient and caregiver situation. Dr. Saunders' broad range of caregiver situations covers the scope of care from stress in critical care, cancer care, end-of-life care, and mental illness as a few examples. The range of settings and emphasizing the impact of nursing interventions that can make a critical difference are important and transferable to current situations nurses face.

Her personal sharing of her own experiences of caregiving for her mother and father highlights her compassion for the family caregiver's experience. The format of the chapters provides the additional reflection needed to integrate the learning needed and the transferability of the caregiver interventions. This book

will make a lasting contribution to the family caregiver literature and the importance of nursing interventions to this growing population of patients and their family caregivers.

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Preface

This book is a wealth of knowledge for nursing students learning how to be a professional registered nurse (RN), all types of nurses and advanced practice registered nurses (APRNs), and any healthcare provider (HCP) wanting to take their practice to a higher level and care for the silent patient—the family caregiver (FC). They are a key to better patient outcomes. This book shines a bright light on the FC who provides the bulk of care and support for patients at home following a hospitalization, in handling a diagnosis like cancer or a chronic disease, needing help with critical healthcare decisions, or supporting them during their final days of life for a peaceful dying experience. They need nurses to guide and support them in their critical role as FCs. This book teaches nurses and HCPs how to acknowledge, listen, assess, coach, and evaluate outcomes related to family caregiving and FC self-care. Studies continue to show the effect of FC care on patient outcomes. We must intervene with these crucial partners in patient care.

This book crosses the spectrum of care settings where all HCPs work to include settings in emergency care, hospitals, critical care, and homecare. It exposes HCPs to different types of care delivery to include end-of-life (EOL) care. It reveals through storytelling of nurse experts (APRNs) the good, the bad, and the ugly of healthcare highlighting throughout those teachable moments and opportunities for improvement.

Nurses will read this book, reflect, and want to quickly identify and partner with the FC. Readers will gain confidence in caring for FCs and learn practical and useful information to guide nursing practice. There is a wide range of clinical scenarios to learn best practices on as well as information on nursing research.

The book engages the reader with reflection and action exercises at the end of every chapter. Not only will readers be drawn into the compelling, heart-warming, and sometimes shocking stories based on facts, they will think critically and creatively when answering the exercises. Each chapter ends with one similar question, i.e., “What statement in the chapter was most meaningful to you and why?” The reader is also encouraged to record reflective thoughts at the end of each chapter in the notes section for later reference.

The stories told support key interventions that every professional nurse can do. Narrowing to 10 key nursing interventions helps establish the scope of FC nursing

care. Yet, much of FC care stems from compassion, “being with,” and supporting the FC through difficult times using evidence-based practice—the art and science of nursing. The key is to just do it—start engaging with FCs, coaching them, and listening to them. They need us! They are key to a better healthcare delivery system.

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Mitzi M. Saunders

Acknowledgments

I would like to thank all the writers in this book. Most are former students of mine who became Adult-Gerontology Clinical Nurse Specialists (AG-CNSs) in a program I have been privileged to lead and teach in since 2007 at the University of Detroit Mercy in Detroit, Michigan. I am thankful for their courage to complete graduate studies while carrying on with full-time jobs and caring for themselves and their families simultaneously. Many of them are family caregivers for parents and other family members too. I am thankful that they are willing to share their expertise in the many stories told in this book using experiences in the workplace as a CNS or as a family caregiver for a loved one with a unique perspective. I am inspired by the giving nature of nurses willing to give back and be a part of this important project. Thank you!

I must thank my mom and dad, both in heaven, and always guiding me forward. My mom always told me, “Be a nurse and help people.” My mom never missed sending me a “Happy Nurses Day” card for National Nurses Day every May 6th until her dementia took over. She showed me what it meant to be a family caregiver for a spouse (Dad), and I was graced to be the family caregiver for each of them too. The picture below is Mom’s 80th birthday celebration before dementia took her life during COVID-19. Most importantly, they taught me those faith-based values that help you succeed in life. Thank you, Mom and Dad!

But overall, I thank my best side, Jeff and our sons, Andrew and Adam. It is their support that has allowed me to continue in a career I love. They know my passion for this beautiful role we call nursing and the specific role of the CNS. They have always supported my scholarly and leadership endeavors. They have celebrated with me during the good times and been there for me during the difficult ones too.

But mostly, I thank my nearly perfect husband Jeff for his wisdom, encouragement, and the occasional reality check when I need one. Thank you, Jeff, Andrew, and Adam.



About the Book

The target groups for this book are nurses at all stages (student to proficient), all HCPs, and others associated with patient care such as social workers or clergy. The book is coauthored by advanced practice nurse experts, mostly in the CNS role, who bring diverse perspectives through storytelling in an engaging way. The chapters are filled with terms in **bold** writing that all HCPs should learn and know, they build from chapter to chapter, and defined at the end of each chapter in the Glossary of Terms section. Excellent references and resources are used in every chapter as well. The book should be read from beginning to end as content builds off earlier chapters. Yet, there is some repetition of important content such as teach-back technique that re-surfaces in chapters. Reflection and action questions are at the end of each chapter to facilitate deeper understanding and growth in caring for FCs.

The “10 nursing interventions” are consistent with the nursing process giving the book a directional flow from the first phase (assessment) to the final phase (evaluation). The final chapters are dedicated to more advanced thinking in advocacy and policy as well as the post-caregiving phase after patient death (sudden or expected) or resolution of the healthcare problem (survivorship).

The book would be an excellent resource in nurse training at all levels including foundations in nursing, adult medical-surgical, mental health or community health nursing, leadership, and policy courses at the undergraduate and graduate levels. It could be used for directed studies in nursing care of FCs or an introductory nursing course because it shows the practice of nursing in real-time situations and contains a generous amount of nursing and medical terms that are described in easy-to-understand definitions. Additionally, there is content on qualitative research in Chaps. 1, 18, and 27 and those chapters could be supplemental reading in a nursing research course at the undergraduate or graduate levels in nursing education. COVID-19 also encompasses several stories in the book as we must never forget the toll it took on patients, FCs, nurses, and all HCPs. The reflection/action exercises could be used by instructors to guide group discussion or individual student assignments.

The book also highlights the different levels in nursing roles (RN and APRN). In particular, the book highlights the role of one APRN, the CNS. This APRN is one of the four APRNs (nurse anesthetologist, nurse midwife, nurse practitioner (NP), and CNS) all trained to diagnose and prescribe medical and nursing care. But additionally, the CNS focuses on improving nursing practice and care delivery across

healthcare settings. This role fits well with the intent of this book with a focus on nursing support for FCs.

The book does not sugar-coat nursing—it highlights both benefits and missed opportunities from the perspectives of nurse experts with first-hand experiential knowledge. Nurses can do better with FCs and need to. This book guides the way.

In Intervention I (Acknowledge the Family Caregiver), the reader learns who the FC is across various healthcare settings, through nursing research, and existing policy. I describe my personal and professional experiences caring for FCs and researching FCs. The need to acknowledge the FC is reinforced through clinical examples and the resources afforded them by national organizations and groups devoted to improving the caregiving experience. Why “storytelling” is used in this book is also revealed as are next steps for the nursing profession to address the gaps in FC nursing care.

In Intervention II (Listen to the Family Caregiver), Chap. 2 shows how critical acknowledging, listening, and respecting FCs is when caring for patients with complex and rare disorders. This CNS holds nothing back describing a subpar care experience but then offers an alternative and hopeful approach to future care for patients and their FCs. Chapter 3 offers a plethora of useful tips on communicating and active listening when caring for a loved one with Alzheimer’s disease—great communication strategies all nurses should know. Additionally, a CNS shares her success in implementing a FC workshop to address caregiver burnout—a common consequence of caring for patients with Alzheimer’s disease and dementia.

In Intervention III (Diagnose and Prescribe Family Caregiver Care), a CNS rallies the FCs around care of Mom to eventually get her safely home (Chap. 4). In Chap. 5, a CNS handles the acute caregiver stress in parents of a young man who is brain dead following an unintended drug overdose (fentanyl) and simultaneously supports the nurse, also suffering from caregiver stress during the COVID-19 pandemic. The chapter gives a real-life view of intensive care nursing. Chapter 6 offers nine scenarios to guide nurses towards competency in immigrant FC care. This chapter includes a wealth of knowledge on culturally sensitive care to help all HCPs avoid biases (implicit and explicit) in patient and FC care. It is also worth mentioning that the term “elder” is used in Chap. 6 where other chapters use the term “older adult.” Regarding immigrant FC care, the term “elder” connotes a high level of respect that translates into care practices that differ from customs and values in the U.S.

In Intervention IV (Educate, Coach, and Role Model Patient Care), CNSs reveal ways to engage FCs and teach them care of a loved one with chronic obstructive pulmonary disease (Chap. 7), cancer (Chaps. 9 and 10), and coaching through the dying experience (Chaps. 11 and 12). These are very difficult and tender moments in FC care and nurse support is critical. There are many tips for improving FC communication that nurses can teach FCs. Chapter 8 affords a different twist on the potential for abuse and neglect in long-term care settings. We learn from this CNS how the FCs experience results in removing her 99-year-old dad and taking him to another facility—something FCs need to do when healthcare fails the patient.

In Intervention V (Coach on Self-Care Practices for Positive Caregiver Experience), self-care practices for FCs are discussed. The healthcare setting for this section is homecare nursing. Chapter 13 is an overview of self-care practices and a CNS describes her success in coaching FCs on self-care. Chapter 14 goes deeper into the art and skill of being an effective homecare nurse. We learn from an expert homecare nurse and NP how she achieves optimal patient and FC outcomes. Getting respite is a crucial self-care practice for FCs. Her story ends with a peaceful and “spectacular” dying experience.

In Intervention VI (Support Critical Family Caregiver Decisions), the focus is on critical healthcare decision-making and advance care planning (Chap. 15). Chapter 16 focuses on alternative housing and living options when patients are disabled or older and need varying level of assistance. The chapter is very informative on all housing options when staying at home is no longer the option. The stories, told by CNSs, address these topics from various and challenging angles. Sometimes the FC and patient do not agree with one another.

In Intervention VII (Evaluate Effectiveness of Family Caregiver Care on Patient Outcome), Chaps. 17–19 show through a variety of clinical scenarios, including Veteran FC care, how FC actions contribute to patient outcomes. Nurses need to focus on FCs who show signs of caregiver burden and patients with poorer outcomes as signs that FCs need more support.

In Intervention VIII (Evaluate Outcomes of Family Caregiver Self-Care), Chap. 20 reveals through a before (ineffective) and after (effective) story of family caregiving. Sandwiched between the two are markers of successful or effective family caregiving and nursing evaluation strategies. Chapter 21 reveals the collaborative work of an inpatient supportive care team with a system program known as Henry Ford Health C.A.R.E. ProgramSM. This program has dramatically improved the lives of more than 96,000 FCs in one healthcare system. It is a template or model program that could be instituted across the country. Through various modalities of care coordination and resource navigation, the FC goes from ineffective to effective caregiving. It takes that special attention to evaluate the FC to get the right resources in place. Learn in this chapter how the program is executed.

In Intervention IX (Teach Patient Advocacy), all three chapters highlight the vulnerability associated with family caregiving. Chapter 22 involves the challenges in handling a patient with mental illness and severe medical issues. Chapter 23 involves the tender care delivered by two FCs (daughters) of their mom in hospice. The CNS teaches them how to care for Mom’s needs the way Mom wants care contrary to what the daughters want done. Finally, Chap. 24 is a wealth of resources that patients and FCs have access to through federal, state, and local policies—the key is to inform and educate FCs of available resources.

In Intervention X (Support for the Family Caregiver When Caregiving Ends), we deliver crucial information to close the loop of knowledge on the FC experience. All caregiving comes to an end in one of three ways: (1) Chapter 25, in sudden death situations, (2) Chapter 26, during remission or cure after a long bout of illness and being in the role of FC (survivorship), and (3) Chapter 27, after the anticipated death of a patient after many years of caregiving. Each has unique nursing care needs and

each is loaded with tips on how to interact with the FC in all contexts after caregiving ends. All chapters are authored by CNS experts who tell their stories of real-life events and how nurses should respond.

The conclusion includes final remarks about the book and next steps for those who have read it. The main message is to be proactive and start reaching out to FCs today. The book has shown the way.

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About the Editor



Mitzi M. Saunders has 35 years of experience as a registered nurse (RN) and a certified Adult Clinical Nurse Specialist (CNS) specializing in medical-surgical nursing. At the time of this writing, she is the President of the National Association of Clinical Nurse Specialists (2023–2024). Dr. Saunders is a nurse researcher in the areas of family caregiving, CNS role, and online education. When she earned her PhD in Nursing in 2006 at Wayne State University in Detroit, Michigan, she was experiencing in her personal life what being a family caregiver (FC) meant in her own family. At that time, her mom was her dad’s FC. Her dad had heart failure (HF) and emphysema.

Her deep dive studies into the science of family caregiving led to a dissertation research study on FCs of patients with HF. That research involved in-depth interviews at the homes of 50 FCs for patients with end-stage HF to identify evidence of FC burden, depression, lower quality of life, and worsening patient outcomes when caregiver burden was present. That work led to other investigations to examine differences between employed and unemployed FCs on FC and patient outcomes as well as homecare nurse perceptions of HF homecare. Dr. Saunders has also studied caregiving among FCs of patients with dementia. Her recent National Institutes of Health funded study as a co-investigator examined the transition to widowhood following dementia caregiving among older, rural and urban widows. She is widely published.

Dr. Saunders is a tenured and full professor at the University of Detroit Mercy, in Detroit, Michigan.

She serves as a graduate level coordinator for the CNS program at the university. She enjoys public speaking to show the value of the CNS role and to inspire nurses about nursing and nursing research. Dr. Saunders has been the guest on podcast shows to include Nurse Alice and BRH Nurse Executive and keynote and endnote speakerships for nursing conferences across the country.

Her hobbies include gardening, spending time with family and friends, time at the family's cabin, long walks in the woods with her Doberman "Ava," exercising, writing, and reading fiction.

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Abbreviations

| | |
|-------|---|
| ADLs | Activities of daily living |
| APRN | Advanced practice registered nurse |
| CNS | Clinical nurse specialist |
| EC | Emergency care |
| EOL | End-of-life |
| FC | Family caregiver |
| HCP | Healthcare provider |
| IADLs | Instrumental activities of daily living |
| LTC | Long-term care |
| RN | Registered nurse |

Part I

Intervention I: Acknowledge the Family Caregiver

Mitzi M. Saunders

It starts with a simple, “Hello, are you the patient’s family caregiver (FC)?” That is the correct title—FC. Nurses need to use those two words every day in practice. Nurses, more than any healthcare provider (HCP), can relate to the role of the FC. No other HCP is consistently present to all the needs of a patient for long periods of time (8 h–10 h–12 h shifts) to appreciate the work of the FC, like the nurse. For many FCs of patients with chronic, debilitating conditions with complex cares, the work may be 24/7 (constant physical or emotional care, worry, etc.). The time is now for nurses to seek them out, show respect, learn from them about patient needs, advocate for them, and be their partner in care. Partnerships mean sharing information on available resources too. A wealth of resources for FCs exists as many organizations and others have made FCs a priority. FCs are everywhere—in clinics, emergency care, hospitals, long-term care facilities, and at home with the patient. Let us unite to acknowledge this very important vital partner in patient care—the FC!

Mitzi M. Saunders

“A family caregiver is a person who takes the lead in helping another with their medical condition through support, hands-on care, or just being there when help is needed—the person the patient names as their family caregiver.”



Who Is the Family Caregiver?

1

Mitzi M. Saunders

Introduction

A **family caregiver** (FC) is a person who takes the lead in helping another with their medical condition through support, hands-on care, or just being there when help is needed—the person the patient names as their FC. That first glimpse of becoming a FC could be over a conversation with a loved one who tells you about a health problem they are experiencing. It could be more abrupt with an acute injury such as a call from an older parent who has fallen. A spouse may begin recognizing memory loss in their partner suggesting the beginning of dementia. A FC might emerge when a friend needs support as they battle cancer and need support during cancer treatments. A family member might need surgery and will likely need assistance when they return home. Family caregiving surrounds us.

Timing and Family Caregiving

Being a FC could be a short- or long-term role in one's life. Some FCs are in the role for short periods of time until the patient's condition improves and they no longer need assistance. An example of this could be a wife whose husband, in relatively good health, sustains a myocardial infarction (heart attack) but with minimal heart muscle damage. The wife would provide the necessary support (emotional and physical) as needed until her husband is medically stable and able to fully perform his regular duties and manage his own medical plan. This short-term FC role could also apply to a loved one who has surgery or a procedure where full recovery of the patient is expected. While being a FC is additional work in one's life, most will

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accept and cope well with these small bursts of family caregiving. These shorter bursts for FCs who are employed are also supported by the Family and Medical Leave Act signed into law by President Bill Clinton in 1993. This labor law protects employees for up to 12 months to care for a family member with a serious illness.

However, the term “family caregiver” is often associated with long-term caregiving experiences. According to Family Caregiver Alliance, a FC is any relative, partner, friend or neighbor who has a significant personal relationship with and provides a broad range of assistance for an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care (Family Caregiver Alliance 2023). For adult and gerontology patients, it is often a spouse/partner or adult child. Generally, it is the person who lives with the patient and spends the most time with them and knows them well. That person likely knows the patient’s desires and wishes. They often know the patient’s routine such as their diet, exercise, hobbies, ability to perform **activities of daily living (ADLs)** and **instrumental activities of daily living (IADLs)**. They would likely know as well if the patient were compliant with their medical treatment plan and may even know what they would want done in the catastrophic event of remaining alive on a machine (ventilator) or not.

Thus, in an emergency, and a patient is unable to answer questions about their care, the FC could be asked a question like, *If (name of loved one’s) heart stops, did he/she express to you their desire for cardio-pulmonary resuscitation (CPR)?* Being a FC is an important role and just magnified in importance when one must consider their response. The importance of who the FC is just went to the top of the list for **healthcare providers (HCPs)** and getting answers about the patient from the FC crucial. This is but one example when a **registered nurse (RN)** or any HCP encounters a FC—it occurs in all healthcare settings and even the patient’s home.

Research on Nursing Interventions for Family Caregivers

Because the nurse is the primary focus of this book or rather the nursing care delivered to FCs of adult or gerontology patients, we turn our focus to the nursing research on nursing interventions for FCs. Alarming, the literature is sparse. In a comprehensive literature search, only six studies related to nursing care of FCs are reported. Of those, three categories emerged: (1) nurses learning about FCs, (2) nurse perceptions about FC care, and (3) nurse interventions with FCs. Each will be briefly discussed.

Nurses Learning About FCs. In studies about nurses learning about FCs, one study showed statistically significant before and after retention scores in nurses on FC needs and caregiving duties when taught by lecture, discussion, case studies, or storytelling (Bhimani et al. 2017). This suggests the relevance of these strategies as useful methods of teaching nurses about FCs. For that reason, this book uses several of those strategies.

In another study, nurses who were educated on ways to improve FC involvement in patient care with cognitively impaired patients did increase the FCs involvement

in patient care (Kang et al. 2017). In a general survey of 152 homecare nurses, half reported participating in some type of professional development activity on FCs (Sunde et al. 2018). Finally, nurses engaged in a communication skills course were more confident when communicating with FCs in **end-of-life (EOL) care** situations in hospital settings (Dosser and Kennedy 2014). Thus, simple learning strategies about FCs can produce improved interactions between nurses and FCs.

Nurse Perceptions About FCs. With regard to nurse perceptions about FCs, nurses in one study agreed that there is a lack of teaching materials to assist them in working with FCs. Yet, when nurses did educate FCs on patient care, homecare nurses reported needing to see patients less frequently (Burgdorf et al. 2022). This suggests the importance of FC education and involvement in patient care that might result in fewer professional nursing services.

In another study, oncology nurses reported feeling moderately confident when communicating with FCs and more so if they had also been a FC or a recipient of care by a FC (Irwin 2018). This might suggest the importance of nurses sharing their personal FC experiences with other nurses as a method to teach nurses about FC care—a strategy used in this book.

Nursing Interventions with FCs. Only two studies focused on nursing interventions with FCs. In one study, nurses reported making referrals to a social worker to address caregiver stress or burden (Irwin 2018). This suggests that nurses are developing relationships with FCs, listening to FC concerns, acknowledging their need for more support, and reacting.

In another study, **teach-back** and return demonstration were strategies used with FCs (Burgdorf et al. 2022). The teach-back method is a common method used by nurses. For example, after teaching a patient or FC how to do a task the nurse would then ask the patient or FC to tell them exactly what they learned and/or demonstrate it. Using this technique, the nurse then knows how well she/he did in educating the patient/FC rather than the patient or FC at fault.

Conclusion on Research. Overall, the small body of research is positive. That storytelling was an effective method of teaching FC care is enlightening considering its use in this book. That nurses are making referrals for FCs for more support and performing the teach-back strategy is also encouraging. Finally, FC care of the patient might result in less professional nursing services when the FC is well informed and equipped to do the care is worthy of more research. Clearly, more research is needed on nurses and FCs.

Nursing Diagnosis: Caregiver Role Strain

While we wait for more research to emerge on nursing care for FCs, the nursing profession acknowledges the problems that FCs may face. In the latest edition from NANDA, the official voice of nursing diagnoses (ND) in the USA, there is one ND to capture the clinical judgment of nurses when a FC is struggling in their caregiving role—**caregiver role strain**. Caregiver role strain is defined as “difficulty in fulfilling care responsibilities, expectations, and/or behaviors for family or

significant others” (Herdsman and Kamitsuru 2021, p. 364). The defining characteristics in a FC with caregiver role strain could be apprehension of or difficulty in performing caregiving duties and/or physical indicators such as fatigue, hypertension, or sleep disturbance. Emotional indicators might range from depressive symptoms to anger.

Socioeconomically, FCs may become isolated and have difficulty maintaining employment or professional gains in employment. FCs may ineffectively cope with the role and caregiver activities could result in around-the-clock care known as “24/7.” Overall, a great majority of FCs are likely to be experiencing some level of caregiver role strain.

It is likely that nearly all FCs who take an older adult patient home following a hospitalization are at risk for caregiver role strain. Most older adults discharged from the hospital have significant care needs and unstable health conditions that require support from a FC. The patient may be dealing with a new diagnosis, more medications to take, and time needed to rest and recover. The patient is likely deconditioned from being in a hospital bed for several days or maybe weeks and experiencing high levels of fatigue. The patient might not be able to do much for themselves to include the usual ADLs like bathing or IADLs like grocery shopping and cooking. The FC becomes their “nurse.” Is the FC ready for the role? Maybe there is a referral for a homecare nurse? A homecare nurse is an excellent asset to the patient and their FC following a hospital discharge (Saunders 2012). But not all patients and FCs get one to help them sort out care and the treatment plan in the home environment. Most patients and their FCs are on their own.

Role as an APRN-CNS

A **Clinical Nurse Specialist (CNS)** is an **Advanced Practice Registered Nurse (APRN)** prepared in a master’s, doctoral, or post-graduate level CNS program. CNSs diagnose, prescribe, and treat patients, lead evidence-based practice, optimize care delivery systems, and advance nursing practice (National Association of Clinical Nurse Specialists 2023). At the heart of CNS practice is to improve patient outcomes and often, the CNS works with nurses to do so. For many years, I worked as a CNS at a level I trauma center in Detroit, Michigan.

As a CNS, I witnessed countless numbers of patients brought into the **emergency care (EC)** setting after suffering a respiratory event at home and revived. In one instance, a 90-year-old husband had called 9-1-1 for his wife who had collapsed at home, quit breathing, and the emergency medical system (EMS) responded. The patient was resuscitated to get a pulse and then placed on a ventilator. However, time was not on this patient’s side in that brain cells were deprived of oxygen for too long between the event, the 9-1-1 call, and when oxygen support was rendered to the patient—approximately 25 min without oxygen to the brain, heart, and all vital organs. Now, this older patient is being kept alive on a ventilator.

The patient’s sister and FC for the patient arrived and stated firmly to the patient’s nurse, “She never wanted to be on a ventilator.”

The nurse came to me and reported her conflict over the care being done for the patient and what the FC told her. The nurse asked me, “If the patient did not want to be ventilated, shouldn’t we pause and examine the situation? If we are operating under ‘What’s best for the patient?’ shouldn’t the FC be recognized, and shouldn’t an emergency family meeting be held to decide the right thing to do and take the patient off the ventilator?”

The nurse was asking all the right questions. In this case, the FC knew the patient’s wishes.

When the rest of the family arrived that evening to see their loved one on a ventilator, they all had the same reaction, “Why is she on a ventilator? She would never have wanted this.” The aunt remained firm as the patient’s FC that this needed to stop.

The CNS is trained for these difficult and complex situations and often hosts these crucial conversations with patients and FCs to decide the next best steps in care. After having this conversation with the family and identifying that the patient did not have an advance directive that would have stated her desires, I spoke to the physicians for their expert medical opinions. They agreed with the families’ wish as the patient in essence was already gone with little to no hope for recovery.

Since all agreed, the EOL care process was initiated, and the patient died peacefully and naturally a few hours later. The importance of acknowledging the FC in this situation and listening to her and the rest of the family prevented this patient from receiving more tests and being on a ventilator longer adding to the emotional trauma being experienced by the FC and the other family members. Furthermore, it would have prolonged the patient’s dying experience and suffering.

Being a Family Caregiver

Being a FC for a loved one is probable for many nurses at some point in their lives. These next three stories are mine. They helped me to understand the FC role having lived through it first-hand.

In the Emergency and Hospital Setting (Mother-in-Law). As my mother-in-law aged, so did her medical conditions. My role as her FC was front and center the day she was admitted to the hospital setting for a life-threatening urinary tract infection (UTI) known as urosepsis and acute heart failure (HF).

She had been having trouble with breathing for a few months. As a CNS, I had many years of clinical experience caring for patients with HF. I knew the signs and symptoms of HF and she was experiencing two key symptoms—shortness of breath and increased fatigue. Yet, when I listened to her lungs with my stethoscope, I could not appreciate the kinds of sounds typical of that condition called rales or crackles. She had also seen her primary HCP who did not identify any acute problems. My mother-in-law equated her breathing issues to allergies, and I could attest to her having mild rhinitis with a runny nose and sneezing.

She was feeling rather ill the day her husband called and reported on her condition. I knew something was wrong and beyond what could be remedied at home.

That was simply gut instinct on my part that something bigger was going on and I could not dismiss the thought that she did in fact have a heart condition. I suggested she go to an EC setting and my husband (her son) and I took her there.

During her hours in the EC, I answered medical questions about her health as her FC and interacted with the HCPs receiving and giving information as needed. I stayed by her side and assisted the nurses in boosting her up in the stretcher to facilitate breathing and fetching ice cubes for her. But mostly, I was her advocate and wanted to be there when the EC physician came in to see her. Overall, she was stable, and HCPs were collecting blood and urine specimens.

When the physician came, she and I filled him in on what brought her to EC that day. He informed us that she did in fact have urosepsis (infection in the urinary system and blood stream) and then he instructed the nurse to initiate intravenous (IV) fluids at a high rate of infusion. Under most circumstances, that would be a therapeutic intervention to flush the kidneys but not when a patient has HF and the extra fluids could worsen her heart condition. I spoke up and informed him of her history of HF. Next, he retracted the order to run IV fluids. Most patients with HF are not given additional fluids but instead IV diuretics to reduce the fluid load on the lungs—less fluid for a weak heart to pump around the body.

When more test results emerged, we learned that she did in fact have acute HF as well. That made her condition grave considering her age—85 years. However, after a few days of IV antibiotics and a diuretic to reduce the fluid build-up in her body, she recovered well. I was there every day to check in on her and there when the nurse gave her the discharge instructions for her to return home.

She continued to recover well at home with the assistance of her spouse's care and attention. I took her to see her primary care doctor a few days later at a clinic. This is one of the most important roles of a FC, to accompany an older adult at their medical appointments as an extra set of ears to hear what is being told to the patient as well as an extra mouth to let the HCPs know important information about the patient.

My mother-in-law was a compliant patient and continued to take her full set of antibiotics, monitor her weight every day, watch her sodium intake for her HF, and take her HF medications as prescribed. I continued to reinforce what the nurse told her during her hospitalization which was to drink fluids just enough to flush her kidneys each day and good hygiene practices like wiping from front to back after every bowel movement. She never experienced another UTI. The FC is important to reinforce what the HCPs have taught the patient. But the FC may only know those perils of wisdom from HCPs if they are present to hear them.

In the Critical Care Setting (Dad). At age 74, my father was still working strong in a business he started from the ground up and he loved it. He had a diagnosis of HF but had been in stable condition for many years. During a routine cardiac catheterization, serious blockage of several arteries wrapped around his heart was identified and he needed cardiac bypass surgery immediately. The surgery was a success. Other than his long-standing emphysema that caused some additional breathing difficulties post-operatively, he recovered fairly well and was discharged home.