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Identifying and Addressing Family Caregiver Anxiety

Karen O. Moss, PhD, RN, CNL,

Post-Doctoral Fellow, Frances Payne Bolton School of Nursing, Case Western Reserve University, 2120 Cornell Road, Cleveland, OH 44106-4904, Office: 216-368-0510 (Office), Phone: 407-765-2416 (Mobile), kxm519@case.edu

Colleen Kurzawa, MSN, RN, MFA,

Doctoral Student, Frances Payne Bolton School of Nursing, Case Western Reserve University, 2120 Cornell Road, Cleveland, OH 44106-4904, Phone: 216-970-2314 (Mobile), cxk46@case.edu

Barbara Daly, PhD, RN, FAAN, and

Professor, Frances Payne Bolton School of Nursing, Case Western Reserve University, 2120 Cornell Road, Cleveland, OH 44106-4904, Phone: 216-368-5994, bjd4@case.edu

Maryjo Prince-Paul, PhD, RN, FPCN

Associate Professor, Frances Payne Bolton School of Nursing, Case Western Reserve University, 2120 Cornell Road, Cleveland, OH 44106-4904, Phone: 216-368-2520, mxp42@case.edu

Family members providing care at home for a loved one with a serious illness are growing in number and diversity.¹ A typical caregiver is a 45–55-year-old female caring for her 65–75-year-old female loved one who has a long-term physical illness, and the duration of that care has been approximately four years.¹ Caregivers are most likely high school graduates who work full time, with an average household income of \$55,000.¹ The family caregiver (sometimes called an informal caregiver) is usually an unpaid individual (i.e., a spouse, partner, neighbor, friend, or other relative) involved in assisting another with activities of daily living and/or medical tasks.² These informal caregivers often provide countless hours of direct or indirect care and support for their care recipients with chronic physical conditions, mental illness, terminal illness, and/or disabilities.¹

The National Academies of Sciences, Engineering, and Medicine (NASEM) 2016 report, *Families Caring for an Aging America*, highlights the increasing numbers of older adults, shrinking families, and the personal impacts of family caregiving.³ A diagnosis of cancer can profoundly impact the overall quality of life of the care recipient as well as the family caregiver; this includes physical, psychological, social, and spiritual well-being.⁴ Family caregivers of persons with cancer experience high levels of anxiety. Along with demographic factors, care recipient quality of life is considered a predictor for anxiety among family caregivers.⁵ Manifestations of anxiety are similar to those of depression; however, they are

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different.⁶ Caregivers are a vulnerable population at risk for psychological distress, including anxiety that can exceed even that of their loved one.⁷

While most of the research in this area comes from studies of caregivers of persons with cancer or dementia, the potential for adverse effects associated with unaddressed anxiety is a concern for nurses interacting with caregivers of persons facing any disease state. In this paper, we focus on the assessment, management, and nursing implications of family caregiver anxiety with use of a case study.

Definition of Anxiety

Anxiety is a common emotional response to a perceived threat. It is an emotion often accompanied by feelings of tension, worried thoughts, and physical changes such as increased blood pressure.⁸ This usually results in a disruption of desirable or usual functioning. Occasional anxiety is normal;⁹ however, this symptom should not interfere with one's ability to function daily. Severe and persistent anxiety may represent a psychiatric condition such as generalized anxiety disorder; however, we will focus on the distressing symptom of anxiety precipitated by the stresses of caregiving.

Case Presentation

Mrs. CM is a 52-year-old caregiver to her oxygen-dependent mother diagnosed with advanced lung cancer. Her mother is a Medicare recipient and receives multiple home visits each week from hospice providers. Mrs. CM's mother is becoming forgetful, is unable to sleep through the night, and is combative at times. CM works full time outside the home and is a mother of three adult children, one of whom resides in the home where she lives and cares for her mother. CM is a high school graduate and has taken several college courses prior to becoming a caregiver. Her husband and one adult daughter intermittently assist with caregiving. Mrs. CM consumes more coffee in the afternoons and evenings than she did before she was a caregiver, as this enables her to stay awake to care for her mother during the night. She does not eat regular balanced meals or healthy snacks; at times, she just does not have an appetite. Mrs. CM has moderately controlled hypertension, but has been missing her scheduled doctor appointments due to lack of time. She complains of being tired, has problems sleeping, frequent headaches, dizziness, feels like her heart is racing at times, and has a stiff neck and shoulders. She has not been feeling well overall, has little time for herself, and has stopped taking her daily walks. She perceives her health as declining and no longer has time participate in health screenings. Based on all information available, there is concern regarding Mrs. CM's physical well-being and overall quality of life.

Signs and Symptoms of Anxiety

Assessing for the symptom of anxiety is well within the purview of nursing, although the signs and symptoms of anxiety may resemble other medical problems; therefore, a careful, comprehensive, and more focused assessment is needed. Caregivers should be screened for both signs and symptoms of anxiety. Differentiation between signs and symptoms may be confusing because anxiety and depression have shared signs and symptoms (e.g., poor

concentration, insomnia, restlessness, and loss of appetite), and they frequently coexist.¹⁰ Biologic manifestations include changes in cortisol levels.¹¹ High caregiver demands lead to a decline in personal health status.¹² Physical and psychological signs and symptoms of anxiety that may exist in caregivers are listed in Table 1.

Assessment and Measurement of Anxiety

Caregivers of persons with serious illness should be screened for anxiety early in the caregiving trajectory and throughout the course of the illness. Screening for anxiety among caregivers can unveil the degree of caregiver burden present.¹⁷ Although several tools exist to measure anxiety, some are more useful in clinical practice.

When measured as a single symptom, anxiety instruments such as the Patient-Reported Outcomes Measures Information System (PROMIS) Anxiety Scale,¹⁸ State-Trait Anxiety Inventory (STAI),¹⁹ Beck Anxiety Inventory (BAI),²⁰ Hamilton Anxiety Scale (HAM-A),²¹ and Hospital Anxiety and Depression Scale-Anxiety (HADS-A)²² may be used. Additionally, visual analog scales such as the National Comprehensive Cancer Network Distress Thermometer (DT)²³ (which is a measure of both anxiety and depressive symptoms) can also be used to quickly assess caregiver anxiety. It is recommended that caregiver-focused screening for anxiety using such instruments should be part of daily clinical routine, and those with positive and borderline results should be referred for interventions such as low-threshold access to psycho-oncology counseling.¹⁷ See Table 2 for selected instruments that can be used to assess anxiety for clinical and/or research purposes. We recommend use of the HADS-A or the DT for use in clinical settings.

Management of Anxiety

Increased anxiety is related to stress, self-care, and the caregiver role. Many caregivers do not seek out support for managing anxiety and this self-care support is essential for improving caregiver wellbeing.⁴ Caregivers often address the needs of their loved ones, with little or no attention paid to their own needs.¹⁷ These caregivers need to acquire skills to cope with daily stressors in the home setting. Caregiver interventions should address the four dimensions of caregiver's quality of life: physical, psychological, social, and spiritual wellbeing.^{4,24} These include symptom management, supportive care referrals, and educational content.⁴ Interventions for the management of anxiety symptoms include psychoeducation, skills training, and therapeutic counseling.²⁴ Understanding caregivers' unique preferences and needs can help to determine appropriate interventions.²⁵

Physical Well-Being

Caregivers are often tasked with the physical care of their loved ones with cancer.²⁴ Stress from providing this care can lead to fatigue, sleep, appetite problems, and pain.⁴ These lead to a decline in overall physical health and can contribute to anxiety. Caregivers must take care of their own health and well-being in order to be able to care for their loved one. They need to find the time to exercise, get sufficient rest, eat healthy meals, get regular checkups, and take their medicines as prescribed.¹⁶ Behaviors that promote physical well-being include activities that help caregivers feel relaxed and refreshed after physical activities.²⁶

Walking, biking, yoga, swimming, and running can help to relieve physical as well as mental stress of caregiving,²⁶ and therefore, reduce anxiety.

Psychological/Mental Well-Being

Anxiety is a threat to psychological well-being.⁴ Family communication patterns are developed from explicit and implicit communication rules that have been established over time and are heightened by the communication crisis of a cancer diagnosis or treatment.²⁵ These can lead to mental exhaustion. Caregivers should be allowed to share their emotional responses to their loved ones' illness.²⁴ This includes talking with their physician(s) about feelings, and how to address them.²⁷ Communication with family and friends is also important,²⁷ and includes relational intimacy with a significant other.²⁴ Encouraging caregivers to take time to relax and communicate with other caregivers are suggested ways to help to address their psychological well-being.¹⁶ Psychoeducational interventions and therapeutic counseling are specific approaches that can assist with improving caregiver quality of life,²⁸ this includes anxiety reduction.

Psychoeducational interventions.—These interventions provide information on how to manage aspects of the care recipient's physical care and include the psychosocial and emotional needs of the care recipient and caregiver.²⁸ This includes exploring the caregiver's self-care needs, including family relationships and what to expect in the future.²⁹ Psychoeducational activities often include providing information on symptom management, physical aspects of care, as well as psychosocial needs of caregivers, care recipients, and family/marital relationships.²⁸ Such activities can include preparing for the caregiver role with information about the disease process, discussing the needs of the caregiver and stress management, problem-solving and decision-making strategies, use of social support and community resources, and understanding the certainties and uncertainties of illness. Caregiver interventions can be delivered during social interactions. Education regarding the use of active coping strategies such as problem-solving can help to reduce denial and avoidance.²⁸ Included in these interventions are strengthening and maintaining caregivers' perceived self-confidence in care provision and care recipient symptom management,²⁸ which can directly reduce anxiety about caregiving responsibilities.

Therapeutic counseling.—This counseling focuses on developing therapeutic relationships to address cancer or caregiving-related concerns.²⁸ Counseling interventions include assisting couples to deal with marital concerns, changing relationships and family dynamics, and developing a support system.²⁸ Caregivers can learn how to listen and pay closer attention to what their loved one with cancer is saying, or how to ask for help from others. Therapeutic counseling can help to guide further decision making to solve future problems that arise. Because counseling requires specific training, the nurse's role is to assess the need for counseling services, and then assist caregivers in accessing resources.

Social Well-Being

This domain addresses interaction between the person with cancer and the family and the impact of cancer on all of their lives.²⁴ Caregivers need support and encouragement, but reaching out for help may be a challenge for them.³⁰ Social support is often critical in

managing anxiety. Caregivers often feel invisible and isolated.³ They withdraw from family and friends, and are then socially isolated. Potential contributors to social isolation include altered family roles, financial concerns, and sexuality.²⁴ It is important that caregivers set aside time to maintain their network of friends²⁶ by connecting with others who are important to them or join a caregiver support group.¹⁶ At a support group they can share stories, receive caregiving tips, and get support from other caregivers who may face similar challenges. Caregivers should participate in activities they enjoy, such as spending time with family and friends, and participating in their hobbies.¹⁶ They should also take the time to focus their thoughts on other things besides their loved ones' cancer.¹⁶ Caregivers can also be connected with medically approved caregiver workshops, and related websites and applications that are helpful in reducing anxiety.

Spiritual Well-Being

Spiritual well-being is an important component of caregiver quality of life and can foster strength and comfort.³¹ It can involve religiosity, maintaining hope, examining issues such as purpose in life and the meaning in the caregiving experience.^{4,24,31} To determine what this means to family caregivers, a spiritual assessment must be completed. Discussing spiritual beliefs can provide a sense of comfort to some caregivers.³¹ Also, for some, praying helps then to find meaning as a coping mechanism.¹⁶ Caregivers can be encouraged to read or listen to uplifting materials; pray or meditate; talk with a priest, pastor, or spiritual leader; or attend religious/spiritual services.¹⁶ For some caregivers, spirituality may not be comforting. However, even without religiosity, components of spirituality such as meaning and faith can remain important.³¹ Therefore, it is important for caregivers to express their feelings to chaplains or other spiritual counselors for needed support and guidance.¹⁶

Delivering Caregiver Interventions

Caregiving interventions should include a focus on self-care, caregiving, and marital or family care. The physical, psychological, social, and spiritual well-being of the quality-of-life framework should be used for this.³² Interventions can be delivered face-to-face, either in the clinical setting or in homes. However, if these modes of delivery are not possible, then phone interventions can be used.³ Care recipient-caregiver dyads benefit when their needs and plans are reviewed jointly (dyadic) as the unit of care.³³ Additionally, non-spousal caregivers should also consider couples-based interventions that target intimacy and dyadic communication.²⁴ The individual caregivers' responsiveness to the intervention (such as a teaching session) must be considered as well as how often it is delivered and practiced. Timely access to resources, information, educational programs, and support is needed to maximize caregivers' knowledge and skills.¹²

Skills training.—These are focused primarily on development of communication, coping, and problem-solving skills that can lead to behavior change.²⁸ Desired outcomes of enhanced caregiver knowledge are to help them acquire the skills and abilities needed for them to care for their loved one and complete needed tasks. Confidence in their ability to meet their loved ones' needs can be an effective way to minimize their anxiety. Skills training should include helping the caregiver learn how to assist with activities of daily living, such moving and transferring their care recipient, addressing combativeness and

forgetfulness, as well as developing communication and problem-solving abilities. Effective skills training (such as through workshops) will help caregivers gain confidence in their caregiving ability, and with the organization of care.²⁸

Caregivers need to maintain their health and need support in doing so. High caregiving demands lead to a decline in personal health;¹² therefore, it is important that caregivers maintain regular appointments with their healthcare providers. This helps to ensure that they remain current with their health screenings, medications, and immunizations. One of the central purposes of caregiver interventions is to support them in building relationships and having open communication with their providers and loved ones. A goal is to enable caregivers to feel comfortable communicating feelings such as anxiety and other symptoms to ensure that they can obtain needed help with symptom relief. Caregivers' healthcare providers need to be made aware that the caregiver is serving in this role and should take steps to assess and assist with addressing health-related challenges associated with this role.³ Table 3 contains examples of self-care strategies that can be used to improve caregiver quality of life.

Case Study Conclusion

The hospice nurse visited on a day when Mrs. CM was off from work. Nurse KC introduced herself to Mrs. CM, and after asking about her mother, began asking Mrs. CM about all aspects of her own quality of life. In order to address Mrs. CM's well-being, the nurse wanted to know if her healthcare provider was aware of her role as a caregiver, and based on the symptoms she described, suggested that Mrs. CM schedule an evening appointment at the clinic. Nurse KC sat with her and they made the phone call to schedule the appointment together. She also connected Mrs. CM with other hospice resources available to her (social work, chaplaincy, and counseling) because of her mother's enrollment.

Mrs. CM was able to schedule an appointment with a primary care nurse practitioner who performed a thorough assessment of her physical and psychological health. At the clinic visit, her blood pressure was elevated. She completed the (HADS-A) anxiety instrument on the handheld tablet and scored high for anxiety. Together, they developed a treatment plan that included blood pressure management, dietary changes, and an exercise plan. Her blood pressure medication was adjusted. She was provided an automated blood pressure monitor and instructions for regular use. Her nurse practitioner discussed the dangers of elevated blood pressure. Mrs. CM was given some healthy options for meal plans and snacks, and made a phone appointment with a dietician to further discuss healthier eating habits. She decided to start walking again for at least 10 minutes per day with her neighbor. To help to improve her psychological well-being, Nurse KC taught Mrs. CM a 5-minute relaxation technique to be performed before bedtime.

The hospice counselor spoke with her about stress management. The nurse also educated Mrs. CM on her mother's disease process and provided skills training on medication, sleeplessness, and combativeness management, and provided her with booklets on family caregiving. Mrs. CM agreed to reduce her caffeine consumption in the afternoons and evenings to help promote better sleep quality. In addition to connecting her with a caregiver

support group and a community resource that provided skills training on feeding, bathing, and positioning to help to meet her mother's activities of daily living. The hospice social worker helped to plan an initial week of respite care followed by a plan for other family members to assist with caring for her mother at regular intervals. This allowed Mrs. CM to begin reconnecting with friends and neighbors, thus promoting her own social well-being. Other family members agreed to alternate sitting with her mother so that Mrs. CM could attend church services, promoting the spiritual aspect of her quality of life. The hospice chaplain consulted with her about maintaining her spiritual well-being. A teleconference visit with Mrs. CM's nurse practitioner was scheduled for a 1-week follow-up, then a 4-week office visit.

Nursing Implications

The NASEM 2016 report on *Families Caring for an Aging America* signaled an urgent call to improve how family caregivers are cared for.³ This report highlighted self-care, counseling, relaxation training, respite programs, and other resources to improve caregiver and care recipient quality of life, thus potentially delaying care recipient institutionalization and reducing re-hospitalization.³ In the NASEM report, emphasis was placed on the need to shift the focus of care from person-centered to person- and family-centered care.³ This approach will promote the engagement of family caregivers in a true partnership in the care model, while addressing important family needs and values.³

Nurses across care settings (home, ambulatory, and acute care) are well positioned to identify, assess, and intervene with the management of anxiety among family caregivers. Crucial to the effective intervention is the identification of the symptom of anxiety in family caregivers. Nurses possess the skill set required to detect manifestations of anxiety in caregivers. In instances in which signs are subtle, early intervention may prevent symptom progression. When severe, the well-being of the caregiver and care recipient is at risk for further decline. Regardless of the timing of the intervention, the nurse is able to facilitate the process of seeking the appropriate therapeutic mechanism towards healing. Reducing caregiver anxiety will help to improve family caregiver quality of life, and subsequently, that of the care recipient.

Nurses translate research findings into evidence-based educational interventions for family caregivers. While this is relevant to all nurses, those in hospice and palliative care may have particular opportunities to address the needs of the caregivers of the patients with whom they work. Given the expertise of palliative care nurses in symptom assessment and intervention, activities of daily living education, and their inclusion in teams managing the care of patients with serious life-limiting illnesses is an avenue for reducing the untoward negative effects of persistent anxiety among family caregivers while promoting their quality of life. The screening tools suggested in this paper should be used in daily clinical practice to assess caregiver anxiety and the strategies suggested to manage them.

Conclusion

Caregivers have a significant amount of responsibility, including 24-hr/day caregiving that includes managing care recipient anxiety and depression, and performing daily home treatments (e.g., feeding, bathing, dressing changes, urinary catheter, and medication management), while adhering to complex medical treatment schedules and maintaining their own well-being. Healthcare professionals should be aware of high levels of caregiver anxiety that might exist, even when it may not be apparent. Routine use of screening tools for caregivers can be a proactive means to identify anxiety in caregivers, who may not otherwise manifest or openly reveal symptoms. This would serve as a method of identifying anxiety before it becomes problematic. As outlined in this paper, there are several screening tools designed to measure anxiety that can be used in the home and clinical setting. It is important for nurse clinicians to use these to assess caregiver anxiety and provide caregivers with education and resources to improve this symptom. This will promote better identification and timely intervention, leading to improved caregiver health outcomes, and subsequently, care recipient health outcomes.

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Table 1:

Signs and Symptoms of Anxiety

Category	Sign ^a	Symptom ^a
Neurological	trembling/shaking ¹³⁻¹⁵	headaches ¹⁴
	restlessness ^{10,15}	dizziness ^{14,15}
		apprehension ¹⁵
		numbness ¹³
		tingling ¹³
		fatigue ¹⁵
		poor concentration ^{10,14}
	nervousness ^{13,15}	
Cardiac	increased pulse rate ^{14,15}	palpitations ¹³
	chest pain or discomfort ¹⁴	
Respiratory		dyspnea ¹³⁻¹⁵
Digestive		loss of appetite ¹⁰
		nausea ^{14,15}
	dry mouth ¹⁵	
	diarrhea ¹⁴	indigestion ¹³
Mood	nervous ¹³	irritability ^{6,14}
Musculoskeletal	muscle tension ¹⁴	
Sleep		insomnia ^{10,14,16}
Skin	sweating ^{14,15}	
Urinary	frequency ¹⁵	urgency ¹⁵

^aList not intended to be comprehensive, nor are all signs and symptoms present in all caregivers.

Table 2.

Measurements of Anxiety

Instrument	Number of Questions	Scoring ^a	Completion Time
Patient-Reported Outcomes Measures Information System (PROMIS) Anxiety Scale ¹⁸	7	7–35 points	5 minutes
State-Trait Anxiety Inventory (STAI) ¹⁹	40	20–80 points	10 minutes
Beck Anxiety Inventory (BAI) ²⁰	21	0–63 points	5–10 minutes
Hamilton Anxiety Scale (HAM-A) ²¹	14	0–56 points	< 5 minutes
Hospital Anxiety and Depression Scale-Anxiety (HADS-A) ²²	7	0–21 points	5 minutes
National Comprehensive Cancer Network Distress Thermometer ²³	1	0–10 points	< 5 minutes

^aHigher scores indicate higher anxiety.

Table 3:

Quality of Life Self-Care Strategies

Quality of Life Self-Care Strategies			
Physical	Psychological	Social	Spiritual
exercise (walk, run, yoga, swim, bike, garden) ^{14,16,34}	talk with healthcare professional ¹⁴	participate in a support group ¹⁶	discuss spiritual beliefs ¹⁶
rest ¹⁶	talk with loved one and family ³⁴	spend time with family and friends ¹⁶	pray ¹⁶
eat healthy foods ¹⁶	seek ways to reduce stress/conflict ³⁴	dance ^{16,34}	attend spiritual/religious services ¹⁶
consider a change of environment ³⁴	seek out professional resource programs (i.e. caregiving websites, books, brochures) ³⁴	seek transportation assistance ¹⁶	talk with chaplain or pastoral/spiritual advisor ¹⁶
seek respite care (in home and out of home) ^{16,34}	laughter and humor ³⁴	seek financial assistance ^{16,24}	identify positive changes/aspects of caregiving role ³¹
gentle stretching ¹⁶	self-relaxation techniques (e.g., deep breathing, massage, reading, journaling, listening to music) ^{14,16,34}	pet therapy ^{16,34}	meditate ¹⁶
regular medical checkups ¹⁶	caregiving education (e.g., disease process, medications/side effects, hygiene, pain and symptom management) ^{16,24}	communicate sexuality/sexual concerns ^{16,24}	talk about the future ¹⁶