

Special Article – Family Caregivers

Shifting Attention to the Family Caregiver: The Neglected, Vulnerable, At-Risk Person Sitting at the Side of Your Patient and Struggling to Maintain their Own Health

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Abstract

Family caregivers are spouses, partners, family members, or friends who provide extraordinary uncompensated care yet are themselves a vulnerable and at-risk population, who must be recognized as “care recipients in their own right.” This article shifts the attention of health care professionals to family caregivers. It moves family caregivers out of the shadow of the patient to more fully understand who they are, the burdens and benefits of care giving, how to communicate with family caregivers, the questions to be asked for a comprehensive family caregiver assessment, and emphasizes the need for the right type, the right time, and the right dose of interventions to lessen the negative health consequences of family caregiving and to promote and protect their health, well-being, and quality of life across the illness experience.

Introduction

As a healthcare provider, who do you see when your patient walks into the office or hospital with another person? From your perspective, do you see this other person as someone who offers the patient physical or emotional support; provides all or supplemental information about the patient's health; gives you information about the patient's physical or cognitive functioning; lets you know if medications you ordered are effective; asks you important questions about the patient's problem and options for treatment; or interprets your conversation and plan of care to the patient? If the answer is “yes” to these questions, your perceptions about this person is as an informal member of the health care team. However, a basic tenet of the first domain of the National Consensus Project for Quality Palliative care [1] is that the patient and their family caregiver are the “unit of care.” The patient and family are the central focus of the interprofessional health care team. Family caregivers actually hold two roles: 1) as informal caregivers, and 2) as “second order patients” in need of attention themselves from health care professionals [2].

In health care today, we speak about patient-family centered care, but our almost exclusive focus on the well-being of the patient. If our focus is also on the family caregiver we would consider the following questions: What is the relationship of the patient and family member and the level of involvement and commitment made by their family caregiver to the patient? How has the illness of their loved one affected the caregiver's life and health? Is there distress in the caregiver's voice, or does their thoughts and behavior indicate anxiety, depression, anger, hopelessness or despair? Do you ask about how the illness is affecting their relationship to the patient or their ability or willingness to care? Do you ask the caregiver if their own health is being compromised or neglected; what plans are on hold as they care for the patient; and are they themselves struggling to

survive, never mind thrive?

Who is this person at the side of the patient and what is our duty to them as health professionals? They are family caregivers who are often invisible, neglected, vulnerable, and at-risk for poor health outcomes. Family caregivers often they feel compelled to sacrifice for the patient and may feel that they have no other option [3], until extreme illness forces a separation to a health facility or death creates the parting. When we ask about the feelings of family caregivers the response may range from being a blessing to care to feelings of tremendous anger, guilt, and suffering, worn down by watching pain and suffering, and being pulled themselves into a place of darkness and despair [3]. As health care providers, do we care about the journey and illness experience of not only our patients but the other person sitting in the office or at the bedside? Health professionals must shine their light on both~ the patient and the family caregiver, known as the “unit of care” in palliative care [1].

The purpose of this article is to move family caregivers out of the shadow and understand who they are, the burdens of caregiving, the benefits of caregiving, communicating with family caregivers, family caregiver assessment, and intervening to lessen negative health outcomes and promote and protect their health, well-being, and quality of life. As you read this article, you may reflect on the following family caregivers who represent family caregivers who appear in your office with your patient~ they are a wife, a daughter, and a sister~ By acknowledging them as a person in need of care and attention, you are taking a very important first step in providing patient-family centered care~ M. R. is a 74 year-old woman who is retired. She cares for her husband, D. R., who is a retired 78-year-old man who was diagnosed with colorectal cancer a year ago. D. R. chose a surgical intervention for treatment of his early-staged cancer a year ago. Since his surgery, M. R. and D. R. have been able to maintain his

colostomy and regularly visit his gastroenterologist and oncologist for routine checkups. At his most recent follow-up visit, D. R. reported worsening gastrointestinal symptoms as well as a yellowing of his skin. Upon evaluation, examination, and the results of a CT scan, D. R. and M. R. were informed that the cancer has spread to his liver and adjacent lymph nodes. D. R., with the support of his wife, chose chemotherapy as an intervention. The abdominal pain, nausea, and fatigue overwhelmed both of them~

D.R. the primary target of his advanced cancer~ with M.R. suffering "collateral" damage~ A.N. is a 22-year-old junior studying in an out of state university. She recently was informed that C.N., her 48-year-old mother, was diagnosed with advanced pancreatic cancer. A.N. is the only person her mother has in the US, with the extended family living in Costa Rica. A.N. is obligated to give up her studies and extracurricular activities to come home and care for her ill mother. Consequently, A.N. can no longer finish her career due to her mother's condition and the family is facing large amounts of financial expenses from the medical treatment C.N. is receiving~ a devastating, rapid illness wreaking havoc on both the lives of a mother and her daughter~

T.G. is 46-years old caring for her 49-year-old sister who has been diagnosed with breast cancer. T.G. has been married for 22 years and has two teenage children at home. Her sister is not married and has no children. There is another sibling who lives out of state, as well as their parents, so T.G. is the only loved one available to assist in providing care and communicating with other family members out of state. With all the treatment decisions that need to be made she listens attentively at every visit to the surgeon and the oncologist~ she brings her sister home to recover from the loss of a breast and tries to offer love and support as the lymph node results are positive and her cancer is diagnosed as extremely aggressive~ T.G. fears for her dear sister's life, reflects on the loss of not only a breast but of hopes and dreams that may never be realized~ she is consumed by the thoughts~ "their by the grace of God go I~ is T.G.s suffering with her sister visible to you as a health professional?

Who are Family Caregivers?

Family caregiver is any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an individual with an acute, chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care. They are responsible for the physical, emotional and often financial support of another person who is unable to care for him/herself due to illness, injury or disability (National Caregiver Alliance, 2013). Family caregivers assist the patient with activities of daily living, identification and treatment of symptoms, as well as taking patients to and from medical appointments [4,5]. The National Caregiver Alliance (2013) reported that there are 65.7 million people in the U.S. who have served as family caregivers, with approximately 30% of people reporting that they have cared for at least one family member. Two-thirds of family caregivers are female (66%), with their average age being 48. Family caregiver's age increases with the age of the care recipient. With a decline among younger caregivers (under the age of 50), there are an increasing number of family caregivers aged 50 to 64, and an even larger increase in the number of caregivers aged 75

or older. One-third of family caregivers are responsible for the care of two or more family members (34%).

The need for family caregivers will exponentially increase as 70 million people will be over 65 years of age in 2030 [6] with multiple chronic conditions, and who wish to remain in their own homes and communities. However, family caregivers often become the "sandwich generation," which describes the caregivers sandwiched between caring for elder parents or grandparents and spouse and/or children. These caregivers are pulled in both directions and often have jobs as well as these dual responsibilities [7]. The caregiving role begins immediately at the point of diagnosis and continues over the illness trajectory [8], with needs for information about care and the disease [9] at the different stages of the patient's illness [10]. Caregivers are a conduit for information between patient and provider and extended family [11]. With the increase in Alzheimer's disease or dementia, the average period of caregiving is 4.6 years. For all caregivers, average caregiving time is 20.4 hours per week and female caregivers are at greater risk than males as they spend greater time caregiving (21.9 vs. 17.4 hours/week) (National Caregiver Alliance, 2013).

What are Negative Consequences or Burdens of Family Caregiving?

Family caregivers are often expected by the health care team to assume the caregiver role for which they are not adequately prepared and which places their own health in a vulnerable, at-risk situation [5]. According to [12] caregiver burden is a multidimensional bio-psycho-social reaction that results from an imbalance of care demands that are relative to caregivers' personal time, social roles, physical and emotional states, and financial resources, and other role responsibilities. The caregiver may have difficulty managing the growing demands of caring for an ailing loved one and this could result in negative effects on the health of the individual and the caregiver resulting in anxiety, depression, and a diminished quality of life [5]. Many caregivers of advanced cancer patients demonstrate impaired cognitive functioning [13] and are treated for psychiatric problems [14]. As disease advances, there is a rapid increase in the needs of both the patient and their family caregiver [5]. For example, in case study number two, A.N.'s strain and burden can be viewed as a change in roles between mother and daughter. A.N., who once depended on her healthy mother to support her emotionally and financially, is now the supporter. One study showed that 49.8% of caregivers felt it is demanding and a heartbreaking struggle living with someone who has been diagnosed with pancreatic cancer; which is higher than the struggle reported by patients [14].

In addition to physical strain, family caregivers also experience fear, confusion, powerlessness and a sense of vulnerability, despite attempts to maintain normalcy [8]. They suffer from symptoms of anger, depression, anxiety, altered household and family roles and communication patterns [12]. Caregivers can experience decreased physical health due to inadequate sleep, reduced energy levels, decrease in physical functioning, and less social interaction [5]. They often become demoralized and exhausted [15] with increased physical illness, exacerbation of co-morbidities, and a greater risk of mortality [6]. As caregivers abandon leisure, religious, and social activities, there is heightened marital and family stress, with long term consequences for the family [16]. Burdens related to time and

logistics, and lost wages or leaving the workforce entirely, have severe personal, economic, social, and institutional implications [17,18]. Such psychological distress has the potential to drastically reduce the caregiver's quality of life [4]. M. R. is likely at risk for this because of her age. As your age increases, your health tends to decline and added stress can be detrimental for M.R.'s health. Caregivers can also face financial burdens due to their new role. Prior to caring for her sister, T.G. had a full-time job and assisted in providing financially for her family. In order to care for her sister T.G. had to leave her job and T.G.'s husband must support the whole family, which required him to obtain a second job. A national survey showed that on average cancer caregivers provide 8.3 hours each day for 13.7 months of care including emotional, instrumental, tangible and medical support [19]. This equates to a full-time job for most Americans. Engerbretson et al. [4] found that 40% of the caregivers stated they had to leave their current employment to care for their loved one.

It is also documented that caregiver well-being is closely linked with patient well-being [20,21]. As patient performance status declines over time [22], negative caregiver outcomes may limit optimal care [23]. Conversely, without family caregivers, patients' survival rates are lower and societal costs for end of life care are greater [15] as patients are placed in more costly hospital or nursing home settings with risk for poor care or neglect [24,25]. Waldron et al. [5] emphasizes those family caregivers of patients with rapidly advancing disease have a brief window of opportunity in which health professionals can intervene to relieve caregiver's severe distress, which lead to long-term consequences on their health. Sautter et al. [26] report that the burden of caregiving occurs early in the course of advanced cancer and therefore early screening and intervention for caregivers should not wait to the end of life. Preventing caregiver strain is vital so they are able to meet the demands of their role, as well as decreasing the strain on the health care system and creating better patient and caregiver quality of life outcomes [5].

What are the Benefits of Family Caregiving?

Caregiving for a terminally ill cancer patient can also be a positive experience. Kang et al. [27] stated some of the positive consequences caregivers experience include: personal growth, satisfaction and sense of accomplishment, strengthening of relationships, and a change of worldview. Family caregivers have listed feelings of reward from a set of different circumstances including: being helpful to the patient, bringing happiness to the patient, making life easier for the patient, and just being there for the patient [2].

The benefits of caregiving are influenced by factors such as religious beliefs, age, gender, and socioeconomic factors. According to Kang et al. [27], caregivers who are religiously inclined tend to report more positive consequences from their caregiver experience. Women family caregivers are more likely to suffer from mental health issue due to caregiver strain but when compared to their male counterparts female caregivers are more likely to develop appreciation for others and reprioritize their values on life based on their caregiver experience [27]. Advanced age family caregivers tend to develop both meaning of life and appreciation of others from their caregiving experience, while younger family caregivers perceive the traumatic events of caregiving to be more stressful [27].

Shifting the healthcare intervention focus to the benefits of

caregiving rather than emphasizing the burden may aid in reducing the negative aspects of caregiving. A study conducted by Ugalde, Krishnasamy, and Schofield [29], indicates that improvement of caregiver's self-efficacy is associated with positive benefits of caregiving. Once a caregiver feels empowered and capable of handling care, they tend to see caregiving as a fulfilling experience. A study conducted by Giesbrecht, Wolse, Crooks, and Stajduhar [30] discussed how caregiver resilience is not only influenced by the individual, but also by socio-environmental concepts such as access to social networks, education, employment status, housing status, geographic location of residence, and life-course stage. Interventions aimed at educating caregivers, assessing housing situations, employment status and social network may improve their resilience. For example, caregivers may not be aware of the possibility of receiving home health care or the social network resources available for caregivers.

Additionally, serious or advanced illness has the potential to create post-traumatic growth in patients and caregivers, despite the adversity of illness. Cormio et al. [31] found that post-traumatic growth leads to a positive evaluation of life's values and relationships, and emphasizes a more protective role of the caregiver, with recognition of their internal strength and resilience. According to Carr [32], resilience is a personal characteristic that influences a person's ability to be committed to care; provides a strong dynamic nexus which leads to less emotional upheaval, and ultimately supports a successful transition in bereavement.

Communicating with the Caregiver ~ Taking Them Out of the Shadow of the Patient

Like any relationship the amount of information divulged depends on the level of established trust, and ultimately the ability of the individual (the caregiver) to feel comfortable with the healthcare provider [33]. The establishment of trust occurs at different stages and is considered a process that requires time [34] and is free of communication barriers between the healthcare provider to caregiver [35,36]. Barriers in communication may hinder the establishment of an effective therapeutic relationship and further minimize the opportunity for successful teaching and exchange of information [36]. According to Inglehart [37], communication and interaction between the healthcare provider and the recipient of information can be affected by the healthcare provider's or the recipient's gender identity and gender stereotype. Gender concordance, or the sharing of the same characteristics (i.e. gender), has been studied to determine its effect on therapeutic relationships [37,38]. Communication satisfaction is revealed to be higher between the healthcare provider and the recipient of information when both individuals are in gender concordance and lower with gender "discordance" [38].

Culture can be defined as the beliefs, values, customs, and behaviors of a particular group of people. In an ever-changing society, healthcare providers must learn to assess and incorporate a family's beliefs within the treatment plan, respect the different values within each culture, and provide culturally sensitive care to improve health care outcomes of diverse populations [39].

In case study two, A.N. and her mother come from another country making English their second language. This may lead to miscommunication or misinterpretation between the healthcare provider and A.N. and her mother. Language can pose a huge barrier

when trying to communicate with caregivers and other family members. Prior studies have shown the extreme negative influence that language barriers have in relations to positive patient and family outcomes [40]. With 61.9 million American households speaking a primary language that is not English, it is important for providers to ensure that provider-caregiver communication is clear and offering appropriate information and support [40]. Should a caregiver not be proficient in the English language and there is a language barrier, providers should utilize the expertise of a medical interpreter to allow for clear communications and give the caregiver the opportunity to comfortably voice concerns or needs, thereby preventing or lessening caregiver burden [40]. There are several important ways of communicating with the family caregiver. Once the healthcare provider has built a trusting relationship with the caregiver, having one-on-one private conversations is of value as well as arranging interdisciplinary and family meetings to discuss the patient's condition, goals of care, and family needs and issues.

Health professionals can further understand the family communication patterns as identified by Wittenburg-Lyles et al. [41]. One dimension of family communication involves high and low communication patterns. Highly active family communication exists when there are open conversations about illness, death, and dying versus low family communication in which family disengages about discussions of illness and treatment. A second dimension of the family communication relates to the degree of conformity. A high degree of family conformity means that there is an established family hierarchy and relatively uniform beliefs and values that emphasize family harmony versus low family conformity which has little emphasis on obedience to other family member's values and thoughts.

Furthermore, for health professionals it is important to recognize the alignment of family communication patterns with four caregiver types: 1) Manager, 2) Carrier, 3) Loner, and 4) Partner types [41]. The Manager tends to have high conformity and frequent conversations, which can limit the range of conversational topics because the homogenous attitudes and beliefs will not allow the exploration of other thoughts and ideas. The Carrier has high conformity and low conversation frequency and topic variability [41]. The Loner is very low in both conformity and conversation. The Partner caregiver has low conformity, which allows a diversity of attitudes and beliefs and high conversation, which allows for frequency of interactions [41].

To better understand these types of caregivers, we can refer to the case studies. MR demonstrates a Manager Caregiver type as she frequently speaks for her husband during conversations with the healthcare team, explaining to them his symptoms and needs. However, if she wanted to continue chemotherapy and radiation, while her husband himself or another family member wanted to stop the treatment due to the side effects and inability to care for him, there would be a family conflict. In understanding the Carrier caregiver pattern, we see that T. G. follows all of the treatment plans and takes her sister to all of the appointments without straying from the plan. However, T.G. is suffering as she has low conversation skills given depression, and a sense of guilt in recognizing that her own son's needs are being neglected and burden placed on her daughter.

The Loner caregiver pattern may be seen in someone young like AN, who has left college life behind to care for her mother. The Loner

pattern tends to not follow the ideas and thoughts of the family and her family could be telling her to stay in school when she feels as though it is important for her to quit her job and come home to care for her mother. AN may also have a low level of conversation because her role has been reversed and it may be difficult for her to understand her own feelings, let alone, describe them to someone else.

Ultimately, the Partner caregiver pattern is the most positive, as it allows for a higher level of conversation and flexibility of ideas and consideration of treatment options. With the Partner pattern, the caregiver's and patient's needs and feelings can be openly explored and addressed.

How do we Begin to Care for the Family Caregiver?

As healthcare providers, we offer patient-family centered care when we acknowledge the presence of the family caregiver, listen attentively, assess their feelings, needs and concerns, and address their issues.

Acknowledging family caregivers

In meeting the patient and family caregiver, we can begin with a simple greeting, "hello, how are you?" as they sit down with the patient. Health professionals need to understand who they are in relationship to the patient and make them feel included in the discussion by eye contact and supportive gestures. By asking the patient if they wish to share protected, confidential information in the presence of the family caregiver, provides information about the level of intimacy in the patient-caregiver relationship. It may be that this family caregiver always accompanies the patient; however, the development of a therapeutic relationship may have to occur with each family caregiver involved in the patient's care.

Listening and paying attention to verbal and non-verbal communication

As healthcare professionals, one of the best things we can do for our patients is just sitting down and listening to what they have to say. The same is true for the caregiver when someone just acknowledges that they are in a difficult situation and provides an ear to listen. Again, much can be learned from personal and private conversation with caregivers when caregivers do not have to hold back their feelings to protect the patient. It is during this conversation where health professionals can more fully appreciate the caregiving experience, including the perceptions of burden and benefit, and determine their needs and preferences for support.

Conducting a family caregiver assessment: making their needs and concerns visible

As an invisible population, health care professionals need to take the family caregiver out of the shadow of the patient and recognize their own needs. According to the Family Caregiver Alliance [6], there are eight categories of information that are foundational to the assessment of the caregiver: (1) caregiver relationship to the patient, (2) physical environment, (3) household status, (4) financial status, (5) quality of family relationships, (6) duration of caregiving, (7) employment status, and (8) general demographics.

Assessment of the caregiver also involves observation of the patient-caregiver dynamic based on both verbal and nonverbal cues.

Table 1: Family Caregiver Assessment Domains, Constructs, and Questions.

| Domain | Constructs | Questions |
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| CONTEXT | <ul style="list-style-type: none"> ■ Caregiver relationship to care recipient ■ Physical environment (home, facility) ■ Household status (number in home, etc.) ■ Financial status ■ Quality of family relationships ■ Duration of caregiving ■ Employment status (work/home/volunteer) | <ul style="list-style-type: none"> ■ What is the caregiver's relationship to the care recipient? ■ How long has he/she been in the caregiving role? ■ Does the care recipient live in the same household with the caregiver? ■ Is the caregiver married? Have children? ■ How many people live in the caregiver's household? ■ Are other family members or friends involved in the care? ■ Is the caregiver currently employed? Full-time or part-time? ■ What is the caregiver's household income? ■ How would the caregiver rate his/her quality of family relationships? |
| CAREGIVER'S PERCEPTION OF HEALTH AND FUNCTIONAL STATUS OF CARE RECIPIENT | <ul style="list-style-type: none"> ■ Activities of daily living (ADLs; bathing, dressing) and need for supervision ■ Instrumental Activities of Daily Living (IADLs; managing finances, using the telephone) ■ Psychosocial needs ■ Cognitive impairment ■ Behavioral problems ■ Medical tests and procedures | <ul style="list-style-type: none"> ■ Can the care recipient carry out ADLs without assistance (bathing, dressing, etc.)? ■ Can the care recipient carry out IADLs without assistance (managing finances, shopping)? ■ Can the care recipient administer his/her medications correctly? ■ Does the care recipient have any mental health diagnoses or emotional problems? ■ Does the care recipient have any memory loss or cognitive impairment? ■ Does the care recipient have any behavioral problems? How frequently do they occur and how much do they bother or upset the caregiver when they happen? ■ What medical tests and procedures have been done or are needed? |
| CAREGIVER VALUES AND PREFERENCES | <ul style="list-style-type: none"> ■ Caregiver/care recipient willingness to assume/accept care ■ Perceived family obligation to provide care ■ Culturally based norms ■ Preferences for scheduling and delivery of care and services | <ul style="list-style-type: none"> ■ Is the caregiver willing to assume the caregiver role? Is the care recipient willing to accept care? ■ Does the caregiver feel he/she is obligated to provide care? ■ What types of care arrangements are considered culturally acceptable for this family? ■ What are the caregiver's (and the care recipient's) preferences for the scheduling and delivery of care and services? |
| WELL-BEING OF THE CAREGIVER | <ul style="list-style-type: none"> ■ Self-rated health ■ Health conditions and symptoms ■ Depression or other emotional distress (e.g., anxiety) ■ Life satisfaction/quality of life | <ul style="list-style-type: none"> ■ Is the caregiver willing to assume the caregiver role? Is the care recipient willing to accept care? ■ Does the caregiver feel he/she is obligated to provide care? ■ What types of care arrangements are considered culturally acceptable for this family? ■ What are the caregiver's (and the care recipient's) preferences for the scheduling and delivery of care and services? |
| WELL-BEING OF THE CAREGIVER | <ul style="list-style-type: none"> ■ Self-rated health ■ Health conditions and symptoms ■ Depression or other emotional distress (e.g., anxiety) ■ Life satisfaction/quality of life | <ul style="list-style-type: none"> ■ How does the caregiver rate his/her own health? Does the caregiver rate his/her health better, about the same, or worse than it was 6 months ago? ■ Does the caregiver have any health conditions or symptoms? ■ How often in the past 6 months has the caregiver had a medical exam or received treatment for physical health problems from a health care practitioner? ■ Depression Scale (See Selected Measures in Appendix III) ■ How often does the caregiver feel anxious or angry when he/she is around the care recipient? ■ How often does the caregiver get a full night's sleep? ■ How does the caregiver rate his/her life satisfaction and/or quality of life? |

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| <p>CONSEQUENCES OF CAREGIVING</p> | <ul style="list-style-type: none"> ■ Perceived challenges ■ Social isolation ■ Work strain ■ Emotional and physical health strain ■ Financial strain ■ Family relationship strain | <ul style="list-style-type: none"> ■ Perceived challenges -Does the caregiver have a social support network or is he/she isolated? -Does the caregiver suffer any work-related difficulties due to the caregiving role? -Does the caregiver suffer from any emotional and/or physical health problems as a result of caregiving? -How much does the caregiver's health stand in the way of doing things he/she wants to do? -What has been the financial strain, if any, on the caregiver due to his/her caregiving role? -How much disagreement has the caregiver experienced with other family members over particular care issues? |
| <p>SKILLS/ABILITIES/ KNOWLEDGE TO PROVIDE CARE RECIPIENT WITH NEEDED CARE</p> | <ul style="list-style-type: none"> ■ Perceived benefits ■ Satisfaction of helping family member ■ Developing new skills and competencies ■ Improved family relationships <ul style="list-style-type: none"> ■ Caregiving confidence and competencies ■ Appropriate knowledge of medical care tasks (wound care, etc.) | <ul style="list-style-type: none"> ■ Perceived benefits -Does the caregiver feel satisfaction in helping a family member? -Does the caregiver feel he/she has developed new skills and knowledge as a result of caregiving? -Has there been an improvement in family relationships (general closeness, communication, similarity of views, degree of getting along) as a result of the caregiving situation? ■ How knowledgeable does the caregiver feel about the care recipient's condition? ■ What are the skills and abilities needed to provide care for the care recipient? ■ How would the caregiver rate his/her confidence and competence in these areas? ■ Does the caregiver have the appropriate knowledge of medical care tasks (wound care, ability to administer medications correctly, etc.) and transfer techniques (moving from bed to chair, etc.) |
| <p>POTENTIAL RESOURCES THAT CAREGIVER COULD CHOOSE TO USE</p> | <ul style="list-style-type: none"> ■ Existing or potential strengths (e.g., what is presently going well) ■ Coping strategies ■ Financial resources (health care and service benefits, Entitlements such as Veteran's Affairs, Medicare) ■ Community resources and services (caregiver support programs, religious organizations, volunteer agencies) ■ Formal and informal helping network and perceived quality of social support | <ul style="list-style-type: none"> ■ Can the caregiver rely on his/her social support network for help (i.e. respite)? ■ What are the caregiver's coping strategies? Are these healthy/constructive? ■ Has the caregiver accessed all financial benefits and entitlements he/she or care recipient is eligible for (e.g., Veteran's Affairs)? ■ What other community resources/services is the caregiver utilizing or aware of (e.g., caregiver support groups, religious organizations)? |

Source: Family Caregiver Alliance (2013, July 25). *An Online Toolkit to Help Practitioners Assess the Needs of Family Caregivers*, retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1709.

Much can be learned about caregiver distress by just observing the interaction between the patient and caregiver. Further conversations provide a greater context of the patient-caregiver relationship, caregiver perception of health and functional status of the patient and themselves, understanding of caregiver values and preferences, the well-being of the caregiver, willingness to serve as caregiver, burdens and benefits of caregiving, as well as an understanding the level of caregiver skills, abilities, and knowledge so that potential resources can be provided [7]. Over the many meetings with the family caregiver both in the presence of the patient and in separate, planned conversations, health professionals can use ask the questions, provided in Table 1, to conduct a comprehensive family caregiver assessment.

Provide immediate caregiver support and resources

It is important for health professionals, to develop over time, a therapeutic relationship with family caregivers. However, even during the first meeting of the caregiver, and with attentive concern and listening, health professionals can acknowledge the caregiver role, responsibilities and concerns. With knowledge of available resources for caregivers, health professionals can direct them to on-

line and web-based information and other caregiver resources. Based on a systematic review of web-based interventions, such as bulletin boards, articles, games, therapy programs, and personal stories, Kaltenbaugh et al. [42] report a decrease in caregiver burden and improved knowledge and skills of family caregivers in providing care. A simple pamphlet offered by health professionals which provide a list of the websites, such as, CHESS, Cancer Coping Online, or FOCUS can provide family caregivers with a much needed life-line for themselves.

Provide family caregiver interventions: the right type at the right time in the right dose

Based on a comprehensive ongoing family caregiver assessment across the illness trajectory, health care professionals can determine the right type of caregiver intervention to be provided at the right time, in the right dose. For example, psycho educational interventions can help at the beginning of the cancer diagnosis [19]. A web-based intervention psycho-social intervention, called CHESS, was shown to have a modest effect on reducing caregiver burden (d =0.387) and caregiver's negative mood (d = 0.436) at six months" [42]. Similarly, an educational intervention offered to patients experiencing prostate

cancer and their family caregiver was shown to increase patient's and partner's cognitive, problem solving, and behavioral coping skills with significant improvement in emotional distress and sexual function within three months of follow-up [43]. A systematic review performed by Waldron, Janke, Bechtel, Ramirez and Cohen [5] suggests that interventions targeting communication and education have an impact on improving caregiver quality of life, promote a more optimistic attitude regarding caregiving, and lessen feelings of uncertainty and fear. More research is needed to further understand differences in caregiver distress and quality of life, for caregivers who have varying relationships to the patient (e.g., spouse/intimate partner or other family member). So depending on the stage of the illness, feelings or amount of burden experienced by family caregivers, the relationship to the patient, different caregiver interventions can be recommended to address the specific needs of caregivers which change over time.

It is also important to assess when there is a need to escalate an intervention by referral of the caregiver to other members of the interprofessional team or to have a multi-focal approach. For example, when there are financial concerns or problems with health insurance, a referral to a social worker is important. If the family caregiver is experiencing emotional or spiritual distress, the chaplain or psychologist may offer support. If the patient's health is clearly declining, a family meeting may be necessary for all family caregivers involved in the patient's care to discuss the goals of care, the patient's and families' wishes and preferences to end of life care. When the family caregiver is becoming overwhelmed, discussion of home health care or the support offered by hospice is extremely important to preserving the well-being of family caregivers.

Discussion and Implications for Clinical Practice and Research

Despite the National Consensus Guidelines for Quality Palliative Care (NCP, 2013), which emphasize that both patient and family should be viewed as the unit of care, health professionals do not intervene in ways that take caregiver well-being into account [44]. Furthermore, health care resources for family caregivers are limited, fragmented, and discontinuous [45]. Health risks and serious illness of caregivers may increase their utilization of health care resources, contribute to escalating health care costs, and place caregivers at greater risk for life-threatening illness [11]. With high burden, depression and a sense of abandonment by professionals, targeted interventions for caregivers are recommended [16].

The ultimate question is what can be done to help family caregivers who are an at-risk and vulnerable population? It is important in clinical practice for health professionals to focus not only on the needs of the patient but the needs of the caregiver. As the needs of patients change over the illness experience, so do the needs of family caregivers. Therefore, as the provider/caregiver relationship deepens over time so should the care and support given to insure the family caregiver's health, overcoming negative health consequences and promoting their well-being and quality of life. Caregiver burden and benefits are two important concepts to understand within the context of patient-family centered care. Caregiver burden increase when caregivers are unprepared to provide instrumental, emotional, and financial support [19]. Caregiver benefits refers to the positive

or practical experience as a direct result of becoming a caregiver for patients, including post-traumatic growth, benefit finding, optimism, positive effects, hope, and meaning in life [46]. An interprofessional approach to the care of family caregivers is extremely important to limiting the burdens of caregiving and promoting the perceived benefits of the experience.

Through a careful review of current intervention literature regarding family caregivers, including systematic reviews [19,47-50], the recommendations regarding future caregiver intervention studies are clearly identified. Specifically, family caregiver interventions need to: 1) be based on caregiver data obtained through longitudinally designed studies; 2) promote the benefits of caregiving, and meaning making, which enhance caregivers' personal growth; 3) consider perceived needs and preferences of caregivers depending on coping styles, and interest in the use of web-based technology; 4) be developed depending on the presenting issues of patients and caregivers; 5) intervene in supporting relationships of patients-caregivers-health professionals; 6) identify sub-groups (age, gender, relationships etc.) in tailoring interventions; 7) be flexible, integrated, multi-faceted, and individualized; 8) be "dosed" based on the degree of baseline and progressive caregiver distress; 9) offered at times perceived as key time-points and transitions experienced by caregivers; and 10) be based on clearly identified and measured caregiver outcomes. Stajduhar et al. [9] state "well-designed studies are sorely needed to test promising interventions," given that little is known about which interventions are most effective in supporting caregivers (p. 124).

Developing trusting relationships with family caregivers and conducting a comprehensive family caregiver assessment are critical to the development of effective interventions across the caregiving experience. The empirical evidence informs optimal palliative care and end of life interventions, offered as the right type, at the right time and in the right dose, based on key healthcare indicators (i.e. physical and emotional caregiver symptoms, and quality of life), and caregivers' coping, needs, and preferences [48]. As health care professionals, we need to: a) prevent and reduce caregivers' illness and exacerbation of co-morbid conditions; b) lessen strain; c) promote positive aspects of the caregiving experience; d) improve physical and emotional symptoms of caregivers; e) enhance the personal growth and the QOL for family caregivers across the illness trajectory and bereavement; and f) allow for wiser and more efficient allocation of limited health care resources.

Who is sitting with the patient during a medical visit or at the bedside? It is the family caregiver~ who also needs your attention as they step out of the shadows and become visible- often desperately needing the support of health care professionals. Family caregivers must be recognized as "care recipients," with a right to their own support, needs assessment and to have their experience evaluated "not as a proxy response for patients but as an outcome itself" [2].

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