

Supporting the Support System

How Assessment and Communication Can Help Patients and Their Support Systems

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ABSTRACT

Purpose/Objective: The benefits of having a support system, such as social relationships with close friends and family, have been well documented for patients with serious health issues. As scientific evidence has shown, individuals who have the lowest level of involvement in social relationships face a greater mortality risk. Support systems, however, are not infallible. Relationship stress can have a negative impact on people—patient and caregiver alike—behaviorally, psychosocially, and physiologically. The purpose of this article is to encourage case managers who take a patient-centered approach to also consider the existence and extent of the support system, as well as any stresses or tensions that are observable within the support system. Although the case manager is ethically obliged to advocate for the individual receiving case management services, that advocacy can be extended to the support system for the good of all.

Primary Practice Settings: This discussion applies to numerous case management practices and work settings including (but not limited to) hospital-based case management, home health, geriatrics, catastrophic case management, mental health, palliative care, and end of life/hospice.

Finding/Conclusions: As part of the assessment phase of the case management process, case managers determine the extent of the patient’s support system or social support network such as family and close friends. Although their advocacy is primarily for the patient receiving case management services, case managers also become aware of the needs of the support system members as they face their loved one’s serious illness, severe injury, geriatric care demands, or end of life. Case managers can use their communication skills, especially motivational interviewing, with patients and their support systems to identify stresses and issues that can impact the pursuit of health goals. In addition, case managers ensure that individuals and their support systems are kept informed such as about the health condition, stage of disease, plan of care, treatment options, and care transition plan.

Implications for Case Management: Professional case managers expand their role as advocates, serving primarily the patients (“clients”) who receive case management services and also members of the support system. By becoming more aware and sensitive to the needs of the support system, case managers help reduce stress on the support system, which can contribute to positive outcomes for patients (“clients”).

Key words: *advocacy, assessment, care transitions, case management, catastrophic case management, education, end of life, geriatrics, motivational interviewing, self-care, support system*

The benefits of having a support system, such as social relationships with close friends and family, have been well documented for patients with serious health issues (Holt-Lunstad, Smith, & Layton, 2010; Umberson & Montez, 2010). Empirical data have pointed to the “medical relevance of social relationships in improving patient care, increasing compliance with medical regimens, and promoting decreased length of hospitalizations” (Holt-Lunstad et al., 2010, p. 2). Scientific evidence has also shown that individuals who have the lowest level of involvement in social relationships face a greater mortality risk—as much as twice the risk among those with the

fewest social ties compared with those with the most (Umberson & Montez, 2010). These findings emphasize the impact of social relationships on health in both the short and long terms.

Further underscoring the importance of a support system, the Commission for Case Manager

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Certification’s (CCMC’s) Case Management Body of Knowledge (CMBOK) puts the “client” (the individual receiving case management services) and his or her support system at the center of a team working together in pursuit of the individual’s health goals. “Success in the case manager’s role requires the work of a team: the client and the client’s support system (family/caregiver), healthcare and service providers—including payor representatives—and other clinicians” (CMBOK, Case Management Concepts; CCMC, 2016, p. 2). As case managers working across the health care spectrum know, and as this article discusses, positive social relationships can improve health in multiple ways, from providing direct care during specific periods to engaging in positive relationships over time that support healthy lifestyles.

Support systems, however, are not infallible. As this article also shows, relationship stress can have a negative impact on people—patient and caregiver alike—behaviorally, psychosocially, and physiologically (Umberson & Montez, 2010), whether due to tensions and conflict that existed before the onset of an illness or injury (e.g., marital strife or family problems) or because of the pressures that mount on nonpaid caregivers who are often family members. In the case of the latter, there can be significant physical and/or mental health risks of caregiver burnout (Mayo Clinic, 2015), as is discussed, which could also impact the individual receiving care. Therefore, case managers, who routinely assess the support system as part of the case management process (CMBOK; CCMC, 2016), should also seek to become more aware of any risks or health issues impacting caregivers and other members of the support system.

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THE PATIENT AND THE SUPPORT SYSTEM

Case managers take a patient-centered approach that is focused on the individual and his or her needs and health goals (Harkey, Sortedahl, Crook, & Sminkey, 2017). According to the CCMC’s Code of Professional Conduct for Case Managers, an underlying value of case management is the belief “that case management is a means for improving client health, wellness and autonomy through advocacy, communication, education, identification of service resources, and service facilitation” (2015, p. 3). Case managers use their communication skills with patients and their support systems to help ensure that individuals are kept informed about their health condition, stage of disease, plan of care, treatment options, and care transition plan. A lack of communication impacts not only the patient but also the support system (CMBOK; CCMC, 2016). The Case Management Society of America (2016), in its definition of case management, specifically refers to “advocacy for options and services to meet an individual’s and family’s comprehensive health needs” (p. 1). The National Association of Social Workers (NASW, 2013), in its “NASW Standards for Social Work Case Management,” emphasizes the expertise of the social worker case manager in developing and improving broadly defined support systems that include “service delivery systems, resources, opportunities, and naturally occurring social supports,” all of which “advance the well-being of individuals, families, and communities” (p. 7). Thus, although case managers, particularly those who are board-certified, are ethically obliged to advocate for the individual (the “client”) receiving case management services, that advocacy can be extended to the support system for the good of all.

When individuals have chronic diseases such as heart disease, high blood pressure, and diabetes, a support system is beneficial to help them adhere to a medical regimen of keeping medical appointments, monitoring blood glucose and blood pressure, taking medicines, eating healthy, and exercising regularly (Johns Hopkins Center to Eliminate Cardiovascular Health Disparities, n.d.). In geriatric and elder care, although some older people are able to

live independently, advanced aging and/or changes in physical and mental health, including cognitive function, often result in older people being cared for by family, who typically provide assistance with activities of daily living and personal care.

Another role for the support system is to help facilitate communication with the doctor and other clinicians. Patients sometimes bring a family member or close friend with them to doctors' consultations to help them "listen." Even when patients display non-verbal cues (making eye contact and nodding) that indicate they are listening to the physician, fear and uncertainty caused by a new diagnosis or a worsening condition can make it difficult for patients to absorb information. A spouse, adult child, sibling, other relative, or close friend can be the support system member who, with the patient's authorization, records information. At end of life, the support system may play a direct role in decision making, in keeping with the individual's wishes, such as expressed in an advance health care directive, do-not-resuscitate order, POLST (practitioner orders for life-sustaining treatment) documents that record patients' treatment wishes, or other documentation.

Determining whether the person has a support system and who is in that support system is part of the assessing phase of the case management process (see Box 1). During the assessing phase, which follows the initial screening, the case manager collects additional in-depth information about the patient's situation. Also during this phase, the case manager gathers information about the individual and his or her support system, including family members, significant other, and caregivers. The existence of a psychosocial network and support system is an important factor to discern when determining the optimal care plan for the individual (CMBOK, 2016).

Case managers can ask gently probing questions, sometimes by simply asking whether the person has a partner or spouse or adult children. With a geriatric patient, for example, determining how the person manages on a day-to-day basis also reveals the extent and functioning of the support system. As rapport between the case manager and the patient is established, the individual is more apt to share information about the family dynamic, sometimes including rifts and conflicts. Or, it may become clear through the case manager's interactions with the patient and

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BOX 1

Determining the Support System

Case managers can use even simple queries to find out the extent of and roles within a support system. For example, asking a geriatric patient living in his or her own home:

- How do you get to your doctor's appointments? Who drives you?
- How do you get your food? Who helps you with shopping? With meal preparation?

his or her support system that an elderly spouse, for example, cannot help with decision making or be the primary caregiver and so the roles change, with duties falling to an adult child or others in the support system.

Given the changes in health care over the years, more care is being provided in ambulatory settings or in the home, reducing inpatient care. This means increased involvement by the support system. At the same time, smaller families, geographic distances between family members, and the reality of busy lives and careers can compound the burden for the support system.

SUPPORT SYSTEM DYNAMICS

Support systems have their own dynamics, which existed before the health crisis. The stresses and conflicts that existed before an illness, an injury, or deteriorating health due to aging will likely be exacerbated as a loved one's health status changes. In geriatric care and end of life, for example, birth order, sibling rivalries, and the parents' relationships with each other and with the now-adult children are often brought into sharp focus. Role reversal is often emotional, as now the adult child is taking care of the parent. Beyond the emotion, the religious or ethnic background of the family may also determine who provides care and who cannot (e.g., an adult son bathing his mother). Or, the opposite can occur: The husband or wife may want to care for the spouse but is physically unable to do so. Or, family members may consider it their duty to keep all care within the family, rejecting any "outside help" such as a home health aide or, even in some cases, adaptive equipment. The family's socioeconomic status also impacts the ability to pay for outside caregivers and even to provide for basic needs.

A case manager's meeting with the family will often reveal insights based on how the support system interacts. "David" was a dementia patient, no longer able to make decisions for himself. A case manager was hired by the family to coordinate his care. All three of David's adult children were at the meeting with the case manager. Although they appeared to get along and there were no visible signs of conflict among them, it became clear to the case manager that

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they had their own opinion of what was best for their father. The case manager sought to establish common ground: "I know you all love your father, and we all want to do what is best for him. We need to start with a complete assessment to see what his needs are and what the requirements would be for providing his care, and then see what is feasible." When the adult children better understood their father's cognitive ability and what he was and was not able to do for himself, an honest discussion ensued. The reality of the kind of care David would need could be balanced against the competing reality of these adult children's lives with their jobs, families, and health limitations of their own.

Consider the example of "Jackie" who arranged care for her 90-year-old mother. When the case manager met with Jackie, he asked about other family members. She mentioned a sister who was largely estranged from the family. "We need to be prepared," the case manager told Jackie. "Your sister may have different information needs or support needs." The estranged sister did not contact Jackie or their mother before her passing. Nonetheless, the potential for conflict within the support system was brought into the open by the case manager and discussed. Case managers who specialize in geriatric care and end of life often observe that the support system members who live the farthest away, who are not present with the patient on a day-to-day basis, often have the most opinions and express them the most vocally.

Support system issues also emerge when a catastrophic injury occurs. A person who was healthy and independent becomes severely limited in terms of mobility or performing self-care. Beyond the traumatic brain injury, spinal cord injury, amputation, or other traumatic injury, the individual may also have preexisting medical conditions that create further complexity. Add to the suddenness of it all (a car accident or a workplace accident), the situation quickly becomes highly emotionally charged for the individual and the support system. The psychosocial impact is typically significant, compounded by fears about whether the person will recover from the accident; whether he or she will be able to work again; and who will take care of the injured person in the long term. Whatever the relationships and coping patterns that existed within the family or support system before, the injury probably will not improve them; rather, it will likely tax them. If those relationships were not strong, as new needs and demands are

placed upon people in the support system, it may be beyond their capacity.

Research shows that family caregivers who are more resilient are more likely to experience positive effects and decreased levels of caregiver burdens (Simpson & Jones, 2012). Thus, addressing these stresses can ease the burden on the support system, support resilience, and lead to better outcomes for the severely injured individual.

As care progresses, in anticipation of the injured person's eventual discharge to home or another care setting, the case manager uses open-ended questions to engage the individual and the support system members. When a good rapport has been established, the case manager may ask about thoughts or fears the patient has about integrating back into the home. In the same way, the support system may be forthcoming about fears and concerns. A spouse or partner, for example, may be wondering how his or her own life will change because of a loved one's severe injury. Common questions in these instances are: "What am I supposed to do? How can I pay the bills? How can we survive?" The case manager will take those questions in as part of an ongoing assessment of the needs of the individual and the support system. Although the primary focus is on providing the care and treatment that the individual needs, a case manager will look to identify other resources that are available such as support groups and organizations in the community that can help with meals, transportation, and other needs (see Box 2).

Conflict within the support system can also erupt over guardianship, such as in the case of a patient with brain injury who does not recover cognitively to a level of being able to care for himself or herself and make decisions. When a legal settlement is involved, and money has to be managed by a guardian, the dynamic may erode further. "Gary" suffered a traumatic brain injury in his workplace and received a large third-party settlement. Because

BOX 2 Exploring Emotions at Transitions

When an injured person is preparing to transition back to the home, the case manager may want to pose some questions. For example: Are you wondering about your integration in the home? What worries you? Are you concerned about your relationship with your spouse/partner? Are you worried about how you are going to do things you used to be able to do? These questions may be the "permission" the person needs to open up about his or her thoughts and feelings about what comes next.

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of Gary's cognitive and physical impairments, and differences of opinion about discharge placement, both his live-in girlfriend and his mother sought guardianship and went to court. As members of the support system were locked in conflict, the case manager kept the focus on Gary, ensuring that his needs were being met and that he was receiving the right care and treatment at the appropriate time.

CAREGIVER BURNOUT

Even when relationships are harmonious, the stresses within the support system and on members can be considerable. Often, when a loved one has a severe illness, catastrophic injury, or is suffering from declining health due to advanced aging, responsibility for care falls primarily on one individual. The person who finds himself or herself in the role of the nonpaid caregiver may be reluctant to take on these duties and responsibilities. Perhaps the caregiver is trying to juggle other responsibilities, including his or her immediate family and/or a job or business. Even the most devoted family caregiver can become burned out.

A few open-ended questions can help determine the signs of caregiver burnout; for example, asking how the loved one's declining health has affected the caregiver. What changes has the caregiver experienced in his or her life or daily routine? This was the conversation the case manager had with "Don," who was the caregiver for his wife, "Beth," who had dementia. After more than 60 years of marriage, Don saw it as his duty to take care of Beth in their home. However, he quickly became overwhelmed with having to care for her every day. When the case manager asked him what activities he had to give up or change in order to care for Beth, he mentioned a weekly card game at the local senior center. Although Don resisted at first, the case manager suggested he investigate enrolling Beth in an adult daycare program for a few hours, 1 or 2 days a week, to give him some time to himself. When Don and the case manager visited the center, bringing Beth with them, he saw how this could be a solution to give him some respite while ensuring his wife was in a safe environment and also receiving stimulation during the day, which also helped her sleep at night.

The case manager who encounters a burned-out caregiver being pushed to his or her maximum

ability to cope will likely see some warning signs. The person may appear to be physically or emotionally stressed, overwhelmed, and/or irritable or hypercritical. A caregiver who is overwhelmed may also appear to be ambivalent, unable to take on or address one more thing. The burned-out caregiver who has established open communication with the case manager may readily admit to these feelings. The message that often needs to be delivered to the caregiver is: If you don't take care of yourself, who will? Umberson and Montez (2010), in their research, found evidence that providing care to a sick or impaired spouse can negatively impact the health of the one providing care even to the point of elevating mortality risk. In addition, caring for a sick or impaired spouse is associated with increased physical and psychological health risks, impaired immune function, reduced self-care, and poorer health for the provider (see Box 3).

The case manager can help the caregiver see that needing to take a break or to seek out additional help is not a sign that he or she is doing a "bad job" of caring for the loved one. Also, when support system members understand the expected disease progression—for example, when a loved one has Parkinson's disease—they are better able to assess their own ability to cope with what comes next and to admit when they need help. Burnout can also be exacerbated by watching the loved one's decline, particularly if he or she is suffering. Suffering is different than pain because it occurs on many levels, including physically, socially, and spiritually (Demoratz, 2016). But what of the caregiver's suffering? Here, the case manager can draw upon the resources of the interdisciplinary care team or those available in the community. A burned-out caregiver who just brought an elderly parent into the emergency department because of chest pains or difficulty breathing may benefit from a conversation with a social worker. Or, a case manager who is working with a patient and support system can ask whether the caregiver has someone to talk to such as a counselor or a clergyman (see Box 4).

BOX 3 Signs of Caregiver Stress

- Feeling overwhelmed or constantly worried
- Feeling tired most of the time
- Sleeping too much or too little
- Gaining or losing a lot of weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain, or other physical problems
- Abusing alcohol or drugs, including prescription medications. (Mayo Clinic, 2015)

BOX 4

Causes of Caregiver Burnout

Expectations that are set too high: Many caregivers think their efforts will have a significant, positive impact on their loved one, but that may not be realistic.

Lack of control: Many caregivers are frustrated that they lack the money, resources, and skills to manage and organize their loved one's care the way they'd like.

Unreasonable demands: Caregivers sometimes take on more caregiving responsibilities than they can handle. (WebMD, 2016)

Case managers do not need to provide all the answers. However, asking the right questions ... can prompt an honest and candid discussion of what support, assistance, or other resources the support system members need to care for their loved one.

SUPPORTING THE SUPPORT SYSTEM

Case managers need not practice in specialty areas such as geriatrics, end of life, and catastrophic injury to encounter support system stresses, nor do they need to be experts in mental health counseling to detect the signs of stress or burnout within the support system. Sometimes it can be as easy as applying the basics of motivational interviewing, a patient-centered communication skill (Petrova et al., 2015). Motivational interviewing is a highly effective technique of gathering information and obtaining insights into the patient's situation and that of the support system. The key is to ask open-ended questions that can help the case manager learn more about a situation while also helping the individual articulate what's on his or her mind. For example, asking a caregiver who appears stressed out, "Who are you talking to about what's going on in your life?" may be enough to spark a discussion. The support system member may recognize the need to reach out for the help, such as seeing a counselor before stresses escalate further. Just as case managers should be aware of how to do a basic depression screening with patients, they should be aware of the "red flags" of tensions and stresses within the support system, which could impact the health of the caregiver, and potentially affect the person receiving the care.

Case managers should also be up to date with referral resources for the patient and/or caregivers, from religious groups or volunteer organizations to resources in the community such as adult daycare centers or support groups for individuals and families. Case managers can also reach out to colleagues, including fellow

case managers from different disciplines such as social work and mental health counseling. These professionals have the expertise that can help the case manager provide resources and support for the caregivers.

Case managers do not need to provide all the answers. However, asking the right questions—How is this impacting you? What has changed for you? What worries or concerns do you have?—can prompt an honest and candid discussion of what support, assistance, or other resources the support system members need to care for their loved one.

CONCLUSION

The benefits of having a support system, including how social relationships significantly affect health, have been demonstrated by research (Umberson & Montez, 2010). As part of the assessment phase of the case management process, case managers determine the extent of the patient's support system or social support network such as family and close friends. Although advocacy is primarily for the patient receiving case management services, the case manager also becomes aware of the needs of the support system members as they face the patient's serious illness, severe injury, geriatric care demands, or end of life. The case manager's abilities to assess, evaluate, and communicate can impact outcomes for the patient and his or her support system.

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