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# The Burden of Caregiving on Families of ICU Survivors

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## Introduction

As a result of increasingly sophisticated therapies for critically ill patients, family members are caring for individuals with complex medical problems at home as the most financially feasible alternative to institutional care. These individuals include older adults with progressive dementia, children and adults who are technologically dependent, such as on home dialysis or respirators, individuals with stroke, survivors of traumatic brain injuries or spinal cord injuries, and individuals with chronic neurological disorders, such as multiple sclerosis. These patients may have survived life-threatening illnesses requiring ICU care, such as severe sepsis, septic shock, acute respiratory distress syndrome (ARDS), stroke, and multi-system organ failure. Patients who, even twenty years ago, most probably would have succumbed to a critical illness are now surviving in increasing numbers [14].

At the same time, third party payors and the current concepts in hospital remuneration are leading patients to be discharged from hospital more quickly than would have been true over the past twenty years. Earlier discharge and improved survival are two very important reasons why informal caregiving is becoming an ever more important aspect of, not only health care in general, but critical care in particular.

In a recent study [5] of seventy-five patients greater than seventy years old, with an ICU stay of longer than 30 days, 47 % were discharged alive from ICU and were found to have a median survival of 204 days. After ICU discharge, these patients were found to have a significant increase in dependence; this included disability in bathing (23 %), toileting (15 %), transfer (26 %), and continence (19 %). The study demonstrated 41 % one-year survival with good quality of life despite a moderate disability. Twenty-five of thirty survivors questioned felt they would want ICU care again. Also of note, the need for special equipment in activities of daily living was not felt to be an important disability by survivors, despite the fact that 16 to 23 % of patients needed some help in bathing. Of interest, in this study, there was no mention about family concerns or needs. The authors concluded that the acceptance of disability is better among elderly patients with good social conditions and with family or friends close to them.

This study points clearly to the importance of addressing the concerns and needs of families early in ICU stay, not just through discharge planning but seeing our

curative attempts in the ICU in the true context of our patients lives. It is not enough for the patient alone to survive, the family must survive to health as well.

Many studies have documented the quality of life for ICU survivors [619]. Reports on the ability of ICU survivors to return to pre-hospitalization levels of function have varied widely in the literature, depending on the severity of illness. Several reports have found a low one-year level of functioning, even in patients less than fifty years old and without traumatic brain injury [10, 11, 16].

While improved survival from critical illness is certainly good news for our patients and demonstrates the ability to bring bench research to the bedside, leading to better care for patients, very little attention has been paid to the price paid for this improved survival – not solely in terms of financial costs, but also the global impact on families of ICU survivors. How do families cope with survivors of ICU care? What impact does critical illness have on the ongoing relationships for the families of these patients? Often the post-ICU and hospital recovery period is prolonged; although several studies document good quality of life after recovery from critical illness, the burden that families bear during this recovery period has long been overlooked. The demands of survival may be considerable, both physically and emotionally. Care for these survivors often falls to family members who then become informal caregivers with little training or preparation in caregiving skills. If our ultimate goal for ICU survivors is to return these patients to the best possible quality of life, the long-term impact on informal caregivers is important to understand. What are the effects of informal caregiving on caregivers, families, and patients? What are the determining factors that affect quality of life for all members of this informal team? Are there interventions that can brighten the long-term outlook of patients who survive critical illness?

For ICU survivors, there is limited available information to answer these important and difficult questions. Much of the available data is in survivors of traumatic brain injury and refers mostly to the parent/child relationship. The absence of good data in the literature on this topic speaks volumes to our lack of appreciation and understanding about the way in which survival from critical illness affects the everyday lives of our patients after they survive critical illness. In our excitement and rush to improve ICU care and survival for our patients, the problems which arise for the families left to care for their loved ones after ICU survival have been inadequately studied. Just as we have long ignored the problem of helping people *die* with dignity in the ICU, we have also ignored the problem of helping ICU survivors and their caregivers *live* with dignity after ICU care.

Although many questions are unanswered, it might be helpful to review some of the major areas identified in the literature, which may have a major impact on families who become caregivers to these survivors.

## **The Impact of Informal Caregiving**

The high cost of long-term health care, combined with current trends to decrease healthcare costs, suggest that responsibility for the day-to-day care of ICU survivors will continue to fall on their families in the home setting. Families of survivors are expected to provide long-term continuous care, often without adequate re-

sources. Families often lack nursing skills, coping skills, support systems, or knowledge of their own rights, available help or how to obtain help. Caregivers experience major psychological stress, including loneliness, social isolation and guilt. There are many reports in the literature that describe the impact of informal caregiving on families of patients who have sustained traumatic brain injury. As an example, in one such study, forty-two patients with traumatic brain injury and their caregivers were evaluated three months after discharge from a rehabilitation facility [20]. In this study, 50 % of the caregivers (most often women: mothers or wives) had quit their jobs to care for the person with traumatic brain injury; 42 % of caregivers reported a decrease in income; and 28.6 % reported that their loved ones required constant supervision. In the forty-two families surveyed, only two patients were able to live independently. The more physical and cognitive impairments the person with traumatic brain injury had, the greater the reported caregiver burden.

## Caregiver Burden

The concept of family burden was first introduced by Grad and Sainsbury [21]. Burden was defined as any cost (negative consequences) to the family in which the patient is a member. Burden can be broadly viewed as a mediating force between the patient's impairment and the impact that caregiving has on the lives of the caregivers and their families. In order to understand the underpinnings of informal caregiving and the factors that may affect outcomes for caregivers, burden has been separated between events and activities that arise during caregiving, from emotions, feelings and attitudes associated with caregiving [22]. This means caregiving has been segregated into subjective and objective dimensions. Objective burden refers to the events and activities associated with negative caregiving experiences. Subjective burden refers to feelings aroused in caregivers as they fulfill their caregiving function.

*Subjective burden* [23-27] is defined as the caregiver's attitude towards or emotional reactions to the caregiving experience, or changes in various aspects of the caregiver's life and household. In this context, caregiver burden is not necessarily perceived as an unavoidable, negative consequence of providing care, but is defined by the subjective perceptions of caregivers related to the degree of problems experienced in relation to the patients specific impairments. This suggests that burden is processed through caregivers subjective perception.

*Objective burden* involves disruption to family life that is potentially verifiable and observable. More recently, instead of describing burden as a subjective/objective dichotomy, caregiver burden is viewed as multi-dimensional. This refers to the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for a chronically ill or impaired family member [28-31].

## The Dimensions of Caregiver Burden

We must begin to quantify the factors that contribute to and describe informal caregiver burden so that appropriate outcome measures can be developed to assess the value of interventions with future initiatives and research. A recent conceptual model was introduced by Chou [32] and may provide a helpful context in which to look at the multiple factors that influence informal caregiver burden. This model of caregiver burden is based on delineation of:

- 1) critical attributes of burden
- 2) predisposing factors that influencing the occurrence of burden
- 3) mediating and or moderating factors and
- 4) consequences or outcomes.

### Critical Attributes

The critical attributes of caregiver burden refer to the characteristics of the concept of burden. These factors could be considered the primary determinants of burden. In this model, the four primary attributes, or determinants of burden include: subjective perception, multidimensional phenomena, dynamic change and overload. Subjective perception has been described above. Many reports have described the process of burden as based on how the caregiver interprets the demands of the care-receiver. In this way, burden develops based on the caregivers subjective perception of the demands of caregiving.

**Multidimensional phenomena:** As already mentioned, the demand that arises out of caregiving is multi-faceted. Broadly speaking, the more objective aspects of caregiver burden appear to fall into four areas: physical, financial, psychological, and social [31].

**Dynamic change:** Most illness, whether chronic or acute, involves a dynamic process. Therefore, it follows that the burden arising for people caring for their loved ones at home will also be in flux. As the demands of care receivers change, whether because of intervening illness or due to deterioration in chronic disease, caregiver burden will also change. Clearly, burden will change as the demands and extent of caregiving involvement change. In fact, burden may change over time in both directions. Caregiver burden changes over time because of increasing disability of the impaired receiver, but it will also change as the caregiver adapts and discovers new coping mechanisms for new, and established, caregiving problems.

**Overload:** Another primary determinant of burden arises from the overload that may occur in the process of caregiving. This overload may lead to changes in the subjective perception of burden by the caregiver but is based on demands that may be easily recognized and that may provide opportunities for intervention to ease caregiver burden. These demands may come from the care receiver, work, family

members, or society. It is really a matter of supply and demand. The caregiver will perceive burden to increase when demands are greater than available resources.

## Predisposing Factors

For any illness, there are predisposing factors that may alter the course of disease. The same can be said for caregiver burden. In the same way that understanding the interaction between predisposing factors and the development of illness may inform the development of interventions that will alter the course of illness, identifying predisposing factors that affect the process of caregiver burden may allow for interventions that will attenuate burden. These factors increase the risk or vulnerability for perceiving burden, and are clearly primary determinants of burden. They include caregivers characteristics, demands of caregivers, and involvement in caregiving.

**Caregivers characteristics:** Pertinent characteristics of caregivers that are likely to affect the likelihood of burden include social situations, health status, and psychological factors.

1. *Social locations:* Social and economic class, race, ethnicity, gender have all been reported to affect the process of caregiver burden. Studies have demonstrated greater burden on female caregivers [29, 33–35]. Women often carry multiple roles including mother, wage earner, and household manager. The majority of reported caregivers are women (47–80 %), and several studies have reported that female caregivers perceived their burden to be greater than men [25, 26, 36–38].
2. *Economic resources* also play an important role in a family's perception of well-being. Income has been found to be the primary determinant of whether and how many services can be purchased to alleviate the burden of caregiving [21, 25, 35, 39]. Insufficient income reduces access to resources that might make caregiving more bearable. Financial expense of caregiving has been reported to correlate with burden.
3. *Race and culture* are important predisposing factors in the development of caregiver burden [36, 40]. Normal levels of intergenerational contact may affect perception of burden. Given the wide variation in this contact across cultures, cultural values [41] may also affect perceived burden.
4. *The health of a caregiver* will affect burden. For instance, two factors for human immunodeficiency virus (HIV) caregivers that may affect the context of caregiving and its outcomes is the caregiver's own HIV status and his or her perceptions of vulnerability to acquired immunodeficiency syndrome (AIDS) [42]. Caregiver health is a predisposing factor for burden and is also a dynamic factor, as burden itself may affect the health of caregivers [25, 29, 3335, 4345].
5. *Certain factors in the psychological makeup of the caregiver* will clearly impact the perception of burden. Some examples of these factors, as reported in the literature include: a sense of obligation and responsibility, affection and reciprocity in the caregiver/receiver relationship, and family history [25, 34, 38, 45–47]. In a study that evaluated the impact of caregiver-receiver relationship

on burden, Snyder [48] reported that the quality of the relationship between the caregiver and care-receiver, and the bonds established between caregiver and receiver, distinguished low burden and high satisfaction. Furthermore, this study found that the history of the parent/child relationship strongly impacts reciprocity in the aging parent/child relationship. In the burdened households, part of the frustration experienced by caregivers could be attributed to the absence of a reciprocal caregiver/receiver relationship and the lack of high quality interactions. These psychological factors may affect motivation for the caregiver as well as the level of burden experienced by the caregiver [33, 35, 43, 49, 50], and understanding these factors is essential to any process designed to moderate caregiver burden.

The demands of caregivers also provide important predisposing factors in the evolution of caregiver burden, and may be viewed as primary and secondary demands. Primary demands are determined by functional limitation and degree of disturbance behavior of care-receiver. The degree of functional limitation has been well documented in the literature to correlate with caregiver burden [40]. Other primary demands include the presence of disturbance behavior, which can lead to caregiver fatigue and anxiety [21, 22, 25, 26, 51, 52]. There are also secondary demands that may serve as predisposing factors for burden. These demands may come from family, work, or society. Demands such as the presence of other children in the house or single caregiver families have been reported to increase caregiver burden [20].

**Involvement in caregiving:** This is another predisposing factor and is defined as the number of caregiving tasks performed and the amount of time the caregiver spends performing them. The number of hours per day caregiving as well as the number of tasks involved has been positively correlated with burden [53]. A positive correlation between activities of care performed by the caregiver and caregiver burden has been reported, and includes both the provision of direct care such as bathing, transfer, continence-related measures, and indirect care such as running errands, preparing meals, helping with medicines and performing housework [33].

### Mediating and/or Moderating Factors

Having described the primary determinants, or attributes of burden and predisposing factors that may influence the development of burden, it is essential to incorporate the role of factors that may modify burden into any model of informal caregiving. These factors may alter the impact of the previously described factors significantly. This may account for contradictory reports on the impact of primary determinant caregiver burden. In some studies, some attributes are reported as major determinants of burden, while in others, the same element may be reported as playing a smaller role in the process of burden. For instance, the functioning level of the care-receiver, while viewed by many as a major determinant of caregiver burden, has been reported to have little impact on burden [20].

The burden experienced by a caregiver is in part determined by the caregiver's choice of coping strategies. Higher levels of interaction with family members, social and spiritual support seeking behaviors, and receiving help from family members have all been reported to decrease burden [28]. Other coping strategies, such as confidence in problem solving, reframing the problem, passivity, use of spiritual or social support, information seeking and extended families may lessen burden [28, 34, 52]. Turner and Catania [43] have reported that the association between objective demands and subjective burden is stronger among caregivers who receive little or no help than among caregivers who feel they have support. Receiving help with caregiving does appear to buffer the negative impact of high care giving demands on burden. Caregiver coping strategies are significantly related to caregiver burden, and may not always have a positive impact. Avoidance coping strategies, for example, have been shown to have a negative impact on burden [54].

### Consequences/outcomes

Finally, any model of caregiver burden must also describe the consequences or outcomes of caregiver burden on the caregiver. Most studies are descriptive, so no precise predictions can be made about the impact of burden on various outcomes. However, impact can, and does, occur on the caregiver, care-receiver, family and health care system:

**Caregiver:** Deterioration in the health status of the informal caregiver has been extensively reported in the literature. These include somatic complaints such as chronic fatigue, sleeplessness, stomach problems, weight change, increase illness rate [33, 36]. Psychological symptoms are also well known in the caregiving population depression, anger, worry, discouragement, guilt, anxiety [23, 29, 51, 54]. A recent report [4] found depression much more common in stroke caregivers (3452 %) than in the normal matched population (1216 %). Using the Commonwealth Fund 1998 survey of womens health, a nationally representative sample of women and men, Donelan [36] reported that women caregivers are significantly more likely than other women to report having a serious health problem that requires medical care.

Obviously, restriction in the social activity of informal caregivers is another common outcome of caregiving, the role of which is often under-appreciated.

The care receiver may also suffer the consequences of caregiver burden. For children, personal distress in the caregiver has been correlated with an increase in withdrawn and apathetic behavior in the care-receiver child [55].

**Family:** In addition to the consequence of caregiving on the caregiver and receiver, families may also experience the negative outcomes of informal caregiving. Family/marital conflict is common when examining caregiver burden. It has been reported that 3056 % of caregivers experienced family or marital conflict as a result of burden. In families of patients with traumatic brain injury, problems with role functioning, marital relationships, drug or alcohol abuse and the physical health

of individual family members become evident during the first few years after injury [23].

**Healthcare system:** Finally, no discussion of caregiver burden is complete without mentioning the enormous financial costs associated with informal caregiving. While healthcare systems may actually save considerable costs by moving care from institutions to families, these cost savings are not passed along to these families who suffer an enormous financial burden as a result.

## Conclusion

Improved ICU survival and the transition to community-based care have increased awareness of the extent and importance of family caregiving. Many individuals are now cared for at home, who might otherwise have been institutionalized. This has placed increased attention on the need to address implications for family life and for the primary caregiver.

Further studies are needed to evaluate the long-term effects of ICU survival on the health and well being of relationships, and measurements of ICU outcomes must take much more than 28-day all cause mortality into consideration. While it is certainly good for ICU clinicians to feel good about the way in which survival is improving for critical illness, we must begin to look at a larger view of our patients' survival and ongoing health. As outcomes from critical illness continue to improve, it is inevitable that the number of informal caregivers will increase. As clinicians, it is important to recognize the impact of survival, not only on patients but on families as well. Given the enormous impact of caregiver burden on patients and their loved ones, evaluating and improving the burden placed on families of ICU survivors must be viewed as an essential aspect of the care we offer our patients who survive critical illness.

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