Screening for Caregiver's Burden in Management of Scleroderma: Pulmonary Arterial Hypertension

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Systemic sclerosis or scleroderma (SSc) is a multisystem disease that is characterized by dysregulation of fibroblasts that result in superfluous collagen deposition and activation of the immune system.[1] This excessive deposition leads to fibrosis of skin and internal organs, most notably the heart, lungs, and kidneys. The precise etiology of SSc is still unknown, but genetics and environmental factors are thought to contribute to increasing host susceptibility.[2] Pulmonary manifestations of SSc are common and include pulmonary arterial hypertension (PAH) and interstitial lung diseases (ILD). In effect, 15% of patients with SSc develop PAH, making it a leading cause of mortality.[3]

In a setting of SSc, PAH is a rare and progressive disease with an overall poor prognosis. However, our knowledge and understanding of the pathological process has improved immensely over the past 40 years, leading to the development of medications to slow disease progression and improve functional capacity and survival. As a result, the overall survival rates of patients with SSc-PAH have improved from 78% at 1 year to 47% at 3 years.[4] As the disease process continues to progress naturally, it can overwhelmingly limit a patient's ability to carry out daily activities, and in so doing affect their quality of life (QoL). These "unwanted" limitations necessitate that patients depend on others for assistance that can range from helping with carrying out activities of daily living (ADL) to administering medication and/or going to doctor's office.[5] There is literature about the psychological impact on the QoL of these patients, but to date, no study has investigated the experience of caregivers of SSc or SSc-PAH.

WHO IS A TYPICAL CAREGIVER?

A caregiver is defined as a relative, partner, friend, or neighbor who can provide assistance to a person with a debilitating condition.[6] The vast majority of caregiving responsibilities cascades to women. As a caregiver, they assist with navigating their partner's ADLs, managing finances, providing nutritional support, shopping, and assisting with medication.[7] In addition to the traditional ADLs, caregivers are responsible for connecting with the partner's physician.[8] It is possible for caregivers, especially family members, to serve as a legal guardian for patients. Thus, as the patient's legal guardian, it is the caregiver's responsibility to maintain open, effective, and productive communication about the patient's disease status. The overwhelming obligations of caregiving can encompass many pitfalls as caregivers try to cultivate relationships, pursue professional careers, and engage in social activities, leading to a fair amount of stress—often referred to as "caregiver's burden."

CAREGIVER'S BURDEN

Caregiver's burden is defined as the multidimensional adverse effect on the physical, emotional, and economic status of a caregiver.[9] Previous research has focused on caregivers of cancer or dementia patients, among other diseases.[10,11] In most cases, caregivers are not trained, have inadequate knowledge about delivering proper care, and receive very minimal instructions from health care providers.[12] Creasy et al conducted a study with 17 caregivers of stroke patients and concluded that these individuals felt very disconnected and ignored, and found there was lack of communication between physicians and themselves.[13] Yet, despite these shortcomings, caregivers believe that their role is a rewarding and satisfying experience.[8]

As caregivers continue to prioritize the needs of their partners, caregiving has an impact on various aspects of their overall physical and psychological health and well-being. Many neglect their own health needs, thus putting themselves at a greater risk of experiencing health problems such as high blood pressure and poor sleep quality.[14,15] Furthermore, the prolonged physical demands of caregiving can also introduce symptoms of anxiety and depression, leading to limitations in their capacity for social engagement.[16] In addition to the physical, the financial strain is a major stress for caregivers because they are often required to take an extended leave of absence or reduce hours. The physical and psychological pressure can also affect work performance, resulting in overall poor productivity.[17,18] The stress from caregiving has also emerged as an independent risk factor for high mortality.[19] A study by Schulz et al established that compared to noncaregivers, there was a 63% increase in mortality in caregivers.[19] These negative inferences, in general, can affect quality of care for care recipients, family members, and society as a whole.

CAREGIVER BURDEN ASSESSMENT

Given the magnitude of screening the degree of burden associated with caregiving, a number of questionnaires have been designed and validated for its assessment (Table 1).

Zarit Burden Interview

The Zarit Burden interview (ZBI) is a 29-item self-reporting questionnaire that was revised to 22, then 18, and finalized into its current format containing 12 items. It is designed to subjectively assess a caregiver's health, psychological well-being, social life, finances, and the relationship between the caregiver and patient. The 12 questions are graded on a scale from 0 (never) to 4 (nearly always), and a score ≥56 indicates intense burden.[9]

Caregiver Burden Inventory

The Caregiver Burden Inventory scale consists of a 24-item multidimensional questionnaire divided into 5 facets: 1) time dependence, 2) developmental, 3) physical, 4) social, and 5) emotional burden.[20] Each facet consists of 5 items, except for the physical burden, which has only 4. Scores for each are evaluated by using a 5-point Likert scale ranging between 0 (not at all descriptive) and 4 (very descriptive). An overall score can range from 0 to 96 and is obtained by summation of scores of each subscale; higher scores correspond to greater levels of perceived burden.

Caregiving Burden Scale

The Caregiving Burden Scale (CBS) is a 13-item questionnaire developed to measure subjective burden of the caregiver.[21] The CBS has 2 subscales: 7 items that measure relationship and 6 items addressing personal consequences. Each item is rated using a 5-point Likert scale ranging from "disagree very much" to "agree very much."

FUTURE DIRECTION

With advancements in innovative treatment therapies and improving survival rates, the demands for caregivers will, without a doubt, continue to grow. As a result, our health care policies will continue to evolve. They should address and acknowledge the essence of being a caregiver and the fact that caregivers represent a "hidden patient" themselves. This would facilitate a collective understanding of identifying burden in caregivers and initiating effective programs to improve health and QoL for caregivers and their families. It is critical to meet this challenge, because a caregiver's physical and mental well-being is, in turn, a predictor of the care recipient's welfare.[5]

A diagnosis of SSc or SSc-PAH can inflict physical and psychological stress because of severe limitation on a patient's ability to function. Since the majority of the caregivers are unpaid and represent an unprepared labor force, it crucial for health care providers to educate them about their partner's disease process. In addition to physicians, other staff members such as nurses, nurse practitioners, and physician assistants can proactively offer meticulous instructions, such as medication administration, follow-up care, and overall disease management.

In addition, joining a support group provides an opportunity to educate, share information and practical advice, and offer emotional support (Table 2). The groups can meet in person, online, or via telephone. Support groups provide another forum for patient caregivers to express themselves and validate their

Table 2: Benefits of Support Groups

Providing sense of empowerment
Improving coping skills
Giving and receiving practical advice
Being open and honest
Sharing insight
Offering educational opportunity

Table 1: Caregiver Burden Assessment Scales

Scale/Author/Year	Number of Items	Response	Score	Description
Zarit Burden Interview (ZBI) **Zarit et al, 1980**	29/22/28/12	5-point Likert scale 0 (never) to 4 (nearly always)	0 (low burden) to 88 (high burden)	Impact of caregiving on caregiver's life
Caregiver Burden Inventory (CBI) **Novak et al, 1989**	24	5-point Likert scale 9 (not at all descriptive) to 4 (very descriptive)	0-96	Measure burden due to time restrictions
Caregiver Burden Scale (CBS) **Gerritsen et al, 1994**	13	5-point Likert scale "Disagree very much" to "Agree very much"	--	Relationship (7 items) and Personal consequences (6 items) of caregiving

feelings. By joining, caregivers can be assured that they are not facing these challenges single-handedly.

Finally, caregivers are critical partners in developing a health care plan for patients with SSc or SSc-PAH. Due to the complex nature of the disease, caregivers and care recipients will face unforeseen challenges that will affect them as the disease progresses. Nonetheless, it is imperative to identify "at-risk" caregivers by using these screening tools so that as a society we can take care of these individuals.

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