

Caregiver's burden in pulmonary arterial hypertension: a clinical review

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Caregiver's burden is a multidimensional phenomenon affecting caregivers physically, emotionally and socially. It is critical to examine the burden of caregivers, because of the complex responsibility they have with their partners. There are relatively few studies that have examined factors linked with psychological burden amongst caregivers of pulmonary arterial hypertension (PAH) patients. Hence, it is pertinent to devel-

op a good understanding of these factors and develop appropriate management strategies, modified to assist PAH caregivers.

Keywords: Caregiver, Burden, Chronic disease, Pulmonary arterial hypertension, Screening questionnaire


INTRODUCTION

Pulmonary arterial hypertension (PAH) is a complex and progressive disease which results in non specific symptoms such as shortness of breath, fatigue and peripheral edema (Galiè et al., 2009). Our knowledge and understanding of the pathological process has vastly improved over the past 30 years leading to the development of medications to slow disease progression, improve functional capacity and increase survival. Even after all these advances, the natural progression of disease can cause profound limitations which result in significant lifestyle changes, thereby affecting one's quality of life (QoL). The insidious onset of the PAH can be enormously demoralizing and concurrently exerting an adverse impact on various aspects of life. It compels patients to request assistance from others, regarding frequent office visits, medication administration and hands-on-care with various activities of daily living. Though there is literature regarding the psychological impact on PAH patients' QoL; information about its impact on their caregivers is limited.

WHO ARE THE CAREGIVERS?

A caregiver is defined as any person providing assistance to a person with debilitating condition (Family Caregiver Alliance, 2006). A caregiver could be a relative, a friend or a neighbor who provides assistance due to patient's limitations without any monetary compensation (National Alliance for Caregiving/AARP, 2004). Much of the caregiving responsibility falls on patient's spouse (National Alliance for Caregiving/AARP, 2004). As a caregiver they focus more time, energy and logistics on assisting partners with their activities of daily living, managing finances, nutritional support, shopping and assisting with medication (Collins and Swartz, 2011).

Effective communication is imperative in conveying information. Caregivers, habitually, have more intimate knowledge of patient's well being and concern than anyone else. Therefore, they can communicate efficiently with their partner's physician (Cohen, 2000). They can provide considerable information, thus, allowing physicians to formulate a clinical judgment and management plan

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about patient's condition. Their ability to communicate constructively with physicians is vital for their partner's well being. In addition to being an advocate for patients, they are expected to have knowledge about the rapidly changing healthcare system. In some cases, caregivers serve as legal and medical guardians, making decisions that impact the patient's health; for example, hospice care or nursing home care.

Caregivers are often responsible for providing emotional support and encouragement to their partners. They serve with great strength and courage, yet their contributions are mainly overshadowed and they remain an indiscernible group. However, as of late, their commitments and enduring challenges are starting to be recognized. There is considerable ideological thinking that having a chronic disease poses a significant challenge to both patients and their caregivers alike, and is often referred to as caregiver's burden.

CAREGIVER'S BURDEN

Caregiver's burden is defined as a multidimensional interaction of physical, emotional and economical hardship experienced by the caregiver (Zarit et al., 1980). It has been under intense focus in numerous conditions such as Alzheimer disease (Iavarone et al., 2014), Cancer (Bevans and Sternberg, 2012), and Stroke (Scholte op Reimer et al., 1998). For many caregivers, a lack of understanding of the disease process is a main cause of concern (Adelman et al., 2014). Caregivers perceive that they are being entrusted with the responsibility without any specific training, support or any prior education. They are concerned about not having the necessary skills which are required for optimal care given to their partners. Creasy et al. (2013) conducted a study of 17 family caregivers of stroke patients and their interaction with physicians. The study found that caregivers felt very disconnected and ignored by physicians and there was a lack of communication between each other.

The physical demands of being a caregiver can result in neglecting their own health, thus putting themselves at an increased risk of having health problems. The physical stress can lead to increased fatigue, cumulative sleep disruption at night, increased blood pressure and elevated heart rate (Family Caregiver Alliance, 2006; Jensen and Given, 1993; Monin et al., 2010). Study by McCurry and Ter (1995) found that of the 168 family caregivers of dementia patients, 68% of them had problems initiating and maintaining sleep along with daytime fatigue. The physical stress can also cause caregivers to neglect their own personal health, maintain a poor diet, be disinclined at maintaining medical ap-

pointments and indulge in harmful health behaviors (Burton et al., 2003). In turn, these can result in an increased utilization of healthcare resources and escalate health care expenditure.

Stress emerges as a prominent symptom regularly. Caregivers may have a sense of being under constant stress because of concerns regarding patient's deterioration overtime, overwhelming workload, and being judgmental about their own capabilities of being a caregiver. The stress of caregiving has been found to be an independent risk factor for an increase in mortality (Schulz and Beach, 1999). Schulz and Beach (1999) in a prospective study, looked at 4-year mortality rate of 392 caregivers and 427 noncaregivers, who were living with their spouses. The main finding of this study demonstrated a 63% increase in mortality of caregiver's when compared with noncaregiver (Schulz and Beach, 1999). The prolonged physical burden can have a profound effect on physical health leading to psychological symptoms and limited social activities.

As caregivers continue to experience high levels of burden, it can contribute to symptoms of depression. For caregivers, depression can emanate as they observe their recipient undergo their terrible and unfortunate ordeal. Caregiver's vulnerability to depression is moderated by the duration of caregiving, decline in recipient's health and emotional well being (Schulz et al., 1995). Caregivers of low socioeconomic status, older population (women) and those with limited support system, experience more psychological effects than younger and more resourceful caregivers (Pinquart, 2001; Schulz et al., 1995; Vitaliano et al., 2003). Denno et al. (2013) found increased risk of anxiety and depression in 153 caregivers of stroke patients. Moreover, depression was also related to an increase in utilization of psychotropic medication by caregivers (Denno et al., 2013). In effect, depression in caregivers can also serve as a predictor of discontinuation of care for the elderly population (Arai et al., 2001). Inevitably, the overall responsibility can also lead to restricted social engagements and sacrificing family relationships (Kasuya et al., 2000).

Aside from the physical and psychological manifestations, financial strain is a reason of major stress for caregivers (Nolan et al., 1990). Many caregivers are unable to balance their work and caregiving duties, resulting in significant loss of income and decreased productivity at work (Ganapathy et al., 2015). Caregivers are subjected to adjust their workload which can overlap with their responsibility towards their care recipient. In other instances, caregivers are compelled to work as part-time employees and in serious circumstances they resign in order to undertake more responsibilities.

While caregiving can present with challenges, it is imperative not to ignore the positive aspects of this experience. Many caregivers find care giving to be very rewarding and a satisfying experience (Cohen, 2000). It gives caregivers profound sense of privilege, altruistic feeling and deep fulfillment in providing assistance. They strongly believe, that caregiving has provided them purpose in their lives and help them learn new skills along the way (Schulz et al., 1997). Lundh (1999) surveyed 123 caregivers by using Carer's assessment of satisfaction index. The survey found (95%) of caregivers were satisfied with their life as a caregiver.

PAH AND CAREGIVER'S BURDEN

Caregiver's burden has been extensively studied in various conditions, but there remains lack of relevant data about association of caregiver's burden with PAH (Table 1). Hwang et al. (2011) focused on understanding the risk of depression and impact of caregiving among 35 caregivers and their recipient, by using a patient health questionnaire (PHQ-8), social support survey and a care-

giver reaction assessment. The study found that a lack of emotional support played a big factor in the well being of family caregivers. In this study, lower levels of social support were associated with increased depression like symptoms in at least 14% of caregivers. Caregivers also felt the financial impact of responsibilities and perceived them to be a hindrance towards their own normal daily activities. These findings were consistent with caregivers of patients' with other chronic diseases (Hwang et al., 2011).

Another survey in the United States (US) was conducted to provide an insight of the lives of 79 PAH patients and their 76 caregivers in US (Pulmonary Hypertension Association, 2013). In this survey, 62% of caregivers felt an overall significant impact on their daily lives, with caregivers assisting in administering medication (54%), doing household chores (61%) (Pulmonary Hypertension Association, 2013). Still majority of caregivers found this experience to be rewarding and believed that this ordeal brought them closer to their partner. The results from this US survey imply that a system of collaborative care, which includes caregivers, should be established to provide optimal care to PAH patients

Table 1. Major studies of caregiver's burden and PAH cohort

Trial/year	Study design	No.	Results
Hwang et al./2011	Cross-sectional descriptive study	35 Dyad of patients and family caregivers	14% Caregivers moderate to severe depression 80% Caregivers lived with patient 14% Quit jobs 54% Available 24 hr/day 91% Attend appointment with health care provider 86% Obtain medication 90% Helped with household work
PHA (USA)/2013	Survey	79 Patients 76 Caregivers	Patients Physical activity: 8/10 had difficulty Social activity: 92% employment difficulty, 83% traveling difficulty Daily life: 83% difficulty with chores, 78% difficulty with errands Relationship: 75% had intimacy problems Caregivers 57% Schedule family life around patients 62% Run errands 54% Helping with medications 64% Future worries 21% Personal health suffered 20% Quit working 51% Felt isolated 72% Found new meaning of life 54% Found fulfillment being a caregiver 83% Contributed significantly to patient's life
PHA (EUROPE)/2012	Survey	326 PAH patients 129 Caregivers	57% Affected caregiver's daily living 43% Exhausted because of responsibility 29% Impacted caregiver's work 85% Patient's work affected 73% Patient finances affected 35% Caregiver finances affected

PHA, Pulmonary Hypertension Association.

(Pulmonary Hypertension Association, 2013).

Similarly, a large scale survey was also conducted in Europe to provide new insight into the impact of PAH on patients and their caregivers in 326 patients and 129 caregivers (European Pulmonary Hypertension Association, 2012). Living with PAH patients, caregivers (57%) found it to be a physically draining and it disrupted their other daily activities (European Pulmonary Hypertension Association, 2012). Nearly half of caregivers surveyed felt they were exhausted because of the additional demands from patients (European Pulmonary Hypertension Association, 2012). In dealing with PAH patients, can lead to significant financial burden, reduced work place productivity and reduced household income. Many caregivers and patients, similarly, felt a loss of intimacy and overcome with feeling of isolation; mainly as a result of little understanding of the disease process. Despite these obstacles, PAH caregivers described their experience to be rewarding, and felt closer to their family (European Pulmonary Hypertension Association, 2012). Similar to the US survey, the findings from this survey draws attention to the importance of psychological support to be included as part of the comprehensive standard of care for both patients and caregivers.

CAREGIVER BURDEN ASSESSMENT

It is essential to assess and screen the degree of burden associated with caregiving. Several validated questionnaires have been developed to understand the consequences of caring for an individual with a chronic disease (Table 2).

Caregiver burden scale

Caregiver burden scale is a self administered twenty two item scale that is separated into 5 domains: general strain, isolation, disappointment, emotional involvement, and environment (Elmståhl, 1996). All the items are scored from 1 (not at all) to 4 (often). The total burden is calculated with a mean of all twenty two items. The scale measures, the caregiver's health, psychological well being and psychosocial aspects of their lives.

Zarit burden scale

The Zarit burden scale is used for measuring subjective burden of caregivers. The scale tests burden associated with functional, behavioral and home environment aspects. The original 29 item scale was modified to 22 items, which was further modified to 12 items (Zarit, 1980). It is a 29 item self administered instrument

Table 2. Selected caregiver burden assessment scales

Scale/Author	No. of items	Response options	Score
Caregiver burden scale/ Elmståhl et al. (1996)	22	Responses include: Not at all Seldom Sometimes Often	-
Zarit burden interview/ Zarit et al. (1980)	29	4-Point Likert scale Self-reporting questionnaire	0–21 Little or no burden 21–40 Mild to moderate burden 41–60 Moderate to severe burden 61–88 Severe burden
Caregiver reaction assessment/ Given et al. (1992)	24	4-Point Likert scale Self-reporting questionnaire Impact on Caregiver's self-esteem (7 items) Financial problems (3 items) Impact on health (4 items) Lack of family support (5 items) Impact on daily activities (5 items)	-
Caregiver strain index/ Robinson (1983)	13	"Yes" or "No" format	≥ 7 Needs further assessment
Caregiving appraisal scale / Lawton et al. (1989)	47	5-Point Likert scale Self-reporting questionnaire Subjective caregiving burden (13 items) Impact of caregiving (9 items) Caregiving satisfaction (9 items) Caregiving/master (12 items) Caregiving ideology (4 items)	Higher Scores (positivity) Lower Scores (negativity)

with scores between 0 (never) and 4 (nearly always). It has confirmed high validity and consistency with score ranging from 0 to 88 (Zarit, 1980).

Caregiver strain index

Caregiver strain index is a brief and easily self-administered thirteen question tool used to measure family caregiving concerns and comprises of their perception of caregiving (Robinson, 1983). Employment, financial, physical and social issues are some of the domains addressed by this index. It can be used by individuals of any age and those who are responsible for the patient. Each item is answered in a "Yes" or "No" format, with "1" point for "Yes" and "0" for "No." A total of seven or more is indicative of a more in-depth analysis (Robinson, 1983).

Caregiver reaction assessment

Caregiver reaction assessment is a multidimensional self rating tool with 24 items used to measure both positive and negative reactions of family members that can occur overtime (Given et al., 1992). The instrument consists of five dimensions of caregiving that are: (a) daily activities (5 items) that measure impact of caregiving on daily basis; (b) financial problems (3 items) measures financial strain due to caregiving; (c) health problems (4 items) measures caregiver's physical deterioration; (d) self-esteem (7 items) only positive domain measuring self worth; (e) lack of family support (5 items) determines caregiver's sense of abandonment and lack of moral support. Each positive or negative measure is on a likert scale of 1.0 (strongly disagree) to 5.0 (strongly agree). A mean score from each subscale is generated ranging from 1.0 to 5.0. A higher score represents a stronger impact of either a negative or positive characteristic (Given et al., 1992).

Caregiving appraisal scale

Caregiving appraisal scale is a caregiver satisfaction survey intended to measure five factors of caregiving that are tabulated on 5-point scales ranging from 1.0 (strongly disagree) to 5.0 (strongly agree). It is a self-administered 47 items questionnaire measuring the positive, neutral, and negative appraisals that are linked to caregiving (Lawton et al., 1989). The five dimensions considered are: (a) caregiving satisfaction, (b) perceived caregiving impact, (c) caregiving mastery, (d) caregiving ideology, and (e) subjective caregiving burden. A higher score reflects positive feelings about caregiving and lower scores reflect negative feelings (Lawton et al., 1989).

FUTURE DIRECTION

As more elderly people are living longer, there is an increase fiscal demand to have sufficient caregivers as well. Therefore, it is pertinent for healthcare policy makers to explore and address the implications of chronic disease on caregivers. Effective public policies should be established in order to recognize the sacrifice caregivers make on a daily basis and reflect changes that can fully address the needs of the caregiver as they serve as a moral fiber to our aging society. In any aspect, it is the physical and mental well being of a caregiver that is a reflection of the overall well being of chronic disease patients.

The diagnosis of PAH can cause profound psychological and physical stress because of the inability to function effectively. Since many caregivers believe they are unprepared and unfamiliar of their partner's condition, it is possible to introduce interventions to educate caregivers about future expectations. Therefore, educating caregivers about the patient's disease and its implications is a first step in relieving some burden (Gillick, 2013). Many caregivers feel secure when physicians have an open and honest communication about their partner's condition (Fleming, 2003). As a physician, it is pertinent to observe that both the caregiver and patient are able to comprehend the progressive and chronic nature of the illness, because it can impact their decision making process in the future. In any circumstance, by listening to patients and caregivers, physicians have the ability to recognize 'at-risk' individuals for caregiver burden (Kasuya et al., 2000).

The office personnel also have a crucial role in clinical practice. Aside from running the office smoothly, they can provide moral support and the proper resources for caregivers to get information (Lynn, 2014). In most healthcare setting, nurses are the prime contact for patients and caregivers. Accordingly, they are well positioned to encourage, educate and motivate caregivers in taking control of circumstances.

With the burden of caregiving having a negative impact on their lives, the most important thing for caregivers to remember is that they are not alone. There are supportive interventions available to reduce caregiver burden (Cohen, 2000; Kasuya et al., 2000). Support groups are often used by patients to ease burden of disease and it possible to extend this service to caregivers as well. Support groups are a useful method to share caregiver's unique experiences and at the same time, create an environment for all caregivers to learn from each other.

Furthermore, respite care is a service available for caregivers who need a temporary relief from the daily challenges of caregiv-

ing. Respite care refers to allowing transfer of care to places such as: in-home help service, adult day care center or overnight care center (Carretero, 2009). For working caregivers, employers can provide some assistance in relieving some burden by providing flexible hours and referral services such as employee assistance programs (Lynn, 2014).

Finally, military veterans and senior citizens are often appreciated for their services. They are frequently eligible for courtesy discounts from many business institutions. Caregivers should receive similar recognition as well. In moving forward towards an effective support system, it is possible to have similar concessions and services be extended to caregivers.

CONCLUSIONS

PAH is a complex disease. The impact of PAH goes further than impairment of health and functional ability. The difficulties faced by caregivers are dependent on progression of PAH. Daily challenges presented to caregivers can create uncertainty in terms of coping with the worsening of disease. It is important for physicians to be aware of the caregivers' attributes that can cause significant burden. More research is needed to establish what factors are detrimental to caregiving, as it will be the responsibility of clinicians to identify these "at risk" caregivers. By way of using these assessment tools, physicians will be in a better position to screen for vulnerable caregivers and provide education along with counseling. As a society, we are indebted to caregivers for making an invaluable contribution; therefore, it is appropriate to 'take care' of our caregivers.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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