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The Psycho Social Effects of Asbestos Disease on the Victim's Chief Caretaker and the Extended Family

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Abstract

The psycho-social effects of asbestos disease on the victim and the victim's family echo the tragedy of asbestos exposure. Due to drastic cuts in health care in the United States, as well as, precarious benefits both through governmental and legal channels, asbestos victims are continually being emotionally and physically disenfranchised. The course of asbestos disease is difficult to chart. Victims' health and their ability to be functioning members of society and family life has a pendulum of highs and lows. The unpredictability of activities of daily living (ADL) functions creates a great deal of stress to the victims and their families. This stress exacerbates the physical and mental health problems caused by asbestos. Survival coping skills require a team approach; the basis of which is a victim's advocacy organization.

Asbestos related disease is insidious in the slow and agonizing ways it ravages the victim's health. As painful and difficult as it is for the victim, the victim's caretaker (which this writer refers to as "the hidden victim") suffers in many ways as well. This paper looks at the various issues inherent in the personal care and upkeep of asbestos victims and the resultant impact on the chief caregiver and the extended family.

In a 1999 report to Congress by the Government Accounting Office (GAO) avoiding institutionalization of extremely ill consumers is dependent on the obtainment of personal care on a daily basis:

“...without help from family, friends, or public programs, affording such assistance may be problematic because individuals with severe disabilities were usually less well off economically than the general population” (Ochinko, Walter, et al p.2).

Another problem raised in this report is that “there is no consensus on what constitutes a severe disability. “Individuals differ in the number of functional areas in which they require help (expressed by ADL [activities of daily living, author's note]) and the level of difficulty they have in performing the activity” (Ochinko, Walter et al, p.8). A great deal of pressure is placed on caretakers who want to avoid the institutionalization of a loved one and realize that the

difference between that and home care rides on their ability to provide needed services. This fact is understood all too well by asbestos victims reported on in this paper through anecdotal evidence (Safchuck, Paul, Oliver, Joe, et al) and the collection of data from a small sample of local Baltimore asbestos victims' families who participate in the White Lung Association (WLA). "The WLA is a non-profit, educational group which advocates against asbestos exposure and is composed of asbestos victims and their families" (WLA, p1).

The level of stress that results from the fear of not knowing what course asbestos disease will run is the primary complaint of "hidden victims". Caretaker Mrs. H. reported that her husband was one of three brothers who had worked in the Baltimore shipyards. Two of the brothers had died from mesothelioma. Her husband was in a milder stage of asbestosis. Because the family had witnessed the horrible course of deterioration and pain from the brothers' cancers, Mrs. H. is constantly in a state of hyper-vigilance about her own husband's health. She indicated that when a nodule was found on her husband's lung the worry was almost too much to bear. The wife also indicated that there was tremendous expense associated with her husband's disease. Mr. H. had to have three CAT scans when the nodule was found. Mrs. H. indicated that an enormous amount of time is devoted to health care activities, leaving little time for the caretaker's respite.

According to the 20 families interviewed, most had stories similar to the H. family. They reported that their chief concerns were stress, financial burden and an exhausting amount of time spent on medically related activities. One caregiver indicated that it took a tremendous amount of patience to deal with her husband's illness. Mrs. M. reported that asbestos disease changed her husband's personality. She felt that many of the side-effects of his medications, as well as, his constant pain and trouble breathing made him irritable and moody. She stated that she tried her best not to take it personally and to understand his feelings, but it was very difficult to maintain an up-beat attitude. Her main concern was that if things got worse she didn't know how long her patience would hold out under more difficult circumstances. Much of the victim's care is contingent upon the care and well-being of those who perform most of the help with ADL. Unfortunately the "hidden victim" is very much overlooked for a variety of reasons that involve a paucity of resources – primarily time and money.

Many families have reported that there is a great deal of anger and irritability directed at them by their loved one. They disclose that the victim is often overly fatigued from a lack of sleep caused by several sleep related conditions like sleep apnea. Other sleep problems include the inability to breathe comfortably in one position or the burden of being hooked up to an oxygen machine. This lack of sleep over a prolonged period of time takes a toll both on the victim and the "hidden victim" who often seeks to find sleep in a different place, away from the restlessness of the asbestos victim. Many times this causes the victim to feel like a pariah, an untouchable, worthless and helpless, making him/her feel more like a burden to their families. This further exacerbates the families' feelings of depression, despair and anger.

Much of the injustice of asbestos victims' poor or improper care is made worse by what Robert N. Proctor has called "a history of scientific deception joining hands with industrial malfeasance" (Proctor, Robert, p. 122). In Barry Castleman's groundbreaking book on asbestos, one of the most remarkable discoveries of his research was that "The earliest recorded historical recognition of the hazards of asbestos goes back to the time of Christ" (Castleman, Barry, p.1). He continues to chronicle in chapter 1 "The Development of Knowledge About Asbestosis" the ways in which industry, medical science and government knew about, but masked, the injurious nature of asbestos fibers beginning around 1897 – the start of the modern asbestos industry. Most victims and their families have some understanding of this deceit and collusion. They, justifiably, have a great deal of anger to express but no constant vehicle or platform from which they can constructively and therapeutically vent their feelings of anger and betrayal. This is made even more heinous by a health care system that can barely handle chronic medical illnesses much less the mental health side-effects caused by stress, fatigue, helplessness, confusion, fear and anger. One has only to look in the faces of the victims photographed by artist and activist, Bill Ravenesi, whose own father died from mesothelioma, to see the devastation and despair of the families chronicled through the various stages of asbestos disease ("Breath Taken: The Landscape and Biography of Asbestos.").

Conclusion

It seems trite, even obvious, to recommend that the entire family should be treated by the medical team as a family unit. Oftentimes the care that is provided to the victim by family members is the buffer between additional home health care services, more frequent office visits, hospitalizations, or worse, commitment to institutions for constant care and monitoring. That they are saving the insurance companies a large amount of money is something that needs to be recognized and discussed. Medical establishments and insurance companies would benefit by offering families comprehensive mental health services, as well as, monetary or in-kind compensation for their services. An even greater solution which extends outside the scope of this paper is the need for a free and universal health coverage plan in the USA.

Caretakers are often lone soldiers in the war against the diseases caused by asbestos' deadly fibers. This is a good reason to recommend support groups like the White Lung Association as a step in the right direction. James Fite, Secretary of the National Board of the White Lung Association and longtime activist in the struggle against all things associated with asbestos poisoning, states:

"Victims and their families are well served by joining together in self help groups, like White Lung chapters. If there is not a chapter in your state or town write PO Box 1483, Balt MD USA to receive the packets for membership and chapter formation"
(WLA meeting October 4, 2004, Dundalk MD).

More research is recommended in order to delve more deeply into the issues that affect families of asbestos victims. Problems suffered by the “hidden victims” should be understood by the medical team and services should be made available for their support and well-being. The crucial and instrumental role that caregivers provide in the service of their loved ones should be rewarded by offering them free mental health services, both individual and group support, and linking them to opportunities which will provide respite from the daily care of their loved one.

In conclusion, like all who have gathered here in this great country to call for a ban on asbestos, the number one task this researcher recommends is that an immediate ban be implemented on a world-wide basis. No longer should we have to fill attorneys’ coffers and hospitals’ coffins. Let a clarion call be heard around the world to stop the import, export and use of asbestos, as well as, to rid us all of asbestos in a safe and healthy manner.

***My sincerest gratitude to the asbestos victims and their families who took the time to share their stories with me; God Bless You.

***This paper is dedicated to Paul Safchuck; a man who taught me much about fighting the good fight against asbestos for the victims and their families, as longR.F. Ruers as there is a breath to be taken, Paul Safchuck–April, 1913 – May, 2003

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