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## PREFACE

Pneumoconiosis is a generic term describing a chronic occupational disease caused by the accumulation of dust motes in the lungs. The two most common diseases are Silicosis and Asbestosis. Victims are usually prone to shortness of breath after expending physical energy and when the condition is serious they experience difficulty breathing, and will suffer from coughing and declining lung function. The Pneumoconiosis (Compensation) Ordinance was passed in 1980. Under the Ordinance, the Pneumoconiosis Compensation Fund Board (PCFB) provides diagnosed pneumoconiosis sufferers with a lump sum or monthly payments compensation.

Most pneumoconiosis patients in Hong Kong are workers who have been employed in quarries and the construction industry all their adult life. As a consequence of the lack of preventive measures against occupational disease in these industries, the health of the workers has suffered. Their poor health not only affects their working ability, but also exerts a negative influence upon their mental health. As Hong Kong lacks rehabilitation services for pneumoconiosis sufferers, the Association for the Rights of Industrial Accident Victims has conducted this research as a comprehensive study of the need of pneumoconiosis patients for rehabilitation services, with the aim of providing practical recommendations for the development of rehabilitation services.

# RESEARCH BACKGROUND

## 1. BACKGROUND AND LITERATURE REVIEW

### 1.1 Background information of pneumoconiosis

Pneumoconiosis is a generic name for a chronic disease commonly known as Pneumocon. Pneumoconiosis is caused by the long-term absorption in the lungs of toxic dust motes from such materials as asbestos fibres and silica dioxide found in some work environments. The more common disease, Silicosis, has an incubation period of 15 to 25 years and causes a steady deterioration of lung function. Most patients suffer shortness of breath after physical labour and difficulties in breathing, and are prone to coughing and will be vulnerable to pulmonary tuberculosis. At the present time there is no cure or effective medical treatment for the disease.

Since the Pneumoconiosis (Compensation) Ordinance came into effect in 1981, more than 3,200 people have been diagnosed with the disease. On average there are 204 new cases every year, totalling around 2,000 patients in Hong Kong up to the present time. According to statistics, more than 90% of sufferers come from the construction industry (PCFB, 1996).

### 1.2 The condition of pneumoconiosis patients and empowerment theory

Pneumoconiosis patients face not only suffering caused by declining body function, but also pressures from their jobs, from their families and from interpersonal relationships. Many scholars who have researched chronic diseases point out that this kind of continuous physical and psychological damage creates feelings of powerlessness which adversely affects the sense of well-being of chronic disease patients and causes further deterioration in their health. (Miller, 1992)

Miller, a scholar who has concentrated on research on the rehabilitation of chronic invalids, believes that feelings of powerlessness, as well as being a product of the patient's disease, are further exacerbated by medical and food treatment failures and the negative side-effects of some medications. Patients develop psychological imbalances and experience deterioration of mental and emotional health. Typically, feelings of panic emerge in daily life, causing uncertainty and fear of what the future holds. Overwhelmed by feelings of powerlessness and the consequent psychological impairment, patient are unable to face themselves—and reality—and will tend to seek isolation from their families and from society, or even take a resistant attitude towards treatment, thus creating even more pain and tension for themselves and their families. (Miller,1992)

In the process of helping patients face their feelings of powerlessness and psychological imbalance, Miller suggests that it is most important, through the process of empowerment, to enable patients to develop a positive concept of self in order to improve quality of life. He asserts that everyone has seven kinds of power resources: physical ability (fostering of body energy), willpower and social support, positive self-conception, energy, knowledge, motivation and belief system (hope). Compared with ordinary people, chronic invalids suffer from severe physical disability and depleted energy and this causes a sense of powerlessness. According to Miller, patients need a compensational strategy to develop alternative resources in order to rekindle hope and self-esteem. Encouraging the powerless to become empowered helps them establish a positive self-image, which is conducive to mental and emotional balance, which in turn fosters the growth of independence of character and capability. Eventually this can enable patients to face their disease with a positive attitude and to establish a good relationship with their family and to integrate into the community. (Miller, 1992)

Empowerment theory and strategy as a way to assist chronic invalids to overcome the hardships they face—at their workplace, at home, and in the community—has been adopted by community rehabilitation organizations in many developed countries. Much research has been done and different strategies and models have been developed to deal with a variety of diseases.

### **1.3 Direction of rehabilitation services in Hong Kong**

According to the classification of the rehabilitation scheme adopted by the Hong Kong Government in 1990, "The Disabled" is a general category which includes the physically disabled, the mentally ill and the mentally retarded, etc. Those suffering from pneumoconiosis are in the physically handicapped category.

The Government has been providing rehabilitation services for the disabled for a long time, but it was not until the "Green Paper on Rehabilitation Policy and Services", issued in 1992, that rehabilitation services for chronic invalids were properly acknowledged:

"Some recovering chronic invalids under recovery (from brain damage, cancer and pneumoconiosis) should be brought into the scope of rehabilitation services. Just like the disabled, chronic invalids need various kinds of medical, community and occupational rehabilitation services to help them resume normal lives as far as possible."

(Rehabilitation Policy and Services Working Committee 1992:37-38)

In accordance with the Green Paper guidelines, the provision of medical, community, and occupational rehabilitation services to chronic invalids are all equally important. Medical rehabilitation aims at helping patients overcome physical or functional barriers so they can lead independent lives and participate in social activities on equal terms with ordinary members of society. Occupational rehabilitation assists the disabled through vocational counseling and training, and helps them develop in work and enables them to integrate into the community.

With reference to the Green Paper, community rehabilitation is targeted to supplement inadequate hospital services, thus further assisting the disabled to integrate into society. Self-help groups are one of the most effective ways of achieving this. Because "the disabled best understand their own needs so they should be allowed to participate in the developmental work of rehabilitation policy and services. Participation itself is a self-help process and self-help is the foundation of mutual aid. The self-help groups emphasize on common experiences, mutual aid and mutual support specifically." ("Green Paper", 1992:76) Empowerment theory posits that a powerless individual can be enabled through the empowerment process to develop a positive self-image, which will help them face their disease with a positive attitude. Individual patients will be more inclined to join forces with fellow sufferers and face difficulties together, thus creating a strong mutual support function.

Since its establishment in 1980, the Pneumoconiosis Compensation Fund Board has provided comprehensive medical care and rehabilitation to pneumoconiosis patients. The Government has set up a pneumoconiosis clinic in Eastern Hong Kong Island to provide disability assessment and regular medical check-up services, but unfortunately there is a considerable underdevelopment of occupational rehabilitation and services within the community. Up to the present time there are only two groups working in this area: a pneumoconiosis patients' mutual aid association organized by a non-governmental organization, and a pneumoconiosis group organized by the Association for the Rights of Industrial Accident Victims. These two groups have to serve the needs of around 2,000 sufferers and several thousand members of their families. It is evident, therefore, that services in these two areas are in need of rapid development by the government.