

## **Final Report**

### **Project Title**

The experience of patient and family caregivers in managing pneumoconiosis in the family context: An exploratory qualitative study

### **Grant period**

1 October 2018 to 30 September 2019

### **Study aim and objectives**

Aim: to explore the illness experience and needs of patients with pneumoconiosis and the caregiving experience of their caregivers.

#### Objectives

- To understand the self-care behaviors and illness experience of patients with pneumoconiosis
- To explore the needs of patients with pneumoconiosis when managing the disease at home and in the community
- To understand the caregiving experience of the family caregivers of patients with pneumoconiosis
- To explore the caregivers' needs when taking care of patients with pneumoconiosis
- To explore how disease management and caregiving take place in patients' home environment and to identify the environment-related facilitators and barriers for managing pneumoconiosis

## **Results**

### Participant recruitment

The participant recruitment was conducted during the annual meeting organized by Pneumoconiosis Compensation Fund Board (PCFB) in October to November 2018. The research nurse approached and invited 258 potential participants to join the study. A total of 85 agreed to participate at this first encounter. The research nurse contacted them by telephone to make the appointment for interviews and home visits. Some of them refused the participation because of health-related reasons (n = 2), admitted to hospitals (n = 3) or personal reasons (n = 14). Some of them cannot be contacted to arrange the interview (n = 14). A total of 52 patients were recruited through the annual meeting. Another 9 patients were referred from the Pneumoconiosis Mutual Aid Association (PMAA). Finally, 61 patients and 21 family caregivers completed the interview.

### Participant characteristics

The mean age of the pneumoconiosis patients was  $72.6 \pm 8.3$  years, all were male. Majority of them (83.6%) had low educational attainment with primary or no formal education. All of them were retired except one. Two-third of the participants lived in public housing estates (68.9%), 5 of them (8.2%) lived in home ownership housing scheme estates, and the others lived in private residence. Most of them belonged to low level of physical dependency as assessed by Modified Barthel Index-Chinese version (MBI-C), 14 of them were categorized to moderate level of physical dependency, 5 of them were having high level of physical dependency. For the caregivers, all of them were female. They were either the wife or daughter of the pneumoconiosis patients.

### Illness experience of patients with pneumoconiosis

Pneumoconiosis negatively affected the functional capacity of the sufferers. Even though the basic activities of daily living were grossly preserved among the majority of interviewed patients, their well-being was jeopardized in different aspects, including physical, psychological and social aspects. Physically, the interviewed patients experienced moderate to high levels of symptom burden. The common respiratory symptoms reported included dyspnea, shortness of breath, severe cough, hemoptysis and chest pain. These symptoms were persistent and become progressively more severe along the illness trajectory. These symptoms limited their functional capacity to various extent. Furthermore, patients often experienced other conditions/symptoms associated with the aforementioned symptoms, such as poor sleep, fatigue and depressed mood. All interviewed patients expressed that their quality of life was significantly adversely affected by the disease.

In the psychological aspect, most interviewed patients experienced moderate level of psychological distress associated with their medical conditions, particularly when there were acute exacerbations of the disease. They described the disease as “suffering”, “uncontrollable”, “incurable” and “restricted”. Patients also expressed distress when they cannot participate in household work and social activities as usual. They described themselves as useless and a burden to the family. The uncertainty associated with the disease trajectory renders them to be anxious and powerless about their prognosis and future. One patient expressed his wish to opt for “do not resuscitate” when his medical condition is getting worse, after he witnessed a co-worker requiring mechanical ventilation for assisting breathing.

In the social aspect, the symptoms restricted patients’ social participation and relationship with others. The patients became more care dependent over time, and they relied to a greater extent on caregivers within their home environment. On one hand, those patients requiring caregiving by their families appreciated the practical help and emotional support offered by their family caregivers. On the other hand, patients perceived themselves as a burden to their families. They could no longer work to support the family. In some patients who were more physically dependent, their spouses or children had to resign from their full-time job and refrain from their social circle, in order to take care of the patients. When the disease progressed, patients became more symptomatic, they could not maintain the relationship with friends as they could no longer or not willing to attend the social gathering of friends.