

The effectiveness of a nurse-led education programme for caregivers of patients with lung disease due to inhalation of dust (pneumoconiosis)

Submission date 24/05/2020	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered
Registration date 05/06/2020	Overall study status Completed	<input type="checkbox"/> Protocol
Last Edited 04/03/2022	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Statistical analysis plan
		<input checked="" type="checkbox"/> Results
		<input type="checkbox"/> Individual participant data

Plain English summary of protocol

Background and study aims

The term 'pneumoconiosis' refers to a group of lung diseases caused by the inhalation - and retention in the lungs - of dusts. The most commonly occurring types of pneumoconiosis (apart from asbestos-related disease) are coal worker's pneumoconiosis, arising from the inhalation of coal dust, and silicosis, arising from the inhalation of respirable crystalline silica (RCS) from dust from building materials based on rock, sand or clay. There is a long delay - up to 10 years or more - between exposure and onset of disease, so most new cases or deaths from pneumoconiosis reflect the working conditions of the past and occur in individuals who have retired.

Pneumoconiosis is a long-lasting lung disease that cannot be cured. Pneumoconiosis patients require their family members to take care of them as the disease progresses. The needs of pneumoconiosis caregivers have been neglected even though their mental wellbeing has been found to be negatively affected. However, there has been little research on how best to support the needs of pneumoconiosis caregivers. To fill this research gap, the aim of this study was to evaluate the effectiveness of a nurse-led education programme on caregivers' mental health, caregiving burdens, unmet direct support and enabling needs. Caregivers were recruited from the community in Hong Kong. They participated in four nurse-led weekly 90-minute workshops.

Who can participate?

Adults aged 18 years or above who are taking care of family members with pneumoconiosis at home

What does the study involve?

The participants attended four weekly 90-minute workshops led by an experienced nurse in a community center. They filled in a questionnaire and had their body mass index (BMI) calculated from their weight and height and blood pressure measured before the first workshop, after the fourth workshop and 1 month after the fourth workshop.

What are the possible benefits and risks of participating?

The possible benefits are that the programme might improve caregivers' mental health, reduce their caregiving burden and address their unmet direct support enabling needs.

The possible risks are that the participants might find the workshop brings up upsetting or overwhelming feelings. The project team monitored the participants' physical and psychological health during the workshops and data collection. A registered nurse, project assistant or social worker was present during the data collection and workshops. Onsite physical or psychological support was provided promptly and further referral to healthcare services was also provided if needed.

Where is the study run from?

Pneumoconiosis Mutual Aid Association (Hong Kong)

When is the study starting and how long is it expected to run for?

September 2018 to December 2019

Who is funding the study?

Pneumoconiosis Mutual Aid Association (Hong Kong)

Who is the main contact?

Dr Kin Cheung, kin.cheung@polyu.edu.hk

Contact information

Type(s)

Scientific

Contact name

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Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

Nil known

Study information

Scientific Title

The effectiveness of a nurse-led education programme for pneumoconiosis caregivers: a quasi-experimental study

Study objectives

After attending the nurse-led education programme, pneumoconiosis caregivers will improve their mental wellbeing, reduce caregiving burdens, and unmet needs for direct support and enabling, as compared to that before attending the programme.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 11/9/2018, Hong Kong Polytechnic University School of Nursing Departmental Research Committee (Hung Hom, Kowloon, Hong Kong; +852 27666378; cherrie.mok@polyu.edu.hk), ref: HSEARS20180902002

Study design

Single-group interventional non-randomised repeated-measures study

Primary study design

Interventional

Secondary study design

Non randomised study

Study setting(s)

Community

Study type(s)

Quality of life

Participant information sheet

Not available in web format, please use contact details to request a participant information sheet

Health condition(s) or problem(s) studied

Pneumoconiosis caregivers' mental wellbeing

Interventions

After enrolment, participants were informed about the venue of the workshops. They were informed that they would attend four weekly 90-min workshops led by an experienced nurse. They were also required to fill in a questionnaire and undergo measurement of their BMI and

blood pressure before the first workshop, after the fourth workshop and 1 month after the fourth workshop. The questionnaire and measurement took about 15 min.

The four educational workshops were on the following topics:

1. Knowing pneumoconiosis and chest percussion
2. Aging process and lifting and transfer techniques
3. Home safety and medication, and assisted feeding techniques
4. Infection prevention and caring for caregivers

Each workshop involved 40 min of teaching of the knowledge and skills demonstration and then 30 min of hands-on practice and return demonstration. The participants could use the rest of the time for questions, if any.

Intervention Type

Behavioural

Primary outcome measure

Psychological distress measured by the Hospital Anxiety and Depression Scale (HADS) at baseline, after the fourth workshop, and 1 month after the fourth workshop

Secondary outcome measures

1. Caregiver burden measured by the Caregiver Burden Inventory
2. Caregiving burden measured by the Caregiving Burden Scale
3. Unmet needs of caregivers measured by Carer Support Needs Assessment Tool
4. BMI calculated from the participant's weight and height measured using a scale
5. Blood pressure measured using a portable blood pressure monitor

All secondary outcome measures were assessed at baseline, after the fourth workshop, and 1 month after the fourth workshop.

Overall study start date

12/09/2018

Completion date

31/12/2019

Eligibility

Key inclusion criteria

1. Aged ≥ 18 years
2. Taking care of family members with pneumoconiosis at home

Participant type(s)

Carer

Age group

Adult

Lower age limit

18 Years

Sex

Both

Target number of participants

50

Total final enrolment

49

Key exclusion criteria

Non-Chinese speaking caregivers

Date of first enrolment

01/08/2018

Date of final enrolment

01/09/2019

Locations

Countries of recruitment

Hong Kong

Study participating centre

Pneumoconiosis Mutual Aid Association

1 to 4, G / F

Chang On Building

Nanchang Village

Sham Shui Po

Kowloon

Hong Kong

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Sponsor information

Organisation

Pneumoconiosis Mutual Aid Association

Sponsor details

Unit 1-4 G/F.

Cheong On House

Nam Cheong Estate

Sham Shui Po

Kowloon

Hong Kong

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Sponsor type
Other

Funder(s)

Funder type
Charity

Funder Name
Pneumoconiosis Mutual Aid Association

Results and Publications

Publication and dissemination plan

The results of the study will be disseminated through journal papers, conference, and sharing sessions.

Intention to publish date
31/07/2020

Individual participant data (IPD) sharing plan

Ethical approval does not permit data sharing. Participants did not consent to data sharing.

IPD sharing plan summary

Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		26/01/2021	04/03/2022	Yes	No