

SRTP - Project Description Form #220

PART I:

Name of Schulich faculty member who will supervise the project Shannon Sibbald

Supervisor's Schulich, Western, Hospital or Lawson Email ssibbald@uwo.ca

Schulich Department Family Medicine

PART II - Project Description

Title of Project The intersectionality of breathlessness and dyspnoea on health experiences of persons living with COPD

Background

Breathing is an automatic and vital experience of human life that rarely catches our attention until we experience a moment of breathlessness [1]. Persons living with COPD (PWC) experience progressive periods of breathlessness, discomfort, and distress due to dyspnoea [2]. The embodied, physical consequences of breathlessness affect quality-of-life [3] and significantly challenge the daily ability of PWC in many aspects. As breathlessness and dyspnoea progress, PWC loses mobility, becomes more fatigued, and increases dependency [9].

Breathlessness and dyspnoea can also take a significant emotional toll on the mental health of PWC. The hidden nature of COPD can make it difficult for those around them to be able to understand and emotionally support PWC. As a result, PWC can be self-conscious, often limit their social interaction, and are fearful of being perceived by others as being weak [5]. While over half of PWC experience depression and/or anxiety [6] there is still much we do not fully understand regarding the mental health experiences of PWC.

Evidence exists of intersections of age, sex, gender, and socioeconomic status (SES) with COPD. We know that PWC are a high-risk and vulnerable population whose condition is compounded by the natural impact of ageing [7]. While COPD is more prevalent within older populations [4], women diagnosed with COPD tend to be younger, and they experience more dyspnoea than men [8]. We also know through gender-based COPD research that women can be delayed in their COPD diagnosis due to barriers to seeking care [9]. Women living with COPD are also more likely to experience anxiety, depression, and undernutrition [9]. Moreover, it has been demonstrated that COPD and SES have an inverse relationship [10]. Despite this growing knowledge base, the impact of intersecting challenges on the physical and mental health of PWC is not fully understood.

Hypothesis

We expect to receive personal accounts of the experiences of living with and caretaking for COPD and how this intersects with gender, sex, age, and SES. We expect this intersectionality to have significant impacts on the quality of life of those with COPD.

Proposed Methodology

This will be a qualitative phenomenological study; we will use a stepwise, interpretive phenomenological analysis approach (IPA) [3]. IPA is an approach that "supports idiographic subjective experiences and social cognition" and by doing so, affords a deeper understanding of human experience [11]. We plan to interview 10 PWC along with 10 individuals who are caregivers of PWC. Participant recruitment will be done through Ontario's lung health support groups and our existing research networks.

We will seek two lived experience knowledge users (KU) to join our research team; one KU who is living with

breathlessness and dyspnoea, as well as one KU who has cared for a PWC. We will use our existing connections with the Strategy for Patient-Oriented Research (SPOR) Evidence Alliance and the Ontario SPOR Support Unit to connect to these KU. We believe these KU will support the development of our interview guide, advise on our participant recruitment materials, participate in data analyses, and support our knowledge mobilization efforts.

Expected Outcomes

- 1) Increase our understanding of the embodied experiences of ageing Canadians living with breathlessness and dyspnoea due to COPD.
- 2) Explore how the intersectionality of age, sex, gender, and SES synergically impact the physical and mental health of PWC and their caregivers.
- 3) Draft recommendations to improve existing support programs for PWC and their caregivers.

Research Environment - Description of the number of research personnel, primary location of research, size of lab, etc

Research personnel will comprise of Sibbald's Lab, in particular the research team assigned to this work. The primary location of this work will be online, while activities such as interviews or focus groups will be held in person or via Western Zoom, depending on the preference of the participant. Any interviews held in person will be held on campus (in accordance with REB guidelines).

The trainee will benefit from an interactive dry lab, with 1 post-doc, 3 PhDs, 6 MSc, and 5-8 undergraduates. The lab meets regularly, is interdisciplinary, and has access to space on campus.

Names and titles of other individuals who will be involved with the research project?

The individuals involved include Elaine Zibrowski, research coordinator, and Madeline Dougherty, MSc student and research assistant.

Can this project be done remotely? Yes

Duration of Project Two Summers

Expected Objectives/Accomplishments for Student for Year 1?

START:

1) Increase our understanding of the embodied experiences of ageing Canadians living with breathlessness and dyspnoea due to COPD.

>> PARTICIPATE IN DATA COLLECTION AND ANALYSIS

2) Explore how the intersectionality of age, sex, gender, and SES synergically impact the physical and mental health of PWC and their caregivers.

>> PARTICIPATE IN DATA COLLECTION AND ANALYSIS

START:

3) Draft recommendations to improve existing support programs for PWC and their caregivers.

>> SUPPORT SHORT TERM KT ACTIVITIES SUCH AS ABSTRACT AND PRESENTATIONS + START MANUSCRIPT

Expected Objectives/Accomplishments for Student for Year 2?

CONTINUE:

1) Increase our understanding of the embodied experiences of ageing Canadians living with breathlessness and dyspnoea due to COPD.

2) Explore how the intersectionality of age, sex, gender, and SES synergically impact the physical and mental health of PWC and their caregivers.

>> STUDIES LIKE THIS ONE CREATE MORE DATA THAN IS POSSIBLE TO USE IN ONE STUDY; THE 2ND SUMMER WILL FOCUS ON EXTENDING THE ANALYSIS OF OUR DATA AND CONSIDERING SECONDARY ANALYSIS; THE STUDENT WILL HAVE A CHANCE TO LEAD A PROJECT CO-DEVELOPED BY THE RESEARCH TEAM IN SUMMER 1

EXPAND:

3) Draft recommendations to improve existing support programs for PWC and their caregivers.

>> CONTINUE WORKING ON MANUSCRIPT, SUPPORT GRANT WRITING

PART III - Certifications

If the project will require any certification - Human Ethics approvals from one or more of the following offices, please check the appropriate box below.

Human Ethics: If you have the protocol information, please enter it below (or enter the status of the approval). UNDER REVIEW (already submitted, currently responding to comments)

Note: certification approval should be obtained prior to the start of the summer. Projects without this approval will not be a priority for funding.