

2017-5

## Informal Caregivers' Experience During Acute Exacerbation of COPD in Older Adults: A Dissertation

Helen M. Flaherty  
*University of Massachusetts Medical School*

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### Repository Citation

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Informal Caregivers' Experience During Acute Exacerbation of COPD in Older Adults

A Dissertation Presented

By

Helen M. Flaherty

Submitted to the Graduate School of Nursing  
University of Massachusetts Worcester  
In partial fulfillment of the requirements for the degree of  
Doctor of Philosophy  
Nursing

May 2017

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University of Massachusetts Worcester

Graduate School of Nursing

Informal Caregivers' Experience During Acute Exacerbation of COPD in Older Adults

A Dissertation Presented

By

Helen Flaherty

Approved as to style and content by:

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Jean Boucher

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James Fain

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Maureen Wassef

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Date

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Joan Vitello PhD, RN, NEA-BC, FAHA, FAAN  
Dean & Professor  
University of Massachusetts Worcester  
Graduate School of Nursing

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## Abstract

Chronic obstructive pulmonary disease (COPD) has been recognized as a leading cause of mortality in older adults involving acute exacerbations as life-threatening events that lead to frequent hospitalization for care. Informal caregivers have been essential to helping older adults with COPD during an acute exacerbation of chronic obstructive pulmonary disease (AECOPD). A lack of empirical knowledge exists regarding the experience of informal caregivers of older adults with AECOPD in situation awareness for recognizing, understanding, and responding to an AECOPD in an emergent situation. This qualitative descriptive study explored situation awareness and its components of perception, comprehension and projection of next steps, including the caregiver's confidence level during the AECOPD event. Fifteen informal caregivers, ages 31-77 years (mean age 48), who provided care for older adults with COPD were interviewed from an underserved community health center. The overarching theme derived from this study was *something was wrong and something needed to be done*. Subthemes emerged as *a heightened sense of awareness, caregiver tipping point, planning next steps, caregiver confidence, and caregiver commitment*. This study utilized situation awareness theory as a relevant guiding framework in exploring the experience of lay informal caregivers caring for older adults with AECOPD events. Study findings provided a description of the complex processes involved, including confidence level, for informal caregiver's in situation awareness to recognize and respond to an AECOPD event in the older adult. Future targeted interventions need to address strategies to enhance individualized care for older adults with AECOPD events for managing care at home.

Informal Caregivers' Experience During  
Acute Exacerbation of COPD in Older Adults

Helen M. Flaherty MS, RN

University of Massachusetts Worcester

Graduate School of Nursing

June 2, 2016

## **Dissertation Proposal**

### **Introduction to Problem and Specific Aims**

Chronic obstructive pulmonary disease (COPD) is the third leading cause of mortality with 120,000 deaths reported annually in the United States (U.S.) (National Heart Lung and Blood Institute, 2013; NIH Research Online Reporting Tool, 2013) . The U.S. population is aging rapidly with 80% of older adults over 65 years old experiencing at least one chronic medical condition (Centers for Disease Control and Prevention, 2011). Chronic obstructive pulmonary disease (COPD) is one of the leading chronic medical conditions experienced by older adults (Akinbami & Liu, 2011).

COPD includes a group of respiratory diseases such as chronic bronchitis and emphysema that affect airway flow with symptoms of cough, sputum production and shortness of breath or dyspnea that worsen over time (National Heart Lung and Blood Institute, 2013). An acute exacerbation of COPD is characterized by self-report worsening in the severity of these symptoms (Criner et al., 2015) that results in an event-based medication change and/or at times health care utilization (Mohan & Sethi, 2014). An acute exacerbation of COPD for older adults is also a serious life-threatening chronic medical condition that can lead to hospitalization (Chandra, Tsai, & Camargo, 2009; Genao et al., 2015), decreased quality of life (Holmes & Scullion, 2015; Xu et al., 2010), and an increased economic burden (Dalal et al., 2015; Guarascio, Ray, Finch, & Self, 2013; Hasegawa, Tsugawa, Tsai, Brown, & Camargo, 2014). Thus, recognition and response is vital when situations of acute exacerbation of COPD in older adults arise leading to prompt treatment and prevention of serious untoward patient outcomes.



Informal caregivers are essential to helping older adults with COPD manage their illness including awareness of situations in which dyspnea and other associated symptoms related to acute exacerbation of COPD occur (Caress, Luker, & Chalmers, 2010; Trivedi, Bryson, Udriș, & Au, 2012; Wang, Sung, Yang, Chiang, & Perng, 2012). Older adults with COPD may have increasing difficulty with cognitive perception and comprehension as part of the slowing thought processes seen in the aging process (Bolstad & Hess, 2000; Caserta & Abrams, 2007) and therefore may need assistance from a caregiver. A literature review of informal caregivers for patients with COPD reported a lack of informational and support needs for symptom management (worsening shortness of breath, cough and sputum) along with supervision in helping to make decisions about when to take action when these events occur (Caress, Luker, Chalmers, & Salmon, 2009; Hynes, Stokes, & McCarron, 2012).

Events experienced by informal caregivers in caring for older adults with situations involving the acute exacerbation of COPD have yet to be explored. Endsley's situation awareness theory is the organizing framework in this study that provides the foundation to ascertain how informal caregivers recognize pertinent symptomatology, understand their importance and ultimately respond to an emergent situation. Perception, comprehension, and projection of anticipating next steps of an event are components of situation awareness (Endsley & Garland, 2000) in which persons or informal caregivers may experience during an acute exacerbation of COPD. According to research done by Endsley and Jones (2011), an individual's confidence level of their situation awareness has an impact on the performance of an action. Informal caregivers' awareness and response to situational events would thus require, having perception and comprehension of the occurrence of AECOPD with a certain confidence level in knowing the worsening nature of the symptoms (shortness of breath, cough and sputum)

while projecting appropriate actions to seek medical treatment for these certain conditions. (Gysels & Higginson, 2009; Nakken et al., 2015).

It is not uncommon for informal caregivers to provide care for the older adult (Spence et al., 2008) especially with the debilitating nature of COPD (Seamark, Blake, Seamark, & Halpin, 2004). Informal caregivers face challenges of not only recognizing but responding to an AECOPD. Little is known about the informal caregivers' experience of an AECOPD in older adults involving aspects of perception, comprehension and projection related to situation awareness of a serious event.

**The purpose of this study** is to explore the experience of the informal caregiver in recognizing and responding to the situation of an AECOPD in older adults. This study will describe the informal caregivers' use of perception, comprehension, and projection including how their confidence level in situation awareness may guide their actions during an AECOPD in older adults.

**Aim 1:** Describe the experience of informal caregivers' when recognizing and responding to the situation of an AECOPD for older adults.

**Aim 2:** Explore the applicability of situation awareness and its components of *perception, comprehension, and projection* including *confidence level* of situation awareness of informal caregiver when recognizing and responding to an AECOPD in older adults.

This study of exploring situation awareness in relation to the experiences of informal caregivers would add to the literature in describing their ability to recognize and respond to the symptoms and serious nature of an AECOPD. There is an increasing need in healthcare to collaboratively support not only the older adult with COPD but also the informal caregiver. Situation awareness theory provides a framework to assist the researcher to develop and

understand components of *perception, comprehension, and projection* of AECOPD events that may be precipitating factors that contribute to one's *confidence level* in taking action.

Advancing knowledge in this area could lead to nursing interventions that would enhance the ability of caregivers to effectively care for the older adult during an acute event, mitigate factors leading to poor outcomes, and promote well-being for informal caregivers and patients with COPD.

## **Background and Significance**

### **Older Adults with COPD**

An estimated 15 million people are reported to have been diagnosed with COPD and it is most prevalent in older adults ages 65-74 years (Centers for Disease Control and Prevention, 2012). COPD is a chronic pulmonary disease that worsens over time and includes emphysema and bronchitis characterized by coughing, wheezing, shortness of breath, and chest tightness (National Heart Lung and Blood Institute, 2013). A diagnosis of COPD is confirmed by measuring airflow using spirometry testing (GOLD, Global Initiative For Chronic Obstructive Lung Disease. 2015). Risk factors include exposure to environmental irritants such as cigarette smoke, chemicals, dust, and/or fumes (GOLD, Global Initiative For Chronic Obstructive Lung Disease. 2015). Individuals may have genetic susceptibility to COPD (Chen et al., 2015; Sorroche et al., 2015) and/or exist with other conditions such as cardiovascular (congestive heart failure, coronary artery disease) or metabolic (diabetes) disorders (Negewo, McDonald, & Gibson, 2015).

### **Acute Exacerbation of COPD**

In an acute exacerbation of COPD (AECOPD), the older adult experiences a change from baseline status and exhibits worsening dyspnea, cough, and/or sputum production requiring a medication change (GOLD, Global Initiative For Chronic Obstructive Lung Disease. 2015). Exacerbation severity is classified as a mild event treated with bronchodilators perhaps managed in a clinic setting; a moderate event treated with corticosteroids or antibiotics perhaps managed in an emergency department setting; to a severe event requiring hospitalization (Mohan & Sethi, 2014). An acute exacerbation of COPD also requires recognition of the worsening symptoms to take action to seek immediate health care utilization and treatment involving COPD medications, steroids, and antibiotics when indicated. Older adults with COPD may lack the ability to recognize symptoms as an exacerbation event early enough. Older adults with COPD may have limitations in cognitive function to process information (Cleutjens, Janssen, Ponds, Dijkstra, & Wouters, 2014; Dodd, Charlton, van den Broek, & Jones, 2013) and/or have difficulty in recognizing or distinguishing symptoms associated with chronic medical conditions (Brandt, 2013; Riegel et al., 2010; Smith et al., 2015). However, many COPD exacerbations are often mild and go unreported due to the nature of the symptoms or from patients treating themselves with medications (Mohan & Sethi, 2014; Trappenburg et al., 2010; Xu et al., 2010). Others with more severe acute exacerbation of COPD seek emergency room care or subsequently need hospitalization (Genao et al., 2015). Regardless of whether an acute exacerbation is mild, moderate or severe, it may require the support of an informal caregiver to recognize the symptoms and encourage an older adult to take action.

### **Role of Informal Caregiver and Acute Exacerbation of COPD**

Informal caregivers are typically family members, close friends, unpaid carers with little to no healthcare training (Gysels & Higginson, 2009; Nakken et al., 2014; Spence et al., 2008;

Wang et al., 2012). In a 2011 national health and aging trends study of informal caregiving for older Americans, nine million older adults received care from informal caregivers, of which 20% were from spouses averaging 110 care hours per month (U S Department of Health and Human Services, 2014). More than 70% of older adults with COPD are typically cared for by a spouse or family member as their informal caregiver (Boyle, 2009; Gautun, Werner, & LurÅs, 2012). Even though the informal caregiver has the advantage of knowing the individual and often recognize and supports an exacerbation event in the older adult (Hynes et al., 2012; Riegel et al., 2010; Riegel, Dickson, & Topaz, 2013), spouses of the older adult have significantly lower COPD knowledge as compared to younger caregivers (Hsiao, Chu, Sung, Perng, & Wang, 2014). These informal caregivers may assist with COPD related events that range from symptom management, avoiding adverse events, emergency care during acute episodes of illness, and/or overall physical and emotional support (National Heart Lung and Blood Institute, 2013). For this study, an informal caregiver is defined as an unpaid carer or a paid family member who provides physical and social care; and has the ability to notice a change in the older adult's respiratory condition (Hynes et al., 2012; Wakabayashi et al., 2011).

The informal caregiver role involves complex processes when recognizing and responding to an AECOPD. Caregivers often feel helpless when responding to care for the older adult experiencing symptoms of breathlessness due to a lack of knowledge of COPD (Gysels & Higginson, 2009). Informal caregivers are commonly not able to manage the older adult's escalating COPD symptoms prompting program's such as the 'Inspired' COPD Outreach Program<sup>TM</sup> to improve care with both patient and family focused support with education (Rocker & Verma, 2014).

An informal caregiver may experience many components of how to recognize and respond to AECOPD when caring for the older adult. Components in recognizing an AECOPD involve perceiving the exacerbations symptoms experienced by the older adult, distinguishing between daily variations in breathlessness versus an acute exacerbation, understanding the urgency of the event, and making judgements on what to do next (Gysels & Higginson, 2009).

Although this study may not be generalizable to other areas, the strength of this study may provide insight that could be studied in other health conditions. In addition, this study will explore informal caregiver's experiences with AECOPD in older adults within the context of the applicability of situational awareness as a guiding framework in recognizing and responding to such events.

### **Situation Awareness Theory**

In general, the concept of situation awareness is “knowing what is going on around you” (Endsley & Garland, 2000, p. 5). The concept of situation awareness originated with aircraft pilots in aviation as far back as World War I (Endsley, 1988) where pilots processed complex information in a highly technical environment. A theoretical framework for situation awareness was finally developed and proposed by Mica Endsley, PhD while many domains of situation awareness were incorporated into healthcare by the year 2000 going forward (Endsley, 1995; Endsley & Garland, 2000).

The tenets of situation awareness propose that information is perceived by persons via the sensory cues taken in from the environment, then gathered, stored, and assigned meaning. Specifically, situation awareness “is the perception of the elements in the environment within a volume of time and space, the comprehension of their meaning and the projection of their status in the near future” (Endsley, 1988, p. 97).

Endsley based her situation awareness model from Christopher Wickens' research on information processing (Endsley & Garland, 2000) regarding the psychological perspective of performing complex tasks. Wickens' influence was in psychology, aviation, and engineering. A portion of Wickens' linear model of information processing (C. Wickens & Hollands, 2000) provided support for Endsley's hierarchical model for situation awareness theory. Endsley's theory perceived information by the sensory cues taken in from the environment, gathered, stored, and assigned meaning similar to the storage and use of short and long-term memory process used in information processing theory.

Currently, situation awareness has been found to be an effective framework in the healthcare and non-healthcare profession but it is a novel application in the lay individual within healthcare. In the healthcare profession, situation awareness framework has been used to teach health care providers in responding to events in the acute care hospital setting (Bleakley, Allard, & Hobbs, 2013; Brady & Goldenhar, 2014; Cooper, Porter, & Peach, 2014; Cornell, Townsend-Gervis, Vardaman, & Yates, 2014; Sitterding, Ebright, Broome, Patterson, & Wuchner, 2014; Tower & Chaboyer, 2014) including areas of anesthesia (Schulz, Endsley, Kochs, Gelb, & Wagner, 2013), nursing (Koch et al., 2013; Sitterding et al., 2014), and interprofessional simulation (Wassef, Terrill, Yarzebski, Flaherty, & D'Esmond, 2015).

In the non-healthcare profession, situation awareness has been used successfully in various environmental domains including safety practices related to emergency preparedness operations such as hazardous weather conditions (Centers For Disease Control and Prevention, 2015) and automobile transportation safety (Crundall, 2016; Jeon, Walker, & Gable, 2015). For example, the CDC provides up-to-date hazardous weather information to the public on hurricanes, flooding, wildfire, and winter weather safety information to promote situation

awareness and support emergency response operations. Research on transportation safety examined drivers' situation awareness on cell phone use (Huth, Sanchez, & Brusque, 2015), conversations (Heenan, Herdman, Brown, & Robert, 2014), and behavior at railroad crossings (Salmon, Lenne, Young, & Walker, 2013).

However, to date no known research has explored situation awareness in the lay population of informal caregivers during chronic illness related events. In particular, it is not known whether informal caregivers of older adults with COPD possess the components of situation awareness in taking appropriate follow-up action with the health care provider. Such action or inaction may make the difference in having a good outcome versus a bad outcome for the older adult experiencing the acute exacerbation of COPD. The importance of exploring this experience with informal caregivers includes whether components of situation awareness also include their confidence level to assist the older adult to respond by taking action during episodes of AECOPD that may reduce hospitalizations and worsening COPD disease.

An informal caregiver experiences complex processes when caring for the older adult with COPD involving the symptoms experienced (Gysels & Higginson, 2009). Situation awareness components of perception, comprehension and projection may play a valuable role for the informal caregiver to recognize when an AECOPD is occurring and understand when to take action. Understanding the processes of perception, comprehension, and projection involved to taking action may provide insight into developing strategies when caring for an individual experiencing an AECOPD. No research to date exists in the area of using situation awareness theory to understand the informal caregiver's experience during an event when an AECOPD occurs in the older adult being cared for.

### **Situation Awareness and Confidence Level**



Simply knowing the information, including cues and characteristics of an AECOPD is not sufficient enough to attend to the impending event to take action. Endsley (2011) also describes how having confidence in such information is an essential component to having situation awareness about an event. Thus, the application of situation awareness would include the confidence level of the informal caregiver in one's ability to recognize and respond to an AECOPD event (Figure 1) (Endsley & Jones, 2011; Patel, Jones, Adamson, Spiteri, & Kinmond, 2015). In other words, it is the subjective confidence level of the caregiver to perceive the worsening of symptoms associated with AECOPD, that include to comprehend the situation, and project the future events to take appropriate action.

The caregiver's confidence level to perceive, comprehend and project an AECOPD event may be associated with the cues and characteristics of the symptoms exhibited by the patient with AECOPD. Such cues and characteristics may be missing, unreliable, not credible, conflicting, not timely, or ambiguous (Endsley & Jones, 2011). For example, the caregiver may perceive the older adult experiencing an event of worsening respiratory symptoms of cough and dyspnea (GOLD, Global Initiative For Chronic Obstructive Lung Disease. 2015) while *missing* critical information that the older adult simply over-exerted himself and may not be experiencing an AECOPD event. After verifying that the respiratory symptoms were not related to an activity or normal day-to-day variation, the caregiver would verify that the older adult is indeed experiencing an AECOPD.

Based on Endsley and Jones' (2011; 1997) model of situation awareness and confidence level, a similar guiding framework will be adapted to describe the informal caregiver's confidence level in recognition and responding to an AECOPD event (Figure 1). When a caregiver has a *high* confidence level of their situation awareness of an AECOPD event, the

caregiver may be more likely to take action on the AECOPD event. In contrast, when a caregiver has a *low* confidence level of their situation awareness of an AECOPD event, the caregiver may likely display indecisiveness, a delay in taking any action, or do nothing. Not taking action when needed may lead to a poor outcome for the older adult.

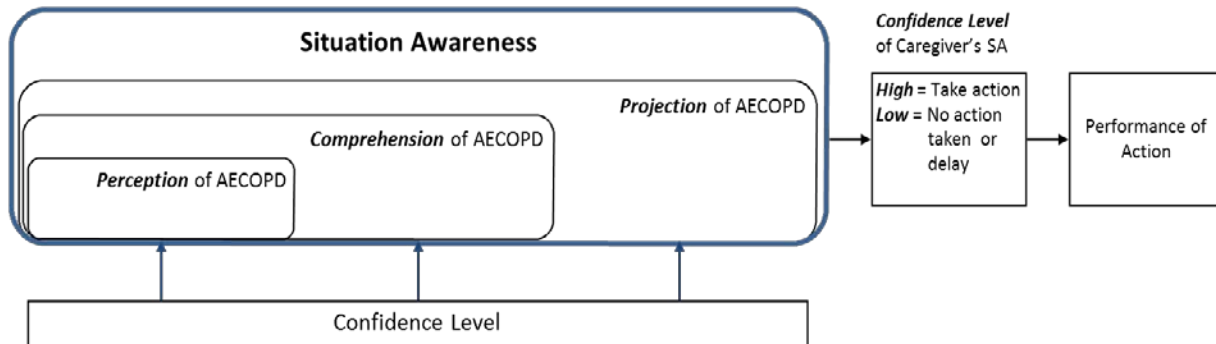


Figure 1. Adapted Model of Endsley's (2011) Situation Awareness (SA) in an Acute Exacerbation of Chronic Obstructive Pulmonary Disease (AECOPD)

### Summary

COPD is a serious chronic disease experienced by older adults who also experience AECOPD. An AECOPD with worsening symptoms of cough, dyspnea and/or sputum production may lead to consequences or a serious life threatening event. It is challenging for informal caregivers to recognize and respond to an AECOPD of the older adult. Situation awareness theory may provide insight into the complex nature involving perception, comprehension and projection that informs the confidence level to take an action. Little is known about the experiences of informal caregivers involving situation awareness in terms of if and when they recognize and respond to these situations when caring of older adults who experience an AECOPD. Exploring the components of situation awareness in relation to the informal caregivers' ability to recognize and respond to the symptoms of AECOPD may lead to an understanding of the processes involved in one's confidence level in performance of taking an

action. Describing these experiences could provide insight into enhancement of the caregiver's ability to effectively recognize and respond to an AECOPD event by the older adult; mitigate untoward factors that lead to poor outcomes such as hospitalization and worsening COPD; and promote a culture of health and well-being for the older adult.

### **Methods**

This qualitative descriptive approach uses naturalistic inquiry whereby informal caregivers in their natural setting will provide their words, meaning, and experiences when caring for older adults experiencing an AECOPD without in-depth interpretation from the researcher; a characteristic of qualitative description (Creswell, 2013; Sullivan-Bolyai, Bova, & Harper, 2005). The purpose of this study is to explore the experience of the informal caregiver during a situation of an acute exacerbation of COPD in older adults. This study will describe the experience of how informal caregivers use perception, comprehension, and projection that informs one's confidence level as situation awareness guides their actions, in an acute exacerbation of COPD in older adults.

Situation awareness theory (Endsley, 1995) will be used as the guiding framework approach to explore highlights of the informal caregiver as to if and when they recognize and take action during an AECOPD occurrence. Based on information processing theory (C. Wickens, 1992), situation awareness theory focuses on the processes leading to performance of an action as an individual recognizes cues from the environment (perception), compiles and interprets information to form an understanding of a situation (comprehension), and proceeds to formulate the plan (projection) prior to implementing an action. Unveiling the complex processes and vulnerable weak points within each level of situation awareness will be discovered.

### **Naturalistic Setting**

The informal caregiver participants of older patients who have had an AECOPD for the study will be recruited from the Family Health Center of Worcester, a primary care health center in an urban setting in Massachusetts. The Family Health Center provides care to the underserved population where 97% of the population have income below 200% poverty level (Family Health Center of Worcester, 2015). In 2014, the center served approximately 33,000 culturally diverse individuals, (Family Health Center of Worcester, 2015) many with chronic conditions. Many older adult patients greater than age 65 with COPD are cared for annually in primary care at the Family Health Center.

### **Sample**

Purposeful sampling will include a minimum of 15 informal caregivers who care for an adult greater than 65 years of age with COPD in their home. Purposeful sampling is chosen to study the experiences of the informal caregiver that occur during an older person's AECOPD event using a maximum variation of ethnicity sampling and sample size to achieve a rich description with a variety of perspectives (Creswell, 2013; Sandelowski, 1995; Sullivan-Bolyai et al., 2005). Sampling will be based on purposive sampling of informal caregivers who are caring for and engages with the older adult experiencing an AECOPD. All informal caregiver participants will have the opportunity to describe their experiences in recognizing and responding to an AECOPD situation. The sample size will be dependent upon when data saturation is achieved for the qualitative interviews (Mason, 2010).

### **Inclusion Criteria**

Inclusion criteria for the informal caregiver will be: 1) 18 years or older; 2) able to speak and understand the English language; 3) acknowledge that he/she is an unpaid individual or

family member attending to the needs of the older adult; 4) provides some type of physical and social care for the older adult; 5) experienced an AECOPD with the older adult within the last six months; 6) able to give consent; 7) self-reports to have the ability to notice a change in the older adult's respiratory condition; and, 8) agreeable to participate in the study.

### **Exclusion Criteria**

Exclusion criteria for the informal caregiver will be: 1) less than 18 years old; 2) non-English speaking 3) paid caregivers that are not family members; 4) provider reports psychological or physical condition that precludes ability for participation; 5) or presence of social issues in the home that may jeopardize the safety of the interviewer as reported by the medical provider.

### **Recruitment**

Recruitment will take place at Family Health Center where the researcher works and will obtain permission to recruit subjects by the FHCW program and policies committee. The researcher will inform providers about the purpose of the study including eligibility criteria. Providers will be asked to self-identify older adult patients with COPD who have informal caregivers. A study information sheet will be given by the provider to the informal caregiver or surrogate (patient with COPD) in the clinic setting. The provider will ask permission of the informal caregiver in the clinic for the researcher to contact them about the study or will instruct the surrogate (patient) to provide the study information sheet to the informal caregiver in order to contact the researcher by phone to further talk about the study. With the potential participant's permission, the researcher may also have the opportunity to briefly meet with the informal caregiver or surrogate at the end of the provider's office visit for an introduction to the study.

At the in-home interview, the researcher will utilize a waiver of written consent utilizing the study information sheet by providing an explanation of the study's purpose, procedure (the interview questions, audio recording using deidentified responses, with length between 30-60 minutes), participant volunteering, confidentiality, rights to refuse to participate, may withdraw from the study, participant risks and benefits, and study contact information. This will be followed by the researcher asking verbally whether he/she would choose to participate in the study. Additional follow-up interviews with the informal caregiver may be needed to verify data findings as member checks. Recruitment will continue until data saturation is achieved by interviews as described in the sample section above.

### **Data Collection Procedure**

Preselected interview questions will be utilized (Appendix A) during the semi-structured face-to-face audiotaped interviews to address the "who, what, where, and why" (Sullivan-Bolyai et al., 2005, p. 128) of the informal caregiver's experience. The interview questions will include components of situation awareness theory where questions are based on the informal caregiver's perception, comprehension, and projection of their plan to take an action. The researcher will have the opportunity to further probe during the interview based on the subject's response by asking the informal caregiver to tell the investigator more about the subject matter. The researcher will take on the role of being fully engaged in the interview with the informal caregiver in order to collect observations. Each interview will be reviewed after completion to inform future interviews in accordance with constant comparative method.

The 30-60 minute audio-recorded interviews by the researcher will be with the informal caregiver and not with the older adult with COPD. During the data collection procedure, ethical considerations of honesty, trust, and respect will be provided during the interview in the

investigator's actions, words, and in a manner that reflects the attention given to the research process (Davies & Dodd, 2002). The researcher will have a plan to address conflict, safety, and sensitive issues. Confidentiality of subjects will be maintained including interviews capturing deidentified data. The researcher will be aware of the cultural considerations in how the informal caregiver receives the researcher's questions and how the informal caregiver provides meaning to the questions based on their values and beliefs. While conducting the interview, the researcher will be an attentive listener and non-judgmental. Field notes and memos from the interview will be documented immediately following the interview; not in the home setting. The field notes will include visual and sensory information from the interview that would not be captured in the audio recordings (gestures, facial expressions, environmental conditions etc.). An audit trail will be maintained throughout the study for the purposes of trustworthiness of data.

The informal caregiver will be asked to complete a demographic data sheet (Appendix B) at the interview in order to generate descriptive statistics of their age, gender, education level, relationship to older adult with COPD, socioeconomic status, frequency of caregiving hours per day, and number of years caring for older adult, and frequency information about the older adult's COPD.

### **Data Management**

Interviews will be transcribed by a transcriptionist into a word document. Field notes will be included in the document. Data management of the recorded interview files will be managed by the researcher to prepare for transcription into MS Word and coding of the data using a secured UMass Medical School (UMMS) computer R drive. Electronic files of deidentified transcriptions will be stored with password protected access to the data. Any field notes or memos will be copied and electronically filed in the secured data folders. Demographics will be

collected and stored in the study data folder as deidentified data for analysis. Each subject will have a unique identifier only known to the researcher. The researcher's dissertation committee will also be allowed access to the secured R drive computer folder for the purposes of assisting in data analysis of deidentified transcripts and related study data.

The researcher will be responsible for collecting, entering, and coding all information. The Institutional Review Board (IRB) research proposal, all original forms, correspondence and modification letters will be kept in one folder. All consent forms, stamped with an expiration date, will be kept in a separate secured folder from other documents that would link the subject ID to the consent form. All HIPAA documents will be kept for at least 6 years.

### **Data Analysis and Validation Strategies**

Descriptive statistics including measurement of central tendencies including mean, standard deviations, median, ranges and frequencies will be used to summarize the sample characteristics. In analyzing the deidentified data, the audio recording will be reviewed by the researcher and compared with the transcriptionist's for accuracy, data information will be read and re-read, and hand coded using the participants own words then coding into categories to then derive themes by the researcher according to the process described by Miles, Huberman, and Saldaña (2014). The identity of the subjects will be kept confidential by deidentifying names or any identifiable related information and assigning an identifier number when presenting the cases.

Data analysis will be performed using qualitative content analysis "directed approach to content analysis" (Hsieh & Shannon, 2005, p. 1281) where the components of situation awareness theory (perception, comprehension, and projection) will be used in the coding categories to determine whether there is applicability of the findings to situation awareness



theory. The first strategy will be to “identify and categorize all instances” (Hsieh & Shannon, 2005, p. 1281) of the informal caregiver’s experience. After this initial step, these initial coded areas will be categorized under the predetermined components of situation awareness theory. If the initial codes do not fit in the situation awareness theory categories, then a new category will be created. According to Hsieh and Shannon, (2005) trustworthiness would be increased if the researcher captures the phenomenon (components of situation awareness) prior to using the predetermined coding. The results of the findings will either support or not support (Hsieh & Shannon, 2005) the applicability of situation awareness theory among informal caregivers caring for older adults who experience an AECOPD. Additional support for the genre of content qualitative analysis will be taken from Miles, Huberman, and Saldaña’s (2014) approach to analysis.

### **Trustworthiness**

To ensure the research is valid and reliable, Lincoln and Guba’s (1985) trustworthiness will be used throughout the study by maintaining credibility, transferability, dependability, and confirmability. Validation strategies to establish credibility will include peer debriefings by nurse colleagues, member checking, and maintaining an audit trail of the debriefing sessions. Peer debriefings will be used to address potential problems and help consider alternative approaches to data analysis, when needed. To establish transferability, purposeful sampling and rich thick detailed descriptions of the text or themes will be compiled to determine if it would be applicable in another setting (Lincoln & Guba, 1985). Dependability will be achieved using a reliability strategy that includes maintaining an audit trail to ensure that the research is appropriately represented (Lincoln & Guba, 1985). Confirmability will be achieved by using triangulation of

data to ensure that cross checking data and information from multiple sources will align (Creswell, 2013; Lincoln & Guba, 1985).

### **Innovation**

Informal caregivers experience an array of subjective data when caring for the older adult member who has an AECOPD. Situation awareness may be used as a process to support a plan to take action for informal caregivers of older adults in recognizing and responding to symptoms of an AECOPD. The topic is innovative because minimal research exists in the area of studying situation awareness in the lay persons of informal caregiver's experience with AECOPD events in the older adult.

### **Limitations**

Due to the culturally diverse setting of the Family Health Center and small sample size, the findings of the study may not apply to informal caregivers of other ethnic populations. Given the age of the population of caregivers, cognitive limitations may be realized when recalling retrospective events when describing the AECOPD experience.

### **Human Subjects Consideration**

In order to protect all research study subjects, an IRB application will be submitted to the University of Massachusetts IRB for review to request an expedited status for approval for the research as deidentifiable data will be collected including the demographic sheet and audio taped interviews. In addition, an application will be submitted to the program and policies committee at the Family Health Center where the subjects will be recruited. A waiver of written consent will be requested for this study including provision of using a study letter of consent and confidentiality given to each participant at the start of the study that describes the purpose, procedure (including amount of time required to participate), confidentiality, right to withdraw

from the study, and researcher's contact information with verbal consent provided by the participant. The protection of human subjects in research is a federal regulation to evaluate the subject's risk and benefit in participating in the research. The IRB reviews and assesses appropriateness of the consent process, research subject selection, design and data collection process, and subject privacy (CITI Program - Collaborative Institutional Training Initiative, 2013). The Collaborative Institutional Training Initiative (CITI) Human Subjects Research training program was completed by the researcher in 2013 (CITI Program - Collaborative Institutional Training Initiative, 2013)

### **Consultants**

Consultants on the project are three dissertation committee members from the University of Massachusetts Graduate School of Nursing and one provider from the Family Health Center of Worcester. Jean Boucher PhD, RN is the Chair of the Committee. Maureen Wassef PhD, RN is the expert on situation awareness theory. James Fain PhD, RN is the third committee member who is an expert nurse researcher. Abdulraouf Ghandour MD is a consultant for the research and he a geriatrician expert who cares for older persons with COPD from the Family Health Center.

### **Summary**

COPD is a serious chronic disease experienced by older adults who also experience AECOPD. Little is known about the experience involving situation awareness in terms of if and when used by informal caregivers when caring for older adults who experience an AECOPD. Exploring these components of situation awareness in relation to the experiences of informal caregivers' ability to recognize and respond to the symptoms of AECOPD may lead to an understanding of what leads to performance of an action. Understanding these experiences could enhance the informal caregiver's ability to effectively recognize and respond to an acute event

experienced by an older adult, mitigate untoward factors that lead to poor outcomes such as hospitalization and worsening COPD; and promote a culture of health and well-being for the older adult.

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**APPENDIX A INTERVIEW GUIDE**

<i>Aims</i>	<i>Participant Interview Questions</i>	<i>Probes</i>
<p>1. Describe the experience of informal caregivers' when recognizing and responding to the situation of an acute exacerbation of COPD for older adult.</p>	<p>1.1 Focus on one example of an experience you had when your loved one's COPD (lung) condition became serious or worse enough that they needed more help.</p> <p>Can you describe to me an experience you had?</p>	<p>What made you think it was serious?</p> <p>Tell me what was worse?</p>
<p>2. Explore the applicability of situation awareness and its components of <i>perception, comprehension, and projection</i> including <i>confidence level</i> of situation awareness of informal caregiver when recognizing and responding to an AECOPD in older adults.</p>	<p>2.1a. Go back again and let's think about that event when you noticed (perceived) his/her worsening lung condition.</p> <p>What cues or characteristics did you look for?</p>	<p>2.1a. Did you notice (perceive) anything about his/her respiratory (lung) symptoms? Cough? Breathing? Sputum? (Phlegm, Coughing up mucous?)</p> <p>2.1b What did you notice that was not normal (e.g. missing, different)?</p> <p>2.1c. Any other symptoms Weakness, tired, fatigue?</p> <p>Are these symptoms that you notice from you or from what your loved one tells you?</p> <p>2.1d. Can you explain further?</p> <p>2.1e. What knowledge do you have about these symptoms of AECOPD?</p> <p>2.1f. What information were you given? Reliable?</p>

	<p>2.1k. Tell me about how <i>confident</i> you were to notice that an AECOPD was occurring?</p> <p>High/ Low confidence?</p>	<p>Conflicting? Missing?</p> <p>2.1g. What about false alarms?</p> <p>2.1h. Did you both agree or disagree on how bad the symptoms were?</p> <p>2.1i. Describe to me how often you tend to check (or watch) him/her. (e.g. intermittently or watch him/her continuously)?</p> <p>2.1j. What information was making you think it might be a false alarm?</p> <p>2.1k. Looking at the whole picture, do you think you had good perception of AECOPD happening? Poor perception?</p>
	<p>2.2a. Describe to me at what point did you know or understand (comprehend) that the situation of his/her worsening symptoms was serious? How did you know?</p> <p>2.2e. Tell me about how <i>confident</i> you were in knowing or understanding</p>	<p>2.2a. Was the information something you already knew from before?</p> <p>2.2b. Symptoms? Signs?</p> <p>2.2c. Could you describe the timing of what you know about the worsening symptoms?</p> <p>2.2d. How did you know that his/her worsening symptoms were not part of his/her day to day variability (or event)?</p>

	<p>about the worsening symptoms.</p> <p>High/ Low confidence?</p>	
	<p>2.3a. Tell me what you did to plan (project) for the course of action when serious or worsening COPD event occurred?</p> <p>2.3d. How <i>confident</i> were you in planning on what to do next about the worsening COPD?</p> <p>High/Low confidence?</p>	<p>2.3a. Strategies used? Call the doctor? Go to hospital? Change medication?</p> <p>2.3b. Did you hesitate or delay before taking an action?</p> <p>2.3c. What was it that made you hesitate or delay before taking an action?</p>
	<p>2.4a. How has being an informal caregiver impacted your life?</p> <p>2.4b. What worries or fears do you have?</p> <p>2.4c. Describe to me anything else that you would like to share about your experience? Of recognizing or responding to a serious or worsening lung disease or AECOPD event that occurs with your loved one?</p>	

### APPENDIX B DEMOGRAPHIC DATA SHEET

Subject # \_\_\_\_\_

The following information will be collected by participant interview:

1. **Age** at last birthday \_\_\_\_\_
2. **Gender** 0.Male\_\_\_\_\_ 1.Female\_\_\_\_\_
3. **Marital Status:**
  1. Married\_\_\_\_\_ 2.Widowed \_\_\_\_\_ 3. Single\_\_\_\_\_
  4. Separated\_\_\_\_\_ 5. Divorced\_\_\_\_\_ 6. Living with partner\_\_\_\_\_
  7. Other\_\_\_\_\_
4. **Occupation:** \_\_\_\_\_
  1. Working full time \_\_\_\_\_ 2. Working part time \_\_\_\_\_
  3. On leave from work\_\_\_\_\_ 4. On disability\_\_\_\_\_
  5. Retired\_\_\_\_\_
- 4a. **Household Income:** Gross annual family income:\_\_\_\_\_
5. **Education:** Circle last year of school completed:
 

1 2 3 4 5 6 7 8 9 10 11 12	13 14 15 16	17 18 19 20 21 22
Elementary / Junior/ Senior H.S.	College	Graduate School
6. **Racial Group:**
  - a) American Indian or Alaska Native\_\_\_\_\_
  - b) Black or African American \_\_\_\_\_
  - c) Asian\_\_\_\_\_
  - d) White or Caucasian\_\_\_\_\_
  - e) Other race (Specify)\_\_\_\_\_
7. **Ethnic Group:**
  - a) Hispanic or Latino \_\_\_\_\_
  - b) Not Hispanic or Latino \_\_\_\_\_
8. **How long** have you been an informal caregiver for your loved one? Years\_\_\_\_ Months\_\_\_\_
9. How many **hours per day** do you provide physical care or social care for your loved one?  
Hours per day\_\_\_\_\_

10. **How long** has the person **had COPD**? Years\_\_\_\_ Months\_\_\_\_

11. **When was the last time he/she had an exacerbation** or worsening of COPD?

Month\_\_\_\_; Year\_\_\_\_

Example: that required you to call the doctor for a worsening of his/her cough, difficulty breathing, or sputum (phlegm), or had a change in his/her medicine, or was hospitalized?

12. **How often** does he/she have exacerbations of COPD?

Number per month\_\_\_\_\_

Number per year\_\_\_\_\_

## Executive Summary

Chronic obstructive pulmonary disease is a serious chronic disease experienced by older adults who also experience episodes of an acute exacerbation of chronic obstructive pulmonary disease (AECOPD) with worsening symptoms of cough, dyspnea and/or sputum. It is challenging for informal caregivers to recognize and respond to an AECOPD in the older adult. Situation awareness theory provided the psychological perspective when performing complex tasks during an AECOPD event as experienced by informal caregivers when noticing, understanding, and planning next steps. While many studies have effectively incorporated situation awareness in healthcare, little is known about situation awareness in the lay population of informal caregivers during chronic illness related events such as an AECOPD event. Informal caregivers were either unpaid caregivers or family member. This IRB approved qualitative descriptive research described the experience of the informal caregiver of an older adult who experienced an AECOPD. The caregivers were recruited from a culturally diverse underserved primary care health center where providers self-identified older adult patients with COPD who had informal caregivers and provided recipients with a study information sheet. Written informed consent was obtained at the request of the health center prior to any in-home or clinic interviews. Audio-taped interviews, data collection, and analysis were performed by the researcher. Data collection was obtained from semi-structured interviews, a demographic data sheet, and field notes. Hand coded themes were categorized using qualitative approach of Miles, Huberman, and Saldana (2014). Trustworthiness (Lincoln & Guba, 1985) was maintained throughout the study to ensure the research was valid and reliable by including peer debriefings by nurse colleagues, member checking with the caregivers, maintaining field notes and an audit trail. Informal caregivers described their experience of recognizing and responding to the situation of an AECOPD in the older adult and the applicability of situation awareness in perceiving, comprehending, and



projecting next steps in the AECOPD event. From this study, we have a better understanding of informal caregivers when caring for and older adult experiencing an AECOPD event.

# Informal Caregivers' Experience During Acute Exacerbation of COPD in Older Adults

University of Massachusetts Worcester  
Graduate School of Nursing  
Helen M. Flaherty, RN, MS  
April 27, 2017



# Acknowledgements

## Dissertation Committee

Jean Boucher, PhD, RN (chair)

Maureen Wassef, PhD, RN

James Fain, PhD, RN

# Introduction

- Chronic obstructive pulmonary disease (COPD)  
3<sup>rd</sup> leading cause of mortality  
120,000/yr. (National Heart Lung and Blood Institute, 2013)
- Acute exacerbation COPD (AECOPD)  
Change from usual respiratory status  
Worsening dyspnea, cough, sputum  
Medication change (GOLD, 2015)

# Background and Significance

- AECOPD
  - Life threatening → hospitalization
  - Requires recognition
  - Older adults may lack recognition related to cognitive impairment
  - Mild events often unreported
- Informal caregivers
  - Recognize symptoms → take action

# Literature Review

- Informal Caregiver defined
  - Unpaid carer
  - Family member
  - Provide physical; social care
  - Ability to notice a change in condition

Hynes, Stokes, & McCarron, 2012; Wakabayashi et al., 2011

# Literature Review

- Informal Caregiver
  - 70% older adults with COPD (Gautun, Werner, & LurAs, 2012)
  - Little → no healthcare training (Gysels & Higginson, 2009; Nakken et al., 2014)
  - Provide emergency care during AECOPD (National Heart Lung and Blood Institute, 2013)
  - Reported lack of information; support needs for symptom management (Caress, Luker, Chalmers, & Salmon, 2009; Hynes, 2012)

# Literature Review: GAP

- AECOPD experience of informal caregivers when caring for older adults:
  - Recognizing symptoms
  - Understanding the serious nature of event
  - Responding to emergent situation



# Purpose

- To explore the experience of the informal caregiver in recognizing and responding to the situation of an AECOPD in older adults.

# Aims

- *Describe the experience* of informal caregivers' when recognizing and responding to the situation of an AECOPD for older adults.
- *Explore the applicability of situation awareness* and its components of perception, comprehension, and projection including confidence level of situation awareness of informal caregiver when recognizing and responding to an AECOPD in older adults.

# Framework

Situation Awareness: “***perception*** of the elements in the environment within a volume of time and space, the ***comprehension*** of their meaning and the ***projection*** of their status in the near future” (Endsley, 1988, p.97).

# Methods

- Qualitative descriptive approach
- 15 informal caregivers
- Cared for an older adult greater than 65 yrs; who experienced an AECOPD
- UMass Medical School IRB and Family Health Center approvals

# Inclusion Criteria

- 18 yrs. or older
- Speak/understand English
- Unpaid individual or family member attending to needs of older adult
- Provide physical and social care
- Experienced AECOPD within 6 mos.
- Give written consent
- Notice a change in respiratory condition
- Agreed to participate

# Exclusion Criteria

- Less than 18 yrs.
- Non-English speaking
- Paid caregivers that were not family members
- Provider reported psychological or physical condition that precluded the ability for participation
- Social issues in home that jeopardized safety of interviewer

# Recruitment and Procedure

- Provider(s) self-identified participants
- Information sheet
- Face-to-face
- Demographic data sheet
- Pre-selected interview questions
- Trustworthiness: deidentified data, field notes, audit trail, member checks

# Interview Guide

Endsley's Situation Awareness Example	AECOPD Interview Guide
Perception of data	What cues did you look for?
Comprehension	At what point did you understand the worsening symptoms was serious?
Projection	Tell me what you did to plan for the course of action when serious or worsening COPD event occurred?

# Data Analysis

- Demographic data SPSS statistics
- Hand-coded qualitative data (Miles, Huberman, & Saldana, 2014)
- Constant comparative method → themes



Age	Mean (Standard Deviation)	Median (Range)	
	48.4 years (13.9)	44 years (31-77)	
Category	n	%	
<b>Gender</b>			
Male	4	26.7	
Female	11	73.3	
<b>Marital Status</b>			
Married	7	46.7	
Single	5	33.3	
Divorced	2	13.3	
Living with partner	1	6.7	
<b>Employment status</b>			
Employed full-time	6	40.0	
Employed part-time	4	26.7	
Disabled	3	20.0	
Retired	2	13.3	
<b>Gross annual family income*</b>			
≤ 30,000	8	66.7	
30,000 – 60,000	3	25.0	
> 100,000	1	8.3	
*3 did not report			
<b>Highest degree earned</b>			
Less than high school	4	26.7	
High school or GED	4	26.6	
Associate degree	4	26.7	
Bachelor degree	2	13.3	
Master's degree	1	6.7	

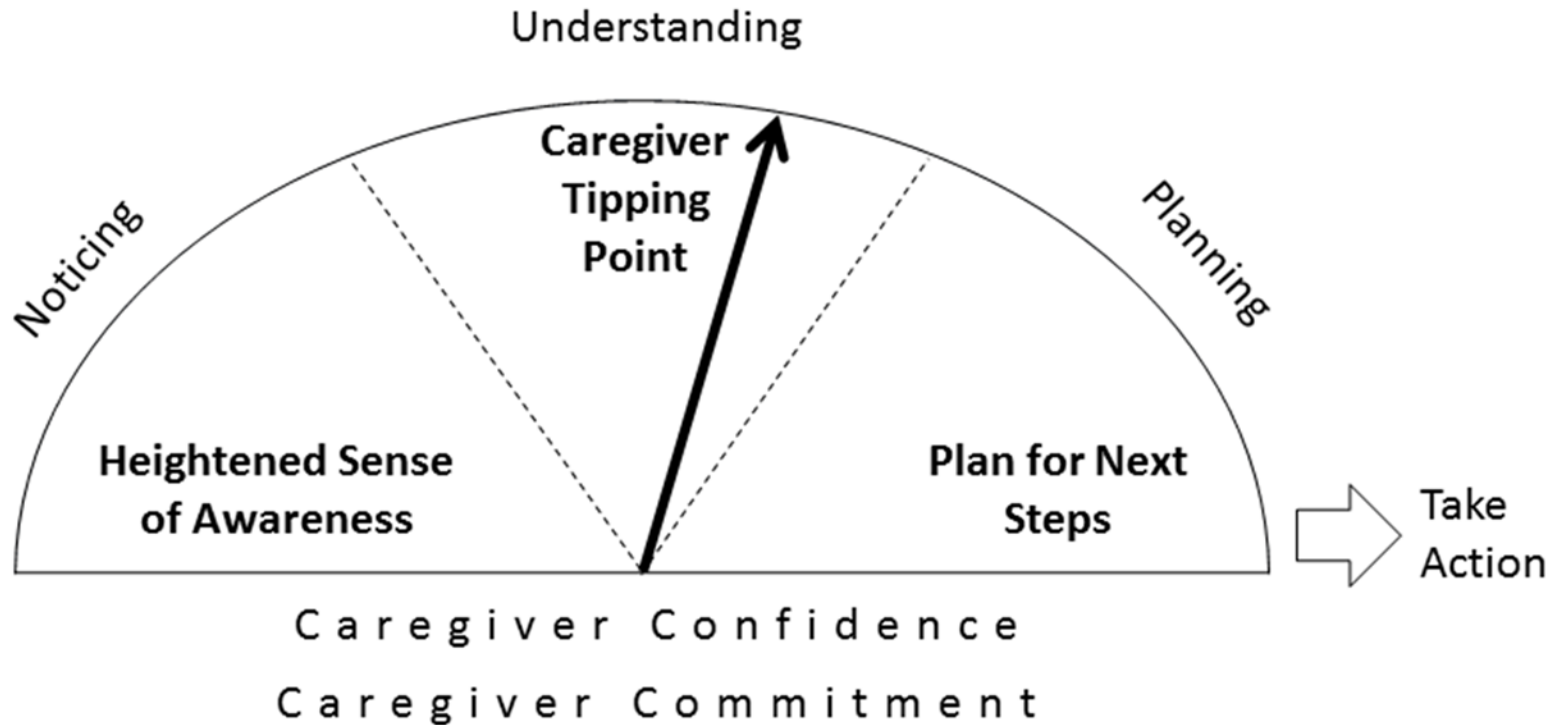
# Socio-Demographic Characteristics of Caregivers

N = 15

Category	n	%
<b>Years as caregiver</b>		
≤ 5 years	10	66.7
6-10 years	3	20.0
> 10 years	2	13.3
<b>Caregiver hours per day</b>		
< 2 hours	1	6.7
2-4 hours	8	53.3
5-10 hours	2	13.3
> 10 hours	4	26.7
<b>Number of years having COPD*</b>		
< 2 years	2	14.3
2-5 years	4	28.6
10-20 years	7	50.0
> 20 years	1	7.1
*1 did not report		
<b>Older adult present during interview</b>		
Yes	3	20.0
No	12	80.0
<b>Caregiver lives with older adult</b>		
Yes	7	46.7

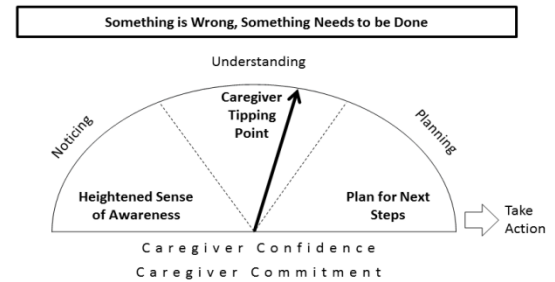
# Characteristics of Caregiver and Older Adult with COPD

Something is Wrong, Something Needs to be Done



Model showing a caregiver's process when recognizing and responding to an acute exacerbation of Chronic Obstructive Pulmonary Disease (AECOPD) in the older adult.

# Overarching Theme

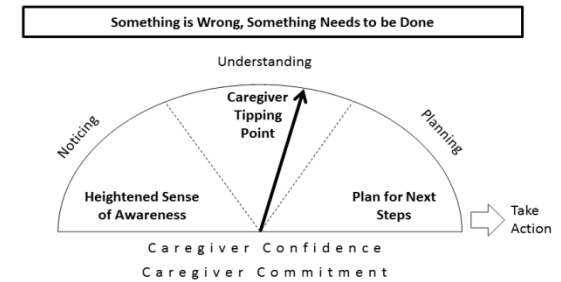


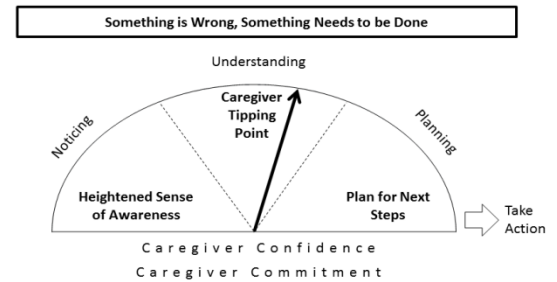
- Something is Wrong, Something Needs to be Done

“It was scary. His breathing was really bad and he just couldn’t get his breath and I felt like he was going to die on me. I asked if he was okay, then he was gasping, wheezing and everything so we had to basically call the ambulance to bring him to the hospital.”

# Subtheme

- Heightened Sense of Awareness
  - Subtle changes in the face
  - Physical changes
    - Changes that were not normal
    - Use of medical devices
  - Behavioral changes
  - Distinguishing between co-existing conditions
  - Caregiver versus older adult differed on perceptions



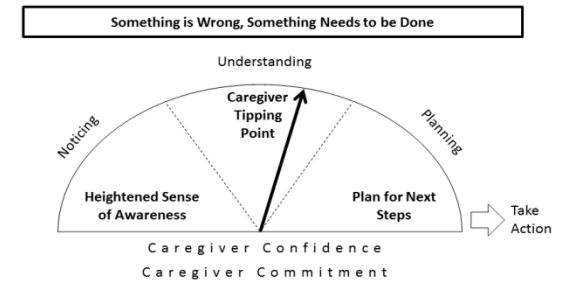


“...there is something with our parents...they don’t speak English so it doesn’t make them feel like confident...because they cannot communicate to the doctor, nurses...[The] hospital, it’s different, it’s kind of cold.”

# Subtheme

- Caregiver Tipping Point

- Persistent condition worsened
- Personal experience
- Failed interventions
- Direct communication versus “gut feeling”
- Baseline knowledge from typical day-to-day COPD symptom as AECOPD



“...it’s come to a point when you see that he cannot handle anymore by himself. ...he needs some extra help...that I cannot give it to him...when I see myself powerless like I cannot help, that’s when I’m like ‘okay now it’s time’ [to go to the hospital].”

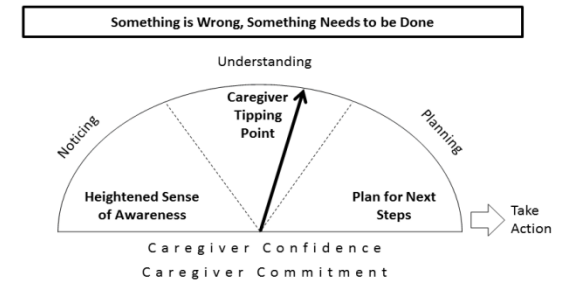
# Subtheme

- Planning Next Steps
  - Utilizing strategies
    - Inhalers versus no strategy

“I drive to my father’s house...if he’s getting that worse [I] just call 911 right away or just drive him, it’s a 20 minute ride.”

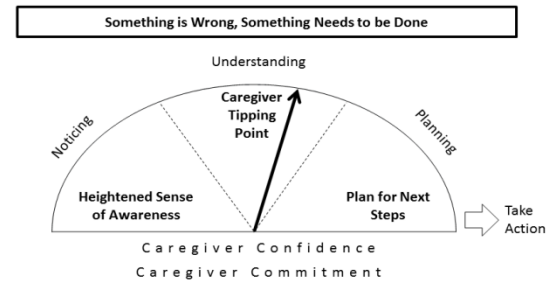
- Hesitation

“Yes...[I] hesitated on calling 911 when he said he was fine.”





# Subtheme



- Caregiver Confidence (High versus Low)

High → To notice cues of worsening symptoms  
→ Strong assertions on decisive actions

“...[to plan next steps, I have] high confidence. I don’t delay things. I’m scared so I don’t delay. I’m scared.”

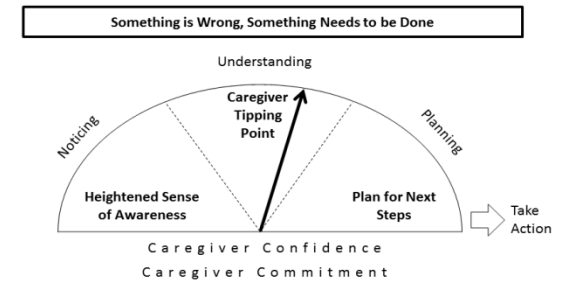
“I would just do it [go to the hospital], I’m not going to let anybody fail.”

Low → Dependent on communication of others

“he [older adult] doesn’t say how he feels.”

“I usually call the doctor when he’s that bad. I’m still learning, I’m not that confident.”

# Subtheme



- Caregiver Commitment: Impact

- Positive

- “...like having a family member...he’s part of your life.”

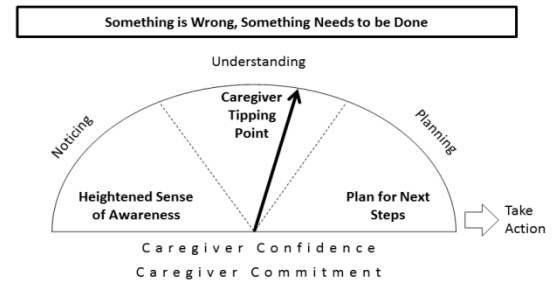
- Negative

- Loss of income; time consuming; exhausting

- “exhausting, mentally and physically. I never realized it would be so.”

- “COPD stinks and it’s a struggle.”

# Subtheme



- Caregiver Commitment: Fear, Worries

- Fear

“I fear that something [might] happen to him and I don’t know how to handle the pain, my pain. I will suffer because he’s part of my life and I am worried about him every single day.”

- Worries

- Belief in faith; acceptance

“...just a part of life.”

# Discussion- Findings

- Adds to understanding of informal caregivers experience during AECOPD
  - Recognition and responding
  - Cues related to breathing, worsening symptoms
  - Subtle facial expressions
  - Physical, behavioral changes

# Discussion

## *Heightened sense of awareness* similar to studies

- Continual assessment of COPD; subtle presentations  
(Bove, Zakrisson, Midtgaard, Lomborg, & Overgaard, 2016; Hynes et al., 2012)
- Muscle weakness (Kharbanda, Ramakrishna, & Krishnan, 2015)
- Fatigue, tiredness (Jones, Chen, Wilcox, Sethi, & Leidy, 2011)
- Dyspnea, insomnia (Kentson et al., 2016)
- Subtle facial expressions, not reported

# Discussion

- Learned from previous personal experience of AECOPD event
- Gut feeling

*Something was wrong, something needs to be done*

- Knowledge deficit; Lacked strategies (Aasbo, Rugkasa, Solbraekke, & Werner, 2017; May et al., 2016)
- Difficulty noting symptoms of AECOPD versus co-existing conditions (Theander et al., 2014)
- Caregiver disagreed with older adult in acknowledging AECOPD symptoms (Janssen, Spruit, Wouters, & Schols, 2012)
- Cognitive impairment (Cleutjens et al., 2014; Dodd et al., 2013)

# Discussion

- Caregivers as knowing seriousness of AECOPD which warrants further exploration

## *Tipping point*

- Lack of caregivers in intervention studies to support older adults with COPD (Bryant et al., 2016)
- Further exploration of multidisciplinary programs ‘INSPIRED’ COPD Outreach Program™ (Rocker & Verma, 2014)
- Difficulty knowing changes in typical day-to-day COPD symptom as AECOPD (Brandt, 2013)

# Discussion

- Majority of caregivers were adult children
  - In contrast, 70% of older adults with COPD were cared for by a spouse (Gauten et al., 2012).
- Majority of caregivers were unpaid with lower socioeconomic status (SES) by education and income with little to no healthcare training.
  - SES for COPD health outcomes showed risk factors for poor COPD health outcomes included patients with low education and household income (Eisner et al., 2011).
  - Continue health disparities research



# Discussion: Framework

<b>Situation Awareness</b> <b>“Knowing what is going on around you”</b> <i>(Endsley &amp; Garland, 2000, p.5)</i>	<b>Something is Wrong,</b> <b>Something Needs to be Done</b>
Perceiving cues in the environment	Heightened sense of awareness (noticing)
Comprehending the seriousness of the situation	Caregiver tipping point (understanding)
Projecting the next steps	Planning for next steps

# Discussion

- Median AECOPD = 8 per year
  - AECOPD of 2 per year = frequent exacerbations (Vogelmeier et al., 2017)
- Possible reasons:
  - Caregiver lack of knowledge about AECOPD symptoms (Aasbo et al., 2017)
  - Inadequate symptom monitoring and management (Warwick, Gallagher, Chenoweth, & Stein-Parbury, 2010)
  - Increased number of unreported exacerbations (Xu et al., 2010)
  - Family Caregivers perception versus the patient's perception of symptoms (Janssen et al., 2012)
  - Misunderstanding of daily breathlessness versus AECOPD (Currow & Johnson, 2015)

# Limitations

- English speaking caregivers
- Recall of retrospective events
- No spouses

# Future Recommendations

- Strategies and educational components to enhance situation awareness
- Targeted interventions
- Stipends to be a paid caregiver

# Summary: This study described

- Experience of the informal caregiver recognizing and responding to AECOPD in older adult
- Theme: Something is wrong, something needs to be done
- Situation awareness theory: understanding of processes
- Further study needed

# Acknowledgements

## Dissertation Committee

Jean Boucher, PhD, RN (chair)

Maureen Wassef, PhD, RN

James Fain, PhD, RN

## Faculty and Staff of UMass Graduate School of Nursing, Worcester

## Staff at Family Health Center of Worcester

Abdulraouf Ghandour, MD

Classmates: Colette Dieujuste RN, Michelle Glowny RN, and  
Cynthia Thompson RN

To my family, thank you.

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## Dissemination Plan

The primary description of this dissertation work was submitted as a manuscript on May 29, 2017 to *Research in Nursing & Health* for review and consideration for publication.