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ORIGINAL RESEARCH



## Personal disaster preparedness of people with chronic obstructive pulmonary disease: Development and validation of a self-report questionnaire

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### ABSTRACT

**RATIONALE AND OBJECTIVES:** The current resources related to chronic disease and disaster preparedness focus on chronic disease in general and do not examine the unique needs and vulnerabilities of people with chronic obstructive pulmonary disease (COPD). The objective of this study was to develop a disaster-preparedness questionnaire for people with COPD, and evaluate validity, reliability, readability and feasibility.

**METHODS:** The questionnaire was validated by pulmonary and disaster experts using the Content Validity Index method. Readability was assessed by participants with COPD, using the think-aloud method and a grade level assessment. Test-retest reliability was assessed in participants with COPD and analyzed using Kappa and prevalence-adjusted bias-adjusted Kappa (PABAK) scores. Feasibility, general and COPD-specific disaster preparedness were assessed in a separate cohort of participants with COPD.

**MEASUREMENTS and MAIN RESULTS:** Based on the validation and readability assessments, the final version of the questionnaire included 27-items (19 general and 8 COPD-specific questions). Readability was measured at a grade 9 level. Test-retest reliability was moderate-good (overall Kappa = 0.54, overall PABAK = 0.69). Twenty-eight people with COPD completed the final questionnaire (time to complete < 15 minutes). A total of 68% reported they had food and water for 3 days; however, only 36% met the criteria for general disaster preparedness and only 37% met the criteria for COPD-specific disaster preparedness.

**CONCLUSIONS:** The questionnaire is valid and reliable and is suitable for use by researchers and health professionals to assess disaster preparedness in people with COPD.

### RÉSUMÉ

**JUSTIFICATION ET OBJECTIFS:** Les ressources actuelles liées aux maladies chroniques et à la préparation aux catastrophes se concentrent sur les maladies chroniques en général et n'examinent pas les besoins et les vulnérabilités uniques des personnes atteintes de maladie pulmonaire obstructive chronique (MPOC). L'objectif de cette étude était d'élaborer un questionnaire de préparation aux catastrophes pour les personnes atteintes de MPOC et d'en évaluer la validité, la fiabilité, la lisibilité et la faisabilité.

**MÉTHODES:** Le questionnaire a été validé par des experts en pneumologie et en catastrophe à l'aide de la méthode de l'indice de validité du contenu. La lisibilité a été évaluée par les participants atteints de MPOC, en utilisant la méthode de réflexion à voix haute et une évaluation du niveau scolaire. La fiabilité test - retest a été évaluée chez les participants atteints de MPOC et analysée à l'aide des scores Kappa et Kappa ajustés en fonction du biais ajusté et de la prévalence (PABAK). La faisabilité et la préparation aux catastrophes générales et spécifiques à la MPOC ont été évaluées dans une cohorte distincte de participants atteints de MPOC.

**MESURES ET PRINCIPAUX RÉSULTATS:** Sur la base des évaluations de validation et de lisibilité, la version finale du questionnaire comprenait 27 éléments (19 questions générales et 8 questions spécifiques à la MPOC). La lisibilité a été mesurée au niveau de la 9e année. La fiabilité test - retest était modérée à bonne (Kappa global = 0,54, PABAK global = 0,69). Vingt-huit personnes atteintes de MPOC ont rempli le questionnaire final (temps de réponse < 15 minutes). 68 % ont déclaré avoir eu de la nourriture et de l'eau pendant trois jours; cependant, seulement 36 % répondaient aux critères de préparation générale aux catastrophes, et seulement 37 % répondaient aux critères de préparation aux catastrophes spécifiques à la MPOC.

**CONCLUSIONS:** Le questionnaire est valide et fiable, et peut être utilisé par les chercheurs et les professionnels de la santé pour évaluer la préparation aux catastrophes chez les personnes atteintes de MPOC.

### KEYWORDS

Chronic obstructive pulmonary disease; questionnaire; management

## Introduction

Disasters, such as the Indian Ocean Tsunami in 2004, Hurricane Katrina in 2005, and the Great East Japan Earthquake of 2011, highlight the importance of disaster preparedness for people with chronic disease.<sup>1-3</sup> After Hurricane Katrina, 24% of hospital visits were due to exacerbations of chronic disease, and those with chronic illness were nearly twice as likely to present to shelters with acute symptoms.<sup>4</sup> Following the Indian Ocean Tsunami, 43.5% of admissions were due to exacerbations of chronic disease, and the largest diagnostic group were those with chronic respiratory disease<sup>2</sup> including those with chronic obstructive pulmonary disease (COPD).

The scale and number of disasters (eg, wildfires, tornadoes, hurricanes) are increasing due to climate change and increased rates of urbanization.<sup>5</sup> In addition to increased age and social isolation common among people with chronic disease, people with COPD may be uniquely vulnerable to the effects of disasters for several reasons, including: disease instability, dependence on medical treatment, and risk of exacerbation from dust, mold and smoke inhalation.<sup>6</sup> After the disaster, living in crowded shelters, decreased physical mobility and substandard living conditions<sup>3</sup> can increase the risk of pneumonia or other infectious diseases.

Personal disaster preparedness includes, but is not limited to, an evacuation plan, emergency contact information, medical information and a 72-hour kit (3 days of food and water per person; a variety of items such as flashlights, a radio, cash, medication and a first-aid kit; and personal information such as credit card and insurance policy numbers).<sup>7</sup> People with chronic disease should consider their specific circumstances when making an emergency plan.<sup>8</sup> As people with COPD have unique characteristics, medical treatments and vulnerabilities to disasters, it is important to assess their disaster preparedness to confirm they are adequately prepared and to support education if necessary. This assessment requires disease-specific assessment tools; however, no such tool exists for COPD. The objectives of this study were to: 1) develop a disaster preparedness questionnaire for people with COPD; 2) assess validity, reliability, and readability of the questionnaire; and 3) pilot the questionnaire to assess feasibility and gain preliminary data.

## Methods

We used a mixed-methods research design to achieve the study objectives. Ethical approval was received from Royal Roads

University and the University of British Columbia (H16-00657). Each participant provided written, informed consent.

### Initial questionnaire development

The first draft of the COPD Disaster Planning Questionnaire had general and COPD-specific disaster preparedness items. Items were derived from the 15-item list by Foster et al.<sup>9</sup> and the Public Safety Canada guidelines<sup>10</sup> on disaster preparedness. Draft COPD-specific items were constructed using a brochure created by the COPD Foundation<sup>11</sup> and work by Motoki and colleagues.<sup>12</sup>

### Content validity, response process validity, and readability

Three disaster and emergency management experts and 3 expert clinicians validated the questionnaire according to the Content Validity Index (CVI) method.<sup>13</sup> Items were first rated on a scale of 1 (poor) to 4 (excellent) based on content, clarity and comprehension. Items with a mean score less than 3 were removed from the questionnaire. The CVI score was then calculated by counting the number of items that were rated 3 or 4 and dividing that number by the total number of items; a CVI score of at least 0.8 or higher is considered acceptable to achieve content validity.<sup>13</sup>

Response process validity is achieved when the actions and thought processes of questionnaire respondents demonstrate they understand an item the way that it is defined by the researcher.<sup>14</sup> To assess this, patients with COPD were recruited from 5 outpatient COPD pulmonary rehabilitation or care programs. Inclusion criteria were: 1) a physician diagnosis of COPD and/or recent spirometric evidence of airflow obstruction with a forced expiratory volume in 1 second (FEV1)/forced vital capacity (FVC) less than 70%; 2) ability to read and understand English; 3) 19 or more years of age; and 4) ability to give informed consent. Participants were excluded if they were too confused or agitated to participate in the study. In the first round, 5 participants attended a cognitive interview session during which they each completed the COPD Disaster Planning Questionnaire in the presence of an interviewer using the “think-aloud” technique.<sup>15,16</sup> The participant answered each item on the questionnaire, and talked about what they thought the questionnaire item was asking. The interviewer also asked probing questions to further elicit information about the participant’s comprehension. Each session was

**Table 1.** A priori codes and definitions.<sup>a</sup>

1.	CLARIFICATION OF QUESTION	Participants asks interviewer for clarification on a word or the entire question.
2.	ADEQUATE ANSWER	Participant gives an answer that is appropriate or suited to the question.
3.	INADEQUATE ANSWER	Participant does not give an answer that appropriate or suited to the question.
4.	DIFFERENT UNDERSTANDING OF QUESTION	Participant does not understand the question in the way desired by the researcher
5.	DIFFICULT UNDERSTANDING OF QUESTION	Participant demonstrates/verbalizes they are having difficulty understanding the question
6.	DIFFICULT UNDERSTANDING OF WORD	Participant demonstrates/verbalizes they are having difficulty understanding a particular word or words
7.	PARAPHRASES THE QUESTION	Participant provides definitions or characteristics of part or the entire question that demonstrates an understanding that is the same as the one desired
8.	EXPLICITLY STATES UNDERSTAND THE QUESTION	Participant states they understand the question

<sup>a</sup>These codes were used to assess the audio transcripts from patients who participated in the think-aloud method to confirm readability and comprehension.

audio-recorded and transcribed, and the transcripts were coded independently by 2 coders using a priori codes (Table 1), adapted from Willis et al.<sup>15</sup> and Willis<sup>16</sup>. The questionnaire was revised based on results and findings from the cognitive interviews, and the revised version of the questionnaire was used for the following rounds of cognitive interviews. In the next rounds, the process was repeated with 2 different participants. Revisions and subsequent rounds continued until less than 5% of the total coding demonstrated different interpretations of the items than the one anticipated.

The COPD Disaster Planning Questionnaire was assessed for grade 7 readability using the Simple Measure of Gobbledygook (SMOG) formula calculated by hand. The SMOG formula is recommended for use in health care settings<sup>17,18</sup> and involves counting the number of words with 3 or more syllables and estimating the reading grade level using the SMOG formula.

### **Test-retest reliability**

A separate sample of participants was recruited to evaluate test-retest reliability using the same recruitment strategy and inclusion/exclusion criteria as the cognitive interviewing. Each participant provided demographic information and completed the COPD Disaster Planning Questionnaire. Each participant returned 2 days later to complete the questionnaire again. For each item, the data were aggregated and analyzed for percent agreement between the 2 dates using Cohen's kappa and the prevalence-adjusted, bias-adjusted kappa (PABAK).<sup>19,20</sup> The strength of agreement between the 2 coders was defined as "fair" (0.00-0.40), "moderate" (0.41-0.60), "good" (0.61-0.80) or "excellent" (0.81-1.0).<sup>20</sup>

### **Feasibility and estimate of disaster preparedness**

A third group of participants with COPD was recruited to assess the feasibility of completing the COPD Disaster Planning Questionnaire and to gain preliminary information of their disaster preparedness. Participant recruitment, administration of the questionnaire, length of time to complete the questionnaire and number of items left unanswered were recorded and analyzed using descriptive statistics. General disaster preparedness was defined as having food and water for 3 days, and answering "yes" to at least 75% of subsequent general disaster planning items.<sup>9</sup> COPD disease-specific disaster preparedness was defined as answering "yes" to at least 75% of the COPD items in the questionnaire.

## **Results**

### **Content validity**

The initial questionnaire consisted of 21 general and 5 COPD-specific disaster preparedness items. Six individuals with clinical (Respirologist, Senior Respiratory Therapist, COPD Clinician-Scientist) or disaster management (Climate Change Adaptation Coordinator, University Program Head of Disaster & Emergency Management, Crisis and Training

Officer) expertise provided a rating for each item and written feedback. The mean score for any individual item was greater than 3 resulting in no items discarded (range 3.5-4.0). Ten items were revised and/or combined based on the experts' comments, and 4 new items were added, resulting in a 27-item questionnaire (19 general, and 8 COPD-specific) for further evaluation. The overall CVI was 1.0, indicating excellent content validity.

### **Response process validity**

Seven participants with COPD (71% men) were recruited and participated in individual cognitive interviews. The participants had a mean age of 62 years and one used supplemental oxygen. All participants lived alone. Two rounds of cognitive interviews were conducted. Coding from the first round identified 13 problems with the questionnaire, requiring revisions prior to the second round. For example, participants had difficulty understanding the polysyllabic word "exacerbation"; this word was subsequently changed to "flare-up." In the second round, 2 cognitive interviews were conducted with the revised questionnaire. The total percentage coded that identified problems with the questionnaire was 4.65%; thus, no further rounds of interviews were conducted.

### **Readability**

Using the SMOG readability formula, the questionnaire scored at a grade 9 reading level, which was higher than the recommended grade 6 reading level. Words that triggered the grade 9 reading level included "preparedness," "supplemental," and "oxygen." As these words were necessary to assess preparedness, they were retained.

### **Test-retest reliability**

Nine participants with COPD (89% women) participated in the reliability study. The participants had a mean age of 70 years and 2 used supplemental oxygen. Table 2 presents the percentage agreement, Kappa values and PABAK values for each item. Percent agreement values ranged from 56-100% with a mean (SD) of 85% (14.7%). Kappa values ranged from 0-1 with a mean of 0.54, demonstrating moderate reliability. There were several questions that demonstrated poor PABAK reliability, including: "Do you have paper cups, plates, and plastic utensils?" (PABAK 0.11) and "Do you have a list of your medication or copies of all prescriptions, and allergies?" (PABAK 0.11). However, the PABAK values ranged from 0.11-1 with a mean of 0.69, demonstrating good reliability.

### **Feasibility and disaster preparedness**

Twenty-eight participants with COPD participated in the feasibility phase. Eighty-two percent of the participants were women and 57% lived alone. The patients' mean age was 69 years and 13 (46%) used supplemental oxygen. Participants did not report any problems with understanding or

**Table 2.** Questionnaire test-retest percentage agreement, kappa ( $\kappa$ ) and prevalence-adjusted bias-adjusted kappa (PABAK) for each general disaster-preparedness and COPD-specific disaster preparedness item on the COPD Disaster Preparedness Questionnaire.

	Percentage Agreement	$\kappa$	PABAK
<b>GENERAL ITEMS</b>	100	1.00	1.00
1a) Water, at minimum 2 liters of water per person per day for at least 3 days			
1b) Food, at minimum a 3-day supply of food that will not spoil, such as canned food, energy bars and dried foods	78	0.53	0.56
1c) First-aid kit	100	1.00	1.00
1d) A working flashlight with extra batteries or a hand-crank flashlight	100	1.00	1.00
1e) A working battery-powered portable radio with extra batteries or a hand-crank radio	78	0.36	0.56
1f) Paper cups, plates and plastic utensils	56	0.14	0.11
1g) Cash in small bills and change	100	1.00	1.00
1h) Non-electric can opener or utility knife	100	1.00	1.00
1i) Antibacterial wipes or hand sanitizer	89	0	0.78
1j) Personal hygiene items such as feminine hygiene products, toilet paper, diapers, wet-wipes, towelettes, etc.	78	0.40	0.56
1k) One change of clothes per person	89	0	0.78
1l) Blanket or sleeping bag per person	78	0.40	0.56
1m) Extra keys for house and car	78	0.57	0.56
1n) A list of friends, family, caregivers and neighbors who are capable of helping you during a disaster and how to contact them	67	0.34	0.33
1o) A 3 days' supply of extra medication	100	1.00	1.00
1p) A list of your medications or copies of all prescriptions and allergies	67	0.18	0.33
1q) A list of all doctors involved in your care and their contact information	56	0.14	0.11
1r) A list of important numbers such as credit card information, insurance information, bank information, healthcare number, etc.	78	0.50	0.56
1s) All items together in a bag, or container	78	0.40	0.56
<b>COPD SPECIFIC ITEMS</b>	100	1.00	1.00
2) If you use home oxygen, do you have 72 hours of extra oxygen cylinders (compressed gas, not liquid)?			
3) If you use home oxygen, do you have a generator or backup battery packs to run your oxygen concentrator for 72 hours?	100	1.00	1.00
4) Do you have an emergency/extra supply of prednisone in case of a flare-up, if prescribed to you by a doctor or Respiriologist?	67	0.44	0.33
5) Do you have an emergency/extra supply of antibiotics in case of a flare-up, if prescribed to you by a doctor or Respiriologist?	67	0.38	0.33
6) Do you wear a medical alert bracelet at all times?	100	1.00	1.00
7) Do you have an emergency plan? (Emergency plans include plans such as how to safely exit home and neighborhood)	100	1.00	1.00
8) If you have decreased mobility/require mobility equipment such as a wheelchair, scooter walker or a walking cane, have you established a plan with someone such as a neighbor, caregiver, family or friend who can assist you evacuate from your home in case of emergency?	89	0.92	0.78
9) Do you know where the closest disaster shelter is (also called disaster support hub)?	89	0	0.78
<b>OVERALL FOR QUESTIONNAIRE</b>	<b>85</b>	<b>0.54</b>	<b>0.69</b>

answering the items. Participants took 10 to 15 minutes to complete the questionnaire. Ninety-six percent of the participants answered all questions and 1 participant missed 2 questions.

Sixty-eight percent ( $n = 19$ ) of the participants reported they had food and water for 3 days. However, only 7 of the 19 (37%) had 75% of the additional items related to general disaster preparedness. Figure 1 shows the proportion of respondents that reported having individual general disaster preparedness items. While most participants had a flashlight, extra medication and set of clothes, less than 50% of respondents had a list of their important information or disaster preparedness items together in a bag.

Participants who used supplementary oxygen ( $n = 13$ ) had 8 questions to answer about their COPD disaster preparedness. Thirty-eight percent of participants using supplementary oxygen reported COPD disaster preparedness (Figure 2). Although a large majority (91%) of participants on supplementary oxygen had an emergency/extra supply of prednisone, or an emergency/extra supply of antibiotics (86%), only 23% knew where an emergency shelter was located.

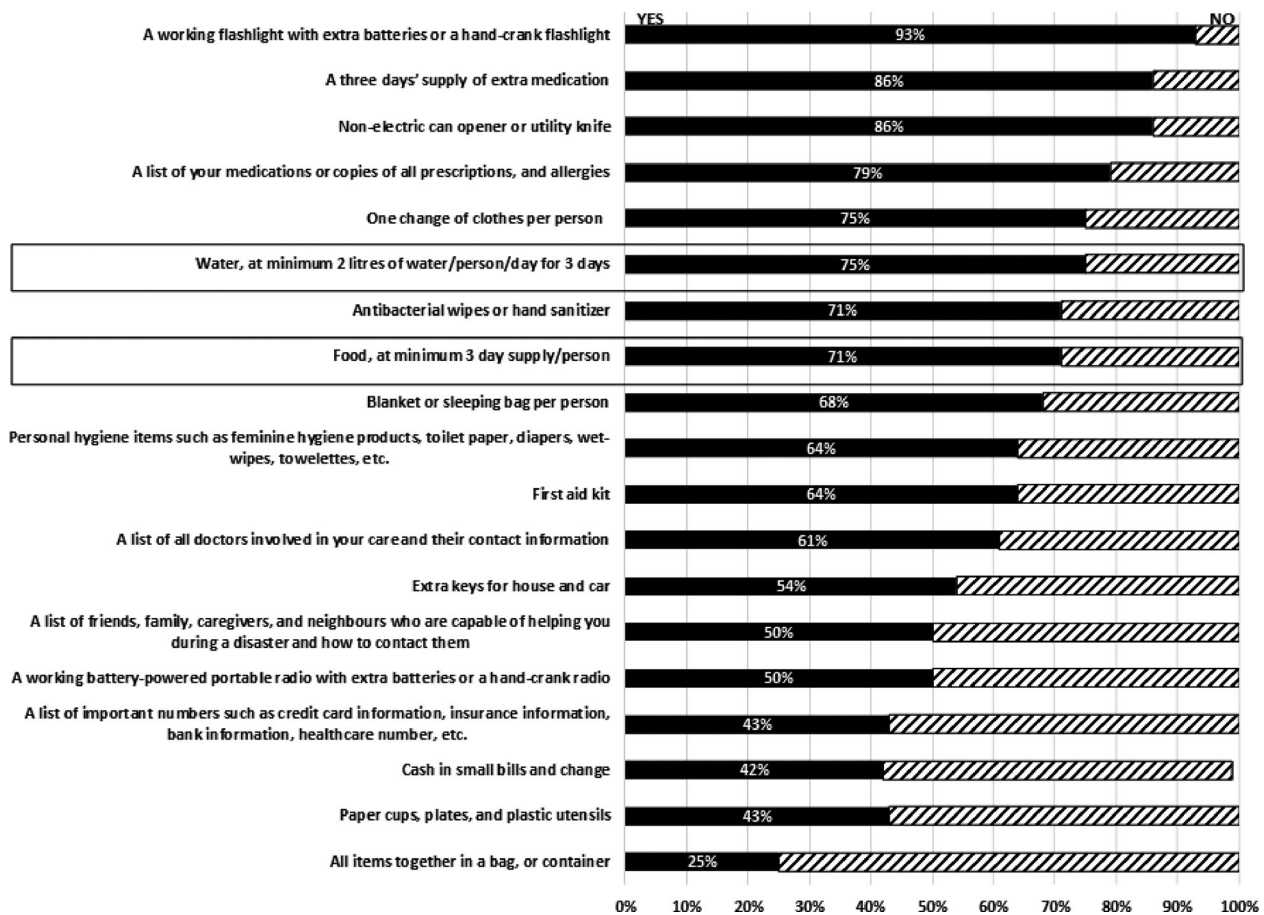
Participants not on supplementary oxygen ( $n = 15$ ) had 6 questions to answer about disaster preparedness. Four

participants (26%) reported COPD disaster preparedness. Similar to those participants on supplemental oxygen, 69% had an emergency/extra supply of prednisone and 54% had an emergency/extra supply of antibiotics, but only 7% of these participants knew where an emergency shelter was located.

## Discussion

The COPD Disaster Preparedness Questionnaire consisted of general and COPD-specific items, was valid, and had moderate reliability. In addition, the feasibility study indicated that participants with COPD were unprepared for disasters. Previous studies<sup>21-23</sup> on chronic disease and personal disaster preparedness used questionnaires such as the Behavior Risk Factor Surveillance System (BRFSS) that focused on health status but included few questions related to personal disaster preparedness. Although valid, the BRFSS only examines: having food and water for 3 days; a battery-operated radio with extra batteries; and a flashlight with extra batteries. The COPD Disaster Preparedness Questionnaire was informed by the work of Foster et al.<sup>9</sup>





**Figure 1.** General disaster preparedness of participants with COPD. The black bar represents the proportion of respondents who answered “yes” to a given question.

who examined the unique disaster preparedness needs of dialysis patients. Similarly, people with COPD also face unique challenges including decreased mobility, increased risk of respiratory exacerbations and potential dependence on supplemental oxygen. This questionnaire included items to address COPD-specific concerns.<sup>6</sup>

Although the readability of the questionnaire was at a SMOG-rated grade 9 level, the SMOG does not consider that word length may not reflect word comprehension, as high frequency words are believed to be processed globally, not syllabically.<sup>24</sup> Although the questionnaire has multisyllabic words such as “oxygen” and “preparedness,” the cognitive interviews confirmed patients with COPD understood the questions.

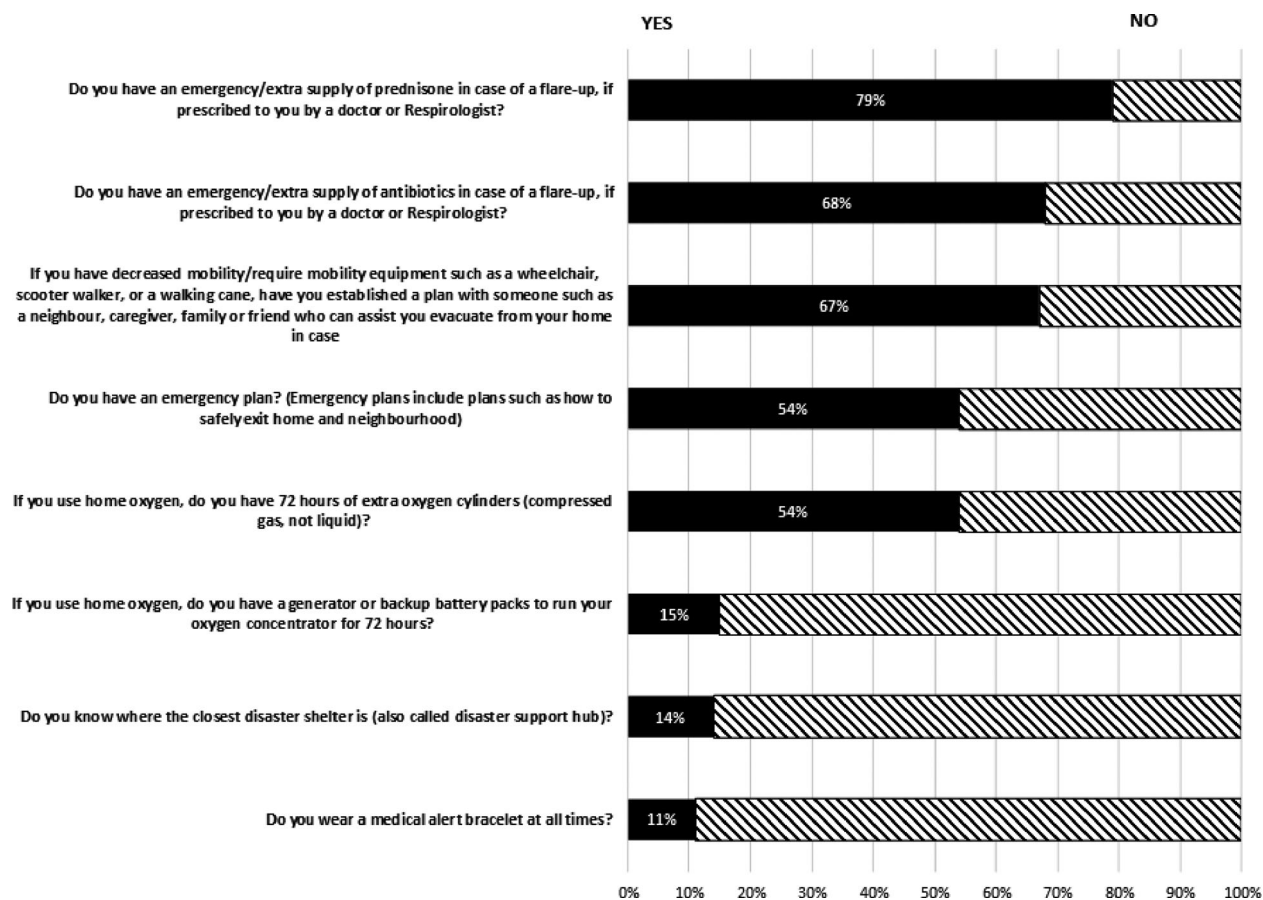
Our feasibility trial indicated that these participants with COPD were not adequately prepared for disasters. Few participants on supplemental oxygen had any of the following: 72 hours of extra compressed oxygen cylinders, a generator or backup battery pack. The low levels of disaster preparedness observed in this study was similar to other reports.<sup>9,25</sup> For example, Statistics Canada<sup>25</sup> reported that in 2014, only 24% households in Vancouver, Canada had completed 4 emergency planning activities (having an emergency exit plan, having an household emergency supply kit, copies of important documents and an emergency contact list) and only 25% had completed at least 3 precautionary measures (having a battery-operated radio; an alternate heat source, a

backup generator or stored water). The high percentage of participants in this study having a 3-day supply of medication (86%) may be because COPD medications are delivered via multidose inhalers; therefore, at a given time, the respondent had more than 3 days of medication. It may be beneficial to have the recommendation of “additional canisters,” rather than a “three-day supply” of medication.

Most participants had an emergency supply of prednisone and antibiotics. This may be artificially high, as a large number of participants were recruited from pulmonary rehabilitation or COPD clinics, which include education on action plans. Further testing on a population-based sample of people with COPD would indicate the true level of disease-specific preparedness.

The low proportion of participants with extra oxygen cylinders or backup power was concerning, as they are dependent on having continuous power to run their oxygen concentrators in order to maintain their oxygen supply. Even relatively small events can result in power failures, which could potentially result in people on home oxygen having to go to the hospital to get supplemental oxygen. In a disaster setting this would further burden the hospital system.<sup>26</sup>

To improve disaster preparedness, education could become included in COPD patient education and become part of the pulmonary rehabilitation education curriculum. In fact, the multiweek structure of pulmonary rehabilitation



**Figure 2.** COPD-specific disaster preparedness of participants with COPD. The black bar represents the proportion of respondents who answered “yes” to a given question.

could be an excellent opportunity for the cohort to improve their disaster preparedness, as the individual participants could 1) assess their preparedness at the first session; 2) use the remaining weeks to address their preparedness needs with the support other participants and program staff; and, then, 3) re-evaluate their preparedness level at the program end.

### Limitations

While the CVI is a widely-reported measure of content validity, it does not take into account the degree of agreement beyond chance.<sup>13</sup> Cognitive interviews were limited by small sample size and as a result may not be generalizable to a large population<sup>27</sup> even though it is recognized<sup>15,16</sup> that small sample sizes may be adequate to identify major problems within a questionnaire or survey. While the questionnaire test-retest results suggest a moderate correlation between test and retest, this was based on a small sample of 9 participants. The questionnaire did not focus on the needs related to specific disasters, for example, the need for air filters in the context of forest fires. As climate change develops, this questionnaire may need to be adapted to reflect specific disaster risks. The participants were all recruited from COPD clinics in an urban setting, thus limiting generalizability to the overall COPD population or and/or those in rural/remote settings.

### Conclusion

A minimal amount of research has been carried out on disaster preparedness of people with a chronic disease. This study addressed this gap by developing and validating the COPD Disaster Preparedness Questionnaire, which can be used as a tool by patients, researchers, clinicians and program planners to examine how people with COPD in their community are preparing for disasters.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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