Agreement between obstructive airways disease diagnoses from self-report questionnaires and medical records

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ABSTRACT

Objective: To evaluate agreement between self-reported obstructive airways disease (OAD) diagnoses of asthma, bronchitis, and chronic obstructive pulmonary disease (COPD)/emphysema obtained from the New York City Fire Department (FDNY) monitoring questionnaires with physician diagnoses from FDNY medical records.

Method: We measured sensitivity, specificity, and agreement between self-report and physician OAD diagnoses in FDNY members enrolled in the World Trade Center (WTC) monitoring program who completed a questionnaire between 8/2005–1/2012. Using logistic models, we identified characteristics of those who self-report a physician diagnosis that is also reported by FDNY physicians.

Results: 20.3% of the study population (N = 14,615) self-reported OAD, while 15.1% received FDNY physician OAD diagnoses. Self-reported asthma had the highest sensitivity (68.7%) and overall agreement (91.9%) between sources. Non-asthma OAD had the lowest sensitivity (32.1%). Multivariate analyses showed that among those with an OAD diagnosis from FDNY medical records, inhaler use (OR = 4.90, 95% CI = 3.84–6.26) and respiratory symptoms (OR = 1.55 [95% CI = 1.25–1.92]–1.77 [95% CI = 1.37–2.27]) were associated with self-reported OAD diagnoses.

Conclusion: Among participants in the WTC monitoring program, sensitivity for self-reported OAD diagnoses ranges from good to poor and improves by considering inhaler use. These findings highlight the need for improved patient communication and education, especially for bronchitis or COPD/emphysema.

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Introduction

In many epidemiologic studies, including the National Health Interview Survey and the World Trade Center (WTC) Registry, participants' self-reports of physician diagnoses are used to estimate the prevalence of health outcomes (Centers for Disease Control and Prevention; WTC Health Registry). Previous studies have compared the prevalence of self-reported physician diagnoses to diagnoses obtained from medical records, particularly for chronic disorders such as cancer, diabetes and cardiovascular disease. Sensitivities of self report range from 7.3 to 71% for cancer, 49.3–91% for hypertension, and 20.5–64% for heart disease, revealing substantial variability by specific condition due to vast differences in methodologies and populations (Barr et al., 2009; Berthier et al., 1997; Bush et al., 1989; Haapanen et al., 1997; Harlow and Linet, 1989; Hiatt et al., 1995; Kehoe et al., 1994; Lampe et al., 1999; St Sauver et al., 2005; Toren et al., 1993; Walker et al., 1998). Despite the

range of sensitivities, studies have found that agreement may be higher for serious conditions (Bergmann et al., 2004).

Examining studies of concordance for obstructive airways diseases (OAD), we found most compare agreement between self-report and diagnostic tests like spirometry or bronchial challenge testing (Mullerova et al., 2004; Toren et al., 1993; Trepka et al., 2009). Among those that do compare self-report with medical records, one found asthma sensitivity and positive predictive value (PPV) to be 35.1% and 66% (Mohangoo et al., 2006), while another calculated the sensitivity of reporting asthma and chronic obstructive pulmonary disease (COPD) in a treated population as 93% and 61.1%, respectively (Abramson et al., 2012). In a large military cohort, the positive agreement between sources was 42% for asthma, 12.9% for chronic bronchitis, and 2.7% for emphysema (Smith et al., 2008).

Respiratory health is an important outcome for WTC-related research and has been studied extensively by the Fire Department of the City of New York (FDNY) and other WTC-associated groups (Banauch et al., 2003; Brackbill et al., 2009; Lin et al., 2005; Mauer et al., 2010; Reibman et al., 2005; Webber et al., 2009). To date, of the more than 125 published studies of respiratory conditions in the FDNY cohort and

other WTC-exposed workers and neighborhood residents, almost all rely exclusively on self-reported diagnoses and symptoms from questionnaire data.

Agreement between diagnostic sources is important. Although we recognize that physician records are subject to diagnostic errors, poor documentation, and coding errors, we believe that respiratory diagnoses from FDNY medical records are more likely to be accurate than community physician records for an important reason: FDNY records are critical in duty determination and hence the need to appropriately document a disorder that could compromise a firefighter's ability to successfully perform his/her job duties. Further, the FDNY workforce is generally well informed about WTC-related health conditions, especially since passage of the federal James L. Zadroga 9/11 Health and Compensation Act of 2010. The FDNY is therefore in the unique position of having self-reported physician diagnoses from questionnaires taken at regularly scheduled medical monitoring exams and electronic records of FDNY physician diagnoses separate from the medical monitoring questionnaires. Although we do not include information from physicians outside of the World Trade Center Health Program (WTCHP), we believe that the majority of patients with respiratory issues seek treatment at FDNY because specialists are available on site, and FDNY treatment visits, including prescribed medications, are available without cost or co-payment.

The current study evaluates agreement between self-reported diagnoses of OAD, which include asthma, bronchitis, and COPD/emphysema, and FDNY physician diagnoses of these conditions within a 12-month time period. To assess this, we measure the sensitivity, specificity and overall agreement between diagnoses from these sources and show how the sensitivity and specificity vary by OAD subtype. Finally, we fit logistic regression models to identify characteristics of those who self-report a diagnosis that is also reported by an FDNY physician in the medical treatment record.

Methods

The FDNY-WTCHP schedules monitoring evaluations of the active and retired WTC-exposed workforce every 12 to 18 months and provides separate visits for evaluation/treatment, as required. Study participants are required to give written informed consent. The study was approved by the institutional review board at Montefiore Medical Center, Bronx, NY.

Participants

Of 15,837 members enrolled in the FDNY-WTCHP, the primary study population consisted of 14,615 (12,528 firefighters and 2087 EMS) who completed a medical monitoring questionnaire on or after 8/12/2005 — the date when questions on self-reported physician diagnoses were introduced (Fig. 1).

Data sources

Demographic information, active or retired work status and service (firefighting or EMS) came from the FDNY employee database. Questionnaire data were used to describe respiratory symptoms, inhaler use, smoking status, and physician diagnoses of OAD. For the majority of participants who had more than one questionnaire since 2005, only the most recent questionnaire was analyzed.

Self-reported OAD diagnoses from the monitoring questionnaires

Self-reported physician OAD diagnoses were based on a positive response to any of the following: "In the past 12 months, has a doctor or health professional told you that you have Emphysema or COPD?"; "In the past 12 months, has a doctor or health professional told you that you have Bronchitis?" and, "In the past 12 months, has a doctor or health professional told you that you have Asthma/RADS (Reactive Airways Dysfunction Syndrome?)". Individuals could respond affirmatively to none or one or more of these questions.

FDNY physician OAD diagnoses from treatment records

Asthma, bronchitis or emphysema/COPD were defined as present if the participant had one or more evaluation/treatment visits with a diagnosis of OAD in the FDNY medical treatment record within 12 months before the index monitoring questionnaire date. We looked specifically at this time period to be consistent with the 12-month time frame of the self-reported questions. If there was no treatment visit within the index period, we considered the participant as not having an FDNY physician visit for OAD. We categorized OAD diagnoses into two mutually exclusive groups: 1) asthma, which included an asthma diagnosis with or without another OAD; and, 2) non-asthma OAD, which included bronchitis and/or COPD/emphysema when asthma was not present during the index period.

Self-reported symptoms, provocability, and inhaler use from the monitoring questionnaires

Respiratory symptom(s) reported on questionnaires were based on responses to the question, "In the past 12 months, apart from when you had a cold or flu, did you have any of the following symptoms?" Possible responses included "none", "wheezing or whistling in your chest", "chest tightness", "shortness of breath", "frequent or usual cough (at least 4 times per day, 4 days per week, 4 consecutive weeks per year)". Except for "none", individuals were not limited to one response. We characterized the presence of shortness of breath and/or wheezing as a single variable that we label 'dyspnea/wheeze'. Provocability was defined as a positive questionnaire response to experiencing the respiratory symptoms of cough, wheeze, shortness of breath, or chest tightness in the last 12 months during exercise/physical activity or when exposed to smoke/fumes, strong odors, dust, allergens, or temperature/humidity extremes. Inhaler use was determined by a positive response to receiving, in the past 12 months, either inhaled bronchodilators, inhaled steroids, or nebulized medications.

Statistical analysis

General population characteristics were represented as proportions. We calculated sensitivity, specificity, positive and negative predictive values for self-reported diagnoses compared to FDNY physician diagnoses in the 12-month index period. We used the following definitions: Sensitivity is the proportion of those with the medical record diagnosis who correctly self-report the same diagnosis on the questionnaire. Specificity is the proportion of those who do not have the medical record diagnosis who also self-report *not* having the same diagnosis on the questionnaire. The positive predictive value (PPV) is the proportion of people with a self-reported diagnosis who have a medical record of the same disorder and negative predictive value (NPV) is the proportion of people *without* a self-reported diagnosis who do not have the same disorder in the medical record. Overall agreement is the proportion of people for whom the presence or absence of diagnosis was the same for both self-report and medical record (Rothman et al., 2008).

We used multivariate logistic regression models to assess the association between respiratory symptoms (dyspnea/wheeze, provocability, and cough), demographic and other characteristics and a self-report of the same diagnosis in those with FDNY medical record diagnoses of OAD (N = 2211), asthma (N = 1287), or non-asthma OAD (N = 924). To test how well our data fit the models, we used the Hosmer and Lemeshow goodness-of-fit test (Hosmer and Lemeshow, 1980).

As a sensitivity analysis, we restricted the primary study population to include only members who had one or more treatment visits to an FDNY-WTC treatment physician (pulmonologist or WTC internist) within the 12 month time frame (N = 8044). FDNY-WTC treatment physicians are more likely to evaluate patients with respiratory concerns and thus this subset had a higher frequency of OAD diagnoses. Analyses were performed using SAS version 9.3.

Results

We assessed 12-month agreement between self-reported OAD diagnoses from monitoring questionnaires and FDNY physician treatment record OAD diagnoses in 14,615 FDNY workers. The average age at the time of the index survey was 48.4 ($\pm$9.5 SD) years. Asthma was the single most commonly reported OAD diagnosis from FDNY physician records (8.8% of total study population) (Table 1). About 14% of those with an FDNY physician diagnosis of asthma in the treatment record
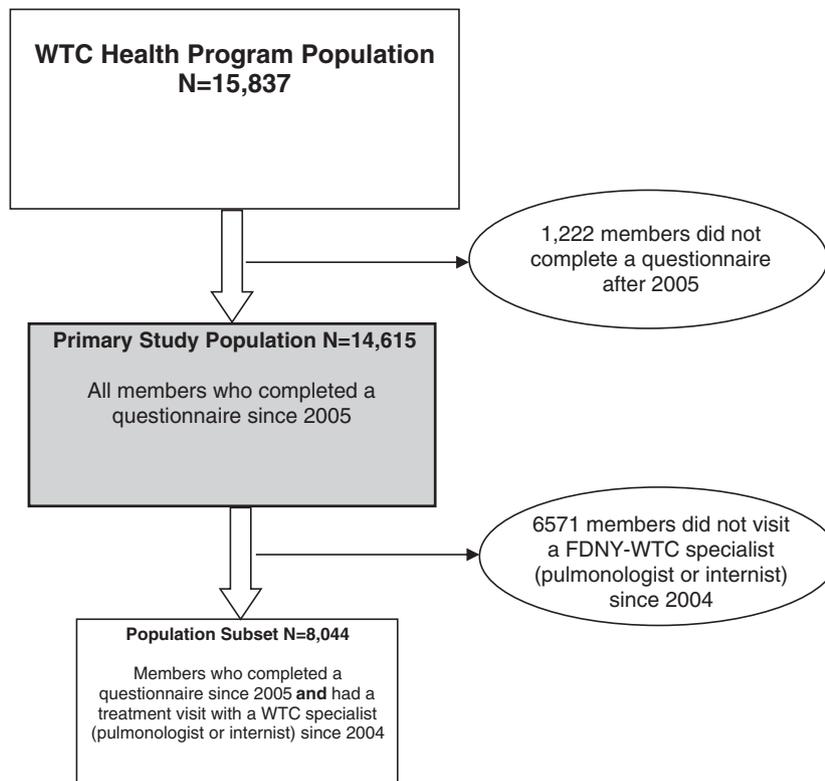
Fig. 1. Description of Fire Department of the City of New York (FDNY) WTC* study population and subset for sensitivity analyses.

also had physician diagnoses of bronchitis or emphysema/COPD (data not shown).

Rates of self-reported OAD, asthma, and non-asthma OAD diagnoses were consistently higher than FDNY physician diagnoses from treatment records: 20.3% vs. 15.1%, 11.4% vs. 8.8% and 8.9% vs. 6.3%, respectively. Agreement between sources was highest for asthma (91.9%), and was lower for non-asthma OAD (88.9%) and for any OAD (84.0%) (Table 2). Sensitivity of self-report varied considerably by diagnosis and was lower than specificity for all conditions. Similarly, the NPV for all conditions was considerably higher than the PPV. When we re-calculated sensitivity, specificity, PPV and NPV in the population subset (only those with one or more treatment visits to an FDNY-WTC treatment physician within the 12 month time frame), we found that sensitivity and specificity were similar across both groups, but the PPV was higher (Table 2). This was expected based on the higher prevalence of FDNY physician diagnosed OAD in this subset (28.9%) compared with 15.1% in the primary study population.

In Table 3 we examined predictors of self-reporting diagnoses in those with FDNY physician diagnoses. Participants with an FDNY physician diagnosis of OAD were more likely to self-report OAD if they reported current symptoms of either dyspnea/wheeze or cough (OR 1.77, 95% CI, 1.37–2.27 and OR 1.55, 95% CI, 1.25–1.92), or if they reported using an inhaler (OR 4.90, 95% CI, 3.84–6.26). Those who had FDNY medical record diagnoses of asthma were more likely to report asthma if they also reported provocable symptoms (OR 2.18, 95% CI, 1.34–3.53) or dyspnea/wheeze (OR 2.03, 95% CI, 1.39–2.95), and especially if they reported inhaler use (OR 5.17, 95% CI, 3.34–8.00). We also found that for each month elapsed between the date of an FDNY physician diagnosis of OAD, asthma or non-asthma OAD and the date the of questionnaire completion, participants were 2–5% less likely to self-report the diagnosis. For example, participants were 55% less likely to report asthma if their treatment visit occurred 12 months prior compared with 1 month prior to taking the questionnaire. Self-reported inhaler use

was the only variable associated with self-report of an OAD in all models. The Hosmer and Lemeshow goodness-of-fit test for the OAD, asthma, and non-asthma OAD logistic models produced p-values of adequate to excellent fit (0.60, 0.97, and 0.13 respectively).

Discussion

Self-reported diagnoses of asthma had the highest total agreement with physician diagnoses from FDNY treatment records; self-reported asthma also had the highest sensitivity, specificity, PPV and NPV as compared with OAD and non-asthma OAD diagnoses. These results suggest that our patients find asthma to be the most recognizable and understood OAD. In contrast, self-reported non-asthma OAD had low sensitivity and PPV. While most non-asthma OAD diagnoses were bronchitis, specialized test results to distinguish between chronic bronchitis, emphysema, COPD and other non-asthma OAD were not available for analyses. We realize that there is considerable variability in the use of these diagnostic labels by physicians (Tinkelman et al., 2006). Lower prediction of self-report for non-asthma OAD may reflect lower health literacy of these conditions, poorer physician–patient communication, and/or less physician confidence in assigning and discussing this diagnosis.

Our multivariate models demonstrate that inhaler use, even more than dyspnea/wheeze, had a strong association with self-reported diagnoses in all outcome categories. We believe that those who report inhaler use are frequently reminded of their illness and may therefore be more invested in understanding or remembering their diagnosis. The association between inhaler use and self-reported disease was strongest in asthma, consistent with the standard of treatment for this disease (Qaseem et al., 2011; U.S. Department of Health and Human Services National Institutes of Health, 2007).

Finally, we were interested in understanding to what extent agreement between self-reported diagnoses and FDNY physician diagnoses was influenced by the population selected for analysis. Our primary

Table 1
Selected characteristics of FDNY[a] primary study population between 8/12/2005 and 1/31/2012.

Characteristic	Study population N = 14,615	
	N	%
Demographics		
Male	14,080	96.3
Firefighting	12,528	85.7
EMS	2087	14.3
Retired on survey date	5639	38.6
Age less than 30 on survey date	200	1.4
Age 30–39 on survey date	2480	17.0
Age 40–49 on survey date	5561	38.1
Age 50–59 on survey date	4710	32.2
Age 60 or greater on survey date	1664	11.4
Never smoker	8750	59.9
Self-reported diagnoses		
Any OAD[b]	2971	20.3
All asthma	1672	11.4
Asthma only	1054	7.2
Asthma with other OAD[c]	618	4.2
All non-asthma OAD[d]	1299	8.9
Bronchitis only	1120	7.7
Emphysema/COPD only	129	0.9
Bronchitis and Emphysema/COPD	50	0.3
FDNY physician diagnoses		
Any OAD[b]	2211	15.1
All asthma	1287	8.8
Asthma only	1105	7.6
Asthma with other OAD[c]	182	1.2
All non-asthma OAD[d]	924	6.3
Bronchitis only	846	5.8
Emphysema/COPD only	72	0.5
Bronchitis and Emphysema/COPD	6	0.04
Respiratory symptoms		
Dyspnea and/or wheeze	5225	35.8
Provocability	7144	48.9
Cough	2958	20.2
Inhaler use (self-reported)	3111	21.3

[a] Fire Department of the City of New York.
[b] Includes asthma, acute and chronic bronchitis, COPD/emphysema.
[c] Other OAD includes bronchitis and emphysema/COPD.
[d] Includes all bronchitis and COPD/emphysema diagnoses with no concurrent asthma diagnosis during the index period.

population was unrestricted, i.e., we analyzed questionnaire data about symptoms and self-reported physician diagnoses without regard to whether the participant saw any FDNY physician in the previous 12 months. Since by definition, no FDNY physician visit in this time frame meant no OAD diagnoses in the treatment records, we reduced the prevalence of OAD to lower levels, thereby minimizing the PPV of a self-reported diagnosis in this general population. As a sensitivity analysis, we selected a population subset with one or more visits to a pulmonologist/WTC specialist during the 12-month time frame. We found that sensitivity, specificity and NPV measurements did not appreciably differ between these populations, suggesting that lower levels of agreement for OAD and especially non-asthma OAD did not result from the inclusion of non-OAD FDNY treatment visits. However, as expected, we saw an increase in the PPV of self-reported diagnoses as disease prevalence increased as a function of the population restriction.

We used physician diagnoses from FDNY medical treatment records instead of diagnostic test results, as this study's aim was to assess the agreement between patient reports and physician records. While we could not validate FDNY physician diagnoses, and we recognize that previous work has suggested under-diagnosis of both asthma and COPD (Abramson et al., 2012; Montnemery et al., 2002; Zwar et al., 2011), we feel that this was less likely to be true in our study because of the importance of OAD diagnoses in the FDNY workforce.

The main limitation of this study is the inability to address potential sources of discordance. Since we were unable to access medical records from community physicians, we could not account for diagnoses that were given by non-FDNY physicians, reducing concordance. We believe, however, that this had minimal impact on our results because the majority of our patients receive their respiratory healthcare from FDNY through our WTCHP, which is the only way for them to access free care, including medications. As evidence, we note that sensitivity and specificity were similar in the primary and restricted study populations.

On the physician side, discordance could result from errors in documentation or coding. On the patient side, discordance could result from self-diagnosis, recall bias, and/or the under- or over-reporting of diagnoses based on their perceived desirability and secondary gain. Physician–patient miscommunication, which is rarely one-sided in nature, may also be a cause of discordance. Physicians should spend more time and better target their communications to the medical literacy of their patients. Medical literacy may partially explain some of the observed discordance, as evidenced by the greater likelihood of EMS workers to self-report an OAD diagnosis, especially asthma. Future studies might test the effectiveness of providing patients with a written explanation of their diagnosis, specifically targeted to this population.

Conclusion

In summary, we believe that this large study of more than 14,600 firefighters and EMS workers provides strong evidence that there is reasonably good sensitivity for asthma patients to self-report their diagnoses. Because patients with asthma are more likely to self-report the diagnosis if they have symptoms and use inhalers, we feel that population screening measures may benefit by taking these factors into account. Since all three diagnostic categories had higher specificity than sensitivity, and higher NPV than PPV, we suggest that self-reported diagnoses may be useful to track trends of disease in population studies when the prevalence is high and may be useful for ruling out a diagnosis when the prevalence is low.

Table 2
Sensitivity and specificity of self-reported respiratory diagnoses between 8/12/2005 and 1/31/2012 in relation to medical record-documented diagnoses in FDNY[a] members.

Analysis type		Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)	Total agreement (%)
Entire population N = 14,615	OAD[b]	64.2	87.5	47.8	93.2	84
	Asthma	68.7	94.1	52.9	96.9	91.9
	Non-asthma OAD[c]	32.1	92.7	22.9	95.3	88.9
Restricted population[d] N = 8044	OAD[b]	67.9	86.2	62	89	81.7
	Asthma	68.7	93.2	65.6	94	89.3
	Non-asthma OAD[c]	34.0	91.7	28.8	93.4	86.5

[a] Fire Department of the City of New York.
[b] Includes asthma, acute and chronic bronchitis, COPD/emphysema.
[c] Non-asthma OAD includes bronchitis and emphysema/COPD in those without asthma.
[d] Sensitivity and specificity of self-reported respiratory diagnoses between 8/12/2005 and 1/31/2012 in relation to medical record-documented diagnoses from a FDNY World Trade Center specialty physician (pulmonologist or internist).

Table 3

Odds ratios (OR) and 95% confidence intervals for self-reporting in an FDNY[a] obstructive airways disease (OAD) diagnosed population between 8/12/2005 and 1/31/2012.

Model A. Predictors of self-report OAD[b] diagnosis in people with FDNY physician diagnosed OAD n = 2211		Model B. Predictors of self-report asthma diagnosis in people with FDNY physician diagnosed asthma n = 1287		Model C. Predictors of self-report non-asthma OAD diagnosis in people with FDNY physician diagnosed non-asthma OAD[c] n = 924	
	OR(95% CI)		OR(95% CI)		OR(95% CI)
Respiratory symptoms		Respiratory symptoms		Respiratory symptoms	
Dyspnea and/or wheeze	1.77(1.37–2.27)	Dyspnea and/or wheeze	2.03(1.39–2.95)	Dyspnea and/or wheeze	0.96(0.68–1.36)
Provocability	1.65(1.24–2.19)	Provocability	2.18(1.34–3.53)	Provocability	1.06(0.74–1.52)
Cough	1.55(1.25–1.92)	Cough	1.47(1.12–1.92)	Cough	1.19(0.86–1.64)
Demographics		Demographics		Demographics	
Age ≥48 on survey date	0.83(0.66–1.05)	Age ≥48 on survey date	0.75(0.55–1.02)	Age ≥48 on survey date	1.00(0.73–1.38)
Male vs female	1.53(0.77–3.04)	Male vs female	0.79(0.33–1.87)	Male vs female	4.40(0.86–22.55)
Fire vs EMS	0.64(0.40–1.04)	Fire vs EMS	0.56(0.31–1.02)	Fire vs EMS	1.52(0.65–3.52)
Ever smoking vs never	1.01(0.82–1.24)	Ever smoking vs never	0.77(0.59–1.00)	Ever smoking vs never	1.75(1.29–2.38)
Retired vs active[d]	1.25(0.96–1.64)	Retired vs active[d]	1.67(1.07–2.61)	Retired vs active[d]	0.42(0.28–0.63)
Other		Other		Other	
2 or more OAD diagnoses in index period	1.20(0.96–1.49)	2 or more asthma diagnoses in index period	1.45(1.08–1.94)	2 or more non-asthma OAD diagnoses in index period	1.38(1.00–1.90)
Months between survey and FDNY physician visit	0.96(0.93–0.99)	Months between survey and FDNY physician visit	0.95(0.92–0.99)	Months between survey and FDNY physician visit	0.98(0.94–1.02)
Inhaler use	4.90(3.84–6.26)	Inhaler use	5.17(3.34–8.00)	Inhaler use	2.01(1.44–2.79)

[a] Fire Department of the City of New York.
[b] OAD includes asthma, acute and chronic bronchitis, COPD/emphysema.
[c] Non-asthma OAD includes bronchitis and emphysema/COPD in those without asthma.
[d] FDNY retirement status as of 1/31/2012.

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