



The hidden complexity of measuring number of chronic conditions using administrative and self-report data: A short report

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Abstract

Objective: To examine agreement between administrative and self-reported data on the number of and constituent chronic conditions (CCs) used to measure multimorbidity.

Study Design and Setting: Cross-sectional self-reported survey data from four Canadian Community Health Survey waves were linked to administrative data for residents of Ontario, Canada. Agreement for each of 12 CCs was assessed using kappa (κ) statistics. For the overall number of CCs, perfect agreement was defined as agreement on both the number and constituent CCs. Jackknife methods were used to assess the impact of individual CCs on perfect agreement.

Results: The level of chance-adjusted agreement between self-report and administrative data for individual CCs varied widely, from $\kappa = 5.5\%$ (inflammatory bowel disease) to $\kappa = 77.5\%$ (diabetes), and there was no clear pattern on whether using administrative data or self-reported data led to higher prevalence estimates. Only 26.9% of participants had perfect agreement on the number and constituent CCs; 10.6% agreed on the number but not constituent CCs. The impact of each CC on perfect agreement depended on both the level of agreement and the prevalence of the individual CC.

Conclusion: Our results show that measuring agreement on multimorbidity is more complex than for individual CCs and that even small levels of individual condition disagreement can have a large impact on the agreement on the number of CCs.

Keywords

Multimorbidity, chronic conditions, agreement, administrative data, self-report data

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Introduction

The overall number of chronic conditions (CCs) as a measure of multimorbidity is commonly used as an outcome, risk factor, or confounder in population-based and clinical research. Differences in multimorbidity estimates have been attributed to the way that multimorbidity is measured, including the selection and number of CCs considered,¹ population differences,² differences among multimorbidity definitions,³ and the data source used, the most common being administrative data and self-report.⁴ While there is not broad agreement on how best to measure multimorbidity, in this short report, we focus on one component, data source. Several studies have previously examined agreement across data sources on individual CCs,^{5,6} and a small number have explored agreement on specific definitions of multimorbidity (e.g. the occurrence of two or more CCs),² but to the best of our knowledge, no researchers have examined agreement on both the number and constituent CCs. In this article, we present agreement between administrative and self-reported population-based data from Ontario, Canada, on the overall number and the constituent conditions from a list of 12 CCs. We further examine the impact of each condition on agreement with the overall number of CCs between the two data sources.

Methods

Study design and population

This study uses cross-sectional self-reported data from the Canadian Community Health Survey (CCHS) linked to administrative data holdings in Ontario, Canada, with a population of approximately 14.6 million people.⁷ A full description of the data sources and study sample is included in other publications^{8–10} and is briefly described below.

Data sources

The CCHS is a national cross-sectional survey that collects information about health status and health determinants. Ontario participants from CCHS cycles “3.1” 2005–2006,¹¹ 2007–2008,¹² 2009–2010,¹³ and 2011–2012¹⁴ who were aged 45 years and older and agreed to linkage with administrative data comprised the study sample ($N = 73,717$; 78.4% of CCHS respondents across cycles agreed to linkage). Administrative data sources included physician visits, inpatient hospitalizations, and emergency department visits. Both CCHS and administrative data sources were used to estimate the frequency of each CC based on the date of CCHS completion (i.e. the index date).

Chronic conditions

The following 12 CCs were used in the analyses: Alzheimer’s diseases/dementia, anxiety/depression, arthritis, asthma, cancer, chronic obstructive pulmonary disease

(COPD), diabetes, heart disease, hypertension, inflammatory bowel disease (IBD), stomach or intestinal ulcers, and stroke. CC status was ascertained through self-reported physician diagnosis (CCHS) or via algorithms developed for research use (administrative data).¹⁵ The number of CCs was operationalized as the sum of the 12 candidate conditions (0, 1, 2, 3, etc.)

Statistical analysis

Agreement was examined for (1) individual CCs, (2) the number of CCs (in which the constituent CCs could differ), and (3) “perfect agreement” on the number and constituent CCs. We assessed raw agreement and chance-adjusted agreement using Cohen’s κ statistics.¹⁶ We further used jackknife methods to examine the influence of individual CCs on perfect agreement. This was done by removing each of the 12 CCs sequentially from the condition list and estimating the resulting increase in perfect agreement. All analyses were done using SAS 9.4.¹⁷

The use of data in this project was authorized under section 45 of Ontario’s Personal Health Information Protection Act. The study was approved by the Hamilton Integrated Research Ethics Board at McMaster University (Ethics certificate no.: 13-590).

Results

Study participants

Approximately 56% of the participants were 45–64 years of age, 56.2% were female, and participants were evenly split among the neighborhood income groups (Table 1). The proportion of participants with no CCs was 18.3% based on administrative data and 24.6% based on self-report. The proportion of participants with each of 2, 3, 4, and 5+ CCs was higher for administrative data than self-report.

Agreement on individual CCs and overall number of CCs

The raw agreement between data sources was over 80% for all conditions except arthritis for which raw agreement was 65.0%. κ (chance-adjusted agreement) varied from 77.5% (95% confidence interval (CI) 76.9–78.2) for diabetes to 5.5% (95% CI 4.6–6.3) for IBD (Table 2). Although there was no clear pattern on which data source led to higher individual condition prevalence estimates, the average overall number of CCs was higher using administrative data (1.87) compared to self-report (1.64). There was disagreement on the number of CCs for 62.5% of participants; 26.9% had perfect agreement on the number and constituent conditions and 10.6% agreed on the number but not the constituent conditions.

Table 1. Prevalence of demographic characteristics and number of CCs based on administrative data and self-report for 71,318 Ontario participants 45 years or older of the CCHS cycles 3-6

Characteristic	Total Cohort (N=71,317)
Sex	
Male	31,210 (43.76%)
Female	40,107 (56.24%)
Age group (years)	
45–54	18,101 (25.38%)
55–64	21,765 (30.52%)
65–74	16,979 (23.81%)
75–84	11,382 (15.96%)
85+	3090 (4.33%)
Neighborhood income quintile	
Lowest	13,796 (19.3%)
2	14,244 (20.0%)
3	14,237 (20.0%)
4	14,620 (20.5%)
Highest	14,418 (20.2%)
Number of CCs based on administrative data	
0	13,059 (18.3%)
1	19,065 (26.7%)
2	17,824 (25.0%)
3	11,671 (16.4%)
4	6081 (8.5%)
5+	3617 (5.1%)
Number of CCs based on self-report	
0	17,533 (24.6%)
1	20,215 (28.4%)
2	16,297 (22.9%)
3	9692 (13.6%)
4	4569 (6.4%)
5+	3011 (4.2%)

CC: chronic condition; CCHS: Canadian Community Health Survey.

Impact of individual conditions on perfect agreement

To assess the impact of individual CCs on perfect agreement, we examined the increase in percent of perfect agreement when each of the conditions was excluded one by one from the list of 12 CCs. In Figure 1, the size of the circle represents the average prevalence (using the two data sources) of the condition, and the individual conditions' agreement is on the x -axis. Alzheimer's disease had the smallest impact on agreement, its exclusion increasing perfect agreement by 0.1%; arthritis had the largest impact, increasing perfect agreement by 13.4%. The increase in perfect agreement depended on both the prevalence and the level of agreement of the individual CC. For example, COPD and arthritis have a similar level of agreement ($\kappa = 30.3$ and $\kappa = 30.2$, respectively), but the average prevalence of COPD was 10.8% compared to 44.8% for arthritis. Removing COPD from the list of CCs increased perfect agreement by 2.5%, whereas removing arthritis led to a five times greater increase of 13.4%.

Discussion

We found that for individual conditions, the level of agreement between self-report and administrative data varied widely and there was no clear pattern on whether using administrative data or self-reported data led to higher prevalence estimates. Although estimates of overall number of CCs were consistently higher using administrative data, almost half of the individual conditions had a higher prevalence based on self-report. It has been speculated that diseases which are less familiar to patients and/or have nonspecific and intermittent symptoms, such as chronic lung disease, tend to be underreported by patients¹⁸ and

Table 2. Prevalence of individual CCs using administrative data and self-report, and raw agreement, chance-adjusted, and chance-independent agreement between data sources.^a

Condition	Administrative data (%)	Self-reported data (%)	Raw agreement (%; 95% CI)	Kappa (%; 95% CI)
Individual CCs				
Hypertension	47.9	44.0	82.8 (82.5, 83.1)	65.4 (64.9, 66.0)
Arthritis (including fibromyalgia)	51.0	38.7	65.0 (64.6, 65.3)	30.2 (29.5, 30.9)
Anxiety/depression	23.1	11.9	81.0 (80.7, 81.3)	35.5 (34.7, 36.3)
Diabetes	16.6	12.8	94.3 (94.2, 94.5)	77.5 (76.9, 78.2)
Cancer	9.8	14.4	93.1 (92.9, 93.3)	67.8 (66.9, 68.6)
Heart disease	10.4	12.5	90.0 (89.8, 90.2)	50.7 (49.7, 51.7)
COPD (emphysema, chronic bronchitis)	15.0	6.7	86.3 (86.1, 86.6)	30.3 (29.3, 31.3)
Asthma	5.1	8.0	91.1 (90.9, 91.3)	27.4 (26.2, 28.7)
Stroke	4.8	2.8	95.3 (95.1, 95.4)	35.2 (33.5, 36.9)
IBD	0.3	7.1	93.1 (92.9, 93.2)	5.5 (4.6, 6.3)
Stomach or intestinal ulcers	2.1	4.2	94.4 (94.2, 94.6)	8.8 (7.6, 10.1)
Alzheimer's disease or dementia	1.2	0.9	98.8 (98.7, 98.9)	42.8 (39.6, 45.9)
Number of CCs (mean, SD)	1.87 (1.45)	1.64 (1.44)		

CC: chronic condition; CI: confidence interval; COPD: chronic obstructive pulmonary disease; IBD: inflammatory bowel disease; SD: standard deviation.
^aConditions are ordered from the highest to lowest average prevalence between administrative and self-report data.

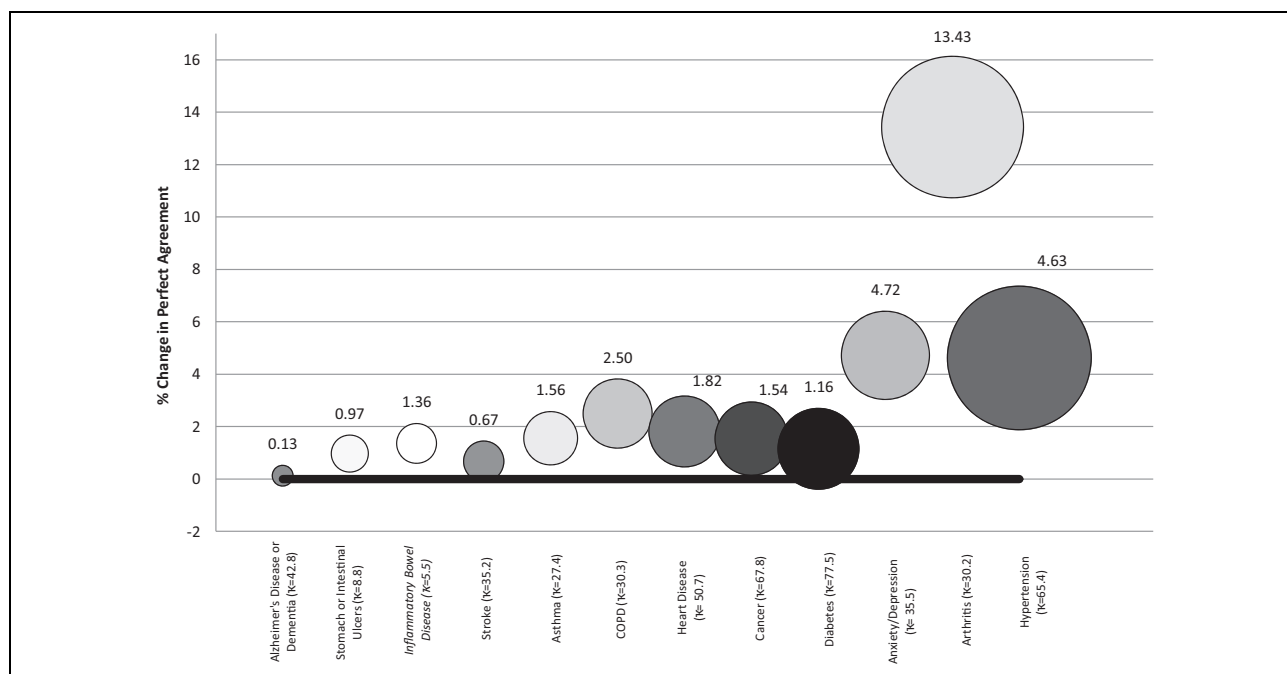


Figure 1. Percent improvement in perfect agreement between administrative data and self-report on the number of CCs when each individual CC is removed from the condition list used to generate the number of CCs. The size of each bubble indicates the relative prevalence of the CCs based on administrative data. The κ for individual condition agreement is indicated on the x-axis. κ : Kappa; CC: chronic condition; COPD: chronic obstructive pulmonary disease.

thus have lower levels of agreement. In contrast, diseases that are well-defined and relatively easy to diagnose¹⁹ or that require ongoing self-management and ongoing contact with the health-care system,^{20,21} such as diabetes, have higher levels of agreement. This is reflected in our results as we found the highest level of agreement with diabetes, heart disease, hypertension, stroke, and cancer. Unlike previous studies, we broke down the overall multimorbidity agreement into agreement on the number of CCs as well as the number and constituent conditions (“perfect” agreement). Although agreement on the number of CCs was low, it was even lower when we required that constituent CCs also agree. In our previous work, we also found that perfect agreement dropped consistently as the number of CCs increased.¹⁰ All of this demonstrates that the way we think about agreement needs to be more nuanced when we get into a complex topic like multimorbidity.

When we further examined the impact of individual CCs on the level of agreement on the overall number of CCs we found that both the individual condition’s level of agreement and its prevalence were important. Excluding a disease with a low level of agreement and low prevalence, for example, stomach ulcers, had a smaller impact on perfect agreement than excluding a disease with higher level of agreement and a prevalence closer to 50%, for example, hypertension. Since disease lists used in multimorbidity research often include the most common CCs,²² even small levels of individual condition disagreement can have a

large impact on the agreement on the number of CCs. This is complicated further by the lack of a standardized disease list to assess multimorbidity across studies, as different conditions being counted will lead to different levels of multimorbidity agreement.

Strengths and limitations

This study has some limitations that need to be considered. We included a restricted list of 12 CCs. Although this list includes the many of the most common CCs in Canada²³ and those commonly included in multimorbidity research,²⁴ we were limited to conditions that could be identified in both data sources. Many disease lists include more than 12 conditions and we do not know the level of agreement between the data sources on other CCs. As well, other methods to measure multimorbidity which rely on weighting²⁴ or that include symptoms²⁵ (which are less well captured in administrative data) will likely have even more complex issues related to agreement. Furthermore, we must take into account that not all administrative data are the same. For example, the use of electronic medical records may provide richer data on symptoms, and we know that CC prevalence estimates have been shown to increase with the number of administrative data sources used^{6, 26} and with increasing duration of retrospective data observation.²⁶ This further complicates our ability to understand how estimates vary across studies based solely on the kind of data used and underscores the importance of

a clear and transparent process for choosing and reporting specific conditions and data sources included in multimorbidity research.²⁷

Conclusion

When considering agreement across data sources we need a much more nuanced approach when we are studying multimorbidity. Each condition used to define multimorbidity has a differential impact on the degree of perfect agreement on the total number of CCs. This underlying complexity needs to be considered in future efforts to improve data for research purposes.

Authors' note

The opinions, results, and conclusions reported in this article are those of the authors and are independent from the funding sources. No endorsement by ICES or the Ontario Ministry of Health and Long-Term Care (Ontario MOHLTC) is intended or should be inferred. Parts of this material are based on data and/or information compiled and provided by CIHI. However, the analyses, conclusions, opinions, and statements expressed in the material are those of the author(s) and not necessarily those of CIHI. Parts of this material are based on data and information provided by Cancer Care Ontario (CCO). The opinions, results, view, and conclusions reported in this article are those of the authors and do not necessarily reflect those of CCO. No endorsement by CCO is intended or should be inferred.

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