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A cross-sectional study assessing agreement between self-reported and general practice recorded health conditions among community dwelling older adults

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Key Points

- Significant variability exists for agreement between individuals' self-reported and general practice recorded comorbidities
- This variability is further affected by individuals' multi-morbidity, cognitive impairment and frailty status
- Individuals' healthcare records should remain the gold standard for determining health conditions in future clinical practice and research

Keywords

Frailty, multi-morbidity, long-term conditions, elderly

Abstract

Introduction

Self-reported data regarding health conditions are utilised in both clinical practice and research, but their agreement with general practice records is variable. The extent of this variability is poorly studied among older adults, particularly among those with multiple health conditions, cognitive impairment or frailty. This study investigates the agreement between self-reported and general practice recorded data among such patients and the impact of participant factors on this agreement.

Methods

Data on health conditions was collected from participants in the Community Ageing Research 75+ (CARE75+) study (n=964) by self-report during face-to-face assessment and interrogation of the participants' general practice electronic health records. Agreement between self-report and practice records was assessed using Kappa statistics and the effect of participant demographics using logistic regression.

Results

Agreement ranged from K=0.25-1.00. The presence of ≥2 health conditions modified agreement for cancer (odds ratio, OR:0.62, 95%confidence interval, CI:0.42-0.94), diabetes (OR:0.55, 95%CI:0.38-0.80), dementia (OR:2.82, 95%CI:1.31-6.13) and visual impairment (OR:3.85, 95%CI:1.71-8.62). Frailty reduced agreement for cerebrovascular disease (OR:0.45, 95%CI:0.23-0.89), heart failure (OR:0.40, 95%CI:0.19-0.84) and rheumatoid arthritis (OR:0.41, 95%CI:0.23-0.75). Cognitive impairment reduced agreement for dementia (OR:0.36, 95%CI:0.21-0.62), diabetes (OR:0.47, 95%CI:0.33-0.67), heart failure (OR:0.53, 95%CI:0.35-0.80), visual impairment (OR:0.42, 95%CI:0.25-0.69) and rheumatoid arthritis (OR:0.53, 95%CI:0.37-0.76).

Conclusions

Significant variability exists for agreement between self-reported and general practice recorded comorbidities. This is further affected by an individual's health conditions. This study is the first to assess frailty as a factor modifying agreement and highlights the importance of utilising the general practice records as the gold standard for data collection from older adults.

Introduction

Self-reported data on health conditions may be used for direct patient care, when patients are asked about their current medical conditions when admitted acutely to hospital or moving to a new general practice. Additionally, self-reported data is often used for research studies when either general practice or hospital data may not be available or when these data sources are incomplete.

Previous studies investigating agreement between individuals' self-reported and general practice recorded health conditions found it is typically low for most conditions[1-13]. Few have investigated agreement among the community-dwelling older adult population, despite this population being among those who have the most contact with secondary care. Furthermore, only a small number of studies included individuals with cognitive impairment [4, 7, 10-12], and none have investigated the impact of frailty.

Objectives

1) To assess the agreement between self-reported and general practice recorded health conditions in community-dwelling older people.
2) To assess whether frailty, the number of health conditions, participants' educational status, the presence of cognitive impairment and whether the participant lives alone affects agreement between participant self-reported and practice recorded health conditions.

Methods

Study design

Cross-sectional analysis of data from the Community Ageing Research 75+ (CARE75+) cohort study.

Participants

CARE75+ is a longitudinal cohort study of community-dwelling people aged 75 and over in the UK[14]. Detailed demographic, health and social information is collected for all patients via interviewer-administered questionnaires with additional information extracted direct from the primary care electronic health record (EHR). Participants recruited between 1st January 2015 and 18th December 2018 were included in the analytic cohort for this study.

Variables

General practice recorded health conditions

General practice EHRs were reviewed by clinically-trained researchers to extract information on the presence of a range of health conditions.

Self-reported health conditions

Self-reported health conditions were collected in face-to-face assessments using the Katz Comorbidity Questionnaire[15]. Participants were additionally asked if they were registered as blind or partially sighted.

Information on the following conditions is recorded in both the practice EHR review and Katz comorbidity questionnaire: any cancer (excluding non-melanoma skin cancer); asthma; cerebrovascular disease; chronic obstructive pulmonary disease (COPD); dementia; diabetes mellitus; heart failure; peripheral vascular disease; registered blind or partially sighted; and rheumatoid arthritis. These health conditions were therefore included in our analysis of agreement.

Covariables

We selected additional participant characteristics as potential explanatory variables to analyse their effect on agreement:

Age
Gender

Number of health conditions (as recorded in the general practice EHR review)
Level of education
Living alone
Evidence of cognitive impairment, defined as a Montreal Cognitive Assessment score <26[16]
Frailty, assessed using the phenotype model (fit, pre-frail, frail), using established cutpoints[17].

Statistical analysis

Prevalence of each self-reported and practice recorded health condition was estimated and the difference calculated. Agreement for each health condition was calculated using Cohen's Kappa (k statistics)[18], Sensitivity and specificity of the participant-reported information was calculated using the general practice recorded diagnosis as the gold standard. Logistic regression was performed to assess whether the explanatory variables, adjusting for all covariables, were associated with agreement of the presence of health conditions from the two sources. Analyses were performed using STATA/SE software[19].

Results

Participant characteristics

Data from 964 CARE75+ participants is included. The median age was 81.1 years (SD:4.9), 47.9% were male, and the majority were white (93.6%). Most participants had no formal educational qualifications (57.1%) and 41.4% lived alone. Half (49.1%) of participants had one or more of the selected health conditions of interest. The majority were classified as pre-frail (53.8%) or frail (30.3%). Half (51%) had some cognitive impairment.

Prevalence of health conditions & agreement

The prevalence of self-report and general practice recorded health conditions, and their agreement, sensitivity and specificity is reported in Table 1. The median (range) K value for agreement was K=0.68 (K=0.25-1.00). The highest agreement was seen for asthma and peripheral vascular disease (K=1.00) and the lowest for rheumatoid arthritis (K=0.25). The number and percentage of events for combinations of general practice and participant agreement and disagreement are detailed in supplementary table 1.

The median (range) sensitivity for participant self-reported data was 78.5% (17.5-100%). The highest sensitivity was seen for asthma (100%; 95%CI:96.4-100.0%) and the lowest for rheumatoid arthritis (17.5%; 95% CI:10.7-26.2%). The median (range) specificity for participant self-reported data was 98.6% (88.2-100%). The highest specificity was seen jointly for asthma and peripheral vascular disease (100%; 95% CI:99.6-100%) and the lowest was seen for any cancer (88.2%; 95% CI:85.8-90.4%)

Tests of association

Covariable-adjusted associations between the selected additional participant characteristics and agreement of participant self-reported data with general practice recorded data for each health condition are reported in Table 2.

The presence of ≥2 health conditions was associated with variable odds of agreement between self-report and the practice record. With ≥2 health conditions, agreement was reduced for cancer and diabetes mellitus but increased for dementia and being registered blind or partially sighted. Agreement was not affected by cerebrovascular disease, COPD, heart failure or rheumatoid arthritis.

Frailty was associated with reduced odds of agreement for cerebrovascular disease (OR:0.45, 95%CI:0.23-0.89), heart failure (OR:0.40, 95%CI:0.19-0.84) and rheumatoid arthritis (OR:0.41, 95%CI:0.23-0.75), compared to people with pre-frailty or non-frail. Pre-frailty was associated with reduced agreement for heart failure (OR:0.44, 95%CI:0.22-0.89), compared to people who are non-frail.

Cognitive impairment was associated with reduced agreement for dementia (OR**:**0.36, 95%CI:0.21-0.62), diabetes mellitus (OR:0.47 95%CI:0.33-0.67), heart failure (OR:0.53, 95%CI:0.35-0.80), being blind or partially sighted (OR**:**0.42, 95%CI:0.25-0.69) or having rheumatoid arthritis (OR**:**0.53 95%CI:0.37-0.76), compared to people with no cognitive impairment.

Participant age, gender, education level and living alone were not associated with a change in agreement between self-reported and general practice record reported health conditions.

Discussion

This study identified substantial variation for agreement between participants' self-reported and general practice recorded health conditions among community-dwelling older people. Agreement may be modified by the participants' number of health conditions, the presence of cognitive impairment and their frailty status. This study is the first to have assessed older adults with frailty and identify that, among this population, self-reported data should not be used to determine the presence of individuals' health conditions due to the potential for significant inaccuracy.

Health conditions have been defined differently among different studies; being analysed as >3 conditions [2, 11], or as a continuous variable[10]. The findings of this study are consistent with previous studies, which have also shown considerable variation between self-reported datasets and practice records among older adults[1-5, 7, 8, 10, 11, 15] as well as both increased and reduced agreement among participants with a greater number of health conditions for cerebrovascular disease, heart failure and diabetes [2, 10, 11].

Increased reporting of conditions by an individual could be due to diagnoses in hospital or outpatient clinics either not being communicated to primary care, or disagreement by primary care clinicians who do add the diagnosis to the patient record[20]. Conversely, under-reporting may occur when clinicians did not clearly explain a diagnosis, participants did not identify as having that condition, where historical conditions were forgotten, participants concealing diagnoses perceived to be embarrassing or stigmatising or their memory repressed, such as with malignancy [20-22]. The mechanism for frailty reducing agreement is unclear, but one potential factor could be multiple interacting physical, mental and functional problems in frailty, which may be of greater importance in terms of day-to-day priorities.

Utilisation of the CARE75+ cohort, which encompasses urban and rural areas with a range of deprivation levels, makes it likely that the results are generalisable to the wider population. Although individuals volunteering to be part of the study may have greater awareness of their health conditions, this would typically inflate the agreement estimates and would not necessarily undermine the findings of this study that agreement is generally poor.

EHRs are increasingly used in healthcare systems worldwide. Responsibility for their maintenance and accuracy lies with the primary point of contact for the record, which in many countries is the primary care team[24]. Recognition of conditions where patient reporting is less accurate demonstrates the importance of integration between the primary and secondary care EHR, whilst identifying areas in which the EHR may be less accurate highlights areas which may be focussed upon for improvement and conditions where clarification with patients should be sought.

This study supports the notion that the gold standard for determining the presence of health conditions in older adults in both clinical practice and research settings should remain the general practice record and that participant reported data should not be used in isolation. This is of particular importance given the increasing recognition of the need to include older adults with multi-morbidity and frailty in future clinical research. We recommend that all future study designs involving older adults include the

necessary resources and permissions to access their participants' healthcare records to ensure correct documentation of individuals' health conditions.

Conclusion

Agreement between participants' self-report of their health conditions and their general practice record is highly variable and modified by an increased number of health conditions, cognitive impairment and frailty. We recommend that the gold standard for recording health conditions should remain the general practice record in both clinical practice and research settings.

Tables

Table 1 Prevalence of self-reported and general practice recorded health conditions, agreement, sensitivity and specificity

Condition	Prevalence % (95% CI)		Absolute difference A - B % (95% CI)	Kappa (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)
	Self-reported (A)	General practice record (B)				
Any cancer[1]	11.4 (9.4, 13.4)	20.4 (17.8, 23.1)	9.0 (-12.3, -5.7)	0.55 (0.49, 0.61)	83.2 (74.7, 89.7)	88.2 (85.8, 90.4)
Asthma	10.7 (8.7, 12.7)	10.7 (8.7, 12.7)	0.0 (-2.8, 2.8)	1.00	100 (96.4, 100.0)	100 (99.6, 100.0)
Cerebrovascular disease	13.1 (11.0, 15.3)	10.5 (8.5, 12.5)	2.6 (-0.3, 5.6)	0.60 (0.53, 0.66)	57.6 (48.2, 66.7)	96.7 (95.2, 97.9)
COPD[2]	5.6 (4.1, 7.1)	6.2 (4.7, 7.8)	0.6 (-2.8, 1.5)	0.70 (0.64, 0.77)	76.6 (62.0, 87.7)	98.0 (96.8, 98.8)
Dementia	1.5 (0.7, 2.2)	2.5 (1.4, 3.5)	1.0 (-2.2, 0.3)	0.77 (0.71, 0.84)	100 (76.8, 100.0)	99.1 (98.2, 99.6)
Diabetes mellitus	9.2 (7.2, 11.1)	20.6 (18.0, 23.3)	11.4 (-14.7, -8.1)	0.77 (0.70, 0.84)	80.3 (69.1, 88.8)	97.7 (96.3, 98.7)
Heart failure	5.8 (4.3, 7.3)	7.2 (5.5, 8.8)	1.3 (-3.6, 0.9)	0.53 (0.46, 0.59)	60.8 (46.1, 74.2)	96.5 (95.0, 97.6)
Peripheral vascular disease	2.7 (1.7, 3.8)	2.7 (1.7, 3.8)	0.0 (-1.5, 1.5)	1.00	100.0 (86.8, 100.0)	100.0 (99.6, 100.0)
Registered blind/partially sighted	2.8 (1.8, 3.9)	2.2 (1.3, 3.2)	0.6 (-0.8, 2.0)	0.66 (0.59, 0.72)	60.0 (38.7, 78.9)	99.4 (98.7, 99.8)
Rheumatoid arthritis	12.4 (10.2, 14.5)	2.9 (1.8, 4.0)	9.5 (7.1, 11.9)	0.25 (0.19, 0.30)	17.5 (10.7, 26.2)	99.1 (98.1, 99.6)

[1] Excluding non-melanoma skin cancer; [2] Chronic obstructive pulmonary disease

Table 2 Adjusted associations of participant characteristics with agreement between the self-report and general practice record for each health condition. Values are odds ratio (95% confidence interval).

	Cancer[1]	Cerebrovascular disease	COPD[2]	Dementia	Diabetes mellitus	Heart failure	Registered blind or partially sighted	Rheumatoid arthritis
Self-report agrees with medical record	No = 183 (19.0) Yes = 781 (81.0)	No = 152 (15.8) Yes = 812 (4.2)	No = 106 (11.0) Yes = 858 (89.0)	No = 80 (8.3) Yes = 884 (91.7)	No = 211 (21.9) Yes = 753 (78.1)	No = 135 (14.0) Yes = 829 (86.0)	No = 90 (0.3) Yes = 874 (90.7)	No = 197 (20.4) Yes = 767 (79.6)
Age (per 5 years)	0.98 (0.82, 1.28)	0.89 (0.74, 1.08)	0.94 (0.75, 1.17)	1.03 (0.80, 1.32)	1.11 (0.93, 1.32)	1.05 (0.86, 1.29)	0.87 (0.68, 1.10)	1.05 (0.88, 1.25)
Gender								
Male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Female	1.15 (0.81, 1.63)	0.84 (0.57, 1.22)	0.97 (0.62, 1.50)	0.87 (0.53, 1.43)	1.22 (0.87, 1.71)	1.01 (0.68, 1.49)	1.05 (0.66, 1.68)	0.81 (0.58, 1.15)
Education								
No qualifications	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
<Degree level	0.90 (0.62, 1.31)	1.12 (0.73, 1.71)	1.07 (0.66, 1.74)	0.89 (0.51, 1.55)	1.12 (0.77, 1.64)	0.96 (0.62, 1.49)	1.00 (0.59, 1.68)	1.01 (0.69, 1.47)
Degree level and above	1.21 (0.66, 2.23)	0.71 (0.40, 1.26)	1.15 (0.54, 2.46)	0.61 (0.29, 1.31)	0.93 (0.53, 1.62)	0.93 (0.48, 1.79)	0.73 (0.35, 1.50)	1.47 (0.78, 2.79)
Lives alone								
No	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Yes	0.86 (0.60, 1.24)	1.12 (0.75, 1.65)	1.08 (0.68, 1.71)	0.91 (0.57, 1.58)	1.26 (0.88, 1.80)	1.13 (0.75, 1.71)	1.16 (0.71, 1.91)	1.08 (0.75, 1.54)
Health conditions								
<2	1.00 *	1.00	1.00	1.00 *	1.00 *	1.00	1.00 *	1.00
≥2	0.62 (0.42, 0.94)	1.01 (0.64, 1.57)	1.30 (0.75, 2.26)	2.83 (1.31, 6.13)	0.55 (0.38, 0.80)	1.20 (0.74, 1.93)	3.85 (1.71, 8.62)	1.38 (0.90, 2.11)
Phenotype								
Fit	1.00	1.00 *	1.00	1.00	1.00	1.00 *	1.00	1.00 *
Pre-frail	0.99 (0.60, 1.62)	0.60 (0.32, 1.13)	0.66 (0.32, 1.35)	0.55 (0.24, 1.26)	0.60 (0.35, 1.03)	0.44 (0.22, 0.89)	0.72 (0.35, 1.48)	0.69 (0.40, 1.20)
Frail	1.10 (0.62, 1.92)	0.45 (0.23, 0.89)	0.58 (0.26, 1.25)	0.53 (0.21, 1.32)	0.54 (0.30, 0.97)	0.40 (0.19, 0.84)	0.78 (0.35, 1.76)	0.41 (0.23, 0.75)
Cognitive impairment (MoCA)								
No (score ≥ 26)	1.00	1.00	1.00	1.00 *	1.00 *	1.00 *	1.00 *	1.00 *
Yes (score < 26)	0.77 (0.54, 1.11)	0.74 (0.50, 1.10)	0.64 (0.410, 1.02)	0.36 (0.21, 0.62)	0.47 (0.33, 0.67)	0.53 (0.35, 0.80)	0.42 (0.25, 0.69)	0.53 (0.37, 0.76)

[1] Except non-melanoma skin cancer; [2] Chronic obstructive pulmonary disease. Asthma and peripheral vascular disease not analysed as there was perfect agreement between self-report and general practice record; * denotes statistical significance

Supplementary Table 1 Comparison between self-reported and general practice recoded health conditions.

Condition	Agree participant no/ general practice no	Disagree participant no/ general practice yes	Disagree participant yes/ general practice no	Agree participant yes/ general practice yes	Overall agreement % (95% CI)
Any cancer[1]	690 (77.6)	92 (10.4)	18 (2.0)	89 (10.0)	81.0 (78.4, 83.4)
Asthma	851 (89.3)	0	0	102 (10.7)	100.0 (99.6, 100.0)
Cerebrovascular disease	742 (83.8)	25 (2.8)	50 (5.7)	68 (7.7)	84.2 (81.8, 86.5)
COPD[2]	820 (92.8)	17 (1.9)	11 (1.2)	36 (4.1)	89.0 (86.9, 90.9)
Dementia	867 (97.5)	8 (0.9)	0	14 (1.6)	91.7 (89.8, 93.4)
Diabetes mellitus	690 (88.8)	16 (2.1)	14 (1.8)	57 (7.3)	78.1 (75.4, 80.7)
Heart failure	796 (90.9)	29 (3.3)	20 (2.3)	31 (3.5)	86.0 (83.6, 88.1)
Peripheral vascular disease	928 (97.3)	0	0	26 (2.7)	100.0 (99.6, 100.0)
Registered blind/partially sighted	856 (96.6)	5 (0.6)	10 (1.1)	15 (1.7)	90.7 (88.6, 92.4)
Rheumatoid arthritis	743 (87.1)	7 (0.8)	85 (10.0)	18 (2.1)	79.6 (76.9, 82.0)

[1] Excluding non-melanoma skin cancer; [2] Chronic obstructive pulmonary disease

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