Good agreement between self-report and centralised hospitalisations data for arthritis related surgeries. Manuscript ID: JCE-12-432.

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Abstract

Objective: To examine the level of agreement between self-reported and hospital administration records of arthritis related surgeries for two large samples of community dwelling older women in Australia, born between 1921-1926 and 1946-1951.

Study Design and Setting: Self-report survey data from the Australian Longitudinal Study on Women's Health (ALSWH) was linked to inpatient hospital data from the New South Wales Admitted Patient Data Collection (NSW APDC). Levels of agreement were compared using Cohen's kappa, sensitivity, specificity, and positive and negative predictive values. Reasons for false positives were examined.

Results: This study found good agreement (kappa > 0.70; sensitivity and specificity > 0.80) between self-report and hospitalisations data for arthritis related surgeries.

Conclusion: This study provides new evidence for good agreement between self-reported health survey data and administrative records of arthritis related joint procedures, and supports the use of self-report surveys in epidemiological studies of joint procedures where administrative data are not available or not readily accessible, or where more extensive contextual information is needed. The use of health survey data in conjunction with administrative data has an important role to play in public health planning and policy.

Key words: Hip; Knee; Health Surveys; Medical Record Linkage; Arthroplasty, Replacement; Self-report.

Running title: *Good agreement between self-report and hospital data for joint surgeries.*

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What is new?

The key findings:

- This study found good agreement (kappa > 0.70; sensitivity and specificity > 0.80) between self-report and hospitalisations data on arthritis related procedures for two large cohorts of community dwelling older women. Discrepancies between the two data sources were mainly due to inaccurate recall of timing of procedures, rather than absence of the procedure.

What this adds to what is known:

- The study met an acknowledged need to verify the accuracy of self-reported joint procedures, an often cited limitation in epidemiological studies.

What is the implication:

- This study supports the use of self-report surveys in epidemiological studies of joint procedures where administrative data are not available or not readily accessible, or where more extensive contextual information is needed.

What should change now:

- Researchers should be confident of the veracity of self-reported data on arthritis related procedures.

Studies of the epidemiology and population burden of arthritis and arthritis related joint surgery most commonly utilise data from health surveys and administrative databases [1-4]. While administrative databases are often considered the gold standard for some measures (such as hospitalisation), health surveys are a valuable epidemiological tool. They can be administered at relatively low cost to a large number of participants [5, 6], they can more readily identify conditions that may be inaccurately reported in administrative data (such as chronic diseases like arthritis) [3, 7-9], and they can ask targeted questions beyond the minimum data set required for administrative purposes. However, the propensity for survey inaccuracy is a weakness that necessitates further measurement and increased understanding.

Numerous studies have assessed the accuracy of self-report health data and factors associated with degree of concordance or agreement with "gold standards" like hospital registries by comparing self-recall of health related events with administrative records and physician adjudication [1-4, 6, 7, 10]. Agreement has been found to vary with the nature of the condition or procedure, method of data collection, length of time between the survey and the event [1, 2, 4, 5, 9, 11-13], variability of contact time with health practitioners or services, and the individual level of understanding about the diagnosis or condition [13, 14]. Agreement can also vary according to characteristics of the respondents, including age, cognitive capacity, reported medications, and the presence of comorbid conditions including depression [2-4, 7, 9, 15, 16]. Inaccurate medical diagnoses, and incorrect or inconsistent coding of medical records have been found to be contributing factors towards discordance in health administrative data [2, 3, 8, 14, 15, 17-20]. Moreover, accuracy of self-reported conditions can vary across data collection points for repeated surveys. For example, Beckett [5] found that only half the respondents who reported arthritis at one survey subsequently reported arthritis when surveyed at a later date.

The few previous studies of arthritis related surgeries have found good agreement between self-report and administrative data [21-28]. Parimi et al. found high concordance overall between self-report of surgery and the reason for surgery (osteoarthritis vs. fracture) [24]; while Lui et al. found 99.8% agreement between self-reported hip and knee procedures and hospital administrative data records amongst 28,524 Scottish women [23]. However, both total knee and hip replacements have been rapidly increasing over time in countries like the US [29] and Australia, [22] and worldwide, rates of knee arthroplasty have increased faster than hip replacements [30]. Although administrative databases can monitor these trends, at least in countries with good centralised registries, only self-report can provide detail, such as the ongoing quality of life and individual health outcomes for those undergoing surgeries, needed to inform public health planning and policy. It is often not possible to survey the relevant sample of people identified through administrative data, due to the ethical procedures surrounding these resources. So, researchers undertaking survey research into the context around arthritis related surgery need to be confident that there is good concordance between self-report and administrative records of these procedures, and to understand why discrepancies may occur.

Arthritis related hip and/or knee surgery is managed in hospitals [22, 31, 32], so comprehensive verification of self-reported diagnoses of arthritis related procedures is only possible through examination of individual medical records, or linkage with hospital admissions administration data [33]. The level of coding errors and inaccuracies in hospital administrative data have been found to be quite low [26, 34], with a previous study finding near perfect agreement for hip replacement (kappa = 1.00), and good-to-excellent coding quality for major diagnoses, major and minor procedures [34], meaning that this data source can generally be considered a “gold standard”. Women suffer a higher proportion of the burden of disease relating to arthritis and musculoskeletal disease [21, 22, 25], and gendered

differences exist in how health is perceived and experienced, so the focus of this study in sample of women is appropriate.

This study sought to examine agreement between self-reported arthritis related joint surgeries with administrative records of hospital diagnoses and procedures, using self-report survey data from the Australian Longitudinal Women's Health Survey (ALSWH) linked to inpatient hospital data from the New South Wales (NSW) Admitted Patient Data Collection (APDC) from July 2000 to December 2008.

METHODS

Self-report: The Australian Longitudinal Study on Women's Health (ALSWH)

The ALSWH is a national longitudinal study that has been investigating the health and wellbeing of Australian women since 1996. Self-report surveys have been conducted every three years with over 40,000 Australian women who were aged 18-23 (1973-1978 cohort), 45-50 years (1946-1951 cohort), and 70-75 years (1921-1926 cohort) when the study began. ALSWH cohorts were randomly selected from the Medicare Australia (the universal health scheme for eligible Australians) database in 1996 [35, 36]. Detailed methods for the ALSWH are available from http://www.alswh.org.au. This analysis only involves data for women from the 1946-51 and 1921-26 cohorts who were resident in NSW.

Hospital procedures: The New South Wales (NSW) Admitted Patient Data Collection (APDC)

The NSW APDC contains all admitted patient services in the state of NSW, Australia, provided by Public, Private, and Repatriation Hospitals, Private Day Procedures Centres and Public Nursing Homes. Each record in the NSW APDC is an Episode of Care (EOC). An EOC ends with a 'separation' (a discharge, transfer or death), or a change in patient type

during one period of stay in a hospital [37]. Each EOC contains limited personal information about the patient, date of admission and separation, all procedures undergone during the EOC and up to 50 diagnoses. The procedures and diagnoses are coded according to the 10th revision of the International Classification of Diseases, Australian Modification (ICD-10-AM) [38].

Self-report (ALSWH) linkage to hospital procedures (NSW APDC)

Records listing a date of separation from 1 July 2000 to 31 December 2008 from the NSW APDC were linked to ALSWH survey records for women from the 1946-51 cohort and 1921-26 cohorts, who had completed at least one of Survey 4 (2004, 2005) or Survey 5 (2007, 2008). The ALSWH and NSW APDC records were linked using probabilistic record linkage methods by the Centre for Health Record Linkage [37], who estimated a false positive rate of 0.3% of records and a false negative rate of less than 0.1%. [37, 39]

Human Research Ethics Committee approval (H-076-0795) was obtained for this study from the University of Newcastle, Australia.

Self-report measures

Participants from the 1946-51 and 1921-26 cohorts were asked in both Survey 4 and Survey 5, “In the PAST THREE YEARS, have you had any of the following operations or procedures”. In both Survey 4 and Survey 5 for the 1946-51 cohort, one of the operations listed was “joint replacement (for example, hip, knee)”. It is important to note that the 1921-26 cohort were asked slightly different questions about arthritis related procedures than the 1946-51 cohort, and that the questions for the 1921-26 cohort varied to some degree between Survey 4 and Survey 5. In Survey 4 for the 1921-26 cohort, two options were listed; “knee surgery or arthroscopy” and “hip surgery”. At Survey 5, women were asked three questions;

"knee surgery or arthroscopy", "hip surgery for hip replacement" and "hip surgery for broken hip". The past three years was defined as the three years prior to survey return date, which was specifically known for each individual.

Hospital procedure measures

For the 1946-51 cohort, joint replacement in the NSW APDC was defined as a knee replacement, hip replacement, and other joint replacement (defined as a procedure containing the word 'arthroplasty') (see Appendix1).

For the 1921-26 cohort, 'knee surgery' was considered to be any procedure containing the word 'knee' or 'patella', except for femoral vein procedures, radiographs and prosthetics to hip. 'Hip surgery' was defined as a procedure containing the words 'hip' or 'femur' (see Appendix 1).

The ICD-10-AM procedural codes used for joint replacements, knee surgery or arthroscopy and hip surgery were taken from the Australian Orthopaedic Association Annual Report, 2009 [40].

Analyses

Analyses included those women who had answered the questions about arthritis relevant procedures at both surveys. Six participants from the 1946-51 cohort were excluded from Survey 5 as they had answered "yes" to every medical procedure listed, so their answers to those questions were considered unreliable.

Separate analyses were undertaken of responses to Survey 4 and to Survey 5, for each cohort. Agreement was checked between self-report of arthritis relevant procedures in the previous 3 years against NSW APDC records for period of 1,105 days prior to return of the survey. As

the surveys were returned by post and the date of admission (not date of surgery) was available from NSW APDC, a period of slightly more than 3 years was used to ensure capture of all relevant procedures. Self-reports were categorised as:

- True positive: participant reported a joint procedure and NSW APDC contained a record of a procedure;
- False positive: participant reported a joint procedure but NSW APDC did not contain a record of a procedure;
- False negative: no procedure reported by the participant, but APDC contained a record of a procedure; and
- True negative: no procedure reported by the participant and no record in APDC of a procedure.

Levels of agreement between the two data sources were compared using Cohen's kappa, sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV) [41]. Reasons for false positives were explored. Agreement between the two data sources when the time frame was relaxed to encompass all available data was also examined.

RESULTS

Sample

Agreement between joint procedure measures were examined for 2,830 women from the 1946-51 cohort at Survey 4 (2004) and 2,779 women for Survey 5 (2007). From the 1921-26 cohort, 2,103 women at Survey 4 (2005) and 1,622 at Survey 5 (2008) were included.

Agreement between self-report and hospital procedures

Table 1 summarises the level of agreement between self-reported and NSW APDC joint procedures in the previous three years for these samples of women. All NPVs were at least 99%. Approximately two-thirds of self-reported procedures could be confirmed in the NSW APDC, with PPVs ranging from 57% to 79%. Measures of agreement were similar for both cohorts, with kappa over 0.70, and sensitivity and specificity over 0.80 in all cases. Self-reported rate of procedures was higher than estimated from the NSW APDC for all procedures by 10% to 70%, and higher among the 1921-26 cohort than among the 1946-51 cohort.

Table 1. Agreement between self-report and NSW APDC, for arthritis related procedures, by survey year, for both cohorts.

False positives and negatives

Thirty-one women from the 1946-51 cohort reported false positives (34 responses could not be verified in the NSW APDC; three women had false positives at both surveys). One hundred and sixteen women from the 1921-26 cohort reported false positives (127 false positive responses; eight women had false positives for both surveys; four women had two false positives in one survey, one for the hip and one for the knee). The reasons for false positives were:

- Participants did not link to the NSW APDC (six women (19%) from the 1946-51 cohort and 11 women (9%) from the 1921-26 cohort);

- Relevant procedures were recorded prior to 1,105 days from the date of survey return or a diagnosis of "presence of hip implant", suggesting prior surgery (11 (35%) women from the 1946-51 cohort, 61 (53%) from the 1921-26 cohort);

- Different joint procedures were recorded in the NSW APDC which were not joint replacements (for example, arthroscopic meniscectomy of knee) (five (16%) women from the 1946-51 cohort); and

- Participants did link to the NSW APDC, but there was no record in the NSW APDC of a relevant procedure in the relevant time period, or from July 2000 to that time period (nine women (29%) from the 1946-51 cohort and 44 (38%) from the 1921-26 cohort).

When responses to Surveys 4 and 5 were combined, agreement between self-report and the NSW APDC, increased:

- NSW APDC joint replacement was found for 76.0% of the 79 women from the 1946-51 cohort who responded to both surveys and claimed at least one joint replacement;

- NSW APDC knee procedure was found for 82.5% of the189 women from the 1921-26 cohort who responded to both surveys and reported having at least one knee procedure.

- NSW APDC hip procedure was found for 85.5% of the 148 women from the 1921-26 cohort who responded to both surveys and reported a hip procedure.

DISCUSSION

This study found good agreement (kappa > 0.70; sensitivity and specificity > 0.80) between self-report and hospitalisations data for arthritis related procedures within a three year time frame, for two large samples of older Australian women, born 1946-51 and 1921-26. This agreement level is likely to be an underestimate if the time frame is widened, given that the

primary reason for false positives was reporting of procedures performed more than three years earlier.

These findings provide support for the concordance between self-report and hospital administrative data for arthritis related surgeries. While we cannot claim that these findings are generalizable beyond older women, the similarity in agreement between the two different aged cohorts does advocate for some confidence in their robustness, and we would expect these findings to be similar in other similar countries. Self-report would seem to be an acceptable alternative when high quality administrative data are not available or not readily accessible, or when the research question requires a depth of contextual data beyond that available within administrative datasets.

Some of the potential limitations of this study are state border issues, quality of data linkage, technical coding or diagnostic errors, and inaccuracies in hospital administrative records [2, 3, 27, 42, 43]. For several women, although the reported procedure was not in the NSW APDC, there was a diagnosis of "Presence of knee implant" or "Presence of hip implant" at an admission, suggesting this procedure may have been done outside the NSW APDC time frame (1 July 2000 to 31 December 2008) or not in NSW. Inaccuracies in data linkage would be expected to be limited, however, as the linkage agent, the Centre for Health Record Linkage (CHeReL), estimates a false positive rate of 0.3% of records and a false negative rate of less than 0.1% for their probabilistic linkage protocols [37]. Similarly, we would expect very low levels of coding errors and inaccuracies in these hospital administrative data [44-47].

Some recall issues were identified, albeit for a small number of women. Some women had relevant procedures recorded in the NSW APDC data, but not within the 1,105 day capture for each survey, suggesting that forward telescoping of recall was occurring, and thus

procedures outside the period of interest were inadvertently reported [2]. Some women misreported joint replacements when they had undergone other procedures on a joint, for example, arthroscopic meniscectomy of knee. It is not unusual for patients to confuse procedures, as found by Parimi et al. [24], in a study of 7,421 women aged ≥ 65 years, where of 18 women who reported no hip replacement, 16 were subsequently confirmed by radiograph to have undergone a hip replacement procedure. Parimi et al. concluded however, that the overall accuracy of self-report for hip replacement in elderly women was generally high when compared to medical records and radiographic findings [24].

A fundamental strength of the current study was the ability to individually track inconsistencies between the two datasets. There were very few cases where an explanation could not be inferred, and when the time frame was widened, agreement was 80% or higher for all procedures of interest. Our findings concur with previous studies such as Parimi et al. [24], and Liu et al. [23] who found good agreement between self-report and hospital administrative data for hip replacement (99.8%) and knee replacement (99.9%). The consensus between these studies provides increased support for using self-report surveys in epidemiological studies of joint procedures.

CONCLUSION

This study provides new evidence for good agreement between self-reported and administrative records of arthritis related joint procedures, and supports the use of self-report surveys in epidemiological studies of joint procedures where administrative data are not available or not readily accessible, or where extensive contextual information is needed. The findings offer a high degree of confidence in the use of self-reported data on arthritis related procedures, given they hold across age cohorts and across time points. Arthritis surveillance

using health survey data, in conjunction with administrative data, has an important role to play in informing public health planning and policy.

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CONFLICTS OF INTEREST

None.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version submitted for publication. Professor Lynne Parkinson had full access to all the data and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design: Parkinson.

Acquisition of data: Byles, Parkinson.

Analysis and interpretation of data: Parkinson, Gibberd, Cunich, Byles.

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Table 1. Agreement between self-report and NSW APDC, for arthritis related procedures, by survey year, for both cohorts.

Cohort	Survey date	N	Arthritis Related Procedure	Self-report procedures % (n)	NSW APDC procedures % (n)	Kappa (95% confidence interval)	Positive predictive value (PPV) %	Negative predictive value (NPV) %	Rate self-report / rate NSW APDC	Sensitivity	Specificity
1946-51	Mar 04 (4)	2,830	Joint replacement	1.2 (33)	1.0 (29)	0.84 (0.74,0.94)	79	100	1.1	0.90	1.00
	Mar 07	2,779	Joint replacement	2.3 (63)	1.4 (38)	0.71 (0.61,0.81)	57	100	1.6	0.95	0.99
1921-26	Mar 05	2,103	Knee surgery or arthroscopy	5.8 (121)	4.7 (98)	0.75 (0.69,0.82)	69	99	1.2	0.86	0.98
	Mar 05	2,103	Hip surgery	4.1 (87)	3.2 (67)	0.76 (0.68,0.83)	68	100	1.3	0.88	0.99
	Mar 08	1,622	Knee surgery or arthroscopy	6.2 (100)	3.9 (63)	0.72 (0.64,0.80)	60	100	1.6	0.95	0.97
	Mar 08	1,622	Hip surgery	4.5 (73)	3.9 (63)	0.74 (0.66,0.82)	70	99	1.2	0.81	0.99

Appendix 1: ICD-10-AM procedural codes for joint surgeries*

Procedure	ICD-10-AM procedural codes
Joint replacement	49534-00, 49517-00, 49518-00, 49519-00, 49521-00, 49521-01, 49521-02, 49521-03, 49524-00, 49524-01, 49512-00, 49515-00, 49527-00, 49530-00, 49530-01, 49533-00, 49554-00, 46306-00, 46306-01, 46307-00, 46307-01, 48915-00, 48918-00, 48921-00, 48924-00, 49115-00, 49206-00, 49209-00, 49715-00, 49821-00, 49824-00, 49839-00, 49842-00, 90537-00, 90543-00
Knee surgery or arthroscopy	44367-01, 47054-00, 47057-00, 47060-00, 47543-00, 47546-00, 47546-01, 47549-00, 47549-01, 47552-00, 47555-00, 47555-01, 47558-00, 47558-01, 47579-00, 47582-00, 47585-00, 47588-01,47591-00, 49500-00, 49500-01, 49500-02, 49500-03, 49500-04, 49503-00, 49503-01, 49503-02, 49503-03, 49503-04, 49503-05, 49509-00, 49509-01, 49512-00, 49515-00, 49517-00, 49518-00, 49519-00, 49521-00, 49521-01, 49521-02, 49521-03, 49524-00, 49524-01, 49527-00, 49530-00, 49530-01, 49533-00, 49534-00, 49539-00, 49539-01, 49542-00, 49542-01, 49545-00, 49548-00, 49551-00, 49554-00, 49557-00, 49557-01, 49557-02, 49558-00, 49558-01, 49558-02, 49559-00, 49560-00, 49560-01, 49560-02, 49560-03, 49561-00, 49561-01, 49561-02, 49562-00, 49562-01, 49562-02, 49563-00, 49566-00, 49569-00, 50348-00, 50363-00, 50366-00, 50369-00, 50372-00, 50390-01, 50411-00, 50414-00, 50417-00, 90553-00, 90555-00, 90598-00
Hip surgery	43506-01, 43515-01, 44370-00, 47048-00, 47051-00, 47516-00, 47516-01, 47519-00, 47522-00, 47525-00, 47525-01, 47528-00, 47528-01, 47531-00, 47540-00, 47982-00, 48200-00, 48203-00, 48424-01, 48424-04, 48427-01, 48427-04, 48500-00, 48506-00, 49303-00, 49303-01, 49306-00, 49312-00, 49315-00, 49318-00, 49319-00, 49324-00, 49327-00, 49330-00, 49333-00, 49345-00, 49346-00, 49348-00, 49351-00, 49354-00, 49357-00, 49360-00, 49363-00, 49366-00, 49366-01, 50375-00, 50378-00, 50381-00, 50384-00, 50390-00, 90552-00

*Source: http://nccc.uow.edu.au/icd10am/icd10am/index.html