Feasibility of measuring comorbidity indices based on medical records in the Iranian Clinical Breast Cancer Registry

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Citation: Eslami B, Alipour S, Seyyedsalehi MS, Nahvijou A, Omranipour R, Rajabpour MV, Zendehdel K. Feasibility of measuring comorbidity indices based on medical records in the Iranian Clinical Breast Cancer Registry. East Mediterr Health J. 2023;29(11):xxx–xxx. https://doi.org/10.26719/emhj.23.091

Received: 12/09/22; Accepted: 28/04/23

Abstract

Background: Comorbidities have a significant impact on treatment and outcome of breast cancer. However, data on comorbidities from low-income countries are limited.

Aims: To evaluate the feasibility and accuracy of using comorbidity data extracted from medical records, and estimate the prevalence of comorbidities in patients registered in the Clinical Breast Cancer Registry of Iran (CBCR-IR).

Methods: We collected data from the medical records of 400 patients on 30 comorbidities included in the Charlson Comorbidity Index (CCI) and Elixhauser Comorbidity Index (ECI). The sensitivity and specificity of comorbidity data extracted from medical records were calculated using interviews as a gold standard in 97 random samples.

Results: The mean age of patients was 51.69 (12.28) years. The sensitivity and specificity of medical records for detecting any comorbidity data contained in CCI versus noncomorbidity was 93.2% and 69.8%, respectively. However, for the comorbidity data included in ECI, both sensitivity (86.9%) and specificity (44.4%) were lower than in CCI. Hypertension (n = 144, 36.0%) and diabetes without chronic complications (n = 77, 19.3%) were the most prevalent comorbidities. There was a higher proportion of patients who had no comorbidity using CCI (72.2%) compared with ECI (44.8%).

Conclusion: It is feasible to construct a comorbidity index using medical records with high accuracy, especially when we extract comorbidities present in the CCI. Further studies are needed to study the association between comorbidity index and breast cancer survival among Iranian patients.

Keywords: breast cancer, cancer registry, Charlson Comorbidity Index, Elixhauser Comorbidity Index, Iran.

Citation: Eslami B, Alipour S, Seyyedsalehi MS, Nahvijou A, Omranipour R, Rajabpour MV, et al. Feasibility of measuring comorbidity indices based on medical records in the Iranian Clinical Breast Cancer Registry. East Mediterr Health J. 2023;29(11):xxx-xxx http://doi.org/10.26719/emhj.20.xxx

Received: 09/12/22, Accepted: 28/04/23

Introduction

Comorbidity refers to a long-term health condition or disorder that coexists with a primary disease (*1*), and multimorbidity refers to the presence of ≥ 2 long-term health conditions (*2*). Comorbidity is common among older cancer patients, and 4 out of 10 cancer patients have at least one comorbid disease and 15% have multimorbidity (*3*). Breast cancer is the most common female cancer worldwide and is the main cause of cancer mortality among women (*4*). The coexistence of breast cancer and comorbidity has an impact on treatment planning and outcome. A systematic review reported that the prevalence of comorbidity in breast cancer patients ranged widely from 0.4% to 87% in different populations (*5*). Different comorbidity measures have been developed and the most commonly used indices are the Charlson Comorbidity Index (CCI) and the Elixhauser Comorbidity Index (ECI), or their derivatives (*6*, *7*).

The impact of comorbidity on management and survival, care cost, and ability to predict outcome of breast cancer patients has been evaluated in several studies (*8–14*). The prevalence of comorbidity and weighted indices vary depending on the target population and the type of cancer. The best strategy for evaluating comorbidity is to develop an index for each type of cancer and a specific weight for comorbidity in the study population (*15*). To the best of our knowledge, no study has reported the development and adaptation of comorbidity indices in low and middle-income countries, although these indicators are of interest in developed countries (*15*, *16–20*).

Accurate recording of comorbidity details in a valid database is the first step in assessing the impact of comorbidity on treatment of cancer patients. The lack of comorbidity

data is one of the shortcomings of some registries. Addition of such data extracted from available records in medical centres, such as paper or electronic medical records of inpatients and outpatients, is a cost-effective method if the reliability is confirmed. The Clinical Breast Cancer Registry of Iran was established in 2014 at the Cancer Institute of Iran and extended to other cancer hospitals across the country (*21*). Trained registrars review the patients' medical records and collect detailed clinical data including diagnosis, staging, treatment, and follow-up information, and register them in a web-based system designed specifically for the Clinical Breast Cancer Registry of Iran. At the time of creating the clinical registry, the entry of comorbidity data was not the goal or priority. Therefore, to optimize research on breast cancer patients, the Cancer Institute Registry Team decided to add comorbidity data.

The aims of the present study were: (1) to evaluate the feasibility and accuracy of using comorbidity data extracted from medical records of breast cancer patients admitted to the Cancer Institute of Iran, in order to add comorbidity data based on CCI or ECI to the Clinical Breast Cancer Registry; and (2) to estimate the prevalence of comorbidity in registered patients.

Methods

This study was approved by the Research Ethics Committee of Imam Khomeini Hospital (code: IR.TUMS.IKHC.REC.1399. 191) affiliated with the Tehran University of Medical Sciences. We collected information on all comorbidities included in CCI (n = 16) and ECI (n = 25). According to a systematic review and meta-analysis in 2018, dyslipidaemia is a prevalent comorbidity in the Islamic Republic of Iran (*22*), and several studies have shown that serum lipid levels are significantly associated with breast cancer risk and mortality (*23*, *24*). Therefore, we added hyperlipidaemia to the list of comorbidities in this study.

Comorbidity information was extracted from the inpatient and outpatient electronic medical records at the Cancer Institute of Iran. There was no single questionnaire containing information on comorbidities in the patients' files. Therefore, initially, we reviewed medical history recorded by physicians; nursing assessment sheets; preoperative cardiac, anaesthesia, or other specialty consultation notes; and results of laboratory and paraclinical assessments. According to the findings of this initial step, we prepared a guideline to help registrars collect comorbidity information from the medical records, and comorbidity data were coded based on the International Classification of Diseases 10th Revision (https://icd.who.int/browse10/2019/en). Trained registrars used the guideline to review all the notes containing relevant data and extracted the comorbidity information. The collected comorbidity data were entered into the Clinical Breast Cancer Registry of Iran.

To evaluate the accuracy of the extracted comorbidity data, we randomly selected 132 of the 400 patients for telephone interview to ask about their comorbidities, and 97 responded (73.5% response rate). The most frequent reason for nonresponse was out-of-date telephone numbers.

We used the comorbidity results reported at interview as a gold standard to calculate the sensitivity, specificity, and accuracy of extracting any comorbidity versus noncomorbidity from medical data. In addition, the accuracy of extracting the presence or absence of 2 common diseases (diabetes and hypertension) was calculated separately. We also studied the prevalence of comorbidities based on CCI and ECI.

The mean (standard deviation) for continuous variables and percentage for categorical variables were calculated using SPSS Statistics for Windows, version 24 (IBM, Armonk, NY, USA).

Results

The mean age of the 400 breast cancer patients was 51.7 (12.3) years, with a range of 24–86 years. There were 395 (98.8%) female and 5 (1.3%) male patients.

The accuracy of the comorbidity data extracted from medical records is shown in Table 1. The sensitivity, specificity, and accuracy of medical records for detecting any comorbidity data contained in CCI versus noncomorbidity was 93.2%, 69.8%, and 80.4%, respectively. The accuracy of extracting the comorbidity data that were present in ECI from medical records was lower than for CCI (86.9% sensitivity and 44.4% specificity). Diabetes was registered in medical records with sensitivity, specificity, and accuracy of 100.0%, 71.7%, and 82.5%, respectively.

Table 2 shows the prevalence of comorbidities according to the CCI and ECI. Among the Charlson comorbidities, diabetes without chronic complications (n = 77, 19.3 %) was the most prevalent. Based on the Elixhauser comorbidities, uncomplicated hypertension (n = 144, 36.0 %) was the most prevalent. Our evaluation showed that the prevalence of hyperlipidaemia was 17.0% (n = 68).

According to CCI and ECI, 72.2% and 44.8% of the patients, respectively had no report of any comorbidity (Table 3). Multimorbidity was seen in 6.9% and 19.1% of the patients according to CCI and ECI, respectively. In the subanalysis, there was no report of comorbidity in patients under 30 years of age. At least 1 comorbidity was reported in 11.4% of patients aged < 50 years compared with 40.9% of patients aged ≥ 50 years. According to CCI, all patients with multimorbidity were older than 50 years, and according to ECI only 2 women younger than 50 years had multimorbidity. The mean (standard deviation) CCI score was higher [0.37 (0.72)] than the mean ECI score [0.06 (1.77)].

Discussion

We investigated the feasibility of comorbidity data extraction using medical records based on the CCI and ECI in order to add data to the Clinical Breast Cancer Registry of Iran. The sensitivity and specificity for detecting comorbidities in medical records showed that obtaining comorbidity data from medical records was feasible and had sufficient accuracy to improve clinical data for breast cancer studies. We found that entering comorbidity data based on the CCI was more accurate; however, the CCI did not capture all types of comorbidities, such as hypertension and hypothyroidism, that may be relevant to health outcomes and quality of life in breast cancer patients. Therefore, we believe that extraction of comorbidity data from both CCI and ECI should be continued to improve the mortality index in our population.

Several studies have investigated comorbidities and the use of hospital or self-reported data by cancer patients. Similar to our study, in the California Cancer Registry, comorbidity information for breast cancer patients extracted from hospital discharge data was compared with comorbidity scores derived using the Surveillance, Epidemiology, and End Results (SEER)–Medicare database. The authors concluded that the sensitivity of hospital discharge data for detecting any comorbidity versus noncomorbidity was sufficiently high (76.5%) to allow the construction of a comorbidity index for breast cancer registries (*19*). The results of the 2 studies confirm that the assessment of comorbidity data using internal data sources, such as paper or electronic medical records in hospitals, is appropriate and reliable. Using and connecting internal data with health databases outside hospitals, such as private laboratories, are cost- and time-consuming and need specific authorization.

In contrast to our study, in women diagnosed with breast cancer, who were part of the California Breast Cancer Survivorship Consortium, the self-reported information and electronic medical records for 4 common comorbidities (diabetes, hypertension, myocardial infarction, and other heart diseases) were compared (*25*). The concordance rate for

myocardial infarction and other heart diseases was not sufficiently high (< 70%) between self-reported comorbidity status and medical records. Furthermore, the sensitivity and specificity varied by comorbidities but not by age, socioeconomic status, or education. An Australian study investigated the prevalence of comorbidity and multimorbidity using self-reported surveys and administrative datasets (*26*). The prevalence of multimorbidity differed significantly between self-reported, medication, and hospital data. These investigations recommended that caution should be applied when assessing comorbidity from a single data source.

Diabetes is important in the CCI and ECI and in our study population; therefore, we assessed the information about diabetes in medical records and found 82% accuracy for reporting diabetes without complications. Our results are consistent with those from previous studies that reported the high sensitivity and specificity in recording diabetes by different methods; therefore, it seems that history of diabetes is well documented in medical records (*19*, *25*). Although comorbid diabetes is mentioned in patients' records, end-organ damage associated with diabetes is not well recorded. In the present study, chronic complications following diabetes were recorded correctly in only 2 of 7 patients. We should note that chronic complications of diabetes may overlap with other comorbidities such as heart and renal disease. The prevalence of diabetes with complications in our study was similar to that in the study of Klabunde et al. (1.8% vs 1%) (*15*). However, in another study by Mehta et al., the rate of diabetes with end-organ damage was higher (4.3%), probably because of the older age of the participants (mean 75.8 years) (*17*).

Based on our results, 72.2% of patients had no comorbidities according to CCI and this was consistent with the California Cancer Registry in 2017, which showed that 75.3% of breast cancer patients had no relevant comorbidities (*19*). Similar to our results, the SEER study in 123 680 breast cancer patients reported that 67.8% had no comorbidity (*3*).

Multimorbidity was higher in the SEER study (9.8%) compared with our study (6.9%), because of the recruitment of older patients aged ≥ 66 years. The difference may also be because of the younger age of onset of breast cancer in Iranian compared with European and North American patients (*27*). Contrary to the studies mentioned above, Fu et al. reported that, among 134 breast cancer patients, 73.8% had at least 1 comorbidity (*28*). That study evaluated all CCI comorbidities and other conditions mentioned in the open-ended interview questions; therefore, it is better to compare with our results for ECI, which captured more comorbidities. The number of patients with at least 1 comorbidity in the Fu study was higher than in our study (73.8 % vs 55.2%). This difference may be because the Fu study had a smaller sample size and higher average age (56 years) compared with our study (52 years).

In our study, the prevalence of comorbidities was assessed using CCI and ECI. Hypertension and diabetes without chronic complications were the most common comorbidities in breast cancer patients. Similar to our study, uncomplicated diabetes and hypertension were the most prevalent comorbidities in studies from the United States of America (*17*) and Australia (*29*). In other studies, the reported prevalence of diabetes without complications ranged from 10% to 22% (*15*, *17*, *19*, *28*, *29*) and that of hypertension from 14% to 58% (*17*, *28*, *29*) in cancer patients. The rate of these 2 comorbidities in our study was within these reported ranges. It seems that the difference between the reported prevalence of comorbidities, especially hypertension, resulted from the age of the patients at the time of recruitment.

To the best of our knowledge, despite several studies in developed countries, there has been no systematic evaluation of the feasibility of medical data extraction from health systems to measure comorbidity index in developing countries. Considering that the comorbidity index needs to be tailored to specific populations (*15*, *19*, *28*), defining the specific comorbidity index and developing weights for comorbidities in breast cancer patients

in each population are necessary. The present study is believed to be the first to systematically investigate comorbidities and add them to cancer registration in developing countries, including the Islamic Republic of Iran. The strengths of our study were that it was conducted in the Cancer Institute of Iran and used data from a high-quality registry and a large study sample.

Our study also had some limitations. Patients can have anxiety at the time of cancer diagnosis, and may not remember their history of comorbidity, or omit details of the diseases during hospital admission or during interview (recall bias). Furthermore, we used interview data as a gold standard measurement in this study, which was subject to recall bias and misclassification. Women with a long history of comorbidity or who are taking medication are more likely to report their diseases. We tried to mitigate this bias by employing a trained interviewer in this study.

We are aware that medical records are often fragmented across multiple healthcare sectors, posing an obstacle to clinical care and research studies. Therefore, we recommend development of electronic records and public–private partnerships to integrate entire records and facilitate accurate registration of comorbidity data, specifically for severe comorbidities that may have a high impact on patient outcomes. Data generated by the private sector, such as laboratories and radiology centres, should be combined with data produced by public and university hospitals to allow exchange of data according to ethical standards. Accessibility to medical records and permission to use personal medical information, while protecting privacy of patients is recommended (*30*).

In further studies we will investigate the prevalence of comorbidities in breast cancer patients throughout the Islamic Republic of Iran and compare the results between health centres of different geographical regions. We will continue to develop a clinical comorbidity

index for Iranian breast cancer patients that can improve prediction of survival. It is hoped that this index will be implemented by other cancer registries across the country to increase the relevance and usefulness of breast cancer registry data.

Conclusion

It is appropriate to use medical records to collect comorbidity information and construct a comorbidity index for breast cancer patients admitted to the Cancer Institute of Iran. Extraction of comorbidity data from medical records considering CCI provides greater accuracy than for ECI. We recommend recording all comorbidities included in CCI and ECI in the CBCR-IR to develop the best comorbidity index for predicting survival in Iranian breast cancer patients. Active data collection and face-to-face interviews with patients and evaluation of medical records are needed for some comorbidities. To overcome the limitation of this type of study and collect comorbidity data accurately, development of integrated electronic medical records is necessary.

Acknowledgements

We would like to thank the Clinical Breast Cancer Registry of Iran for providing the data for this research and registrars working there.

Funding: This study was supported by the Cancer Institute, Tehran University of Medical Sciences (No# 98-3-259-45418).

Conflict of interest: None declared.

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Table 1. Sensitivity, specificity, and accuracy of extracted comorbidity data from medical records for CCI/ECI comorbidities, diabetes, and hypertension

	TP	FP	FN	TN	Sensitivity, % (95% CI)	Specificity, % (95% CI)	Accuracy, % (95% CI)
CCI	41	16	3	37	93.2 (81.3–98.6)	69.8 (55.7–81.7)	80.4 (71.1–87.8)
ECI	53	20	8	16	86.9 (75.8–94.2)	44.4 (27.9–61.9)	71.1 (61.1–79.9)
Diabetes	37	17	0	43	100.0 (90.5–100.0)	71.7 (58.6–82.6)	82.5 (74.4–89.5)
Hypertension	13	31	2	51	86.7 (59.5–98.3)	62.2 (50.8–72.7)	65.9 (55.7–75.3)

Sensitivity, specificity, and accuracy of medical records data for detecting any comorbidity versus noncomorbidity were calculated for CCI and ECI. CCI = Charlson Comorbidity Index; CI = confidence interval; ECI = Elixhauser Comorbidity Index; FN = false negative; FP = false positive; TN = true negative; TP = true positive.

Table 2. Prevalence of comorbidities according to CCI and ECI in breast cancer patients

CCI	Frequency (%)	ECI	Frequency (%)
Diabetes without chronic complication	77 (19.3)	Hypertension	144 (36.0)
Old myocardial infarction	29 (7.3)	Diabetes, uncomplicated	77 (19.3)
Chronic obstructive pulmonary disease	7 (1.8)	Hypothyroidism	44 (11.0)
Diabetes with end organ damage	7 (1.8)	Depression	12 (3.0)
Renal disease	5 (1.3)	Drug abuse	7 (1.8)
Mild liver disease	3 (0.8)	Chronic pulmonary disease	7 (1.8)
Cerebrovascular disease	3 (0.8)	Diabetes with chronic complication	7 (1.8)
Connective tissue disease	2 (0.5)	Renal failure	5 (1.3)
Congestive heart failure	0	Liver disease	4 (1.0)
Peripheral vascular disease	1 (0.3)	Anaemia	1 (0.3)
Moderate / severe liver disease	1 (0.3)	Neurodegenerative disorders	3 (0.8)
Acute myocardial infarction	0	Obesity	1 (0.3)
Peptic ulcer disease	0	Valvular heart disease	2 (0.5)
Dementia	0	Rheumatoid arthritis/ connective	2 (0.5)
Hemiplegia/paralysis	0	tissue	
AIDS/HIV	0	Weight loss	2 (0.5)
		Peripheral vascular disease	1 (0.3)
		Congestive heart failure	0
		Cardiac arrhythmia	0
		Paralysis	0

		Peptic ulcer disease	1 (0.3)
		AIDS/HIV	0
		Coagulopathy	0
		Fluid and electrolyte disorders	0
		Alcohol use	0
		Psychosis	0

CCI = Charlson Comorbidity Index; ECI = Elixhauser Comorbidity Index.

Table 3. Comorbidity rate according to CCI and ECI

No. of comorbidities in 1 patient	CCI	ECI
0	289 (72.2%)	179 (44.8%)
1	84 (21%)	145 (36.2%)

2	21 (5.3%)	61 (15.3%)
≥3	6 (1.6%)	15 (3.8%)

CCI = Charlson Comorbidity Index; ECI = Elixhauser Comorbidity Index.