RESEARCH ARTICLE

Agreement of Iranian Breast Cancer Data and Relationships with Measuring Quality of Care in a 5-year Period (2006-2011)

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Abstract

**Objectives:** To investigate data agreement of cancer registries and medical records as well as the quality of care and assess their relationship in a 5-year period from 2006 to 2011. **Methods:** The present cross-sectional, descriptive-analytical study was conducted on 443 cases summarized through census and using a checklist. Data agreement of Nemazi hospital-based cancer registry and the breast cancer prevention center was analyzed according to their corresponding medical records through adjusted and unadjusted Kappa. The process of care quality was also computed and the relationship with data agreement was investigated through chi-square test. **Results:** Agreement of surgery, radiotherapy, and chemotherapy data between Nemazi hospital-based cancer registry and medical records was 62.9\%, 78.5\%, and 81\%, respectively, while the figures were 93.2\%, 87.9\%, and 90.8\%, respectively, between breast cancer prevention center and medical records. Moreover, quality of mastectomy, lumpectomy, radiotherapy, and chemotherapy services assessed in Nemazi hospital-based cancer registry was 12.6\%, 21.2\%, 35.2\%, and 15.1\% different from the corresponding medical records. On the other hand, 7.4\%, 1.4\%, 22.5\%, and 9.6\% differences were observed between the quality of the above-mentioned services assessed in the breast cancer prevention center and the corresponding medical records. A significant relationship was found between data agreement and quality assessment. **Conclusion:** Although the results showed good data agreement, more agreement regarding the cancer stage data elements and the type of the received treatment is required to better assess cancer care quality. Therefore, more structured medical records and stronger cancer registry systems are recommended.

**Keywords:** Cancer data agreement - care quality measurement - breast cancer care - process of care - Iran

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**Introduction**

In general, taking care of breast cancer is quite complex and costly (Rosselli et al., 2010). Moreover, investors, consumers, and providers are highly interested in measuring the quality of cancer care and emphasize obtaining high-quality information (Pearson et al., 2002). Care quality measurement is a mechanism which quantifies the quality of a dimension of care by comparing the services provided for the patients with the standard criteria (Malin et al., 2002; Moher et al., 2004). The present study has focused on the process of care quality. According to the evidence, the better the process of cancer care, the more desirable the results will be.

Up to now, a large number of studies have confirmed the relationship between the process and output of breast cancer care (Rosselli et al., 2010). In general, the data provide the opportunity for measuring the care quality (Moher et al., 2004) and the best data resources for evaluating the quality of cancer care are medical records and hospital cancer registrations (Coory, 2009). Overall, in order for the data resources to accurately assess the quality of care, reliable data on the intended care must be available (Malin et al., 2002).

In fact, the best way for data validation is comparing the registered data with the main source (Malin et al., 2002; Ferlay, 2005) and data validity can be used in case the main source is the gold standard. This is not usually possible in reality and, as a result, data agreement should be utilized (Guamin, 2009). Therefore, in the present study, the process of breast cancer care quality for the cases registered in Nemazi hospital-based cancer registry (NHBCR) and breast cancer prevention center (BCPC) affiliated to Shiraz University of Medical Sciences, Shiraz, Iran was analyzed according to their corresponding medical records and the relationship between the data agreement and assessment of care quality was investigated, as well.

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Materials and Methods

In this study, the medical records corresponding to all the cancer cases registered in NHBCR and BCPC of Shiraz University of Medical Sciences, Shiraz, Iran in 2006 (315 and 388 cases, respectively) were collected using the demographic characteristics. Then, all the medical records were integrated and the patients who had medical profiles, were diagnosed with stages I, II, and III of cancer, were female, and lived in Fars province were enrolled into the study. Afterwards, the medical records were summarized regarding the data related to chemotherapy, radiotherapy, lumpectomy, mastectomy, hormone therapy, tumor features and spread, initial treatment, demographic characteristics, and existence of co-morbidities using Charlson co-morbidity index which has been standardized for breast cancer (Charlson, 1987) for 5 years after cancer diagnosis. After summarization, 238 and 205 cases revealed to have the inclusion criteria of the study in BCPC and HBCR, respectively. It should be noted that the data elements of the summarization instrument were obtained from American Joint Commission on Cancer (AJCC) (Edge and Compton, 2010), Charlson index (Charlson, 1987), similar studies (Malin et al., 2002; Moher et al., 2004), national standards, and the experts’ opinions. Moreover, the reliability of the summarization instrument was confirmed by a number of experts.

Overall, the study was conducted in 3 stages: investigation of data agreement, assessment of care quality, and determination of the relationship between data agreement and care quality assessment. In the first stage, data agreement of the intended variables was determined by comparing the resources and using observed agreement, unadjusted kappa, and adjusted kappa, such as prevalence adjusted bias adjusted kappa (PABAK), bias adjusted kappa (BAK), and weighted kappa (WK) (Byrt, 1993; Hoehler, 2000; Ben-David, 2008). Then, the rate of data agreement was interpreted based on the kappa ranges; i.e., 0 (weak), 0.1-0.2 (mild), 0.21-0.40 (almost average), 0.41-0.60 (average), 0.61-0.80 (good), and 0.81-1 (excellent) (Sim and Wright, 2005). In the second stage, cancer care quality was assessed using the following 4 quality indicators (QI) obtained from national (Partoeipour, 2010) and the experts’ opinions:

QI1: The patients with stage I through III breast cancer should have chemotherapy. QI2: The patients with stage III breast cancer who have undergone mastectomy and their tumor is equal to or more than 5 cm as well as those with stage I or II breast cancer who have had mastectomy and their lymph node is positive should have radiotherapy. QI3: The patients with stage I or II breast cancer, those with stage III breast cancer whose tumor is equal to or more than 5 cm, and stage I, II, or III breast cancer patients over 70 years old should have lumpectomy. According to the above-mentioned indicators, if a case was located in an indicator and had received the standard care, the care quality was scored as 1 out of 1 or 100%.

Moreover, if a case was engaged in 3 indicators and had received the standard care in 2 cases, the care quality was scored as 2 out of 3 or 66%. In order to assess the quality of care, the variables of age, co-morbidities (based on Charlson’s table of co-morbidities, cancer stage (I, II, or III), and type of inpatient or outpatient care were computed in percentile and compared with each other. Finally, chi-square was used in order to analyze the relationship between data agreement and care quality assessment. All the statistical analyses were performed through the SPSS statistical software (v. 16) and SAS software.

Results

According to the results obtained from the 4 data resources, the highest incidence of breast cancer had occurred between 40 and 49 years of age and stage II was the most prevalent cancer stage at the time of diagnosis.

Based on the data of the medical records corresponding to NHBCR, 71.7%, 28.3%, 81.5%, and 90.2% of the patients had received mastectomy, lumpectomy, radiotherapy, and chemotherapy, respectively. These measures were reported as 58%, 10.2%, 62.9%, and 71.2%, respectively based on the NHBCR data. In addition, 100% of the patients according to the medical records and 68.3% according to the NHBCR data had undergone surgery. Furthermore, the rate of receiving chemotherapy, radiotherapy, mastectomy, and lumpectomy in the medical records of the patients below and equal to or above 50 years old was 89.1-91.9%, 84-77.9%, 67-77.9%, and 32-22.1%, respectively. These measures were reported as 67.8-75.6%, 64.3-61.1%, 55.7-61.1%, and 10.4-10%, respectively in NHBCR.

Based on the data of the medical records corresponding to BCPC MR, 71.2%, 68.3% according to the NHBCR data had undergone surgery. Furthermore, the rate of receiving chemotherapy, radiotherapy, mastectomy, and lumpectomy in the medical records of the patients below and equal to or above 50 years old was 89.1-91.9%, 84-77.9%, 67-77.9%, and 32-22.1%, respectively. These measures were reported as 67.8-75.6%, 64.3-61.1%, 55.7-61.1%, and 10.4-10%, respectively in NHBCR.

Table 1. Agreement of Care Data of Cancer Registry Centers and their Corresponding Medical Records

<table>
<thead>
<tr>
<th>BCPC</th>
<th>MR</th>
<th>NHBCR</th>
<th>MR</th>
</tr>
</thead>
<tbody>
<tr>
<td>PABAK Kappa</td>
<td>Agree N</td>
<td>N</td>
<td>PABAK Kappa</td>
</tr>
<tr>
<td>Inpatient Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>0.843</td>
<td>0.738</td>
<td>0.623</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>147</td>
<td>119</td>
<td>163</td>
</tr>
<tr>
<td>Outpatient Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>0.619</td>
<td>0.422</td>
<td>0.816</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>0.671</td>
<td>0.487</td>
<td>0.780</td>
</tr>
</tbody>
</table>

*MR: Medical record, N: Number, Agree: %agreement

Table 2. Agreement of Non-Care Data of Cancer Registry Centers and their Corresponding Medical Records

<table>
<thead>
<tr>
<th>BCPC</th>
<th>MR</th>
<th>NHBCR</th>
<th>MR</th>
</tr>
</thead>
<tbody>
<tr>
<td>WK</td>
<td>BAK Kappa</td>
<td>Agree No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0.912</td>
<td>0.882</td>
<td>0.901</td>
</tr>
<tr>
<td>2</td>
<td>104</td>
<td>85</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>76</td>
<td>65</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>0</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Co-morbidity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have</td>
<td>151</td>
<td>181</td>
<td></td>
</tr>
<tr>
<td>Don’t, have</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ER, PR receptor</td>
<td>0.516</td>
<td>0.668</td>
<td>0.505</td>
</tr>
</tbody>
</table>

*NA: Not applicable, N: Number, WK: Weighted kappa, BAK: Bias adjusted kappa, ER: Estrogen, PR: Progesterone
to BCPC, 69.3%, 30.3%, 73.1%, and 87.2% of the patients had undergone mastectomy, lumpectomy, radiotherapy, and chemotherapy, respectively, while these measures were reported as 66.2%, 30.8%, 61.1%, and 71.2%, respectively in BCPC. Besides, surgery was performed for 100% of the patients according to the medical records and 96.6% according to the BCPC data. Moreover, the rate of chemotherapy, radiotherapy, mastectomy, and lumpectomy in the medical records of the patients below and equal to or above 50 years old was 97-92.2%, 77.8-64.1%, 63.7-76.7%, and 35.6-22.3%, respectively. On the other hand, this rate was reported as 86.6-84.6%, 67.2-51%, 60.4-71.2%, and 35.8-23.1%, respectively in BCPC.

Regarding NHBCR and medical records, data agreement of outpatient services was higher than that of inpatient services. Moreover, the study findings revealed good, average, and average kappa for surgery, chemotherapy, and radiotherapy, respectively. Of course, by applying PABAK and eliminating the prevalence and bias effects, the rate of kappa increased for all the cases. PABAK showed to be excellent for surgery, while it was found to be good for chemotherapy as well as radiotherapy (Table 1). Considering BCPC and medical records, the other hand, data agreement of inpatient services was higher than that of the outpatient services. Furthermore, the study results showed excellent, average, and good kappa for surgery, chemotherapy, and radiotherapy, respectively. PABAK was also revealed to be excellent, good, and good, respectively (Table 1).

Overall, the agreement between NHBCR data and the medical records related to age, marital status, histology of cancer, nuclear grade, and histology grade was reported as 100%, 91.7%, 98%, 100%, and 76.1%, respectively. On the other hand, the agreement between the BCPC data and the medical records on the above-mentioned variables was 100%, 80.3%, 96.21%, 100%, and 95%, respectively. It should be noted that BCPC did not collect the data related to the co-morbidities and, consequently, data agreement could not be computed in this regard (Table 2).

NHBCR data reported the assessed quality of chemotherapy, lumpectomy, radiotherapy, and chemotherapy, respectively 12.6%, 21.2%, 35.2%, and 15.1% lower than the medical records. Moreover, the results obtained from the medical records corresponding to NHBCR showed that the quality of chemotherapy, radiotherapy, and mastectomy was lower among the cases with co-morbidities. In addition, the quality of radiotherapy and mastectomy was lower in equal to or above 50 ages (Table 3).

On the other hand, BCPC data reported the quality of mastectomy, lumpectomy, radiotherapy, and chemotherapy, respectively 7.4%, 1.4%, 22.5%, and 9.6% lower than the medical records. Besides, the results obtained from the medical records corresponding to BCPC also showed that the quality of chemotherapy, radiotherapy, and mastectomy was lower in the cases accompanied by co-morbidities. Nevertheless, due to the lack of information about co-morbidities in BCPC, the process of care quality could not be assessed (Table 4).

Overall, the findings of the study revealed significant a relationship between the data agreement of chemotherapy, radiotherapy, and surgery and assessing the quality of these services. A statistically significant relationship was also found between cancer stage data agreement and assessing the quality of each of the above-mentioned services (P<0.05).

**Discussion**

The findings of the present study showed that the agreement of the BCPC data was higher than that of the NHBCR data, which might be due to the fact that the patients’ status is followed up in shorter time intervals in BCPC. Moreover, in NHBCR, agreement of the outpatient care data was better than that of the inpatient care data, which is consistent with the results of the study by Brewster (Brewster, 2002). Considering the BCPC data, on the other hand, the agreement of inpatient care data was higher than that of the outpatient care data, which is in line with the findings of the studies conducted by Gulliford (1993), Moher et al. (2004), and Zhang (2010). This
difference might result from the close relationship between chemotherapy and radiotherapy wards and NHBCR.

Overall, in comparison to the radiotherapy data, chemotherapy data agreement was higher in both centers, which is consistent with the studies by Zhang (2010) and Elbasmi (1987), while on the contrary to the results obtained by Moher et al. (2004).

The study results also showed better agreement of the demographic data compared to the care data. The studies conducted by Elbasmi (1987) and Pollock and Vickers (1995) have also shown that the highest data agreement is related to demographic and non-medical data. The low agreement of the care data might be due to being more specialized, the need for more knowledgeable specialists for cancer registration and summarization of the medical records, undesirable structure of the medical records, and lack of 6-month follow up of the patients’ data.

In the current study, compared to radiotherapy, chemotherapy services benefited a higher agreement with the standards after the surgery. This was also confirmed by the findings of the studies by McEvoy et al. (2004), Wyld (2004), Guadagnoli et al. (1998), and Malin et al (2002).

The study results showed that age and co-morbidities reduced the quality of radiotherapy and mastectomy. Besides, as the age increased, using radiotherapy after the surgery decreased. These findings are in line with those of the studies conducted by Farrow (1992), Ballard-Barbash (1996), and Schuster (1998).

Furthermore, considering the fact that most of the cases were with stage II breast cancer at the moment of diagnosis, cancers can be diagnosed in the first stage by regular, complete screening which, consequently, results in increasing the quality of care.

The study findings showed that the data agreement of chemotherapy, radiotherapy, surgery, cancer stage, and tumor size caused a significant difference in assessing the quality of care. In other words, the difference in the care quality measured in the two centers showed the low quality of the data for being used in assessing the quality care. In the same line, the results of the study by Bickell and Chassin (2000) and Malin et al. (2002) showed that insufficient reporting of chemotherapy and radiotherapy for breast cancer in hospital registrations directly affected the care quality assessment. Yulei also performed a study in order to measure the quality of cancer care by combining the medical records and the cancer registration data. The results obtained from assessment of care quality in both data sources and comparison of the two showed that direct utilization of cancer registration data led to the unreliability of the analysis (Yulei and Zaslavsky, 2009).

In this study, although the data of estrogen and progesterone receptors were available in both the medical records and BCPC, the quality of care could not be assessed due to the incompleteness or no registration of hormone therapy data in the medical records as well as the cancer registration resources. Smith also conducted a study on the inequality of the data in medical records and cancer registry centers for evaluating the cancer services and faced problems, including incomplete data details, low follow up of the care data, incomplete data registration, and incomplete registration of the details for the patients who had received a part of their care service in other treatment centers. Besides, since he was not able to find any data regarding the estrogen receptors, he could not evaluate the quality of hormone therapy services. Therefore, incomplete data is one of the greatest limitations in assessing cancer services in cancer registry centers (Smith et al., 1997).

Overall, although the study results showed desirable data agreement, more agreement regarding the cancer stage data elements as well as the type of the received treatment is required in order to assess the process of cancer care quality. Therefore, more structured medical records and stronger cancer registry systems are recommended.

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