Completeness of medical records of elderly women with breast cancer: a trend study

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Abstract
Objective: To assess completeness and trends in completeness of medical records of elderly women with breast cancer who were diagnosed and admitted from 2001 to 2006 at a center for women's health in the State of São Paulo.
Methods: This was an analytical and descriptive study based on secondary data. For non-completeness analysis, the following classification was used: excellent (< 5%), good (5-10%), regular (10-20%), poor (20-50%), and very poor (>50%).
Results: Socio-economic and demographic variables, as well as risk- and behavioral-factor-related variables, scored mainly as regular, poor, or very poor. The best scores were seen in post-treatment variables, followed by diagnosis- and treatment-related variables. The only variable to show a downward non-completeness trend was family history of breast cancer (p=0.05). A growing non-completeness trend was seen in the following variables: race/color (p=0.01), years of formal education (p=0.01), use of oral contraceptives (p=0.002), time of use of oral contraceptives (p=0.002), hormonal replacement (p=0.007), and breastfeeding (p=0.004).
Conclusion: Variables classified as regular, poor, and very poor showed a predominantly constant completeness trend, followed by an growing in non-completeness trend. Only one variable showed an improvement in completeness trend. Full recording of all patient data on medical record is an inherent task for the entire healthcare team. Such recording is fundamental to establish care protocols, develop research studies, as well as implement public health policies.

Keywords
Acuity of data; Breast neoplasms; Quality improvement; Hospital information systems; Medical records hospital service

Descritores
Acuidade dos dados; Neoplasias da mama; Melhoria de qualidade: Sistemas de informação hospitalar; Serviço hospitalar de registros médicos

Métodos: estudio descriptivo analítico basado en datos secundarios. Para el análisis de no completude, se utilizó la clasificación: excelente (< 5%), buen (5 a 10%), regular (10 a 20%), malo (20 a 50%) y muy malo (>50%).
Resultados: Las variables socioeconómicas e demográficas, así como las de factores de riesgo y comportamentales, predominaron en las clasificadas como regular, malo y muy malo. Las mejores puntuaciones fueron en las variables relacionadas con el diagnóstico y el tratamiento. La única variable con tendencia de no completude decreciente fue la historia familiar de cáncer de mama (p = 0.05). Aumentó la probabilidad de no completude en las siguientes variables: raza/color (p = 0.01), años de estudio (p = 0.01), uso de anticonceptivos orales (p = 0.002), tiempo de uso de anticonceptivos orales (p = 0.002), reposición hormonal (p = 0.007) y amamantamiento (p = 0.004).
Conclusión: Las variables clasificadas como regular, malo y muy malo, la tendencia de completude decreciente como constante, seguida de una tendencia de completude creciente. El registro completo de los datos en el historial clínico es una tarea inherente a toda la plantilla de salud, fundamental para establecer protocolos de asistencia, desarrollo de investigaciones, así como implementar políticas públicas de salud.

Resumen
Objetivo: Evaluar la completude y la tendencia de completude de datos de historias clínicas de ancianas afectadas por cáncer de mama, diagnosticadas y atendidas entre los años 2001 y 2006 en un centro de referencia en salud de la mujer del estado de Sao Paulo.
Métodos: estudio descriptivo analítico basado en datos secundarios. Para el análisis de no completude, se utilizó la clasificación: excelente (< 5%), bueno (5 a 10%), regular (10 a 20%), malo (20 a 50%) y muy malo (>50%).
Resultados: Las variables socioeconómicas y demográficas, así como las de factores de riesgo y comportamentales, predominaron en las clasificadas como regular, malo y muy malo. Las mejores puntuaciones fueron en las variables relacionadas con el diagnóstico y el tratamiento. La única variable con tendencia de no completude decreciente fue la historia familiar de cáncer de mama (p = 0.05). Presentaron tendencia de no completude creciente: raza/color (p = 0.01), años de estudio (p = 0.01), uso de anticonceptivos orales (p = 0.002), tiempo de uso de anticonceptivos orales (p = 0.002), reposición hormonal (p = 0.007) y lactancia materna (p = 0.004).
Conclusión: Entre las variables clasificadas como regular, malo y muy malo, la tendencia de completude decreciente como constante, seguida de una tendencia creciente de no completude. Solo una variable presentó mejora de la tendencia de completude. El registro completo de los datos en la historia clínica es tarea inherente a todo el equipo de salud, primordial para establecer protocolos de atención, desarrollar investigaciones, así como implementar políticas públicas de salud.
Introduction

Aging is one of humanity’s greatest achievements, an achievement of civilization. A healthy aging is reflex of an good health status, access to sanitation, labor, and home. In summary, ageing is an evolving process. Globally, in the next two years, the unlikely will occur: the elderly will outnumber children younger than the age of 5 years. Women will be the majority of the senile group, as their life expectancy is higher. Consequently, this fact highlight an important concern, the need of a better understanding about aging and senescence.

To help such understanding, the development of epidemiological cohort studies, prospectively or not, including elderly patients are warranted. However, unexpectedly, elderlies are excluded from many epidemiological studies for several reasons, such as low life expectancy to be included in long-term medical follow-up and the fact that older people may present comorbidities related to the process of senility, which may be confounding for certain outcomes.

In addition, the lack of inclusion of elderlies in population monitoring and screening strategies for early detection of some diseases that age is the predominantly risk factor, e.g., breast cancer, leads us to believe that a major failures are about to happen, and in such extent, that they contribute for maintenance of questionable practices.

Among countless non-communicable diseases (NCDs), cancer has a prominent position. This disease incidence in 2018/2019 is estimated at 600,000 cases a year, breast cancer alone accounts for 59,700 cases. From 2010 to 2015, 83,746 breast cancer-related deaths were documented in Brazil. Of these deaths, 43,051 patients were women aged ≥60 years.

To monitor some diseases’ behavior, in addition to documenting in medical records, which have long been used to assess and register data about a patient’s health status— is also supporting tools developed to group population data and by the analysis to easily access other information. The RHC, a Brazilian hospital-based cancer record, is one of such tools. The tool is used to assess the quality of care based on data collected from all patients diagnosed with cancer and who received hospital care. The tool uses as the main source data from the medical record, which causes a cascade reaction.

Quality of information regarding significant clinical and socio-demographic variables in patients’ medical records is often not enough to understand the cancer phenomenon. Lack of completeness, illegibility of a number of records, damages, state of conservation, lack of commitment of healthcare professionals, and difficulty to access medical records for analysis may compromise the study of secondary data, which could shed light upon an unclear situation. In addition, such problems may compromise planning and promoting of public health initiatives, as well as, monitoring and assessing of existing initiatives.

This study assessed completeness and trends in completeness of medical records of elderly women with breast cancer who were diagnosed and admitted from 2001 to 2006 at center for women’s health of a public hospital in the State of Sao Paulo, Brazil. This study is part of a larger project that sought to analyze survival rate within a 10-year period of elderly women diagnosed with breast cancer. The project found weakness and several variables such as low completeness, which led to an increasing in the interest to understand better the problem.

Methods

This was an analytical and descriptive study based on secondary data from a retrospective cohort that analyzed survival within 10-years, and prognostic factors among elderly women with breast cancer, who were diagnosed and admitted from 2001 to 2006 at center for women’s health within a public hospital in the State of Sao Paulo, Brazil.

Data were collected from printed versions of medical records of all elderly women first diagnosed with breast cancer at the hospital during the period of the study. We excluded patients who medical record was not available. In total, 1,318 elderly women were admitted. We could not access 77 medical records.
records. Thus, 1,241 medical records were included in this study. All data, documents, and exams in medical records were considered, including notes from the multi-professional team and administrative data.

The authors considered “elderly” women aged ≥60 years old, based on the Elderly Rights Act (Law nº 10,741, of October 1, 2003). (12)

Data were collected from 2013 to 2016 (based on a 10-year after breast cancer diagnosis) from the medical record archive of the hospital where this study was conducted. Collection was undertaken by the Principal Investigator, who received training from RHC, and an nurse who were trained to collect data. The time for analysis of each record varied from 30 minutes to 1 hour and 40 minutes.

A collection instrument was developed based on an existing form to register type of tumor, (13) as well as imperative variables for natural history of the disease, and variables that were not discussed elsewhere in the literature but were significant for later investigation and to determine relationship with women’s age. In the end, we studied the following categories and variables: socio-economic and demographic variables (family income, religion, years of formal education, race/color, occupation, marital status, place of residence); risk- and behavioral-factor-related variables (height, PO contraception, PO contraception time of use, weight, age at menarche, age at menopause, hormonal replacement, breastfeeding, duration of breastfeeding, alcohol abuse, family history of breast cancer, smoking, benign breast condition, nulliparity, hormonal status); diagnosis- and treatment-related variables (number of affected lymph nodes, tumor markers HER2 and P53, presence of calcification, more than one primary tumor, tumor laterality, presence of tumor necrosis, estrogen and progesterone receptors, type of surgery, tumor histology, primary location of tumor, biopsy method, staging, T, N, M, nuclear grade, histology grade, tumor size, surgical margin, type of treatment, previous diagnosis and treatment); and post-treatment variables (reurrence, metastasis, and death/non-death). A pilot study including 30 medical records were conducted to adequate and design the instrument of data collection.

For analysis of completeness, we adopted the classification proposed by Romero and Cunha (2006), in which consider the following evaluation classification: excellent (<5%), good (5-10%), regular (10-20%), poor (20-50%), and very poor (≥50%), based on the percentage of missing data. (14)

Inferential analysis with curve fitting was selected for handling the percentages of missing data in the studied variables. Best model equations and goodness of fit (R² value and p-value for the F-test of goodness of fit) were obtained using the SPSS software, version 19.0. The level of significance was established at 5%.

This study adhered to conventions of the Brazilian National Health Council Resolution nº 196/96, and it was approved by and by the hospital board of directors, and by the ethical and research committee of the Federal University of São Paulo, protocol number 378.803..

**Results**

We analyzed 48 variables including socio-economic and demographic data related to risk and behavioral factors, diagnosis and treatment, and post-treatment variables.

Description of studied population’s profile was based on missing data, which were included in an analysis category, considering that this is a completeness study. Participants’ mean age was 70.07 years old, median was 69 years old, and mode was 63 years old, with a standard deviation of 7.34 years. Elderly women aged 60 to 69 years old accounted for 54% of the sample. Most of participants were white (43.4%), 34.1% had up to 8 years of formal education, 8.3% were illiterate, 38.9% were married or in a stable union, 37% were widowed, 34.8% showed an income of up to 2 minimum Brazilian’s wages, 51.3% were homemakers, and 45.8% were catholic. Of the sample, 75.2% showed no previous history of cancer, 87.5% did not present with any benign breast condition, 13.2% showed nulli-
parity, 21.1% showed menarche before the age of 11 years old, and 4.9% were post-menopausal at 56 years of age or older. Those who breastfed their children accounted for 55.4% of the sample, 85.4% patients did not consumed alcohol, and 72.5% had never smoked. Most of the women did not use oral contraception (40.6%), nor hormonal replacement therapy (67.4%).

Most of breast cancer was diagnosed in 2006 among elderly women at the studied hospital (22%), followed by the year of 2003 (18.1%). In 91.8% cases, women were first admitted without any previous diagnosis or treatment showing II to III staging (66.7%) and 29.7% were admitted with later staging cancer (III and IV). The most prevalent cancer site was “Breast, unspecified” (C50.9) accounting for 97.9% cases, tumor histology of invasive ductal carcinoma was the most prevalent in 78.1% patients, and the left breast was most common malignant site (50.8%). Calcifications were absent in 61.3% cases, and nodules were present in 87.8%. In 26.7% patients, tumors were ≥4 cm in size, given 48.4% varied from 1.6 cm to 3.9 cm. Free surgical margins (81.2%), estrogen positive (62%), progesterone positive (52.1%), HER-2 negative (55.2%), P53 positive (40.1%), nuclear grade II (70.2%), histology grade 2 (66.6%), absence of necrosis (58.5%), and no lymph node involvement (45.1%) were prevalent in the study population.

Family income, height, use of oral contraception, and duration of use of oral contraceptives were the variables to show the poorest completeness scores, with 718 (57.9%), 624 (50.3%), 709 (57.1%), and 719 (57.9%) missing data, respectively (Table 1).

Table 1. Completeness score of socio-economic and demographic variables, as well as risk- and behavior-factor-related variables, in elderly women with breast cancer patients diagnosed and admitted at a public hospital in Sao Paulo

<table>
<thead>
<tr>
<th>Variable</th>
<th>Missing data (%)</th>
<th>Completeness score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family income</td>
<td>718(57.9)</td>
<td>Very poor</td>
</tr>
<tr>
<td>Religion</td>
<td>253(20.4)</td>
<td>Poor</td>
</tr>
<tr>
<td>Years of formal education</td>
<td>478(38.5)</td>
<td>Poor</td>
</tr>
<tr>
<td>Race/color</td>
<td>247(19.9)</td>
<td>Regular</td>
</tr>
<tr>
<td>Occupation</td>
<td>169(13.6)</td>
<td>Regular</td>
</tr>
<tr>
<td>Marital status</td>
<td>96(7.7)</td>
<td>Good</td>
</tr>
<tr>
<td>Place of origin</td>
<td>13(1)</td>
<td>Excellent</td>
</tr>
<tr>
<td>Height</td>
<td>624(50.3)</td>
<td>Very poor</td>
</tr>
<tr>
<td>Oral contraception</td>
<td>709(57.1)</td>
<td>Very poor</td>
</tr>
<tr>
<td>Duration of use of oral contraceptives</td>
<td>719(57.9)</td>
<td>Very poor</td>
</tr>
<tr>
<td>Weight</td>
<td>605(48.8)</td>
<td>Poor</td>
</tr>
<tr>
<td>Age at menarche</td>
<td>453(36.5)</td>
<td>Poor</td>
</tr>
<tr>
<td>Age at menopause</td>
<td>339(27.3)</td>
<td>Poor</td>
</tr>
<tr>
<td>Hormonal replacement</td>
<td>312(25.1)</td>
<td>Poor</td>
</tr>
<tr>
<td>Breastfeeding</td>
<td>307(24.7)</td>
<td>Poor</td>
</tr>
<tr>
<td>Duration of breastfeeding</td>
<td>550(44.4)</td>
<td>Poor</td>
</tr>
<tr>
<td>Alcohol abuse</td>
<td>126(10.2)</td>
<td>Regular</td>
</tr>
<tr>
<td>Family history of breast cancer</td>
<td>147(11.8)</td>
<td>Regular</td>
</tr>
<tr>
<td>Smoking</td>
<td>123(9.9)</td>
<td>Good</td>
</tr>
<tr>
<td>Benign breast condition</td>
<td>107(8.6)</td>
<td>Good</td>
</tr>
<tr>
<td>Nulliparity</td>
<td>123(9.9)</td>
<td>Good</td>
</tr>
<tr>
<td>Hormonal status</td>
<td>0</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

In the socio-economic and demographic category, table 1 shows only place of origin, permanent place of residence, scored as excellent. The following category, hormonal status, which characterizes pre-menopause or post-menopause patients, shows the best completeness score without any missing data. Family history of breast cancer scored as regular, along with alcohol abuse. The most prevalent score was poor, which applies to weight, age at menarche, age at menopause, hormonal replacement, breastfeeding, and duration of breastfeeding (Table 1). Data from post-treatment variables, followed by diagnosis- and treatment-related variables, where those that showed the most completeness. In the first case, all variables were presented as excellent and, in the second case, they ranged from regular to excellent, where excellent was the prevalent score. Variables showing the worst completeness score were tumor markers HER2 and P53, with 190 (15.3%) and 231 (18.6%) incomplete medical records, respectively (Table 2).

Table 3 shows trends in completeness from 2001 to 2006 for variables scoring regular, poor, and very poor. Most variables remained constant. Only family history of breast cancer showed a downward non-trend in completeness, i.e., there was an improvement in medical records over the years. Race/color, years of formal education, oral contraception, duration of use of oral contraceptives, hormonal replacement, and breastfeeding showed a continued with tendency for worsening and growing for non-completeness.
Discussion

All analyzed studies on data completeness were not stratified by age group to determine results of analyses and information in medical records. The studied variable was the general context only, for this reason, we could not compare old people subgroups. So far, we could not determine whether the medical record of elderly patients are the most negligent, and whether the prevalence of such negligence applies mostly to those in older groups.

To understand the health-disease process, as well as for the assertive intervention in this cycle, we need to understand socio-economic status, family history, behavioral habits, as well as diagnosis-, treatment-, and post-treatment-related variables.

Completeness regarding race/color variable showed a worsening, with an growing trend for non-completeness. This variable is classified as regular, in quality. This is a complex variable, which is not restricted to biology alone. This variable also represent a whole set of meaning and socio-cultural exposure, which reflects imbalance in the healthcare setting. Black women show the highest breast cancer mortality rates, as well as the highest chance of a late diagnosis. (15) Non-completeness of race information, as well as incorrect register of patients’ data
with a tendency of register to disappear,\textsuperscript{(16)} therefore, imposing barriers for rethinking public health policies.

Religions practiced by women largely impact their lives, and consequently their disease, not only in terms of spirituality, but also in terms of strategies to confront conflicts and counting on the emotional support from a group of people who share the same faith. Their practice sheds light on the particular customs of each religious community, such as not consuming alcohol, not smoking, having healthy eating habits, caring for the body as a sacred temple. In summary, these practices play an important role in the social control of behavior and mental health rehabilitation in the context of certain malignant conditions, as well as in the control of social iniquity.\textsuperscript{(17)} Completeness of this variable was not only poor, but also constant, and completeness did not show improvement over the years.

Years of formal education, family income, and occupation that presented poor, very poor, and regular score, respectively, were not well documented in the medical records—whereas the first variable showed a non-completeness trend. These are noteworthy and supplementary variables, especially years of formal education and family income,\textsuperscript{(18)} which point to a late diagnosis due to obstacles faced by patients. They reflect iniquity in terms of access, process, treatment, and prognosis.

Variables such as weight and height, which are essential for calculating body mass index (BMI), showed a high non-completeness rate. High IMC is knowingly associated to breast cancer outcomes.\textsuperscript{(19)} These variables show a constant non-completeness trend, despite the need for this information to be collected in detail.

Evidence shows that alcohol abuse is associated with increased risk of developing countless tumors, including breast tumors,\textsuperscript{(20)} in addition to being related to behavioral risk factors.\textsuperscript{(21)} As the measurement of alcohol abuse is subjective, there may be bias when quantifying its use. According to the World Health Organization, there are no safe levels for alcohol consumption. The presence of alcohol consumption implies the presence of health risks, which increase proportionally as the consumptions increase.\textsuperscript{(22)} This variable showed regular completeness (revealing a lack of thoroughness) and constant trend.

Presence of certain mutations (especially BRCA1 and BRCA2), family history of breast cancer in men and ovarian cancer are considered high risk factors for the occurrence of the disease.\textsuperscript{(21)} Family history of breast cancer along with genetic and hereditary factors, showed downward non-completeness, which points to a trend of improvement of registers in medical records. However, their completeness is still regular.

Risk factors for reproductive history and history of endocrine disorder included in the analysis variables were: early menarche and late menopause, oral contraception and prolonged use of oral contraceptives, as well as hormonal replacement.\textsuperscript{(21)} Both age at menarche and menopause presented a constant trend for poor completeness, which pose difficulties in the understanding of the correlation between the impact of exposure time to such hormones and the incidence of breast cancer in elderly women. Other related variables, such as oral contraception, duration of use of oral contraceptives, and hormonal replacement, showed a growing non-completeness trend. This is of especial concern, given that these variables, especially the first two, were particularly poor in quality of information found in the medical records.

Breastfeeding is a protective factor against the development of breast cancer, especially if the cancer is diagnosed before or after menopause. However, there is no consensus on a duration of breastfeeding that lead to this kind of protection.\textsuperscript{(23)} A study conducted in Nigeria showed that every 12-month increment in duration of breastfeeding resulted in a 7% decrease in the risk of developing a malignant condition.\textsuperscript{(24)} In the United States, no similar association was seen in a study of over 60,000 women.\textsuperscript{(25)} Further studies are needed to fully clarify this association. Unfortunately, completeness of was considered poor with growing and constant trends for non-completeness for breastfeeding and duration of breastfeeding.

Diagnosis- and treatment-related variables showed excellent scores in 13 of all 23 study variables. These results were higher than those seen in
socio-economic and demographic variables, as well as risk- and behavioral-related-factor variables. It is possible that these result may be due to a belief that factors may play a bigger role in impacting cancer, in addition to a hospital-centric model focusing mainly on the medical condition, which may lead those collecting patient information to ignore the medical condition’s multi-factorial nature.

Lymph node involvement may be associated to advanced staging and unfavorable outcomes.(26) The human epidermal growth factor receptor, or HER2, when positive, is associated to metastatic breast cancer, as well as to high histology grades and poorly differentiated tumors.(27) The P53 protein presents a cell-cycle arrest function. This protein is considered the safe-keeper of the genome, and in a cascade reaction, it stops cells with a mutated genome sequence from beginning the mitosis process and finalizing cell division. To do so, this process corrects them by repairing proteins or inducing cellular death through apoptosis.(28) In all cases we observed a constant trend for regular completeness. These are highly significant variables for selecting therapy. Improving information quality for these variables is paramount, and may significantly impact patient prognosis.

All three post-treatment variables showed 100% completeness, therefore, showing quality related to followed-up register where the study was conducted.

To complete patients’ supplementary data in a legible and enough completed manner, in addition to patient care, is the responsibility of the whole healthcare team. The nursing team is responsible to register 50% of all information listed in medical records, as they are usually perform countless procedures. Brazil’s Federal Council of Nursing recommends the adequate completing of patient data, and highlights the function of the medical record, in addition to information sharing, quality assuring, permanent reporting, legal evidence and auditing using, and also teaching and research promoting. The medical record constitutes an alternative source of data and, in some cases, it is even the main source of data.(29)

Global initiatives and trends, such as implementation of electronic medical records, are able to store data in accurate and reliable way, particularly considering that many of these data should be used by applying a checklist model. Such initiatives can facilitate data collection, ensure improved completeness, and turn patients’ access to data easier and faster. All services depending on these records can be optimized. There is a pressing need for training staff and the adoption of technologies to support built-in electronic systems, which would allow less use of paper and physical space.

For printed medical records, however, which are still a reality in most of hospital and services of the Brazilian Public Healthcare System, there is a need to adopt standardized protocols, specific to each condition, to optimize time required for completeness, reduce the risk of non-completeness, and facilitate data collection. It is important to highlight the fundamental role that medical records play as an organized and strategic information source.

The medical record is a document with legal status, and an indicator for continued provision of care to patient. Non-completeness of the form, in addition for being a disservice to society, is a misconduct. The training of healthcare professionals and raising awareness on this pressing issue is surely one of the pathways that may be taken by healthcare teams toward improving medical record quality.

The limitation of our study include, as the main complicating factor, illegible handwriting on medical records. Due to its illegibility, it is possible that percentage of missing data on study variables was overestimated, once interpreting or inferring meaning from handwritten medical records was unfeasible, as they were not clear enough to be taken into consideration. Another limitation was the disorderly and illogical fashion in which notes on progression, documents, and test results were listed in medical records. Lastly, another limitation was related with conservation of certain portions of these documents, which were illegible, due to physical and chemical agents.

**Conclusion**

There was predominance of socio-economic and demographic variables, as well as risk- and behavior-
al-factor-related variables, mainly classified as regular, poor, or very poor. The best scores were seen in post-treatment variables, followed by diagnosis- and treatment-related variables. The only variable that showed a downward in non-completeness trend was family history of breast cancer. Variables showing a growing in non-completeness trend were race/color, years of formal education, duration of use of oral contraception, hormonal replacement, and breastfeeding. We believe that collaboration of nursing team, in the form of auditing medical records for quality control or even developing and printing protocols for standardizing record of the most relevant data, will improve care, provide better understanding of the patient's health status, and allow the advance of scientific research. Implementation of electronic medical records is of noteworthy consideration. The adoption of this electronic medical record format will bring more dynamic for health service, and will improve the quality of documented data. Training healthcare professionals and promoting of continuing medical education activities for the entire team are also important tools for the development of an effective and permanent improvement strategy.

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Collaborations

Brandão-Souza C, Amorim MH, Zandonade E, Fustinoni SM, and Schirmer J contributed to conception of the study, analysis and interpretation of data, drafting the paper, critical review of content, and approval of final version to be published.

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