Brazilian Public Healthcare System (SUS) Information Systems capability to sustain a patient centered and outcomes-based reimbursement system

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Introduction

- Brazil accounts for the vastest universal cover healthcare system (Sistema Único de Saúde - SUS), which holds administrative data in digital Information Systems (IS), representing the largest real-world data (RWD) of health services in the country.
- Evaluating the usability of the current data available on the IS represents a first step to starting the journey of using RWD to establish a more patient-centered and outcomes-based reimbursement system.

Objectives

This study aims to evaluate the availability of variables present on SUS-IS and to compare with the Case-mix, Treatment, and Outcomes variables defined by the ICHOM Standard Set for Heart Failure (HF).

Methods

- HF disease was selected as a case study.
- Mortality, hospital, and outpatient IS data dictionaries were extracted from the Information Department of SUS.
- Variables analyzed in terms of availability, quality, and feasibility to be used to attend ICHOM Standard Set recommendations.
- Complementary data collection: suggested for variables identified with poor data quality.
- **Consistency score calculated**:

$$\frac{\sum (\text{Variables available} * \text{Weight})}{\text{Total number of variables required for each category}}$$

* 0.5 points: variables with poor data quality; 0.75 points: variables needing data linkage.

- A final score was calculated as a weighted mean of the three variables category subscores.

Results

From the 33-items of the HF Standard Set, 18 (54.5%) are absent in the SUS-IS including all Functional and Psychosocial Outcomes, in addition to 'Financial Burden' (Figure 1).

- From the **'Baseline health status'**, only 'diagnostic categories' and 'cardiovascular comorbidities' are available which are usually related to the main procedure performed, being considered usually imprecise.
- From **'Treatment'** variables, only surgical and cardiovascular procedures are recorded in the Hospital IS and only a partial or indirect recording of outpatient non-pharmacological treatment and cardiac rehabilitation is provided.
- From **'Burden of care'** assessment is limited, with no records of medication side-effects. For treatment complications, device-related complications may be tracked by procedures and disease codes, while hospital infections have a specific indicator available but with a low reporting adherence. The number of hospital admissions and appointments can be estimated by applying data-linkage, as there is not a unique ID number to identify individual patients within and across services. Hospital and Outpatient IS only register deaths occurring during cycles of care. However, linking data from the Mortality IS allows survival assessment.
- Consistency score calculated was 44.9%.

Figure 1: Classification of data availability for the ICHOM for Heart Failure Standard Set in the Brazilian Public Healthcare Information Systems (IS)

Variables (Score)		Measure	Reporting source	Data availability and quality by IS		Complementary actions need
				Hospital	Outpatient	
Case-Mix (43.3%)	Demographic factors (70%)	Year of Birth	Clinical	Yes	Yes	No
		Sex		Yes	Yes	No
		Gender	Patient-reported	No	No	Full data collection
		Ethnicity		Only natives	Only natives	Partial data collection
		Race		Yes	Yes	Improve data reporting adherence
	Baseline health status (16.7%)	Cardiovascular comorbidities	Clinical	Imprecise	Imprecise	Partial data collection
		Smoking status (current or in past year)		No	No	Full data collection
		Alcohol use (>1 drink a day)		No	No	Full data collection
		Body mass index		No	No	Full data collection
		Ejection Fraction		No	No	Full data collection
		Diagnostic categories		Imprecise	Imprecise	Partial data collection
Treatment (60%)		Pharmacological therapy	Clinical	No	No	Full data collection
		Non-pharmacological therapy		Indirect/Imprecise	Partial	Partial data collection
		Cardiovascular Procedural Treatments		Yes	NA	No
		Cardiac surgery procedure type		Yes	NA	No
		Cardiac rehabilitation		Indirect/Imprecise	Indirect/Imprecise	Partial data collection
Outcomes (31,3%)	Functional (0%)	Maximum level of physical exertion	Patient-reported and Clinical	No	No	Full data collection
		Symptom control: SOB		No	No	Full data collection
		Symptom control: Fatigue and tiredness		No	No	Full data collection
		Living independently/self-care	Patient-reported	No	No	Full data collection
		Employment		No	No	Full data collection
		Peripheral oedema		No	No	Full data collection
		Symptom control: Disturbed sleep		No	No	Full data collection
	Psychosocial (0%)	Health-related Quality of Life	Patient-reported	No	No	Full data collection
		Depression and anxiety		No	No	Full data collection
		Confidence/self-esteem		No	No	Full data collection
	Burden of Care (50%)	Medication side-effects	Clinical	No	No	Partial data collection
		Complications of treatment		Indirect/Imprecise	No	Partial data collection
		Number of hospital appointments		Yes	NA	Need of data linkage
		Number of hospital readmissions		Yes	NA	Need of data linkage
		Length of stay		Yes	NA	No
		Financial burden	Patient-reported	No	No	Full data collection
	Survival (75%)	Mortality	Clinical	Yes	Yes	Need of data linkage

IS: information system; NA: not applicable; SOB: shortness of breath.

Conclusions

To ensure clinical excellence and system's sustainability, a review of the payment policy is needed and requires technology structure to measure outcomes at a patient level in scale over the country.

Although presenting national coverage, the SUS-IS provides insufficient information to sustain an outcome-based payment policy for HF patients. These analyses emphasis the importance of active initiatives to collect and improve individual-level data.

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