

## BACKGROUND

Brazil is the largest country in the southern hemisphere, and the 5<sup>th</sup> largest country worldwide. Its health care relies on a mix of public and private initiatives. There is an universal government-funded health care program (SUS – Sistema Único de Saúde). However, a significant proportion of the population purchase additional health care coverage from insurance companies and private providers. This is due to the difficult access to the public services.

As it happens with most developing countries, Brazil is experiencing a demographic transition, with an increase in life expectancy (average of 74 years in 2011, as opposed to 62 years in the 80's and 43 years in the 40's). As a direct result of the demographic transition, nowadays the two major causes of death are cardiovascular diseases and cancer, which are evidently amenable to receive palliative care. There were, according to the Brazilian Health Care System Database (DATASUS), 326,371 cardiovascular deaths and 178,990 cancer deaths in 2010. It is fair to state that only a minority of them received adequate (if any) palliative care during the disease trajectory.

Palliative care was mostly unknown in Brazil until the beginning of the years 2000, with provision only by small individual efforts. In fact, the "Economist Intelligence Unit" 2010 report on Quality of Death placed Brazil on the 38th position among a total of 40 surveyed countries. The combination of population ageing and the growing interest by some groups culminated with the determination of Palliative Care as a patient right and a health care team mandate on the 2010 revision of the Federal Medical Council Code of Ethics. This, in addition to some judicial decisions, shed light to the matter in the country. As of 2012, Brazil recognized Palliative Medicine as a medical subspecialty and the first training programs began to flourish – even though they are yet to graduate their first professionals.

There is widespread impression that the palliative care services in the country are scarce and poorly organized at best, with a minority of better-established "traditional" programs. However, to date there is not clear evidence to support this impression. To better understand and integrate the palliative care services in Brazil, Grupo MAIS organized the "I Brazilian Encounter of Palliative Care Services" in September 2012 in São Paulo, Brazil.

## OBJECTIVE

To characterize the profile of Palliative Care Services in Brazil.

## METHODS

We have conducted structured analyses of presentations given by the service leaders on the "I Brazilian Encounter of Palliative Care Services" (IBEPCS).

Services were invited by email to participate, free of any charge. All individuals with names on the electronic mailing lists from the National Academy of Palliative Care and also from the MAIS Group were contacted and invited to register their services if they were responsible for or working on a dedicated palliative care team.

Registered services were requested to present a poster at the IBEPCS and deliver a 10-minute structured presentation about their service organization. Mandatory information were:

- Service name, city and state, start date
- Funding structure and academic relationship
- Type of service (if inpatient hospital service, outpatient clinic, consultation team, inpatient hospice, home hospice...) and service statistics (number of patients and consults, primary diagnoses, patient follow up time while in Palliative Care).
- Referral rules and patterns
- Team composition, palliative care training, pay structure and dedication
- Presence of a bereavement program and sponsorship of educational activities

Presentations' data were compiled into a database and descriptive statistics were used to analyze the data.

## RESULTS

**30 services** responded to our invitation and presented data at the I Brazilian Encounter of Palliative Care.

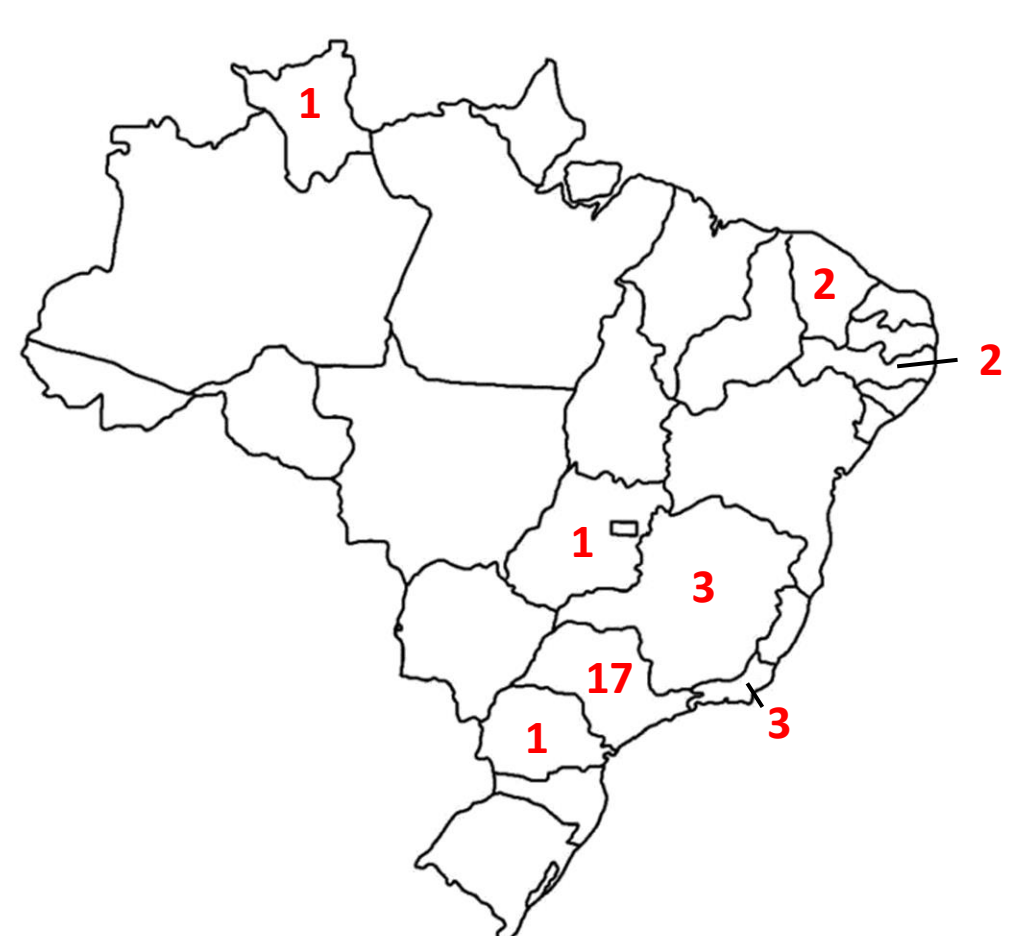


Figure 1 – Distribution of participant services



**Ranked 38/40 on Quality of Death**

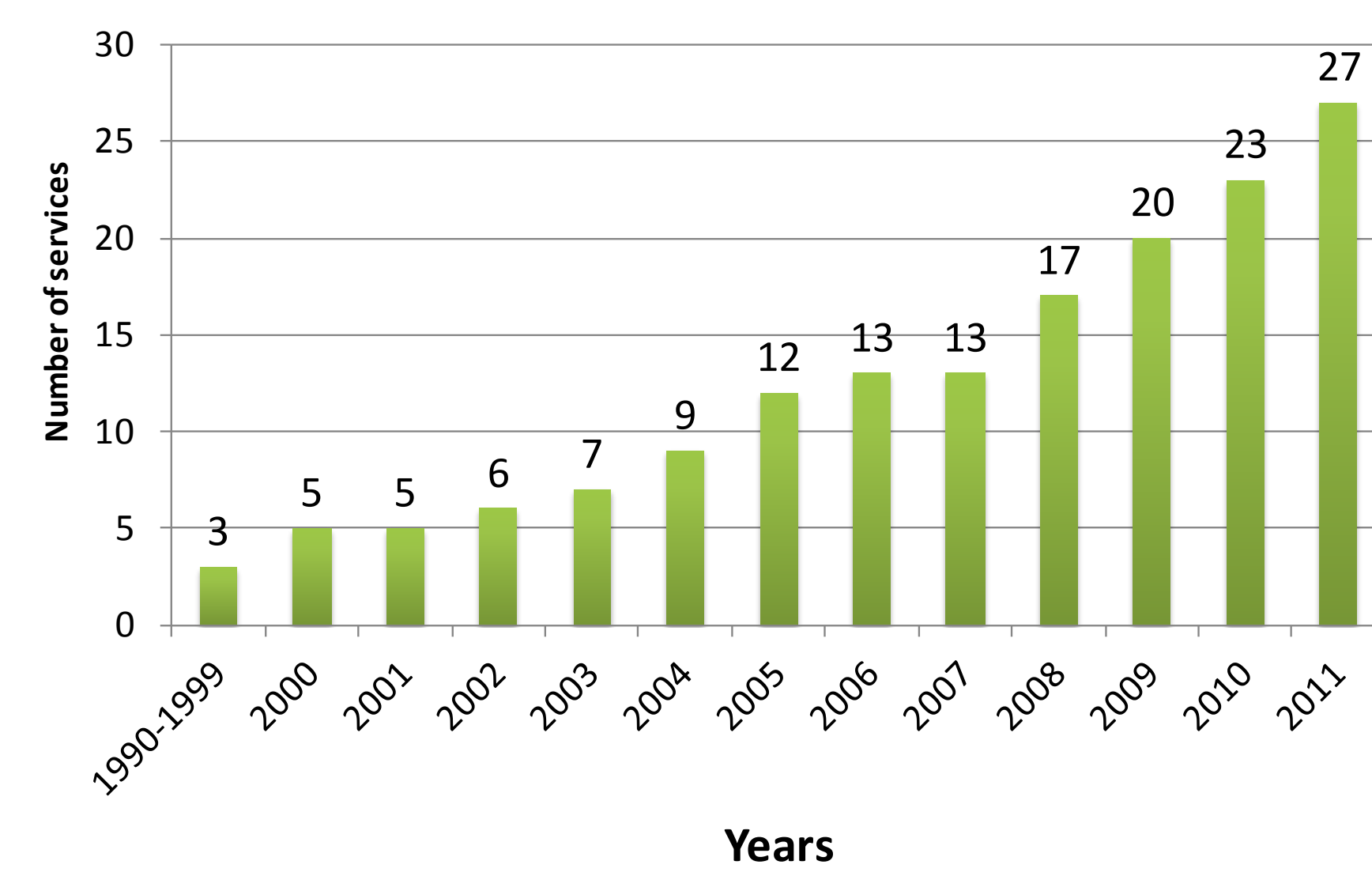


Figure 3 – Evolution of service availability per year (N=27)

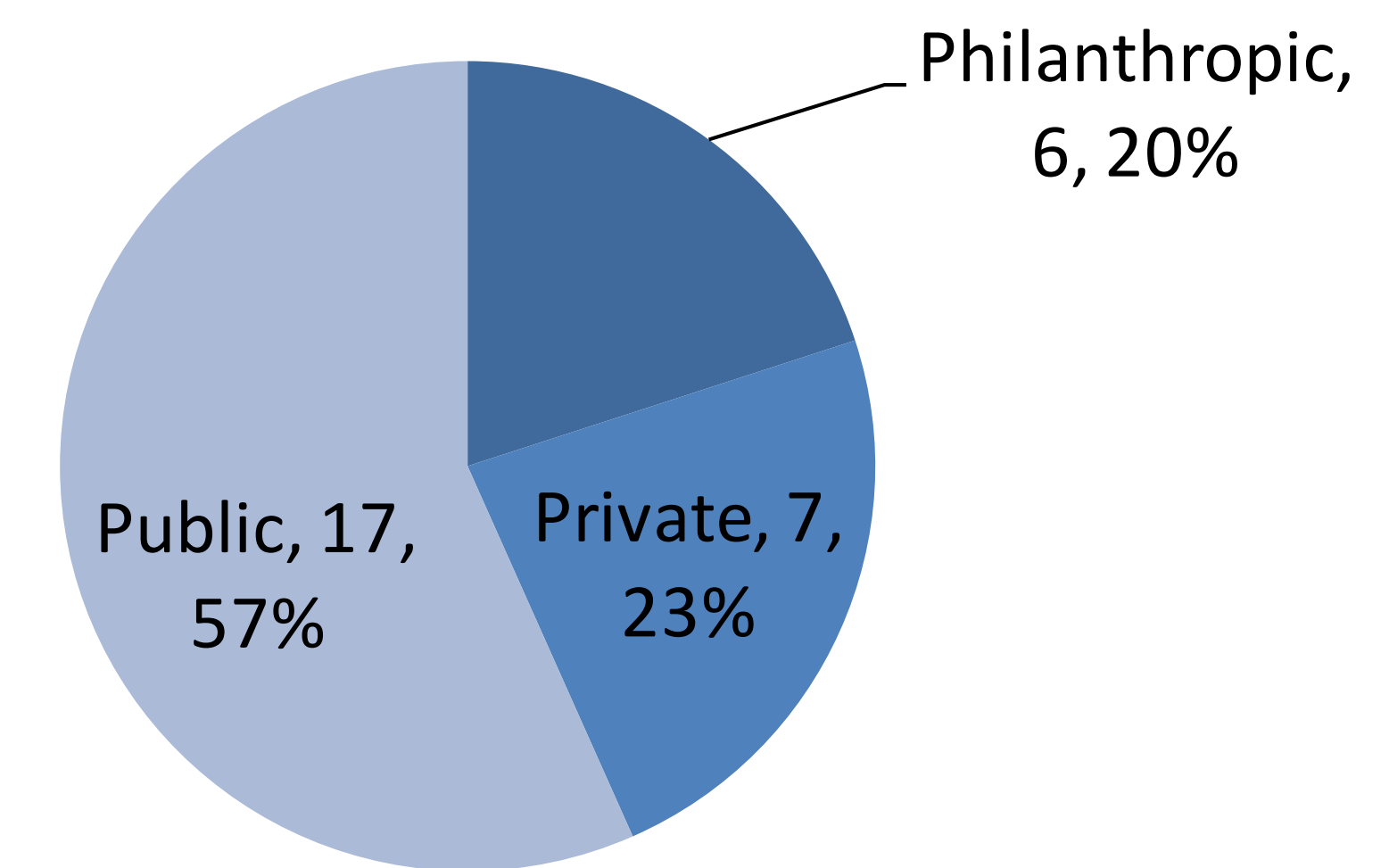


Figure 4 – Funding source of participating services (N=30)

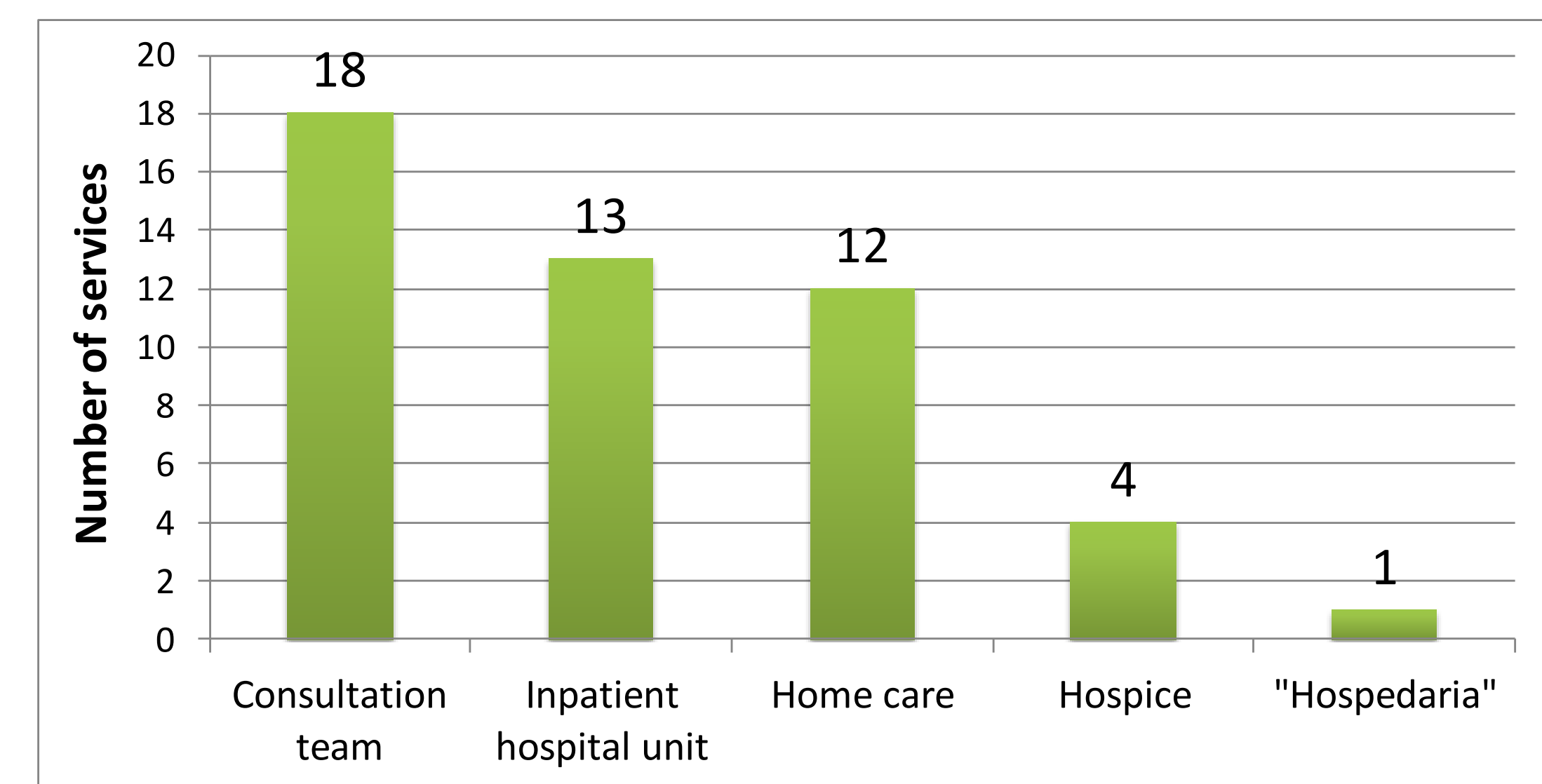


Figure 5 – Service modalities – a service can provide care in more than one modality. "Hospedaria" is a hybrid modality combining hospice and long term care facility.

The referral system for all services was very similar. None accepted patients directly, getting referrals from the primary teams, mostly clinical and surgical oncology 17/30 (57%), geriatrics 16/30 (53%), and internal medicine (17/30, 57%) (multiple responses allowed).

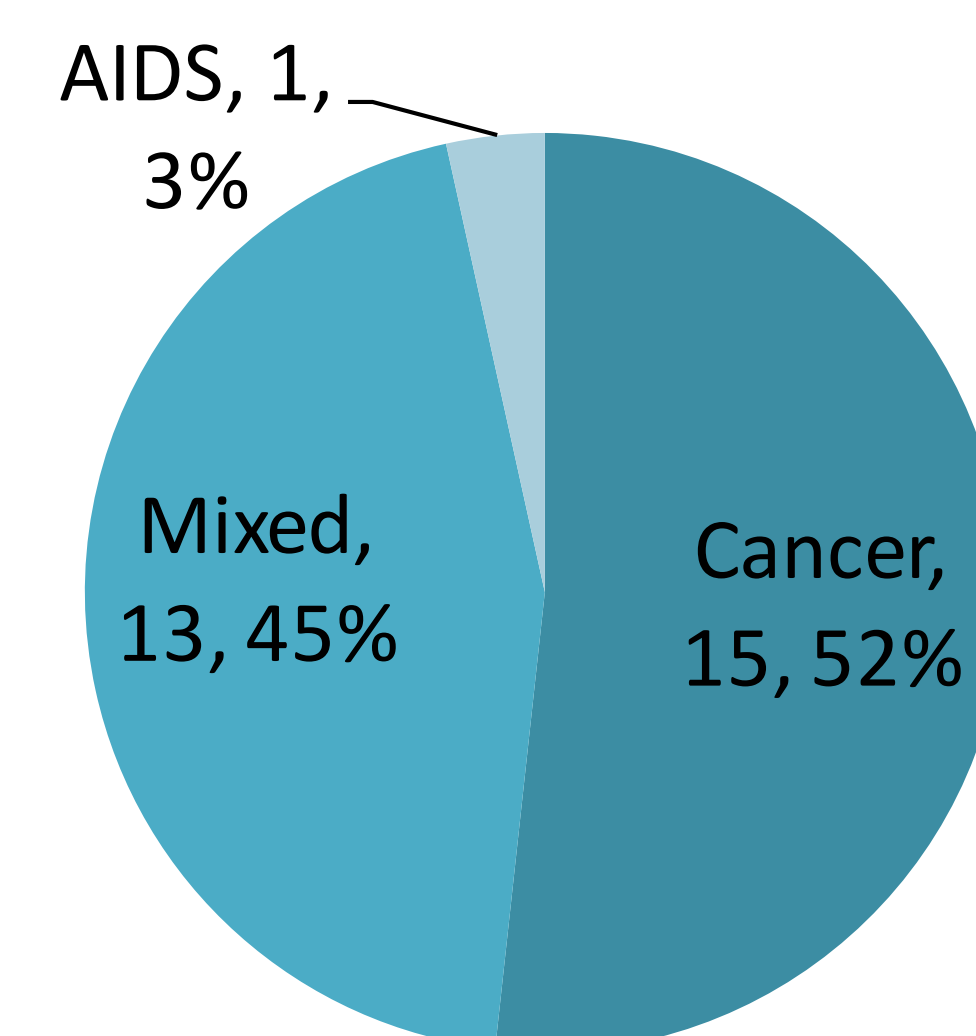


Figure 6 – Populations catered by participating services

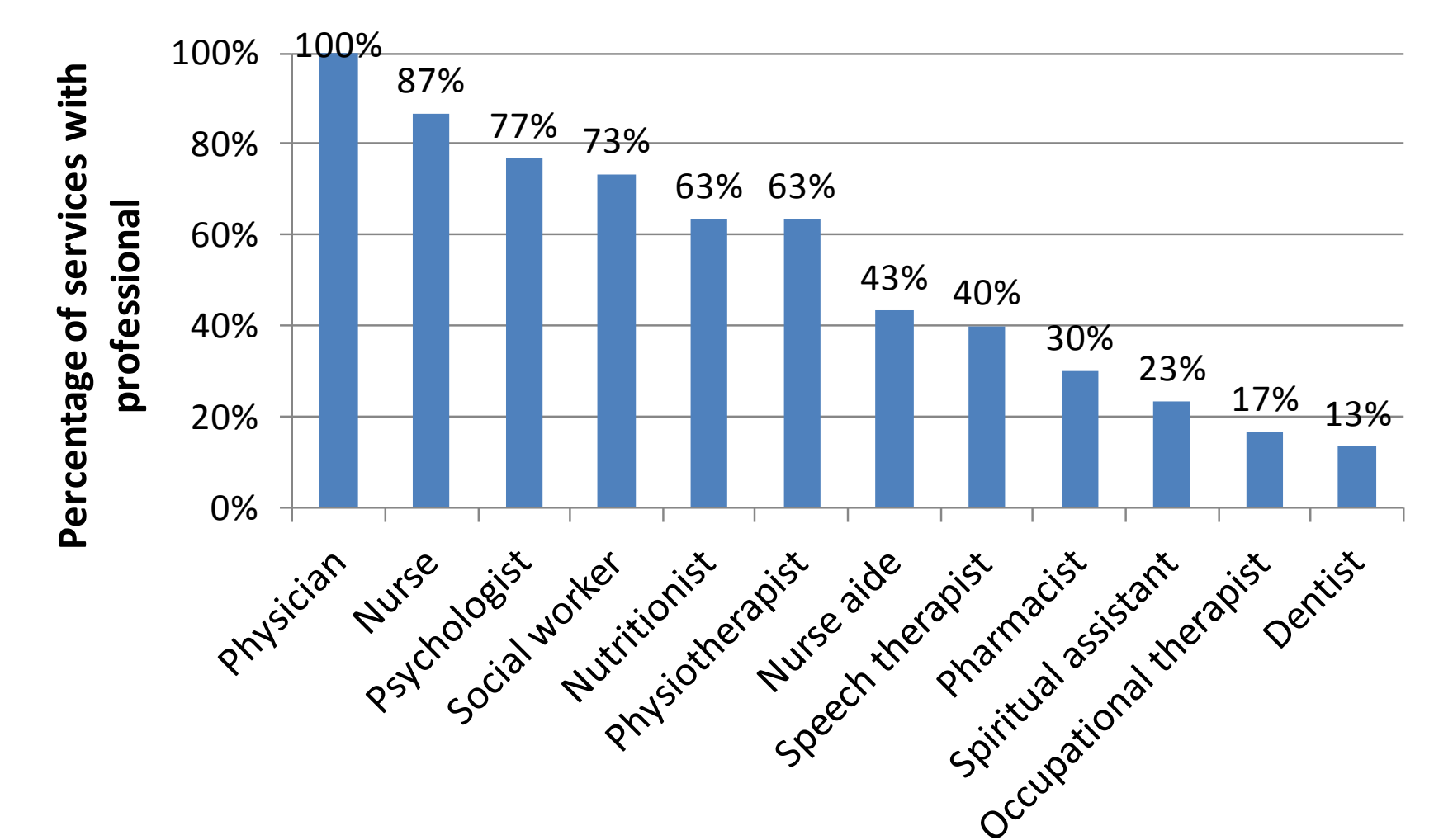


Figure 7 – Professional percentage in participating services

	Exclusive	%
Physician (n=30)	24	80%
Nurse (n=26)	18	69%
Psychologist (n=23)	11	48%
Social worker (n=22)	11	50%
Physiotherapist (n=19)	8	42%
Nutritionist (n=19)	10	53%
Nurse aide (n=14)	8	57%
Speech therapist (n=12)	6	50%
Pharmacist (n=9)	4	44%
Spiritual Assistant (n=7)	6	86%
Occupational therapist (n=5)	2	40%
Dentist (n=4)	3	75%

Table 1 – Dedication of professionals to the Palliative Care Team

A minority of services use the services of volunteer non-skilled workers (5/30, 17%) to assist with patient care. Bereavement care is provided by 12/30 (40%) services.

7/30 (23%) services have academic association, while 11/30 (36%) sponsor some kind of educational activities (ie. seminars, observerships, lectures).

## DISCUSSION/CONCLUSIONS

We have reported the results of the I Brazilian Palliative Care Services Encounter. The participating services report a very mixed composition, with most of them relying on the work of Physicians, Nurses and Psychologists. The number of services has been increasing since 2000 with the majority being consultation teams catering to cancer patients.

It is worrisome that we have observed a marked concentration of services in the country's southeastern region and also that the overwhelming majority of services only assist adult patients. It is also a matter of great concern that half of the services have no trained professionals at all, and that when training is present it is mostly restricted to short-term courses for physicians. The small proportion of services with dedicated professionals and the dismal involvement in academic activities are also indicators of possible poorer quality of service.

This study is not without limitations. There is a possibility that our sample does not include all palliative care services in the country, and we have limited data on the number of patients treated. Further broader questionnaires are warranted to provide better information. However, we believe that this study provides useful insight regarding the stage of development of Palliative Care in Brazil.

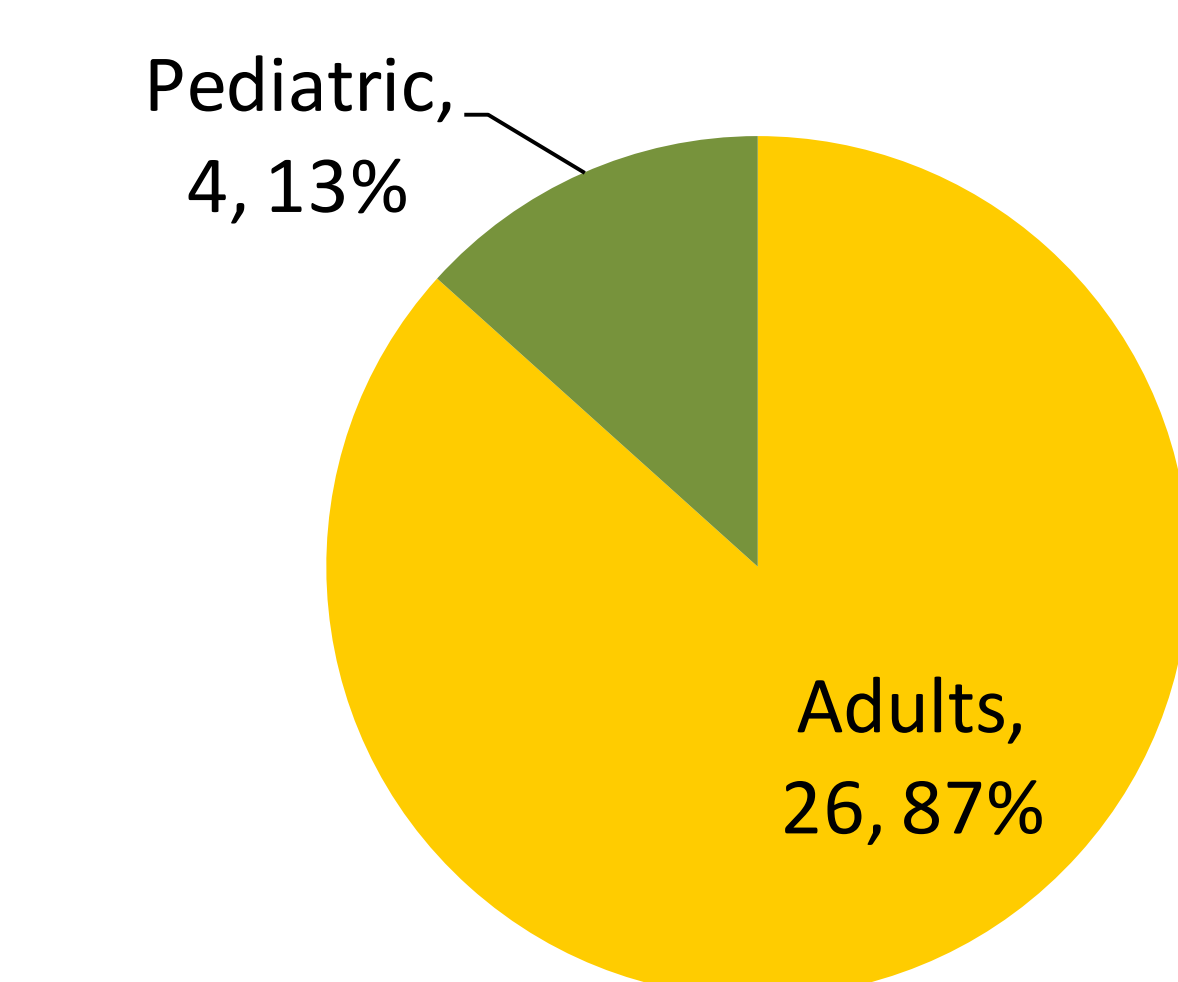


Figure 2 – Populations assisted by participant services

**15/30 (50%)** services are staffed by professionals with **SOME training** in Palliative Care. The overwhelming majority of the trained professionals are physicians (only one service reported trained psychologists and one service reported a trained nurse). Training is restricted to short-term post-graduation courses.