



Establishing a Cancer Rehabilitation Service in a Middle-Income Country: an Experience from Brazil

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Abstract

Purpose of Review Our aim is to provide a historical review of the implementation of a cancer rehabilitation center in Brazil, active since 2008. We expect this data to support the implementation of other centers both in Brazil and worldwide.

Recent Findings Cancer rehabilitation delivery is fragmented and punctuated in most cases, and cancer rehabilitation centers are rare. Data on how to establish rehabilitation centers could facilitate the implementation of new centers. We provide data on what was our strategy for hiring, establishing treatment protocols, barriers, and facilitators. We also provide figures on the number of each rehabilitation specialist, as well as the general standard operating procedures of our rehabilitation center, among other features.

Summary Establishing cancer rehabilitation centers in a middle-income country is feasible. We expect that our experience may facilitate the establishment of new cancer rehabilitation services and the improvement of current ones.

Keywords Cancer rehabilitation · Brazil · Rehabilitation center · Rehabilitation program · Middle-income country · Health facilities

Introduction

Cancer and its treatments can cause several impairments, which rehabilitation has the potential to mitigate and treat [1•, 2, 3]. Unfortunately, comprehensive cancer rehabilitation programs are the exception rather than the rule since

the great majority of cancer care centers have punctuated and fragmented rehabilitation care [4–8]. Many barriers hinder the implementation of such programs, for instance, lack of funding, paucity of trained rehabilitation specialists, and lack of a cohesive survivorship care plan [1•, 6, 7]. The knowledge and lessons learned by established cancer rehabilitation centers may serve as valuable tools for the implementation of new centers. Our objective is to provide a narrative review of how we were able to implement and maintain a cancer rehabilitation center in a middle-income country since 2008, and to provide data on rehabilitation usage, personnel, and physical structure of our rehabilitation center. We expect this report will assist with the implementation or improvement of other cancer rehabilitation centers globally.

Brazilian Healthcare

Understanding Brazilian healthcare and how rehabilitation and cancer care are structured in this system is a necessary context for appreciating our experience. Brazil has a universal government-funded public healthcare system, Sistema Único de Saúde (SUS), as well as a supplementary

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paid system operated by several private operators. The entire population has access to the SUS free of charge, and currently over 25% of Brazilians pay for a supplementary health system [9], as some treatments are not covered by SUS, and also to avoid the delay that may result from the high demand in the public healthcare system. However, about a quarter of those who hire a private health insurance still use the SUS for their cancer treatment [10]. Healthcare is provided by the SUS using three escalating levels of complexity [11]. Primary care is delivered throughout the country by teams responsible for over 3000 citizens each. As the complexity of care grows, more specialized care is provided by fewer institutions.

Rehabilitation services are offered in all levels of healthcare. At the primary level, care is provided by Family Health Teams that provide education, orient the use of assistive technology, and provide community-based rehabilitation, among a spectrum of different services [12]. At the secondary level, rehabilitation care is provided at dedicated rehabilitation facilities, where more specific rehabilitation interventions are provided, including provision of assistive technologies [12]. The primary and secondary levels are responsible for longitudinal rehabilitation care, caring for the subacute/chronic rehabilitation phase, occupational and social reintegration, supported by multi-professional teams and home-based activities among others.

At the tertiary level, rehabilitation care is provided in a more specialized manner, for instance, in cancer or stroke centers [12]. Some of the challenges for providing rehabilitation in the SUS are the chronic public underfunding in rehabilitation care and the need for more rehabilitation specialists [12].

Cancer care is provided in the secondary and tertiary levels of the SUS. There is disparity in the geographical availability of resources for healthcare, as 70% of the specialized cancer care units are concentrated in the south and southeast regions of Brazil, which account for about 22% of the population [10]. Consequently, median length of distanced traveled for cancer care can reach about 500 km (310 mi) in several states, compared to 100 km (62 mi) in São Paulo [13].

Our Experience

Our Institution

The Cancer Institute of the State of Sao Paulo (ICESP—*Instituto do Câncer do Estado de São Paulo*) was launched in 2008 and is a tertiary-level public university-based hospital dedicated to adult cancer care. This cancer center is part of the biggest university-based public hospital in Latin America, the Hospital das Clínicas of the University of São

Paulo's School of Medicine. ICESP is a tall vertical structure, with a total area of 84,000 m² (approximately 900,000 ft²), distributed in 28 floors. It has 476 beds (85 of them located at Intensive Care Units), 124 ambulatory offices, 18 surgery rooms, 100 chemotherapy infusion rooms, 6 linear accelerators, 1 for brachytherapy, 4 magnetic resonances, 6 computed tomographies, 1 single photon emission computed tomography, high-intensity focused ultrasound, endoscopic clinic, and robotic surgery. By the end of 2020, it had 5229 employees and had attended 116,000 patients, with 44,000 under current care.

Setting Up the Practice

Since the beginning of ICESP's activities, rehabilitation services were available at the institution. That was facilitated by a national regulation published in 2005 that mandated the provision of rehabilitation care for all high-complexity oncology services [14]. This determination was a landmark and promoted an important advance for the greater provision of rehabilitation care for cancer patients in the country.

Hiring

As very few professionals with experience in the rehabilitation care of oncological patients were available in 2008, we sought rehabilitation professionals that had experience in specific needs that were prevalent in the cancer population (e.g., musculoskeletal impairments, neurologic rehabilitation, lymphedema, chronic pain, cardiopulmonary rehabilitation). Currently, the Rehabilitation Service has 132 professionals that were progressively hired during the first 2 years of the Institute and now are composed as follows: 100 physical therapists, 8 speech therapists, 6 physiatrists, 5 occupational therapists, 4 neuropsychologists, 3 exercise physiologists, 3 coordinators, 1 manager, 1 nurse assistant, and 1 administrative assistant.

Guidelines and Procedures

Due to the scarcity of cancer rehabilitation guidelines and standard operating procedures (SOPs) at the time when ICESP was launched in 2008, the rehabilitation and clinical teams mobilized to elaborate evidence-based guidelines for rehabilitation protocols and SOPs, which lead to published articles and a Cancer Rehabilitation Manual [15–20]. We also adopted international healthcare quality standards to structure, procedures, and outcome measures (e.g., Functional Independence Measure (FIM), Six-Minute Walk Test, hand grip strength). Our Rehabilitation Service was accredited by the National Accreditation Organization (ONA), followed by the Joint Commission International (JCI) and the Commission on Accreditation

of Rehabilitation Facilities (CARF). The Rehabilitation Service of the ICESP was the first one outside of the USA to receive a specific Accreditation for Cancer Rehabilitation Services, at the end of 2014.

Our Rehabilitation Service supports the patients being currently cared for at ICESP, that is, beginning at the initial cancer diagnosis, following active cancer treatment and active surveillance, and ending after cancer care is finished. Cancer survivorship is not usually performed at ICESP. Post-cancer transition of care and rehabilitation are provided by primary- and secondary-level institutions.

In our institution, the physiatrists act as a gatekeeper of outpatient rehabilitation care, managing all rehabilitation referrals using our electronic healthcare system. Currently, we receive about 50 weekly referrals to outpatient Physiatry/Rehabilitation. A Physiatrist of our team will then assess the health records of the referred patient and will schedule the eligible patients for an initial in-person visit with either a physiatrist or with our rehabilitation team. Most patients are directed to first undergo a comprehensive initial visit with a physiatrist, who will then determine the rehabilitation needs of the patient. However, there are specific situations in which patients will be assigned directly to a rehabilitation program (“fast track”) before an initial visit with a physiatrist occurs, for instance, post-operative care and range of motion limitation that restricts radiotherapy initiation, among others. These protocols aim to reduce the waiting time for time-sensitive conditions.

The outpatient rehabilitation program may take two forms in our institution: (a) a comprehensive, individualized rehabilitation program including one or all of the following: physical therapist, speech therapist, occupational therapist, neuropsychologist, and/or exercise physiologists; or (b) orientation groups—in which education and exercise orientation are provided to a small group of patients, in a few visits to the rehabilitation clinic, by one or more of the rehabilitation professionals, depending on the groups’ needs. There are specific orientation groups for the more common impairments, such as lymphedema prevention, lymphedema follow-up after discharge from the rehabilitation program, compliance to physical activity after discharge from the rehabilitation program, and chronic pain long-term care. Orientation groups are also an option for patients that cannot travel to ICESP. Weekly, the rehabilitation team and each physiatrist convene to assess the progress of selected patients, including their progress during therapies, and possible next steps that may be therapy adaptation, extension, or discharge.

Rehabilitation of hospitalized patients follows specific protocols that include at least one of the abovementioned rehabilitation specialists. In case the clinical/rehabilitation team following the inpatient identifies a more complex rehabilitation need, a physiatrist is consulted.

Rehabilitation Center—Structure and Outcomes

Our Rehabilitation Center is located at the ground floor of ICESP, in an area of 190 m² (around 2000 ft²) (Fig. 1), comprising offices for the delivery of rehabilitation therapies, a gymnasium, and several resources such as treadmills, stationary bicycles, rowing machine, a walking track (for the Six-Minute Walk Test), parallel bars, therapeutic beds and platforms, orthostatic bed and table, spaces that simulate daily activities, and virtual reality resources. On the 17th floor, there is a smaller rehabilitation room (of around 30 m² or 300 ft²) for inpatient rehabilitation activities.

Our rehabilitation team provides around 8500 therapy sessions/month for inpatients and 2500 therapy sessions/month for outpatients. The current weekly hours of therapy provided by each rehabilitation professional are as follows: 3000 h of physical therapy (300 h for outpatient, 2700 h for inpatient), 240 h for speech and language pathology, 150 h for occupational therapy, 120 h for neuropsychologists, and 90 h for physical educational professional/kinesiologist. Physiatrist care is provided for 120 h/week.

Demographics, primary cancer site, and main reason for referral to rehabilitation therapies in 2021 are expressed in Table 1. Most common reasons were pain (28%) and range-of-motion limitation (20%). Although most patients presented with more than one rehabilitation need, those data relate to the primary reason. Criteria for referral to therapy have not changed over the years.

Characteristics and outcomes of the rehabilitation program can be found in Table 2. Since our outpatient rehabilitation center was closed for several months during 2020 and 2021 due to the COVID-19 pandemic, data from 2019 was reported. The duration of the rehabilitation program is about 3 months. We have a high satisfaction rate (98%), and about three quarters of patients met our rehabilitation goals either partially or completely.

Over the 14 years of the Rehabilitation Service, we observed a growing complexity of cancer patients treated in our Rehabilitation Center. Despite that, we were fortunate



Fig. 1 Rehabilitation Center of the Cancer Institute of the State of São Paulo of the University of São Paulo School of Medicine

Table 1 Characteristics of outpatients referred to rehabilitation therapies in our service in 2021

	Prevalence
Primary cancer sites	
Breast	48%
Head and neck	8%
Hematologic	7%
Gastrointestinal	6%
Urogynecological	6%
Nervous system	6%
Bone and soft tissue	5%
Thoracic	4%
Female	69%
Age	
18–40	14%
41–65	62%
66–85	22%
> 85	2%
Main reason for referral	
Pain	28%
ROM limitation	20%
Lymphedema	19%
Neurological deficits	12%
Post-COVID syndrome	11%
Cancer-related fatigue	8%
Post-surgical care	3%

ROM range of motion

Table 2 Outpatient rehabilitation data from our service in 2019

Average time from referral to 1st rehabilitation session	16.9 days
Duration of rehabilitation program	84.1 days
Percentage of missing rehabilitation sessions	19%
Patient satisfaction (NPS)	98%
Rehabilitation goals at the end of the program	
Fulfilled (76–100%)	68%
Partially fulfilled (51–75%)	9%
Partially unfulfilled (26–50%)	8%
Unfulfilled (0–25%)	6%
N/A	9%
Reason for unmet goals	
Nonattendance	41%
Clinical complications	36%
Patient requested to be discharged	11%
No improvement with therapies	6%
Non-compliant with orientations	3%
Deceased	3%
Social issues	2%

NPS net promoter score

to have a history of no severe adverse events occurring with patients during rehabilitation care throughout these years. We documented the safety of rehabilitating patients with metastatic bone disease in a study published in 2021 [21]. In this retrospective study, we assessed outcomes of patients with bone metastasis who underwent rehabilitation therapy at ICESP and found only one pathological fracture during the rehabilitation period, which was unrelated to rehabilitation therapy. We also observed two other skeletal-related events, resulting in a total event rate of 11.8 per every 10,000 h of therapy.

Academic Activities

ICESP's cancer rehabilitation service is part of the fourth-year medical students' curricula. We are also a mandatory 1-month rotation for third-year PM&R residents of the University of São Paulo (10 per year), frequently receiving PM&R residents from other institutions [22]. A Cancer Rehabilitation fellowship is being organized and it will be the first one in the country.

ICESP has a multidisciplinary residency program in oncology for physical therapists, occupational therapists, nurses, and case managers.

Our Rehabilitation Service has also played an important role in international societies. We are participants of the Special Interest Group in Cancer Rehabilitation of the International Society of Physical and Rehabilitation Medicine (ISPRM) since its formation. We have collaborated in the promotion of the area and in the creation of scientific content since then [15–21, 23]. In 2022, a Cancer Rehabilitation Manual was published as a result of this collaboration with ISPRM [24].

Our main areas of research include pain management, impact of supervised exercise programs, breast cancer, and cognitive rehabilitation [15–21, 23, 25–28].

Rowing Boat Team

In 2013, we started a rowing program for breast cancer patients, called REMAMA, inspired by the international rowing movement for breast cancer patients that started in Canada (the International Breast Cancer Paddlers Commission—IBCP), which was present in 12 countries at that time. It is now present in 32 countries, comprising 250 teams. Each team has 22 participants that practice in dragon boats. The international festivals occur every year and attract more than 4000 participants. We have two teams from REMAMA (both called REMAMA Dragão Rosa—Pink Dragon) over a total of 16 currently existing teams from Brazil [29].

Barriers and Facilitators

We experienced barriers to the provision of cancer rehabilitation that are common to those reported by other countries, including low awareness of the benefits of rehabilitation services among patients and providers, under-identification of rehabilitation needs, uncertainty around referral pathways, lack of infrastructure that streamlines the referral process, lack of funding, paucity of trained rehabilitation specialists in the area, need of greater inclusion of rehabilitation intervention in cancer care treatment guidelines, and an under-recognition of potential cost savings and reduced complications with the use of early rehabilitation programs [3, 5, 19].

One of our facilitators is that we are located in a large cancer center with strong interdisciplinary vision. We also observed a growing perception, both in the medical community and in other stakeholders, about the need for and importance of rehabilitation care for cancer patients.

Conclusion

In this report, we aimed to narrate our experience in structuring and maintaining a Cancer Rehabilitation facility in a middle-income county for the past 14 years. Our trajectory was facilitated by the support of the local government and by a national ordinance mandating the provision of rehabilitation services in specialized cancer centers. Our service provides interdisciplinary rehabilitation coordinated by physiatrists, and in contrast to our foundation where we had difficulty recruiting cancer rehabilitation specialists, we now have an important role in the formation of those professionals in Brazil.

Since the prevalence of cancer survivors will increase significantly over the next decades, it is crucial that rehabilitation services organize their resources to respond adequately to the growing need of rehabilitating cancer-associated impairments. Several organizations and governments have established resources and efforts to improve cancer rehabilitation worldwide, including several guidelines [1•, 30•]. We expect that our report assists in the implementation or improvement of cancer rehabilitation services.

Declarations

Conflict of Interest The authors declare no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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