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Editorial

Challenges of Developing a Pulmonary Rehabilitation Programme: Practical Aspects with India as a Model Country

Pulmonary rehabilitation is advised for patients with chronic lung conditions who have dyspnoea or other respiratory symptoms, reduced exercise tolerance, restriction in activities because of their disease, or impaired health status despite being on optimal pharmacological treatment. Pulmonary rehabilitation is an evidence-based, multidisciplinary and comprehensive non-pharmacological intervention that has emerged as a recommended standard of care. Both supervised, as well as domiciliary programmes have shown to improve dyspnoea, quality of life and functional capacity in different types of respiratory patients, such as chronic obstructive pulmonary disease (COPD), persistent bronchial asthma and interstitial lung disease. However, these improvements are not necessarily accompanied by significant improvement in lung function parameters.[1-4] A comprehensive pulmonary rehabilitation programme includes patient assessment, optimisation of pharmacological treatment, exercise training, self-management education, nutritional intervention and psychosocial support. Exercise training is the cornerstone of pulmonary rehabilitation programme, and wherever possible, attempts should be made to offer a supervised training programme even with minimum resources.

Several challenges, such as hospital-based, patient-based and society-based, are encountered while establishing and delivering a pulmonary rehabilitation programme.

In hospital management usually prioritise approval of setting-up conventional out-patient clinics, emergency and critical care/intensive care unit (ICU) services over opening of a rehabilitation clinic. Since, rehabilitation programme is quite labour intensive, time consuming and visible benefits are slow to emerge, perhaps, for this reason, preference is given to establish a critical care facility where results are instantaneous (as in ICU) and where there is a matter of life and death. It is generally felt that financial returns in acute care clinical practice (both for insured and non-insured) is more as compared to rehabilitation services. On the contrary, it has been found that rehabilitation is more cost-effective as compared to routine services.[5,6] Usually, there is low acceptance among medical professionals on the beneficial effects of pulmonary rehabilitation programmes due to lack of awareness and exposure of its concepts and usefulness during undergraduate and postgraduate training and later on, during clinical practice. This 'ignorance' generally leads to delay in rehabilitation referral at an appropriate time which reduces the prospects of improvements that can otherwise be achieved by rehabilitation.

There are financial implications while setting-up a pulmonary rehabilitation programme. Hospital has to incur expenditure under two categories: first, initial expenses, when equipments required for assessment and training are to be procured and second, recurrent expenses that includes salary of personnel in rehabilitation team, maintenance of infrastructure and equipment. Addition of existing or new versions of training devices, whenever, expansion of programme is required also adds up to the costs. Different ways from where hospital can generate money include funding from state governments, donations/charity from non-governmental organisations/philanthropists and community support programmes. Making rehabilitation services chargeable and bringing it under insurance reimbursements is another way of recovering funds.

Clinical services, which run without prior appointments and cater to ill-defined patient-catchment area, are usually over-burdened, as is the case of government run hospitals of major cities. Load sharing among team members becomes difficult as there are limited health professionals at a given health-care facility. Diagnostic labs are usually overloaded with routine work which can lead to delay in pre-rehabilitation assessment. Existing staff might not be trained for pulmonary rehabilitation programme specific assessment. Some assessments, like respiratory muscle strength testing (maximal inspiratory pressure [MIP] and expiratory pressure [MEP]) or overnight oximetry are not routinely carried out; though these are important for pre-rehabilitation assessment. Requesting these tests puts additional burden on health professionals and hospital laboratories. Adding new services in the existing infrastructure is also quite challenging. Adequate space, patient accessibility and safety are the prime issues that often hold back successful establishment of rehabilitation clinics. Since both testing and training require secluded tracks and dedicated rooms (e.g., six-minute walk test, walk practice, exercise training), at times, it becomes difficult to carve out a separate space from already constrained hospital corridors and rooms. Also, there can be a paucity of beds for providing in-patient rehabilitation programme. Even if the beds are there, separate cubicles might not be available for segregating relatively non-infective rehab patients from the infective ones in order to prevent hospital-acquired pneumonia (HAP).

Best outcomes and widely researched disease for rehabilitation is COPD. It is common knowledge that, in India, tuberculosis and its sequelae, COPD, bronchial asthma, interstitial lung disease constitute the main burden of cases attending pulmonology

clinics. There is often under-reporting or wrong diagnosis of the disease, which delays the management and optimisation of medication and subsequently, rehabilitation referral. Since severity of the disease is very high as patient's report at a later stage in natural course of the disease, the enrolment and outcome in rehabilitation clinics is not very encouraging. Besides, high density of population *vis-à-vis* less number of hospitals compounds the disease burden. Since majority of the population requiring rehab do not have access to rehabilitation programmes even in the developed countries,[8] providing the same in India with high disease burden along with limited resources and lack of appropriate skilled manpower makes it even more challenging. Tele-rehabilitation and engagement of primary and secondary level health centers for delivering community based/domiciliary rehabilitation programmes could be one of the ways of overcoming the shortfalls of limited rehab centres.

Despite being on optimal medications, patients are severely breathless and disabled in activities of daily living which leaves them exhausted, depressed and socially isolated. When advised rehabilitation, they are very sceptical, show disapproval, question its merits, and mainly prefer medicines over exercise for their disease management. Patient motivation is foremost for a successful rehabilitation programme. Patients with severe disability in activities of daily living are more inclined to enroll in rehabilitation programmes. The ones with moderate disease severity usually do not consider rehabilitation as an additional modality in their treatment plan. An earning member of the family is more motivated than a non-earning member. Due to lack of adequate information and benefits of rehabilitation programme, patients are not enthused enough to undertake frequent visits to hospital for supervised training sessions. Best approach to motivate patients for enrolment in rehabilitation programme is to introduce them to patients who have either completed or are currently enrolled in the programme and have gained benefits. Peer motivation works best here as patients can relate with them.

All the patients who enroll in a rehabilitation programme may not complete it. Even best of the rehabilitation centres around the world have completion rate ranging between 50% to 80%.[7,8] Patients do start with good motivation or on a trial basis but drop-out due to either, improvement in their health status or they do not find much improvement after attending few sessions. Sometimes, their priority changes or they contact infection. Many a times, they get weighed down with other pressing family responsibilities. Usually, working patients are unable to afford long absenteeism/ leaves from work. Inconvenience in accessibility to rehabilitation programme is also one of the major cause of drop-out. Since patients have already spent a lot of money on medications,[9] they are either not willing or are unable to afford additional burden of purchasing domiciliary oxygen, attending rehabilitation sessions or purchasing devices/equipment for domiciliary programme. Many patients drop-out in middle of the programme as they find attending supervised sessions quite expensive. High prevalence of malnutrition and un-affordability for nutrient rich food also affects outcome of rehabilitation. Exposure to intermittent/constant indoor and outdoor pollution mitigates the beneficial effects of medical treatment and rehabilitation. Patients lacking support from family/society are less likely to enrol into rehabilitation programme as they are more anxious, feel insecure and have restricted outdoor mobility. Psychosocial burden of care-givers also contributes to non-adherence to pulmonary rehabilitation programme.[10] Further, co-existing disease conditions can also affect benefits that could be obtained from rehabilitation either by reducing the compliance or augmenting the disease severity.

'Knowledge attitude practice' (KAP) at community level also influences enrollment into a rehabilitation programme. Lack of infrastructure, illiteracy, taboos and misrepresentation of facts prevents patients from initiating a rehabilitation programme. For example, when patients are advised portable and long-term oxygen therapy, it is generally assumed that the patient has reached terminal stage and that is why they have been asked to use 'oxygen' and consequently, many patients refrain from using oxygen therapy.

Multi-speciality medical centres are usually desired over a single speciality facility as there is an incentive of co-morbid conditions being taken care off. Also, centres that are well connected to public transport and located in the heart of city or town are preferred to those located in isolated area due to safety and security concerns.

Limitations also arise in using standard assessment protocols or tools because of cultural, regional and linguistic differences prevalent in India. Pulmonary rehabilitation related rules or policies are still being formulated and are yet to be included in the mainframe health-care services in India. Even health insurance companies (Medicare in USA) provide limited coverage to rehabilitation programme and long-term oxygen therapy. Generally, patients have to manage on their own to avail these facilities except few countries where entire health-care is government funded. For example, Canada has 'Home Oxygen Program' in which domiciliary oxygen is funded by the government for providing long-term oxygen therapy; other countries (including India) have yet to give this kind of coverage to its citizens (barring few, who are covered under central government health schemes). Due to heavy expenses involved in it, majority of the patients withhold home oxygen therapy that leads to gradual decline in their health status. Further, there are restrictions on

travelling with portable cylinders in public transport due to security concerns which limits patient mobility.

Sales and support network of vendors dealing in rehabilitation equipment is also limited. Equipment that are standardised and validated internationally are quite expensive and have limited availability. Easily available equipment are of low cost, but are not validated, and therefore, are not reliable. These equipment often have frequent breakdowns and require high maintenance cost. It has been seen that most oxygen suppliers are restricted to main cities, and therefore, services in peripheral areas are quite limited and delayed, leading to lots of inconvenience and risks to the patients. To add on, barring few major cities, power supply in India is quite erratic which affects patients who frequently require oxygen concentrator, non-invasive ventilator or nebuliser. Besides, lack of both indoor and outdoor air pollution control aggravates lung diseases. Scattered, limited and poor road or railway connectivity to specialised health-care facilities adds on to the misery of the patients and increases their morbidity and mortality.

Developing a pulmonary rehailitation programme in high disease burden and resource-scarce settings is quite challenging, but nevertheless, initiating the programme with minimum resources and gradually building-up the facility will certainly reduce health-care utilisation and improve quality of life in patients with chronic respiratory diseases on long-term basis.

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