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Editorial

Looking Ahead: Assured of a Vibrant Indian Association of Palliative Care to Lead the World of Palliative Care

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Good evidence-based research must also promote and translate into best practices. Hence, evidence-based best practice is a goal for all of us to pursue as it helps us to provide the best care for those suffering from an incurable illness. 'The Essential Guide to Evidence-Based Practice-2022' is a useful resource to understand the evidence-based practice.[2] Strengthening of palliative care as a component of comprehensive care throughout the life course and integration of palliative care into national health systems, as part of the World Health Assembly 2014 resolution on palliative care is key to best outcomes.[3] There is an urgency for us as IAPC to achieve this and we need to take quick and bold measures to influence and help the government to implement it and also for all teams to seriously practice integrated care. Following are a few suggestions to consider towards integrated palliate care with public-private partnerships.

1. Combined clinics: Each set-up to plan its own way of doing this to facilitate early involvement of palliative care and desired outcomes.
2. All hospitals (Government/NGO/Corporate) which have an ICU must also have (mandatory) the following – (a) a palliative care department that works closely with all other specialties. (b) About 1% of the beds are set apart for long stay care for those who do not have family or suitable conditions to be managed at home. (c) To provide palliative and EOLC at home within a 5 km radius of the hospital. Dying at home, which most people desire, will only be possible by scaling-up home care. Good and peaceful death at home with comfort, dignity and hope can be and should be achieved.
   All these measures and also networking among free standing units will ensure providing of palliative and EOLC throughout the disease trajectory.
3. At present, we have training and certification for Advanced Life Support (ALS). To attempt resuscitation or Allow Natural Death (AND) is two sides of the same coin of life and all clinicians could get combined training and certification for ALS and AND together. It will help all involved in making appropriate decisions in this difficult situation.
4. In palliative care provision, we strive that no one is left behind. From the professional carer's point of view, to capture the great ideas and practices, all conference proceedings with abstracts and posters must be published in the IJPC so that it is available for any scoping review, meta-analysis or meta-synthesis. This could also include abstracts and posters of past conferences as much as possible. In addition to the excellent article by Dr. Salins *et al.*, a full historical record of the past and all pioneering work could be compiled as planned by IAPC leadership. This would also help in advocacy with the government to integrate palliative care into all healthcare.
5. The use of the subcutaneous route as an alternative for providing medications when the oral route is not possible is an example of well-established evidence but an inadequately practiced method in our country. Providing this by Continuous SC infusion (CSCI) by a syringe driver is not practical for our home care situation due to the cost, technology and training involved. Furthermore, in general, the common method of medication is taking the drug at regular intervals and not continuously. This is the basis for oral administration of morphine. Then why, when the system is slowing and gradually shutting down, do we have to flog it with continuous working?! Due to our great family involvement and social capital, we have a method of intermittent, regular and as needed

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medication combinations in a 10 ml syringe, 23-gauge butterfly needle and cannula. 1 ml of the combination is given by the family q4 hourly and prn and adequate symptom control is achieved at a minimum cost. The family driver speaks, smiles, listens and touches the person at no extra cost! Various palliative home care services are now effectively using this method. In honour of our great families, we have called it the 'family driver'.

Perhaps, it is time to review the age-old practice of CSCI by a syringe driver and replace it with the 'family driver', certainly after a well conducted and robust research. We should not be seduced by technology and not squander our resources. In our Indian society, 'family' is the most important resource and the 'family driver' will always be just as good or better than a syringe driver. Perhaps, it is the family involvement that helps us to get away with smaller doses of morphine! Empirical qualitative evidence for the concept of 'family driver' through various presentations and publications is provided by a PPT presentation accessed by the Google link provided. Details of individual posters and documents may be viewed with the Google links provided in the slides.[4]

Legal support for this has been through the IAPC Position Statement since 2003.[5] Palliative end-of-life care will be supported further by the EOLC Bill 2 drafted by ELICIT and Vidhi, which is awaiting review and action by Parliament.[6] This Bill will prevent inappropriate EOLC happening in high-cost ICUs and will also ensure continuing of good end-of-life care at home. It will facilitate the withholding and withdrawing of life-sustaining treatment and give legal validity to advance directives in pursuance of patients' fundamental right to die with dignity. In the context of healthcare, the unfortunate situation in India for the majority is 'Out Of Pocket' expense for healthcare and exploitation due to unscrupulous commercial medicine. Sixty-three million Indians are pushed into poverty by health expenses each year, and drugs are the chief cause.[7] As a 2015 Government of India report states, 'incidence of catastrophic expenditure due to health-care costs is growing and is now being estimated to be one of the major contributors to poverty. The drain on family incomes due to health-care costs can neutralise the gains of income increases and every government scheme aimed to reduce poverty.'[8] Access to good end-of-life home care can prevent this. It will thus help reduce poverty in our country as millions are pushed into abject poverty due to healthcare costs, especially at the end of life.

It is said that 'where there is no vision the people perish'. An incurable illness shatters our whole well-being. As a vision, palliative care tries to restore this shattered wholeness. Palliative medicine is 'good medicine' and since it aims to restore wholeness, perhaps, the emphasis could be on the restoration of the family- and faith-based values rather than a pursuit of more technology. Loneliness is the upcoming pandemic. Can our legacy of faith-based values and the 'family driver' be our gift of solace to a broken and hurting world?

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