

Respite Model of Palliative Care for Advanced Cancer in India: Development and Evaluation of Effectiveness

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Abstract

Palliative care need is highest among low and middle-income countries and a significant gap exists between palliative care need and provision in India. Patients with life limiting illnesses such as cancer are discharged home prematurely with poorly controlled physical symptoms, unresolved psychological and social issues, and unprepared caregiver and with no plans for continuity of care. Respite model of palliative care is a step down from acute setting, where patients are admitted briefly to a respite home for symptom control, and management of psychosocial issues, caregiver empowerment, liaison and networking with local family physician and local palliative care network and planned discharge home. The effectiveness of the project will be measured using four parameters (a) improvement in symptoms using Edmonton symptom assessment scale (ESAS) (b) quality of life using EORTC QLQ-PAL15C (c) family satisfaction using selected items of FAMCARE questionnaire and d. care giver empowerment using a semi structured questionnaire. This project is expected to benefit around 1500 adult palliative care patients and 150 paediatric palliative care patients. The research article highlights needs assessment, concept, project development, research design and proposed impact of the project.

Keywords: Cancer, India, Palliative care, Respite model

Palliative Care in India

South East Asia Region (SEAR) constitutes 22% of world palliative care needs and among SEAR countries highest need for palliative care was perceived in India and China [1]. Across the world in 2011, 29 million people needed palliative care at end of life due to advanced HIV/AIDS, end stage non-communicable diseases and advanced cancer. Seventy to eighty percentage of these patients belonged to low and middle-income countries where access to palliative and end of life care is very limited [1].

In India 1 million new cancer cases are diagnosed every year and up to 70-80% of them present with Stage IV disease diagnosis where options of cancer directed treatment are very limited. At present it is estimated that there are around 3 million patients with cancer in India at any one point in time; with 2/3 of them having pain and 1/3 of them having severe pain needing strong analgesics. It is estimated at least 60-80% of these patients need palliative and end of life care. In India less than 5% of patients have access to palliative and end of life care and less than 2% of the patients have access to strong analgesics needed for pain relief. Annual palliative care need in India is estimated to be 3-4 million [2-5].

A study conducted by the Economic Intelligence Unit of Lien Foundation Singapore on quality of death and end of life care showed that India ranked last among the 40 countries studied. The report showed that in India access to end of life care, quality of end of life care services and basic infrastructure needed for end of life care was lacking and bleak. The public awareness amongst Indian population about end

of life care was very limited and cost involved in India for end of life care provision was very high [6]. The Human Rights Watch in their report – Unbearable Pain: India's obligation to ensure palliative care, stated how people in India die in pain and misery and very little is done to address these needs [7]. This report was followed by special report of Human Rights Council, United Nations 2013, which stated that all United Nations (UN) signatory countries have an obligation to provide good pain relief and symptom control in end of life and omission of these amounts to torture [8]. Though India is a signatory of UN, it has made little progress in terms of having an end of life care policy, access to essential medications for pain and symptom control, end of life care education and provision of essential infrastructure needed to provide good end of life care.

Studies have shown that in India, 83% of patients prefer to die at home [9]. However due to lack of knowledge and skills about end of life care, majority of the patients with end stage organ failures and advanced cancers are managed in the intensive care units, causing significant distress to both patients and their families. These practices by the doctors in India, are mainly due to their inability to recognize the dying process in these end stage illnesses, lack of knowledge about end of life care, fear of being blamed for 'not doing enough' and ambiguous Indian laws. A recent report from Lancet showed that every year, 39 million Indians are pushed into poverty due to rising health related costs and most of these are costs are attributed to health care expenditure for the last few days of life, where resources are inappropriately spent with no outcome benefits [10]. Non-availability of end of life care and rising cost have forced up to 78% of patients in intensive care with advanced illness, to leave hospital against medical advice. The families unilaterally initiate these discharges due to lack of

funds and these discharged patients do not receive any symptom relief during end of life [11].

A study on knowledge of palliative and end of life care among Indian medical, nursing and allied health professionals showed significant gaps in knowledge. A very small percentage of health care providers are trained in palliative and end of life care, and these aspects are completely missing from the Indian health curricula [12].

Amongst the 29 million people needing palliative care in 2011, 69% of them were aged 60 and above. Among the elderly population, the burden of pain and physical symptoms are very high, which is complicated by presence of co-morbid illness, cognitive impairment, depression, frailty and falls. Increase in life expectancy, changes in family structure to nuclear families and the higher incidences of cancer and chronic illnesses in the elderly population; have tremendously increased the palliative and end of life care needs [13]. At present, India has about 100 million elderly and number is expected to increase to 324 million by 2050. Indian Council of Medical Research (ICMR) population-based cancer registry report, shows that by 2021, the prevalence of cancer patients in India above the age of 60 will be more than 1 million. At present the current health care system in India is neither aware nor educated to meet the needs of elderly with life limiting illness [14,15].

Respite Model of Palliative Care

Public tertiary cancer centres in a developing world, serves a large patient population, with a high hospital bed turnover rate. Significant numbers of patients are declared as only to receive palliative care treatment from the oncology teams, and are discharged prematurely to make way for patients with a curative intent of treatment. These discharged patients often have unresolved physical symptoms, early and late adverse effects of cancer treatment, psychosocial and emotional concerns, nursing related issues, compromised physical functions and a poor quality of life. These needs demand attention in a responsive and timely manner, at a non-acute setting, away from hospital before they are finally sent home. This arrangement provides patients a respite from hospital, caregivers respite from the care process, management of physical and non-physical issues, empowerment of family/caregivers, planned and safe discharge and continuity of care through liaison with family physicians and local palliative care network [16,17]. Study by Ingleton et al. focused on description of respite care programmes, referral criteria and impact on patients. However there is insufficient literature on the impact of caregivers, who are a key stakeholder in any respite care facility. Studies have shown that respite palliative care reduces hospitalization of palliative care patients by 80% and facilitates home deaths [18]. Studies have shown that home based palliative care provision helps patients and families to maintain a sense of normalcy and control, suffer less distress and reduces health care related expenses. Hence respite model of palliative care is an effective bridge between hospital and home based palliative care [19]. An Australian study on community respite palliative care has demonstrated relief for families and caregivers experiencing moderate to severe caregiving fatigue [20]. A study on family/caregiver perceptions on in-patient respite care, showed improved satisfaction among those families and caregivers receiving in patient respite [17]. Another study on a family based approach to respite palliative care provision, showed respite palliative care in children, enhanced quality of life and facilitated expression of supportive care needs by the parents [21-23]. The addition of respite care services in paediatric palliative care, decreased overall operational

costs to health care system [24]. Review of paediatric respite palliative care in New Zealand showed that there were gaps in respite palliative care service provision and identified the need for research in respite palliative care [25]. Though respite palliative care is one of the crucial factors involved in palliative care, there is lack of research to support its efficacy [26]. In a resource limited setting like India, out of pocket spending for health care is around 85%. The cost of continued hospitalization in an acute care setting remains high, draining all the financial resources of the family. Hence this interim care provides respite to patients and caregivers and presents with a cost-effective and sustainable alternative for continued palliative care beyond the auspices of hospital. The proposed research project aims to evaluate its effectiveness and applicability in an Indian setting.

Conceptualization

Our tertiary cancer care setting draws patients from all corners of India and from few neighbouring countries. The centre ensures that all patients receive good quality care at a very subsidized cost; hence a significant number of patients serviced in this hospital are from economically weaker sections of the society. The hospital bed turn over time is rapid and hence, a significant number of patients get discharged with poorly controlled symptoms, physical and psychosocial needs not completely addressed. At least 75 to 80% of these patients do not belong to the geographic purview of the hospital home care services and have to travel long distances to reach home or to their native places. Hence to bridge these gaps, it was conceptualized to create a respite care facility at an existing facility that is already housing out of city patients.

The trust approached the tertiary hospital with the idea of creating a new model of palliative care in India other than hospital or hospice based model to help a significant number of out of city population with unmet palliative care needs. The hospital identified the facility and the trust assisted the hospital in designing the project, providing technical support and funding.

The objectives of this program are -

Create a multi-disciplinary clinical service comprising of palliative care physicians, palliative care nurses, medical social worker, clinical psychologist, rehabilitation specialists and volunteers who will manage symptoms, undertake measures to improve quality of life, wellbeing and optimize independence.

Provide period of respite for the caregivers, provide psychosocial support and counselling.

Provide support towards economic and vocational rehabilitation with the help of social workers and volunteers trained in vocational rehabilitation such that they are equipped to manage the patient, family and self on return to their home at native places.

Facilitate continuity of care by good discharge planning, creating a liaison system with family physicians and local palliative care network and establish after hour telephonic support.

Help in forward and anticipatory planning and prepare patient and family to deal with the rapidly changing needs.

Empower the family and care giver to maintain continuity of care on discharge.

Train doctors, nurses, social workers and volunteers in palliative care.

To study the health economics of respite model of palliative care.

Needs assessment

In the year 2013, there were 3077 new registrations under Adult Palliative Care and 258 new registrations under Pediatric Palliative Care. 78.61% of patients were out of city and out of home care service area of the hospital. At least 60% of these patients had unresolved physical and psychosocial issues needing brief respite admission. Hence number of people needing respite palliative care admissions per year was estimated as 1300 adult patients and 150 paediatric patients.

Development

The project is developed as a tripartite agreement between a tertiary cancer care centre, a facility that has offered space for respite beds and a philanthropic trust that has funded this project. The tertiary cancer care centre will provide mentorship, recruit staff, conduct training programs, facilitate research work, perform internal audit and assist the facility in fund raising and advocacy programs. The facility will provide floor space that can accommodate 34 respite palliative care beds, clinical examination rooms, office space for doctors and nurses, children's palliative care room and admin office space. Added amenities are access to in house rehabilitation services, kitchen and others. The philanthropic trust will help in construction and refurbishment of the area in the facility earmarked for respite palliative care. The trust will also support a. salaries of doctors, nurses, social workers and psychologists, administrative and assisting staff b. running costs including consumables and medications c. training programs and d. research initiatives. It is envisaged as a 5-year project and at the end of 5 years we are hoping that it will be demonstration centre for respite model of palliative care. The Institutional Review Board of the Tata Memorial Centre (Project No 1548) has provided ethical clearance for the study.

Evaluation of Effectiveness

During the 3-year period of the project, the effectiveness of a respite model of palliative care in the Indian setting will be evaluated. The objectives of this research will be to evaluate role of respite care in improvement of symptoms, improvement in quality of life, empowerment of family and caregivers and improvement in family satisfaction.

The study planned is a non-randomized, non-controlled prospective observational study where 500 eligible subjects will be recruited over 24 months. All recruited patients will have (a) symptom control interventions, (b) comprehensive palliative care nursing management, (c) caregiver education and empowerment, (d) discharge planning (e) liaison with local family physicians/local palliative care network and after hours telephonic support. Effectiveness will be measured using Edmonton Symptom Assessment Scale [27,28] on admission and discharge, Quality of life using EORTC QLQ-PAL15C [29] on admission and discharge; Family satisfaction using selected items of Famcare scale [30,31] on discharge and Caregiver empowerment will be measured on discharge, using a semi-structured questionnaire. Caregiver empowerment questionnaire will measure ability of the caregiver to care for the patient, family and self and access health resources locally. Analysis will be done using descriptive statistics for overall population and paired t test for comparison of baseline and discharge scores of symptoms and quality of life. Themes will be identified from the questionnaires on family satisfaction and

empowerment. An independent evaluation of health economics of respite model of palliative care will be carried out along with evaluation of a category wise costing system in the facility such that few private beds will subsidise the costs of vast majority general category beds so that the service becomes self-sustainable over three to five years. The educational component of this project is training doctors, nurses and social workers in adult and paediatric palliative care and psycho-oncology. Effectiveness of these educational programs will be evaluated independently.

Impact of the Project

The project is expected to benefit around 1500 adult patients and 100 children with palliative care needs annually. It will also empower and educate equal number of families and caregivers of adult and paediatric palliative care patient. Respite model of palliative care is expected to improve symptoms and quality of life for patients and provide a period of respite to care givers, provide psychosocial support and empower caregivers and families to care for patient, self and family along with accessing local health resources. The project is also expected to significantly reduce healthcare related costs in patients with advanced life limiting illness needing palliative care. Annually around 20 specialist doctors, 50 general practitioners and 100 nurses are expected to undergo basic training in adult palliative medicine and around 10 specialist doctors, 20 general practitioners and 30 nurses are expected to undergo basic training in paediatric palliative care and around 30 specialist doctors and general practitioners, 30 nurses and 30 medical social workers are expected to undergo basic training in psycho-oncology. This project is planned and developed as a comprehensive respite palliative care model that involves service, education, research and advocacy domains. At present respite model of palliative care is neither developed nor tested in India, hence this project provides a unique opportunity to determine its effectiveness and demonstrate its applicability to Indian setting.

Study Limitations

This is a prospective non-randomized study involving a single group of patients. No comparison will be made with other patients in the facility with advanced cancer not receiving respite model of palliative care or with hospitalized patients receiving palliative care.

The mean duration of stay at respite palliative care facility is foreseen as 5-7 days hence it may not be completely possible to empower caregivers in economic and vocational domains.

Note

The paper highlights interim and respite palliative care needs assessment, concept, project development, research design and proposed impact of respite model of palliative care in India. This study is a part of on-going large service project providing respite palliative care in India. This is a concept and methodology paper and results of the study will be published after study completion.

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Late Dr. Ernest Borges a world-renowned humane surgeon of the Tata Memorial Centre on whose name Ernest Borges Memorial Home was established. Ernest Borges Memorial Home houses poor out of Mumbai cancer patients, who are receiving treatment at the Tata Memorial Centre. It provides accommodation at a very nominal or no

charges, provides medical and round the clock nursing support, access to rehabilitation services and free transport service to the hospital.

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Tata Trusts are amongst India's oldest, non-sectarian philanthropic organizations that seek to be catalysts in development through giving grants to institutions in the areas of Natural Resources Management, Rural Livelihoods & Poverty, Education, Enhancing Civil Society & Governance, Health and Arts, Crafts and Culture. Over several decades, the Tata Trusts have made significant investments in infrastructure, technology, education and research aimed at providing world-class treatment and care for cancer patients in the country. This project was co-conceptualized, co-authored and funded by the Tata Trusts.

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