

1. A Research Proposal

Care for the Caregivers (a research project proposal)

Introduction: Palliative care is a person-centered, rather than disease-centered clinical subspecialty. Its goal is to maximize a patient's and family's quality of life during serious illness and beyond. To achieve this goal, an inter-disciplinary palliative care team attends to the physical, emotional, social, and spiritual quality of life of family caregivers as well as patients. Palliative care is a human right, a basic value of human culture.

Target population: the set of "caregivers", which includes both palliative care teams (doctors, nurses, therapists, counsellors) and family/personal caregivers. The physical, psychosocial, and spiritual needs of caregivers are often neglected, and can result in burnout, conflict, stress, psychosomatic morbidity, and even suicide.

Meeting a Need: The growing global burden of non-communicable disease is increasing the need for high functioning palliative care teams and family caregivers. Palliative care should be seen as an attractive, positive, and enriching practice rather than a stressful and unrewarding career or personal burden. The proposed project will cultivate a sense of empowerment and growth in caregivers, while assisting them to better care for themselves, each other, and their patients. When self-care and care of others becomes a way of being, rather than of doing, it is sustainable and can be modeled and taught to others. This is the aim of our model global program.

The Project: We envision drawing on the rich cultural traditions and palliative care practices involving palliative care givers of four model units within three EU countries (Germany, Spain, GB) and one non-European country (India). The goal is to create a synergistic pool of **practical resources to support** the physical, social, and spiritual **wellbeing and training** of caregivers that can be adapted as a best practice model.

Methodology: Identify "model care-support systems, tools and training" for carers country-wide; promote intense exchanges between the model systems, and identify models of international utility for specific countries; expert workshops; training in these models and/or implementation of models in other foreign units; do research on that, prepare a final report on how to process and discern possibilities to include the general health system in one's own country and other non-included countries.

Outcomes: The program will improve outcomes in the domains of work satisfaction, conflict management, and strategic planning, all of which are deficient in the majority of palliative care environments. Participants in each country will be trained for sustainability to continue to support on another and to serve as trainers for teams in their own and other countries and regions. There will be a final conference and report.

Project duration: three years: September 2015 – September 2018.

Phases: conduct needs **assessment** in the 4 countries; discuss **implementation** tools/ training, identify **evaluation** methods and goals; **communicate:** homepage, facebook, twitter, other interactive social media platforms; real-time site meetings/trainings...

Practical tools: a) recommended **20-days-EAPC-Palliative Care Training** b) **Team Supervision** (ongoing monthly or quarterly) c) **Individual** meditation/**Self-awareness practise:** Christian contemplation (like the way of Franz Jalics); Buddhist self aware-ness practice (like vipassana); Hindu Self inquiry (like atma vichara of Ramana Mahrshi)

Partners: RWTH Aachen / MediAcion Hamburg (Ger), Manipal KMC Mangalore (India), Cures Pal•liatives de les Illes Balears (Spain), MCPCIL Liverpool (GB)