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Alexis Ribereau, J Palliat Care Med 2016, 6:5(Suppl)
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TOWARDS A PHILOSOPHIC CARE ?

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In front of the technoscientific construction of medicine, philosophy must intervene by analysing the ethical issues that arise in the healthcare environment. This applied ethics approach is now the strongest link between care and philosophy. However, it is not the only one that can be conceived. There is currently a strong reflection on the end of life, supported in France by the palliative care movement. An important part of philosophy consists of a reflection on the meaning and value of life. However, this meaning is particularly questioned at the end of life. This reflection led by philosophy does not serve a purely speculative purpose. The Socratic maieutic is an example of support for others in their questioning. Is it possible to achieve a 'philosophical care' for terminally ill patients? Psychology and religion have their place in the healthcare context. Can it be the same for an active philosophy? In this way, it could prevent that the dechristianisation of our society undermines existential assistance to patients at the end of life.

Biography

Alexis Ribereau has completed his master's in Human Science, with a speciality in philosophy, at Paris 1 Panthéon-Sorbonne University in Paris, France, in 2013 when he was 22. After a work experience in the palliative care service in the hospital of Châteauroux (Indre, France) he continues his contribution to the ethic reflexion in Centre Val-de-Loire.

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Notes:

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RELIGION, SPIRITUALITY AND CLINICAL SYMPTOM MANAGEMENT: A CASE STUDY ON POLICY IMPACTS

Craig O'Malley[a]
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Aim: To discuss the impact on policy development of the palliative care approach resulting from the review of consumer case studies. Religion and Spirituality are not always mutually exclusive and this case study analysis focuses on the impact of care delivery, clinical symptom management and the associated implications to policy frameworks.

Methodology: The Salvation Army Aged Care Plus reviewed numerous case studies associated with consumers who expressed strong religious ideology with at times conflicting spirituality needs of loved ones who were ultimately decision makers during the terminal phase of care. These case studies resulted in numerous policy impacts on the delivery of palliative care services which focussed on meeting the individual consumer needs and provision of contemporary clinical management.

Findings: The understanding of religious practice and theology coupled with consumer and consumer representative's lived experience of spirituality has a significant impact on the psychological and spiritual wellbeing during end of life care. An understanding of synergies and dichotomies are essential from a policy perspective to ensure appropriate clinical care provision is holistic and person centred. The effective integration of the psychological and spiritual needs associated with religion and spiritual awareness / practice results in improved care outcomes.

Biography

Craig O'Malley is a Registered Nurse who has worked a variety of roles across the nursing and education sector. For the past 5 years Craig has been the Centre Manager of an 83 bed Residential Aged Care Facility in NSW Australia. A deep understanding of the aged care sector has come from Craig's progression in the industry from a Care Worker, Enrolled Nurse, Registered Nurse and Nurse Educator. Previously Craig has spent 10 years in the acute sector as a Clinical Nurse Specialist (surgical) and 3 years as a Clinical Facilitator and Lecturer for North Coast TAFE & University of Newcastle. Craig holds a Bachelor of Nursing and Certificate in Training & Assessment.

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Notes:

Lilly EJ et al., J Palliat Care Med 2016, 6:5(Suppl)
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PALLIATIVE CARE IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE: THE CASE FOR EARLY INTEGRATION

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[c]Baycrest Health Sciences System, Canada

Chronic Obstructive Pulmonary Disease (COPD) is the only major worldwide cause of mortality increasing in prevalence. Furthermore, COPD is currently incurable, with oxygen being the only therapy shown to have a mortality benefit. Compared to patients with cancer, patients with COPD experience similar levels of pain, breathlessness, fatigue, depression, anxiety, and have a worse quality of life, but have comparatively little access to palliative care. When these patients do receive palliative care, they tend to be referred later than do patients with cancer. Many disease-, patient-, and provider-related factors contribute to this phenomenon, including COPD's unpredictable course, misperceptions of palliative care among patients and physicians, and lack of Advance Care Planning (ACP) discussions outside of crisis situations. An integrated palliative care approach would introduce palliative treatments alongside, rather than at the exclusion of, disease-modifying interventions. This approach has the potential to address many of the barriers to palliative care in these patients.

Biography

Lilly is a second-year resident in the Department of Family Medicine at the Schulich School of Medicine and Dentistry at Western University in London, Canada. He has a strong interest in Palliative Care and Oncology, and hopes to pursue additional training in Palliative Care after completing his Family Medicine residency. He has previously conducted research on the hidden curriculum in medical education, and is currently investigating the attitudes toward Palliative Care and Medical Aid in Dying among family physicians in Southwestern Ontario. Lilly also has an interest in the role of medical humanities play in the provision of quality palliative care, and plans to be involved in medical education after completing his post-graduate training.

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Notes:

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CONSUMER DIRECTED CARE AND SPIRITUALITY: END OF LIFE FROM A DIFFERENT PERSPECTIVE

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Session Description: Care planning in residential aged care is a regulatory requirement. Despite a compliance framework, the importance of individualism, one's story and spirituality is integral to the holistic care provision for the older person, especially during end of life. The session will outline clinical assessment processes which achieve a holistic framework of care provision for terminal phase care grounded in the uniqueness of individuality and one's spiritual self. The session will outline how clinical assessment is completed from a lifestyle approach to ensure the most positive end of life experience during the terminal phase of palliation.

Findings: The Salvation Army Aged Care Plus has implemented a number of systemic changes in relation to care planning and assessment to ensure spirituality is a primary consideration as part of the person centred approach to care delivery. The uniqueness of individuality and the interface with cultural, religious practice and spiritual expression are key considerations associated with end of life care planning (Advanced care planning). The Changes to care planning includes a focus on the importance of "story" and encapsulates individuality and the "inner spirit" of Older Australians. Comprehensive spiritual assessment and care planning are paramount to a person centred approach. During palliative and terminal phase care, spirituality is a significant consideration, it cannot be underestimated in its significance to the completion of an individual's story through dying and end of life.

Objectives: An understanding of clinical assessment processes from an individualised perspective which embraces persons lived experiences associated to end of life.

Clinical assessment of a nursing and medical model perspective has a very prescriptive framework that often does not include adequate analysis of spirituality. When completed from a person centred philosophy which embraces an understanding of spirituality the assessment process can encompass a more meaningful context. These results in improved well-being and a quality of end of life experience for not only the individual, but their family and loved ones as well.

An understanding of staff awareness and how to overcome bias when being confronted with spiritual planning and end of life is important. One's own story and spiritual awareness are critical to the success of assessing others and putting this into practice in a consumer directed approach to death and dying.

Personal bias is present in all individuals; this is a consequence of our own individual stories. In order to ensure a comprehensive, holistic spiritual assessment which underpins care planning processes, biases need to be made aware. Staff impacts are significant as spiritual assessment results in confrontation of our own spiritual awareness.

An understanding of the multi-collaborative approach between clinicians and chaplains to achieve optimal outcomes for residents in their dying experience.

Biography

Heidi Dowse is currently employed by The Salvation Army Aged Care Plus, Australia, as the Clinic, Quality and Compliance Manager. Heidi has worked in Aged Care for almost 30 years, holding a variety of positions, including Dementia Specialist and Learning and Development Manager. She currently has a Master's Degree in Nursing where she has researched culture change in aged care.

Heidi is passionate about education and believes the key to change lies in moving the heart of staff before being able to move their thoughts to change. She is able to do this by sharing the stories of the people she had the honour to care for, particularly at the end of their life. Heidi believes in always looking for the shiny in life. So often we spend our lives looking for mud. If that is all you look for, you will miss the shining moments in life.

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Rashidah Nakabugo Adams et al., J Palliat Care Med 2016, 6:5(Suppl)
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SUPPORTING CHILD CARE GIVERS: EXPERIENCES FROM THE PALLIATIVE CARE ASSOCIATION OF UGANDA'S (PCAU) ROAD TO HOPE PROGRAM

Rashidah Nakabugo Adams[a], Rose Kiwanuka[a], Mark Mwesiga[a], Denis Kidde[a] and Roberta Spencer[b]
[a]Palliative Care Association of Uganda, Uganda
[b]Centre for Hospice Care Indiana, Uganda

Aims of the Project:

- To contribute to children's future through supporting their formal education.
- To provide psychosocial support to child care givers and their families based on their specific needs.
- To advocate for and promote the rights of child care givers in their communities. Problem statement

Children give up key roles when they become child care givers to sick/dying parents. One of these significant areas is their education. Along with Caregiving they look for food, walk miles to obtain medications and attend to the daily running of their home. PCAU, together with the Center for Hospice Care, USA, established the Road to Hope Program in 2012 to address the educational needs of these children.

Methodology: Children are identified through palliative care practitioners in different health facilities. They are selected annually, consideration given to the most vulnerable. An assessment of a child's status is completed. Regular follow-up/monitoring is undertaken to ensure sustained wellbeing of the children.

Results: PCAU is currently supporting 42 children with school fees and psychosocial support. Health workers are relieved of stressful concerns about these children and parents are relieved to know there is something for their children's future. There is a greater engagement between the PC practitioners and the community resulting in increased visibility for PCAU.

Conclusion: Child care givers are a unique group neglected in the wider palliative care response. Palliative care providers should provide specific support to meet their needs in order to complete the cycle of care. They should also be exposed to equal opportunities as other children.

Lessons Learnt:

- The program has improved the children's quality of life through empowering them to share, speak out and express themselves better.
- Children are more outgoing, their self-esteem has improved and their hopes are restored.
- Given equal opportunities, child care givers can become important people in society. Recommendations

Palliative care programs should consider addressing the rights and special needs of the child's caregivers in palliative care at policy level.

Biography

Rashidah Nakabugo Adams has done her graduation from Makerere University. After completion of her graduation, she attended a number of training programs. Presently she is working as a Programs Officer in Palliative Care Association of Uganda.

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A CASE REPORT: THE DYING PATIENT'S EXPERIENCE OF BEING HEARD HELPED TO RECOVER HER AUTONOMY

Akiko Nishikawa[a] **Seiji Kunikata**[a] **and Yoshie Shizusawa**[a]
[a]Nara Hospital, Japan

Background: In Japan, in many situations families are notified of a patient's terminal cancer diagnosis prior to the patient being notified. In addition, some families can also be opposed to the patient, even being notified of their terminal cancer diagnosis, which can leave the patient isolated in anxiety and suffering leading to spiritual pain.

Case Presentation: I would like to present a 68-year-old Japanese woman with bladder cancer with peritoneal dissemination. She underwent surgery for bowel obstruction, but it re-occluded after surgery. It was explained to her husband that no further treatment options were possible. Her husband was strongly opposed to his wife being told about this news because he was concerned by its effect on her emotional state. Despite the woman's continual questions about why she was not recovering, she was given no information about it and became depressed.

Later, she started to communicate her awareness of her impending death with us while sharing feelings of regret and loss. After she finished talking, she also told us about her hope that she wanted to live without suffering for a short time, so we decided to tell her husband about her desires.

We would like to focus on the process of recovering her autonomy, by using Murata's Supportive Communication Theory with its focus on the skills of repetition and silence when communicating with others. The experience of being heard appropriately may help the patient to recover her autonomy and develop resilience.

Biography

Akiko Nishikawa, after completion of cancer OCNS (Oncology Certified Nurse Specialist) course in 2012 at Mie University, Graduate School of Medicine, has experience as a professional nurse at Nara hospital, Kindai University, Faculty of Medicine, and was certified as CNS in 2013. She has also learned at the Research Society of interpersonal Assistance and Spirituality, and done a lot of practice in clinical setting of palliative care. Currently, she works exclusively for palliative care team at current workplace. Rather than belonging to particular sections, she enjoys being with patients with independent, cross-sectional position and offers spiritual care to suffering patients.

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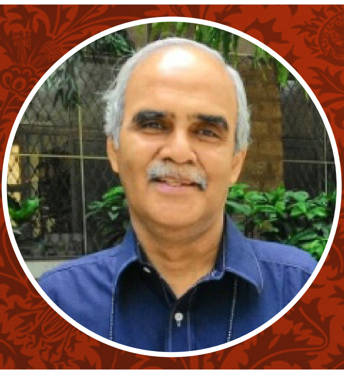

Santosh K Chaturvedi
National Institute of Mental Health & Neurosciences, India

ETHICAL CHALLENGES IN PALLIATIVE CARE IN DEVELOPING COUNTRIES

There are intriguing and challenging ethical dilemmas in the practice of palliative care in a traditional developing society. This presentation reviews the different ethical issues involved in cancer and palliative care in developing countries with special reference to India. Published literature on pain relief and palliative care in the developing countries was reviewed to identify ethical issues and dilemmas related to these and discuss ways by which ethical principles could be observed in the delivery of palliative care in such countries. The literature review demonstrated a number of ethical dilemmas and challenges professionals, cancer patients and their family encountered during palliative care. It was noted that patient's preferences and decisions are influenced by the family members. Dilemmas leave the professionals and families confused about how ethical their actions have been. Specific ethical issues were noted in relation to availability and use of oral morphine for pain relief, spiritual care, lack of adequate palliative care services and palliative care education. The were difficulties in understanding the complex ethical issues in a developing country with traditional background. Ethical issues need to be handled delicately and sensitively in palliative care settings within the framework of traditions and culture of the society and financial constraints. The possible role of ethics committees in palliative care settings to help decision making needs to be studied and discussed.

Biography

Santosh Kumar Chaturvedi is the Dean of Behavioural Sciences and Professor of Psychiatry at the National Institute of Mental Health & Neurosciences, Bangalore, India. He is a Member of the International Psycho-Oncology Society and Indian Association of Palliative Care and was a Member of Board of Directors, International Psycho Oncology Society. He regularly conducts Workshop on Communication Skills in Oncology and Palliative Care settings, and also trains trainers in teaching Communication skills. His areas of interest include consultation liaison psychiatry, chronic pain, psychosocial oncology, palliative care and quality of life research.

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ASSISTED SUICIDE, INTERNATIONAL POLICY AND PALLIATIVE CARE: THE IMPLICATIONS ON SYMPTOM MANAGEMENT AT END OF LIFE

Heidi Dowse[a]
[a]The Salvation Army Aged Care Plus, Australia

Aim: This presentation explores the premise of assisted suicide and the impacts on symptom management with a consumer directed palliative approach. There is significant debate around assisted suicide and the premise of good palliative care. Legislation in many countries indicates assisted suicide is only available for 'insufferable pain', when this is considered from a symptom management perspective; no one should experience insufferable pain through the implementation of appropriate interventions to meet a person's pain experience. The debate from a social, spiritual and ethical position is diverse and complex, however, regardless of one's position in the debate, there is no substitute for best practice palliative care. Clinicians need to have an awareness and understanding of the issues, as well as keys to manage personal bias on this matter in order to ensure effective symptom management is achieved for the consumer.

Evaluation: As a not for profit Christian organisation, there are significant moral and ethical considerations associated with Assisted Suicide, however from a consumer directed focus, there is a requirement to ensure that individual needs are met and this means viewpoints which are plastic. The Salvation Army Aged Care Plus operates in an environment of dichotomies and to meet individual needs, there first needs to be an understanding of the issues; we have achieved this through education. Our education resources include –

- Assisted Suicide
- The Sanctity of Life
- Spirituality
- Palliative Care Interventions to ensure appropriate Symptom Management

Implications for practice: The resource was prompted by a realisation that all people experience the end of life differently and have specific views on euthanasia and assisted suicide. It is imperative our staff have a good understanding of the issues and ensure that best practice palliative care is not taken into consideration as a sil approach. There is always a need for appropriate symptom management regardless of the circumstance. Our aim is to ensure symptom management is not confused as something it is not by either clouding this by religious ideals or social ideations based on decisions which are made in regards to one's own life choices.

Biography

Heidi Dowse is currently employed by The Salvation Army Aged Care Plus, Australia, as the Clinic, Quality and Compliance Manager. Heidi has worked in Aged Care for almost 30 years, holding a variety of positions, including Dementia Specialist and Learning and Development Manager. She currently has a Master's Degree in Nursing where she has researched culture change in aged care. Heidi is passionate about education and believes the key to change lies in moving the heart of staff before being able to move their thoughts to change. She is able to do this by sharing the stories of the people she has had the honour to care for, in particular at the end of their life. Heidi believes in always looking for the shiny in life. So often we spend our lives looking for mud. If that is all you look for, you will miss the shining moments in life.

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Megan Vierhout et al., J Palliat Care Med 2016, 6:5(Suppl)
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THE VIEWS OF PATIENTS WITH BRAIN CANCER TOWARDS PALLIATIVE CARE: A QUALITATIVE STUDY

Megan Vierhout[a], **Maureen Daniels**[b], **Paolo Mazzotta**[c], **Warren Mason**[b] **and Mark Bernstein**[a,c]
[a]Toronto Western Hospital, Canada
[b]Princess Margaret Cancer Center, Canada
[c]University of Toronto, Canada

Palliative care is a specialty aimed at providing optimal care to patients with life-threatening conditions and has been shown to improve length of survival and quality of life, especially when introduced early. It can be administered in a hospital, a hospice (i.e. palliative care unit) or in a home-based setting. In this study the perceptions and attitudes regarding palliative care of patients with brain cancer were explored using qualitative research methodology. Convenience sampling was used to accrue patients at the Brain Tumor Clinic at Princess Margaret Cancer Center, University Health Network and 35 semi-structured interviews were conducted over a four-month period. Interviews were audiotaped and transcribed, and the data were subjected to thematic analysis. Seven overarching themes emerged from the data: 1) Patients prefer to be educated about palliative care as an option early in their illness, even if they are fearful of it; 2) there is a pre-conceived idea that palliative care is directly linked to active dying, and this generates fear in some patients; 3) patients are open to palliative care if they believe it will not diminish optimism; 4) patients would prefer to receive palliative care in the home; 5) increased time with caregivers and family are the main appeals of home care; 6) patients believe palliative care can contribute to their emotional well-being; 7) patients express dissatisfaction with brief and superficial interactions with health care providers. Overall, when educated on the true meaning of palliative care, most patients express interest in accessing palliative care services.

Biography

Megan Vierhout is a fourth year Honors Life Science undergraduate student at McMaster University and a research student at Toronto Western Hospital, working under Mark Bernstein. She has been a volunteer in various palliative care settings, including Hamilton Health Sciences St. Peter's Hospital and St. Peter's Residence at Chedoke since 2013. She is currently interested in qualitative research, and her past research focuses have included palliative care for brain cancer patients and the immunological gut-brain axis.

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Jaydeep Sengupta et al., J Palliat Care Med 2016, 6:5(Suppl)
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DYING IN INTENSIVE CARE UNITS IN INDIA: MEDICAL PRACTICES, POLICIES AND POSITION PAPERS ON PALLIATIVE AND END-OF-LIFE CARE

Jaydeep Sengupta[a] **and Suhita Chopra Chatterjee**[a]
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ICU deaths are common in India. Many of the patients, admitted in ICUs, are medically futile. This compels attention to palliative and end-of-life (EoLC) care within ICUs. Since early 2005, till 2015, the Indian Society of Critical Care Medicine and the Indian Association of Palliative Care published total 6 Policy Papers and Guidelines, focusing on palliative and EoLC within ICUs. However, these documents, written solely from a medical perspective, failed to elicit wider public responses. This paper therefore takes non-medical stand for critically exam these 6 documents to find: discrepancies between the medical rhetoric and the contextual realities; and the extent to which the policies are able to clarify various clinical and ethical issues of palliative and EoLC within ICUs. The review comments are substantiated with field information, collected from a 550 bedded private hospital during 2015. It was found that although barrier-free doctor-patient communication, upholding patient's autonomy, shared decision-making and compassionate Caregiving were strongly recommended by these guidelines, they were grossly missing in clinical practice. By and large, the physicians avoided taking the risk of shifting ICU patients from rescue to palliative care mode primarily due to inadequate infrastructure, poor human skill, medico-legal hassles and public rage associated with such shift of care. The policy documents failed to guide physicians in tackling these deficiencies. In addition, their over-simplistic model of palliative and EoLC in ICUs did not take into account several clinical and ethical complexities. The paper concludes by highlighting the need to contextualize the policies in Indian situations.

Biography

Jaydeep Sengupta is pursuing his PhD at Indian Institute of Technology Kharagpur, West Bengal, India. He is formally trained in Anthropology and Development Studies. His area of interest is in issues related to palliative & EoLC, Death & Dying and Public Health.

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UNDERSTANDING THE ROLE OF SPIRITUALITY AND FAITH IN RELATION TO LIFE EXPECTANCY AND END OF LIFE EXPERIENCE IN TERMINALLY-ILL CANCER PATIENTS

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[a]Islamic Azad University Karaj Branch,Iran
[b]Iranian CancerResearch Cencer, Iran

Spiritual beliefs and faith are important in the lives of many terminally cancer patients, spiritual beliefs and faith can help patients cope with the emotional experiences of end of life and face death and also influence life expectancy in terminally cancer patients. The spiritual and faith dimensions fuse the essential estimations of terminally cancer patients, their considerations on what gives life meaning and religious or non-religious perspective. It additionally incorporates convictions about what happens after death. The purpose of this literature review was to describe the role of spirituality and faith in life expectancy and end of life experience in terminally Cancer patients. The reviewers searched electronic databases, and performed a manual search for studies published. The inclusion criteria covered spirituality and faith for terminally cancer patients in relation to life expectancy and end of life experience. The studies were, originally, randomized controlled trials or quasi-experimental designs. Studies were selected using the inclusion criteria. The results indicate that spirituality and faith produce positive effects on patients' end of life experience and psychological conditions and an increase their life expectancy. Spirituality and faith improve the adjustment and coping strategies with cancer. Further research into the cost effectiveness of spirituality, faith and its long-term effectiveness for cancer suffering is needed.

Biography

Leyla Fallahi is a PhD student in health psychology at Islamic Azad University. She is a psychologist in the cancer section in Shohadaye Tajrish hospital. She has held more than 40 workshops about psycho-oncology and palliative care. She is a board member of the clinical psychology community in Tehran. Also she is a member of specialized psycho-oncology committee in Iran. She has written and translated a number of books in the field of psycho-oncology and health psychology. She has actively been engaged in teaching and researching of spirituality.

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Cordula Dietrich
Gandhigram University, Germany

MUSIC THERAPY FOR PALLIATIVE CARE PATIENTS:THE BODY TAMBURA

The Body Tambura, a new string instrument in the field of receptive music therapy is inspired by the classical Indian Tambura. It has received increasing attention by German therapists working in the field of palliative care or with coma patients. The instrument was designed by B.Deutz/ Berlin to be placed on the human Body. The sound of the Body Tambura is characterized by playing the 28 strings of the instrument evenly to produce fine vibrations and create a softly enveloping monochromatic acoustic space for the listener, which is supposed to induce a state of trance and relaxation. The sound can be heard and felt. The aim of the workshop is to get to know about the BodyTambura in a practical demonstration,to individually experience the effect of its sound and to learn about the handling of the Body Tambura like tuning and way of playing. No special musical background or musical talent is required to participate.

Biography

Cordula Dietrich has completed her medical specialisation in psychiatry and psychotherapy in 2005. Since then she has been working in her own private practice in Berlin as a psychotherapist, musictherapist and relaxationtherapist. Besides her medical education, she is a trained classical singer and underwent a further training in receptive music therapy.(GIM). Since 2010 she was seriously involved in two research studies in receptive music therapy with the Body Tambura in the field of palliative care in Lazarus hospice in Berlin and St. Joseph´s hospice in Dindigul/ Southindia. She recently completed her further training in palliative medicine. She is the chief trustee and founder of Zuflucht e.V germany, which is constantly supporting the work of St. Joseph´s hospice/ Dindigul, Southindia.

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