#### Conference Abstracts

#### **FACULTY ABSTRACTS**

F-1 SURVEY ON THE ATTITUDE AND KNOWLEDGE OF POSTGRADUATE DOCTORS ON END-OF-LIFE ISSUES IN INTENSIVE CARE IN A TERTIARY **REFERRAL HOSPITAL** 

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Background: The mission of intensive care includes avoidance of inappropriate use of aggressive interventions. The training in intensive care includes skills of palliative and end-of-life (EoL) care, and this requires the same high level of knowledge and competence as other aspects of intensive care. Effective end-of-life care is considered as one of the top priorities for the Indian intensive care units and end-of-life care was the focused theme of the Indian Society of Critical Care and Palliative Care Society of India for the year 2014. Literature suggests that intensive care residents in the US are only moderately comfortable in dealing with this important topic. There is very limited information available on the attitudes of intensive care residents towards end-of-life care, in India.

**Methods:** We decided to conduct a postal survey on the attitudes of our intensive care residents towards end-oflife, the training they receive in this field and the skills they acquire during their placement in intensive care. Residents from all the intensive care units at Amrita Institute of Medical Sciences, Kochi, who have completed at least one month's placement in intensive care were included. The questions are based on a 5 point Likert scale. A response rate of 50% or more is considered an acceptable response rate and a reflection of the study population. Ethics committee approval will be obtained from the hospital ethical committee.

**Results:** The results will be discussed later.

**Conclusion:** The conclusion will be discussed later. Key words: Attitudes, End-of-life, Intensive care

THE WORLD HEALTH ASSEMBLY RESOLUTION ON STRENGTHENING PALLIATIVE CARE: A PROGRESS REPORT

#### Stephen R Connor

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In this plenary, participants will hear about the latest developments and plans for the implementation of the 2014 resolution "Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course." This resolution passed at the World Health Assembly (WHO's governing body), is a major turning point in the global development of palliative care. Countries agreed to call on themselves to include palliative care in all major health policies, to improve the availability of essential palliative care medications, to bring palliative care education into health care professional training at all levels, to begin to fund palliative care program implementation, to do more research on palliative care and more. WHO itself is called on to provide guidance to countries on palliative care and to develop clinical guidelines as well as many technical assistance documents to help countries to strengthen palliative care. The Director General of WHO will report on implementation progress in May of 2016 at the WHA in Geneva. An Ad Hoc Technical Advisory Group has been formed to assist WHO in plans for implementation and a strategic plan has been developed to guide work in the coming years. Learn more about how you can use this opportunity to spur palliative care development in your own country and to monitor progress; also how to use the WHO/WHPCA Global Atlas of Palliative Care at the End of Life to benchmark progress.

Key words: Audience interaction, Lecture, PowerPoint

### COMPREHENSIVE CARE PLANNING IN PALLIATIVE CARE

#### **Cherian Koshy**

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The word "comprehensive" means all-encompassing. It means channelling our resources to make complete, as far as possible, the scheme or event proposed, addressing its different and difficult facets.

In Palliative Care we need to look into various aspects to make things not only feasible but to simplify them. The best example is simplification of narcotic licensing procedures.

As NGOs form an important group in delivery of Palliative Care, particularly domiciliary care, we need to have a seamless relationship with them as well as the policy makers.

Kerala became the first state to have a Pain and Palliative Care Policy passed in 2008 (GO (P) No 109/2008/H&FWD

dated 15-04-2008) and to put in place Standard Operating Procedures for availing licence, storing and dispensing of oral morphine in 2009. These two important documents have detailed means and methods in making the message of Palliative Care a movement and it is happening.

To bring into fruition Palliative Care at different levels, we need to have a viable, visible and visionary relationship with the different stake holders. "Link, liaise, learn" should be the guiding motto. The aphorism "Knowledge is power, unity is strength but attitude is everything" is as relevant as "Cure sometimes, relief often but comfort always."

To address "Total Pain" we need a T E A M approach (Together Everyone Achieves More). A comprehensive model is mandatory.

The patient and family was, is and shall be central.

Conclusion: A well-planned comprehensive Palliative Care policy helps to "reduce formality and increase humanity". It helps the patient and family to make the difficult transition from being "seriously ill and fighting death to being terminally ill and seeking peace" (Robert Twycross).

## F-4 THE NEED FOR PALLIATIVE CARE AT THE END OF LIFE IN INDIA

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In this parallel session, the results of cross-sectional research estimating the need for palliative care for adults and children in India will be presented. This research project used the methodology published in the WHO/WHPCA Global Atlas of Palliative Care at the End of Life to develop a minimum estimate of the need for palliative care at the end of life. Due to limitations in the WHO methodology used, the end-of-life need is only part of the estimated need. However, having these WHO approved estimates is an important starting point to advocate for the growth of palliative care in India and to monitor progress in meeting the unmet need. Estimates will be presented for all diagnoses, states and union territories.

Key words: Audience interaction, Lecture, PowerPoint

# F-5 PALLIATIVE MEDICINE IN NON-ONCOLOGY: SYMPTOM BURDEN MANAGEMENT IN PATIENTS WITH CHRONIC KIDNEY DISEASE

#### **Professor Max Watson**

Northern Ireland Hospice E-mail: max.watson@nihospice.org The rapid increase in patients with Chronic Kidney Disease (CKD) across India poses many clinical, societal, ethical and financial challenges for health care providers. With numbers of patients with CKD rising year on year, and with prognosis for patients with CKD often worse than for some cancers, palliative care professionals need to be able to be versatile in responding to the different palliative needs of patients dealing with CKD. Crucial to the care of CKD patients is the ability of palliative care professionals to build collaborative relationships with renal teams as patients need a combination of renal replacement therapy or conservative therapy with high quality holistic symptom control. This presentation covers common clinical pitfalls in managing patients with palliative care needs in the setting of CKD, including careful use of medication, over- and under-attributing symptoms to CKD, muddling management options in acute and chronic renal failure, under- and overtreating symptoms and ignoring so called "soft issues."

#### F-6 CARING FOR THE CAREGIVERS: DEALING WITH THE INEVITABLE

#### **Ganpathy KV**

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In our effort to view the world from the perspectives of sufferings, "we suffer". Taking care of someone with chronic illness is like running a deluge of grey days leaving one drenched in worries and responsibilities. As the disease progresses, choices appear limited and the burden heavy. Constant worry about the patient's comfort and uncertainty about the future can be exhausting. Making plans, while constantly monitoring the symptoms can test our nerves.

To summarize, care giving is all about:

- Commitment to taking care of those who are in the terminal stages of their illness and their families.
- Learning to initiate painful discussion, voicing regrets and hopes; and dealing with complexities that involve intense emotions.
- Listening effectively, managing defensiveness in both patient and family.
- Helping make the final journey of the patient more comfortable, more caring and more loving.

#### Selfless care givers:

There are enough resources available and practiced to ease the suffering of those facing terminal illness.

However, one group of individuals, who spend their lives caring for the special needs of others in the face of constraints, are overlooked, and they are the selfless care givers. Remaining in the background, they are stoic and yet empathic to the needs of the terminally ill:

- Laying aside their own feelings, needs and wants,
- Making the waning days as pleasant as possible,
- Feeling isolated and alone, yet remaining strong for the sake of those around them,
- Handling multiple responsibilities, subsisting on limited finances, sometimes maintaining two establishments for want of a support system,
- Handling treatment-related activities, and importantly,
- Living in constant uncertainty of the patient's mortality.

#### Care-giving burden:

According to one study, the most obvious consequences of care giving burden are anxiety, depression, worry and loneliness. These psychological reactions are related to the caregiver's appraisal of the experience. Caregivers of cancer patients have to modify their lifestyles to accommodate the patient's needs including restricting leisure activity and contact with friends and family. Thus, at a time when caregivers are most in need of the restorative benefits of relaxation, they have the least amount of time and resources available. As a result, caregivers have numerous health-related problems, such as sleep disturbances and fatigue, which worsen as the patient's physical function and symptom burden increase.

#### Compassion fatigue:

In the last five years of dedicated counselling, the writer has had the opportunity to witness deep emotional and physical exhaustion, and a perceptible shift in the carer's sense of hope and optimism about future. This is called compassion fatigue. It can strike even the healthiest of care givers, who go against reality and believe that:

- They can handle everything perfectly
- Stay in control and always have their spirits up
- Work long strenuous hours
- Know all right things to do
- Ignore their own needs and wants.

Other challenges contributing to compassion fatigue

- An unexpected problem: many a times, things do not go as planned.
- Self-neglect: Generally, caregiver neglects his career, family and social life.
- Family relations too often is rife with arguments over who
  is responsible for care, with very little time to attend to
  other responsibilities like children, spouse or other things
  that one cares about.
- Caregivers sometimes tend to believe that if only they had done something differently, the person cared for might not be in this condition.
- In many families, there are patterns of holding grudges, and displaying ingratitude

- Care givers also seem to wallow in anger and end up with more guilt, more shame and more attempts to hide the feelings of anger. The anger and resentment bottle up inside, causing greater discomfort.
- Normally, feeling of grief is associated with death. But it's normal to feel the grief even when anticipating the loss.
- At times, caregivers experience old hurts and find caring for someone who once had little time for them thankless.
- Caregivers also sink into depression, staying at home all the time taking care of the ill person, feeling isolated, bored and tired.
- The person who is being cared for is generally the centre of attention and the caregivers may not even be aware of the feeling of jealousy creeping in.
- An uncomfortable feeling of embarrassment, when the ill person stumbles, or spill something, have unpleasant odour, bowel and bladder incontinence etc. may also be a constant source of worry for the caregivers.
- Finally, the denial that can be indeed surprising, to the
  point where the caregiver can be in the denial of his/her
  own feelings. As caregivers we want to put up a front of
  courage and strength, ignoring the emotions that come
  in the way.

#### Symptoms of compassion fatigue

Intrusive symptoms

- Feeling of inadequacy as a care giver.
- Obsessive, compulsive desire to help certain clients.
- Inability to let go of work-related issues.

#### Avoidance symptoms

- Loss of enjoyment in pleasurable activities.
- Loss of hope; sense of dread working with clients.
- Loss of sense of competency.
- Secretive medication.

#### Arousal symptoms

- Increased anxiety, impulsivity, frustration and anger.
- Sleep disturbances.
- Difficulty concentrating.

#### From compassion fatigue to compassion satisfaction:

How do we find a way to respond to life crises caused by deeply troubling conditions or circumstances such as care giving?

Research has shown that feelings are infectious, particularly for highly sensitive people. If you tend to be empathic and know what others are feeling it is quite possible that you are absorbing psycho-toxic contamination from others. Unless one is consciously and regularly working on a self-care regimen, one can become less enthusiastic and resentful

towards the people who are being cared for. Care giving can seem like a jumble with all these difficulties.

#### Finding a way out:

Coping together lessens the burden and loneliness of a care giver. The right way of being responsible (basing action on accurate perception of reality) is to be supportive and loving. However, in time of crisis, there is the risk of assuming too much responsibility, or becoming over responsible. Intense fear coupled with an all-consuming sense of responsibility can add to the burden, which may warrant your needing care rather than you being a care giver.

#### Be rightly responsible:

Assess your situation realistically. You know it better than any expert. Prioritise your responsibilities. Downplaying or dramatizing can only worsen the situation.

- It is important to accept your powerlessness over the person, who you are caring for. Trying to manage the unmanageable will only be damaging.
- Objectively review your behaviour, for its positive and negative consequences to your significant others.
- Differentiate caring and care-giving. Base your responsibility on reality, coming from a well thoughtout plan and confidence that also allows flexibility. Let it not be an overreaction that stems out of fear, and a behaviour that is rigid and uncompromising.

However, the most important thing the caregiver ought to do is to ADMIT. Admit that we are powerless over those whom we care. There is simply nothing we can do; it only creates new problems. The need to prove ourselves is the most counter-productive.

Peace is the result of retraining your mind to process life as it is, rather than as you think it should be.

Wayne dyer

#### F-7

#### DEVELOPING A HOME CARE NETWORK IN INDIA

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By delivering healthcare home, we have opened up a new dimension in healthcare in India. Because of inaccessibility, ignorance or plain inertia to seek medical attention, a whole lot of health parameters have been neglected. By proactively addressing each of these, stepwise, we are counteracting the clinical inertia, which patients suffer from and bringing health to their doorstep. Diabetes and ageing are rampant issues in our country with its own trappings like immobility problems, hypertension, cancer etc. Every 3<sup>rd</sup> or the 4<sup>th</sup> patient in the 60-plus category is a diabetic, a hypertensive or with stroke and various other problems. Chronic diseases are here to stay and they are going to explode in our faces if we do not take appropriate action at the right time. We are giving them care which they never had before and thereby bringing a whole

lot of people onto the medical mainstream. The hospitals also appreciate this particular benefit because they realise that instead of 4 or 5 patients with dressings changes, they can focus on one patient who needs THR, TKR, appendectomy etc. By delivering efficient homecare and we can avoid feeling the pinch of the shortage of doctors and medical personnel. Home healthcare can bring a huge change in the lives of the patients and benefit the patient, hospitals and the nation as well.

#### F-8

#### HOME HEALTHCARE NEEDS IN ONCOLOGY

#### Rajiv Yeravdekar

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Home care is a broad term that describes a wide variety of health and health-related services provided at a person's home to maintain or restore the person's health and wellbeing. Services include nursing care, physician consultation, lab sample collection, physical/occupational/speech/ infusion/respiratory therapy, medical equipment and supplies, physiotherapy, pharmacy support, in-home aides, nutrition and related medical services in a home setting. Through the home visits, the Home Healthcare Provider develops a good understanding of the patient's health status and is able to assess the progress of the disease condition accurately. This in turn helps him/her to review and revise the care plan as per patient's needs. Every day, millions of Indians rely on home care to stay out of a hospital, nursing home, or other institutions. Patients treated include those recuperating after surgery or accident, infants and their mothers, elderly, and chronically sick. Home Healthcare providers for oncology patients particularly have to focus on four broad domains: physical symptoms, psychological symptoms, social needs which includes interpersonal relations, care giving and economic concerns. A changing landscape encompassing changing demographics, changing economies, changing lifestyle and culture, and change of care focus, all amply justify the need for home healthcare services. Further, substantiation is by way of the inherent advantages of home healthcare services which include, amongst other factors, patient convenience, cost effectivity and avoidance of prolonged of hospitalization with its inherent possible complications. The flip side of this potential and advantages of home healthcare services are the challenges faced; from being an unorganized sector to dearth of well laid down structures and processes to absence of a consensus on scope of services to be provided with its inherent medico-legal implications. However, the fundamental challenge is of acquiring, training and retaining the right talent. If we as a nation, are to inch anywhere closer to the WHO prescribed manpower ratio in the healthcare space, this sector of Home Healthcare Services needs to be tapped deep and wide. Indeed, it has the potential to become a big game changer!