IAPCONKochi 2019 Abstracts

PLENARY AND PARALLEL SESSIONS

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PLENARY SESSIONS

1. "VOICE OF THE DISABLED"

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In India, especially in Kerala, people with disabilities are included in palliative care. I believe that disability is not an individual's responsibility or a family's responsibility, but our society's responsibility. It is the inaccessible environment and attitude of society which makes you disabled than your physical limitations. When you have a physical disability, you have to depend on a caregiver for many activities on a daily basis. Often you are controlled than supported in a family. You are loved and cared for but not given any freedom because of the fear of getting injured or sick. Individuals are expected to be happy and grateful for the help they receive. Without even realizing, you lose your individuality. It is quite natural for the parents to think that their child is an infant as they still bathe and feed him/her daily.

Palliative care can play a significant role here. Individuals need to be empowered to understand their rights and reach their full potential. Parents and caregivers should understand the concept of autonomy and difference between supporting and controlling. Society should provide a barrier-free environment and equal opportunities to people with disabilities. Kerala model of palliative care has already shown how community participation can facilitate removal of health-related suffering.

Our joy of success comes from our ability to take risks. What makes us most human is our ability to enjoy our successes by having the ability to own our own failures. When you infantize and control someone because he/she has a disability, you are denying them their fundamental right for autonomy and the joy of taking risks.

2. DIRECT STAKEHOLDERS AND PALLIATIVE CARE

Stephen R Connor, Lucy Watts

Executive Director, Worldwide Hospice Palliative Care Alliance, London, UK

Appointed Member of the Most Excellent Order of the British Empire (MBE) in the Queen's New Years Honours 2016 for services to young people with disabilities Awarded an Honorary Degree of Master of the University from the Open University for commitment to public services in September 2018 Named on the Shaw Trust Disability Power 100 List 2018 - recognising Britain's most influential disabled people

Fellow of the Royal Society for the encouragement of Arts, Manufactures and Commerce (RSA)

Dr Stehen Connor: In this plenary the focus was on the importance of inclusion of direct stakeholders of palliative care in all major aspects of palliative care including advocacy, communications, policy development and governance. Direct stakeholders are defined as "persons currently accessing palliative care or living with a condition, or reaching and age, where you may require palliative care in the future."

Advocacy – Most advocacy is done by professionals working in palliative care. Professionals have been reluctant to involve direct stakeholders in advocacy out of a misplaced belief not to want to impose on affected persons who may be too ill to be effective advocates. We impose a fiduciary responsibility on ourselves to ensure that direct stakeholders (DS) do not feel they have to advocate for us when in reality many DS's would like to be more involved in promoting the care they are receiving. Actively working on palliative care advocacy encourages a sense of meaning, dignity, and interdependence in DS's. DS advocacy is also much more effective than that done by professional advocates, who can appear self-serving when advocating. While professionals have a great deal of experience observing the impact of palliative care, they also lack the lived experience whose sharing has much greater impact on policy makers.

Communications – Sharing lived experience has great impact and engages the listener. Direct stakeholders can discuss the impact of palliative care on quality of life and are the best spokespersons for palliative care. Stories and personal experience can move people, including high level policy makers to realize the importance of palliative care and the need to support its growth and development.

Policy Development – The term "nothing about us without us" is an important statement of why direct stakeholders need to be involved in all aspects of an organization's growth and development. No policies should be developed without the input and review of those most affected. This includes public policy position statements as well as organizational operational policies and procedures.

Governance – The role of the governing body is to set policy for the organization and to monitor its operation and performance as well as to contribute to achieving the mission of the organization. Palliative care organizations should all have at least one direct stakeholder as a board member or trustee. This ensures that the voice of affected people is included in all aspects of organizational operation.

Ms. Lucy Watts: "*My experience of being a palliative care recipient clearly indicates the need; the importance and value of using direct stakeholders in advocacy, communications, policy and governance*". It is important to know that it is not only possible and desirable to utilize direct stakeholders but it also can be beneficial to the quality of life and sense of meaning and purpose of DS's".

3. CAREGIVER SAATHI: VOICE OF THE CAREGIVER

Bhavana Issar

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> "There are only four kinds of people in the world.
> Those who have been caregivers,
> Those who are currently caregivers,
> Those who will be caregivers,
> and those who will need a caregiver"
>
> —Rosalyn Carter

One way or the other, each one of us is a caregiver or at best 1 degree away from a caregiver.

Let's listen to the story of a caregiver – (video) https://www.youtube.com/watch?v=8HXZV3RCTWY

You would have noticed the body language of the caregiver; it was difficult for her to face the camera as she narrated her story. While we were recording, she broke down many times and recollecting her story was like reliving a traumatic, difficult journey.

This is the story of my mother, who was the primary caregiver to my father as he grappled with a rare neurological and terminal condition, Shydrager syndrome, or Multiple System Atrophy (MSA).

Caregiver Saathi is an endeavour to acknowledge and support Caregivers of patients with terminal illness or chronic conditions, so that together we can improve the quality of their lives, their well-being and those that they care for.

Caregiving to a dear one is who is facing terminal illness, or a chronic condition is a uniquely challenging and often a traumatic journey for the primary caregiver. As the Caregiver's well-being is pivotal for the well-being and healing of the patient / care-receiver, we aim to be a one-stop solutions provider for a caregiver and to build an ecosystem that empowers them and enables their well-being.

We partner with doctors, health practitioners, employers and well-wishers of caregivers to build a supportive community for the caregivers. In order to service these needs and build this ecosystem, we use digital/online systems, offline in-person workshops and one-on-one interactions.

Increasingly, nuclear families and fragmented communities are the reality of urban India [Figure 1]. Longer lifespans, rising incidences of terminal illness and chronic conditions demand a greater role of caregivers, professional or family (who is unpaid for this).

A caregiver (https://en.wikipedia.org/wiki/Caregiver) plays a significant role in the well-being and healing of the patient. The traditional narrative around caregiving in Indian society is that the immediate family is expected to be caregivers and caregiving is largely a gendered role significantly played by women (60-80% of the time the caregiver is a woman). This, of course is changing as the families are smaller and men and women are going beyond their gendered roles, albeit gradually and mostly in urban areas. We have myths, stories and Bollywood movies that have reinforced stereotypes about ideal women (Sita, Savithri), ideal caregivers and dutiful sons (Ram, Shravankumar), who go above and beyond their self, thereby making caregiving a significant and even more complex challenge.

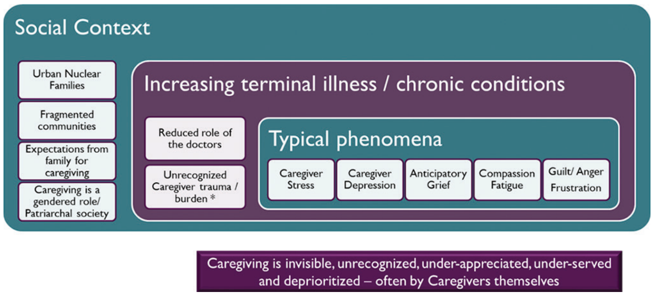

Figure 1: Phenomenon impacting caregivers in India

Caregiving to a dear one who is facing terminal illness or a chronic condition is a uniquely challenging and often a traumatic journey. 'Caregiver Burden' leads to 'Caregiver Stress' and can lead to 'Caregiver Depression'. Caregiving in terminal illnesses, chronic or life-limiting conditions is traumatic and has other associated psychosomatic phenomena like Caregiver burden, Caregiver stress, Caregiver depression, Ambiguous loss, Anticipatory grief, Compassion fatigue, Unexpressed emotions (like fear, anger, frustration, guilt, shame or sorrow) and Post Trauma Stress Disorder. Caregiving is invisible, unrecognized, under-appreciated, underserved and deprioritized – often by caregivers themselves, let alone the extended family and social circles.

In order to shine the light on the invisible force and unheard voices of the caregivers, I would like to highlight that as per our research the following are the top 5 dilemmas (or dharma sankatas) faced by the caregiver:

- Self-care vs Patient care – which comes first, what is more important?
- Who can I talk, who will understand me?
- Can I share my challenges at the workplace?
- Do-it-yourself, or Do-it for me - can I get help?
- How can I get the right information for quick decision making?

Our Model – this is our approach [Figure 2]

If the dyad of the primary caregiver and the patient is at the center, and the influencers are around them, this can be pictorially represented in the following way:

We believe that our role is that of a sensitive and concerned companion who helps the caregiver navigate the complex and ever evolving needs of the patient, while ensuring optimal utilization of resources. The capacity and capability building across all these constituents is provided through ongoing offline and online engagements which enable the dual tasks of delivering value and understanding current/future needs.

In our research we have found that the most significant influencers for caregivers are

a. doctors, healthcare professionals like nurses,
b. the well-wishers like extended family and friends and finally
c. their co-workers.

The two most significant places other than their homes where caregivers are likely to be found are

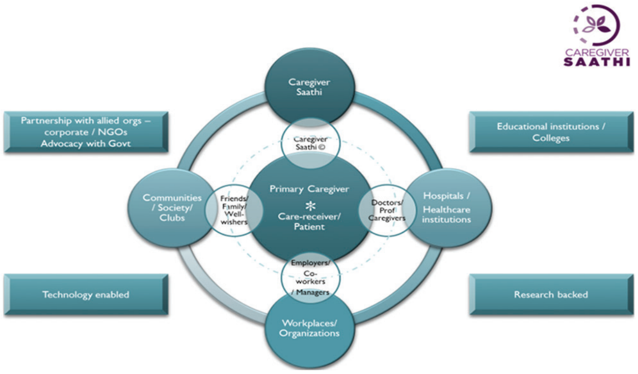

Figure 2: Co-Creating a new paradigm for well-being and healing: The Caregiver Saathi Model

a. healthcare institutions like hospitals, clinics and
b. workplaces - In case of unemployed caregivers, workplaces are places where their well-wishers can be found who understand the challenges and are looking for ways to contribute.

If we were to look at these influencers and the systems they belong to, the doctors and healthcare professionals would belong to the healthcare systems (institutions including facilities, services/product providers, education/training and professionals), the wellwishers (friends and family) belong to communities (societies, clubs, associations) and co-workers belong to workplaces (formal/informal organizations, networks).

Organizations and workplaces need to transition from the industrial mindset of ensuring worker availability at fixed locations on fixed times dedicated to production in a production only environment to the new-age network organizations. Today's organizations to be effective need to recognize that the personal and professional boundaries are significantly blurring, and the diversity and inclusion initiatives will need to be gender and life-stage agnostic. Across corporates, nearly 40% women fall off the workforce at various life stages to address domestic caregiving responsibilities. This means that organizations will need to start becoming caregiver-friendly workplaces. We will be consulting with organizations on how they can undertake this transition and enable organization development in a meaningful way.

Each of these influencers would need to be taken through programs for awareness, sensitivity, skill-building and capacity creation through a variety of modes that are digital like online videos, webinars, podcasts and offline like 1:1 counselling and coaching, support groups, helpline, respite care, volunteering programs, experiential workshops, seminars, conferences, learning cohorts etc.

Caregiver Saathi aims to be that entity which integrates this ecosystem by working with the caregivers, the influencers, collaborating with the government, other organizations, NGOs etc., across boundaries to enable bringing into play international best-practices in order to bring out the best of the overall healthcare ecosystem in the Indian context.

Caregiver Saathi partners with all these entities to provide a research backed and technology enabled solution to provide tools to continually enhance positive health outcomes for the caregiver and thereby the patient. The tools, techniques, services would be research-based and technology-driven to achieve scale and impact. While these entities, linkages and partnerships influence each other and need to be worked with simultaneously to change the current healthcare ecosystem, we also need to partner with educational institutions like schools and colleges so that the citizens of tomorrow can be educated in a manner that they value holistic personal and social development and not just individual achievement or wealth creation.

We will also have a certification program for those individuals who may have been caregivers and now that are no longer in the role, who would like to leverage their life experience within a structured program to meet their economic and other needs.

As professional caregivers, doctors, healthcare professionals, you have the potential to impact and influence the caregivers. The caregiver is most likely to listen to the advice of the doctor/ healthcare professional. So, the next time you ask the wellbeing of the patient, remember to ask the caregiver – how are you? And how are you taking care of yourself?

You have the power to gently nudge the caregiver to seek help, get the support and learn how to manage the role of the caregiver.

We must remember the role the caregiver plays in the healing and wellbeing of the patient. The environment is crucial and the caregiver's wellbeing significantly determines the energy field and the ground for healing. After all there has been enough research that has established the placebo effect exists.

4. Redefining Palliative care

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I travel quite a lot professionally, as president of our German palliative care association and chair of the board of directors of the International Association for Hospice and Palliative Care (IAHPC). And when I get asked what I do professionally, I usually have to explain what palliative care is, as most people are not familiar with the term. I do have a short explanation for taxi drivers ("it is caring of the severely ill and the dying"), but when I get to discuss with my colleagues what palliative care really is, I find it rather hard to boil that down to a short definition that captures it all and does not allow for misunderstanding.

The "official" definition used most often is from the World Health Organization: Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[1]

However, that definition has been criticized, as it is restricted to life-threatening illness (what about chronic diseases with severe disabilities?) and requires impeccable assessment and treatment (what if lack of resources does not allow impeccable performance?). There is an ongoing discussion on whether palliative care should focus on life-limiting or life-threatening diseases or should offer care for all chronic health conditions. In resource-poor settings many patients may not even be able to access any diagnostic procedures, and a diagnosis of life-limiting illness might not even be possible. Palliative care nurses in the rural area in South Africa reported that many of their patients will not see any health care professional apart from their palliative care service, thus will not have any clear medical diagnosis and in consequence, they are not sure who will die and who will live.[2]

The definition sees palliative care as an approach, which is consistent with the public health approach required in low resource settings. However, there is a need to reconcile the provision of palliative care by primary care professionals with the need for specialist palliative care for complex cases and as training centres and motors of innovation.

Palliative care has come a long way from the predominant focus on cancer patients with far advanced disease, with very short survival times and with pain management as the major problem. By now it is patients with HIV/AIDS, but also other infectious diseases such as multiresistant tuberculosis, cardiac, lung or renal failure, neurological diseases such as motor neuron disease or Parkinson disease or even frail elderly or patients with dementia. The model of care and organisation has changed accordingly, from late identification in specialist (for example oncology) services to early identification in community or other general settings, from limited prognosis as the main admission criteria to level of complexity as admission criteria, and from a dichotomy curative versus palliative to a combined and shared care with increasing integration of palliative care in mainstream health care.[3]

For these reasons the IAHCP has undertaken a revision of the definition of palliative care, based on the WHO definition of 2002. The methodology followed a multi-step consensus process, starting with a core group that revised and approved the project proposal and a larger expert group that rated the main components of the WHO definition and identified additional components. In the next phase a panel of 420 IAHPC members was selected, stratified according to socioeconomic levels of their countries (high income, middle income, lower middle income and low income countries). In two rounds these panellists ranked the components according to their level of agreement and offered free text comments where appropriate. Components that lacked adequate approval were removed and other components revised according to the feedback of the panellists. The resulting definition was again sent to the expert group and revised again following their feedback.

The resulting final definition of palliative care of IAHPC is as follows: Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

The definition uses two terms that require explanation. The concept of serious health-related suffering has been introduced by the Lancet Commission on Palliative Care.[4] Health-related suffering is serious when it cannot be relieved without intervention by a health care professional and when it compromises physical, social, spiritual and/or emotional functioning.

Severe illness should be understood as a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress.

The definition also includes a number of bullet points, many of them similar or identical to those in the WHO definition of 2002:

- Includes prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.
- Is applicable throughout the course of an illness, according to the patient's needs.
- Is provided in conjunction with disease modifying therapies whenever needed.
- May positively influence the course of illness.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
- Provides support to the family and the caregivers during the patients' illness, and in their own bereavement.
- Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).
- Can be provided by professionals with basic palliative care training.
- Requires specialist palliative care with a multiprofessional team for referral of complex cases.

In addition to these bullet points, the definition also includes some points aimed at governments. In order to achieve palliative care integration, governments should:

- Adopt adequate policies and norms that include palliative care in health laws, national health programs and national health budgets;
- Ensure that insurance plans integrate palliative care as a component of programs;
- Ensure access to essential medicines and technologies for pain relief and palliative care, including paediatric formulations;
- Ensure that palliative care is part of all health services (from community health-based programs to hospitals), that everyone is assessed, and that all staff can provide basic palliative care with specialist teams available for referral and consultation;
- Ensure access to adequate palliative care for vulnerable groups, including children and older persons;
- Engage with universities, the academia and teaching hospitals to include palliative care research as well as palliative care training as an integral component of ongoing education, including basic, intermediate, specialist, and continuing education.

The resulting definition is disseminated via the IAHPC website. A publication on the definition is currently in preparation. The definition is also offered to WHO, as the development of the definition was part of the remit of IAHPC as an official collaborator of WHO.

Throughout the development of the project and all steps of the consensus process it became clear that there is a wide range of different perceptions and interpretations of palliative care among experts. To a large degree this depends on the setting, with stark differences between developing and developed countries. The core group used the consensus process to identify the common middle ground, and the final definition was finely honed to consider all settings of palliative care, in resource-poor and rich settings, with a primary care approach and in specialist services, for early integration but without neglecting patients in the final stage of life.

The greatest challenge faced by the core group was the difference between those who think that palliative care is the relief of all suffering, and those who believe that palliative care describes the care of those with a very limited remaining life span. This was evident in the discussion on the term "severe illness". Some panellists objected to this term because they found it too broad, others wanted to keep the definition even broader. However, all potential substitutes were similarly challenged in the discussion, and the core group finally decided to stick with this term in the definition.

The new definition has been published on the IAHPC website (https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition). The consensus process has been completed, but IAHPC welcomes feedback from the palliative care community on the new definition. The discourse on what palliative care is or what it should be will continue, even though the consensus-based IAHPC definition has provided a new cornerstone for this discourse.

References

1. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: The World Health Organization's global perspective. J Pain Symptom Manage 2002;24:91-6.
2. Campbell LM, Amin N. A post structural glimpse at the World Health Organization's palliative care discourse in rural South Africa. Rural Remote Health 2012;12:2059.
3. Gomez-Batiste X, Connor S, editors. Building Integrated Palliative Care Programs and Services. Barcelona: Liberdúplex; 2017.
4. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, *et al.* Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: The lancet commission report. Lancet 2018;391:1391-454.

5. INSPIRING THE NEXT GENERATION

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'Nurses lead by Inspiring, Innovating and influencing'

Inspiring the next generation is a challenge and to bring the changes and recognize the importance of palliative care nurse in the health system is not that easy. Palliative care is a model that is consistent with basic nursing values, which includes caring for patients and their families regardless of their age, culture, socioeconomic status, or diagnoses, and engaging in caring. Nurses serve as cost-effective health care coordinators for patients and families with both chronic and life-limiting illnesses, to reduce suffering and improve the quality of living and dying. Nurses offer support for unique physical, social, psychological, and spiritual needs of the patients and their families. Palliative care nurses work independently in home care settings and have demonstrated a commitment to palliative care.

We have to take steps to include palliative care in the nursing curriculum, develop nurse leaders and nurse practitioners, encourage research work and use telehealth in caring for the patients. Taking into account the increase in the need of palliative care, concepts of palliative care for patients and guidelines for care givers should be incorporated throughout nursing curricula. Nurses who deliver care presently have not received specific undergraduate education in palliative care and this is reflected in symptom relief, psycho-social care or continuity of care, leaving the patient with long term illness to endure un-acknowledged, unmet continued suffering.

We have to develop nurse leaders in palliative care, to ensure high-quality outcomes for seriously and chronically ill patients and their families. Nursing research and practice must continue to identify and develop evidence-based improvements to care, and these improvements must be tested and adopted through policy changes across the health care system. Nursing leaders must translate new research findings to practice and into nursing education and from nursing education into practice and policy. Strong leadership is critical if the vision of a transformed health care system is to be realized.

Nurses should be full partners with physicians and other health professionals, in redesigning health care globally. A palliative care nurse practitioner can provide comprehensive care to patients and families living with chronic and terminal illness. They can develop protocols for end-of-life care, educate others about palliative care, conduct research to expand knowledge about palliative care and also assume administrative roles in health care organizations. Registered nurses have acquired knowledge and skills after graduation, through palliative care training programs. Nurses are playing an important role in telehealth offering education, consultation and advice to people living in remote areas. To inspire nurses it important to provide them with adequate training, opportunities, support and renumeration.

Parallel Sessions

1. Voices in Palliative Care: The Impact of Hearing the "Child's" Voice in Children's Palliative Care

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Introduction: Creating solutions and strengthening voices are essential to the implementation of the WHA Resolution on palliative care. The voice of the direct stakeholder has long been recognised as a key component of advocacy, e.g. within the field of HIV and cancer. However, within palliative care, due to the nature of the work that we do, and the vulnerability of the people that we care for, particularly children, we have been slow to strengthen the child and families voice in advocating for children's palliative care.

Objectives: This workshop aims to share different examples of how the child's voice can be strengthened and promoted in the ongoing advocacy and development of children's palliative care in India.

The Workshop: General information about listening to the child and their family, and how their voices have been heard and strengthened globally will be used to set the scene. Following on from this there will be three paper demonstrating how the child's voice has been strengthened and utilised in different programmes in India.

Discussion: Listening to the child and their families is an important concept within palliative care, and underpins the philosophy of children's palliative care itself as we seek to ensure that our care is 'child centred', 'focuses on the family' and has the child and their family 'at the centre' of all we do. Thus listening to the child is not a new concept. Examples will be shared of some of the work that ICPCN has been involved in with regards to listening to the child, including: a study in the USA, Haiti, South Africa and Uganda on children's understanding of illness, death and dying; a study to develop a children's palliative outcome scale in sub-Saharan Africa where over 120 interviews have been undertaken with children in Uganda, Kenya, South Africa and Namibia, listening to what is important to them; individuals experience of utilising the ICPCN pain app. Regularly children are participating in national and regional meetings and conferences, giving their experiences, and advocating for children's palliative care. The development of Palliative Care Voices spearheaded by Lucy Watts in the UK has strengthened the user voice and enabled individuals such as Lucy and Sharon Thompson to be able to advocate for children's palliative care at the highest levels e.g. the World Health Assembly. Several projects in India have been working closely with children and their families as they develop their palliative care services and advocate for scaling up of services. These include: the children's palliative care project in Maharashtra co-ordinated by Tata Memorial Hospital; the experience of Cankids in enabling children's to speak and promote cancer awareness in Delhi and across the country; and, work being undertaken at MJN Institute of Oncology and Regional Cancer Centre in Hyderabad with children at the end of life.

Conclusions: Hearing the voice of the child and their families within palliative care for children and young people needs to be an integral part of the integration and development of children's palliative care. The impact of listening to their voices is far greater and policy makers can hear the importance of palliative care from those using it.

2. Progress in palliative care - Voice from Telangana

Priya Kumari D, Gayatri Palat[1], Jagannath JN[1], Vineela R[1], Swaroop I[1], Venkatesh T[1], Naresh P[1]

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India faces huge burden of non-communicable diseases (NCDs) and there is an increasing need for palliative care. Out of the 7 million people who die every year, almost 5.4 million need palliative care but less than 1% are able to get it. There are 2.8 million new cancer cases every year.

Two thirds of these are incurable by the time they reach the hospital and 70 to 80% of them have severe pain. Almost 80% of HIV/AIDS and 40 to 50% of heart failure patients have moderate to severe pain. Telangana the new state of India also faces the burden of NCDs. CMNNDs (Communicable, maternal, neonatal, and nutritional diseases): 27.6%, NCDs: 59.2%, Injuries: 13.2% (www.icmr.nic.in). The results of door to door survey of houses in rural villages conducted by Pain Relief and Palliative Care Society (PRPCS) a not for profit organization revealed the burden of NCDs as - stroke, paralysis – 60%, Cancer – 25%, Other (AIDS, Kidney diseases, Children with disabilities etc)- 15%. 12,000 new cancer cases are seen in Mehdi Nawaz Jung Institute of Oncology and Regional Cancer Centre (MNJIO & RCC), Hyderabad and 70% patients report in advanced stage and need palliative care. Nine of every ten patients (88%) reported experiencing moderate or severe degree pain and 57.5% of new patients travelled more than 100 km with untreated severe pain. National Health Policy, 2017 recommends universal, easily accessible palliative care in all states of India.

Pain Relief and Palliative Care Society (PRPCS) a not for profit organization has strived over a period of 10 years towards the advocacy of Palliative care in the states of Telangana and Andhra Pradesh. Some of the milestones include,

- 2006 - Establishment of department of palliative care in Mehdi Nawaz Jung Institute of Oncology and Regional Cancer Center (MNJIO & RCC), Hyderabad
- 2007 - Establishment of Pain Relief and Palliative Care Society (PRPCS)
- 2008- Inclusion of Palliative and Supportive Therapy into State Health Insurance scheme.
- 2009 – Amendment of Narcotic Drugs and Psychotropic Substances Act to relax the legal barriers to opioid access
- 2011- Official recognition to Department of Pain and Palliative Medicine, MNJIORCC.
- 2014- Post Doctoral Fellowship in Palliative Care by State University of Health
- 2017- Post Doctoral Fellowship in Paediatric Palliative Care in collaboration with Two Worlds Cancer Collaboration (TWCC)
- 2017- Guided Telangana state government to apply for PIP
- 2018- Permission to procure, stock and dispense Methodone in MNJIO & RCC

Understanding the need of Palliative Care for patients suffering from life limiting NCDs, The National Health Mission/CH&FW – Telangana partnered with PRPCS and United Care Development Society (UCDS) to establish district Palliative Care centres which would offer palliative care for all in the state and neighbouring states. As a result over a period one year 8 district palliative care centres were established in,

1. Area Hospital, Chevella Mandal, Ranga Reddy District, Telangana State
2. Community Health Centre, Choutuppal mandal, Yadadri District, Telangana State
3. Area Hospital, Gajwel mandal, Siddipet District, Telangana State
4. District Hospital, Mehbubnagar, Mehbubnagar, District, Telangana State
5. District Hospital, Khammam, Khammam, District, Telangana State
6. District Hospital, Jangaon, Jangaon, District, Telangana State
7. Mahatma Gandhi Memorial Hospital, Warangal, Warangal, District, Telangana State
8. Rajiv Gandhi Institute of Medical Sciences (RIMS) Hospital, Adilabad, Adilabad District, Telangana State

The services offered at District Palliative Care centres are IP, OP services, homecare (until their death and support of the family thereafter) and survey to identify patients who would benefit by palliative care.

Services offered are,

- Symptom control
- Care plan and coordination.
- End of life care.
- Counselling in psycho-social needs, on prognosis.
- 24/7 care.
- Family empowerment and education (to identify and deal with symptom like pain, breathlessness, seizures, bleeding etc in the home, caring of the bedridden patients in the home, use of medication, feeding, exercise)
- Training and awareness programmes for all health workers, Village panchayat members, Mahila groups, Youth etc
- Community networking

Role of partners:

- Site visit, meeting with the stakeholders aided by Commissioners, district collectors and district health society
- Recruitment of staff
- Training of staff
- CME and ongoing mentorship
- Training of Health workers
- Developing protocols
- Helping with getting morphine and its safe use
- Filing the Gaps (proving furniture, mobile van etc)
- Awareness and Networking with the community

Fulltime staff included 1 Doctor, 5 Nurses, 1 Physiotherapist, 2 ANMS, 4 Ayyamas / Cleaners and 1 Driver. As the facilities were established within the government hospital premises it required lot of coordination with district health society and hospital management in terms of consultation, labs, laundry, mortuary, food, medicines, consumables, mainstreaming data and registration and utilities like water and electricity. The grants needed for the programme were transferred by state CH&FW under two heads, Human resources grant which was transferred to PRPCS and consumables grant to district health society of concerned district.

Within few months of its establishment the centres gained lot of good will in the community due the quality palliative care services offered, home care and massive awareness programmes.

The Government of Telangana aspires to establish such model Palliative Care centres in all the districts.

3. PROGRESS IN PALLIATIVE CARE - VOICE FROM RAJASTHAN

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Background: Rajasthan is the largest state (area 342,239 square km) in India with a population of 75 million. The crude death rate is 8.2 (2011 census)[1] An estimated 300000-400000 people will benefit from palliative care. Forty thousand to sixty thousand new cancer diagnoses each year. One lakh eighty thousand people live with cancer.

Challenges in delivering palliative care to all with serious health related suffering. Patients find it difficult to access medical care due to difficult terrain, unfriendly desert climate (extremes of temperature) and huge distances.

Health care services are overstretched. Using mortality rates as an index for health care provision in 2016, the infant mortality rate of the country was 34 per 1,000 live births, whereas in Rajasthan the rate was 41. (website Niti Aayog)[2] Similarly, the national average of under-5 mortality rate was 39, Rajasthan (45). Neonatal mortality rate was 28 compared to national average 24, early neonatal mortality rate 22 compared to 18 and perinatal mortality rate 25 compared to 23.

The Population is 200/square km spread over 33 districts and 289 development blocks. Seventy percent of the land mass is the Thar desert (6 districts), 7 tribal districts and 20 plain districts. The literacy rate is 66 percent (2011.)

McDermott et al (McDermott, 2008)[3] surveyed availability of palliative care services across the country. They documented a big disparity in number of centres in in the various states Kerala (140), UP (1), Bihar (1), MP (1), Haryana (0) and Rajasthan (5).The ratio of services to the number of people being served in Rajasthan was 1 per 11301,000 as compared to 1 per 384,000 in Kerala.

Only one centre had an uninterrupted supply of Morphine in 2008 -Bhagwan Mahaveer Cancer Hospital and Research centre, Jaipur) and there was sporadic availability at the RCC (ATRCTRI, Bikaner) and Khailshankar Durlabhji Avedna Ashram Jaipur. This is the ironical because Rajasthan is one of the largest producers of opium.[4] (Pressley) The barriers for morphine availability are fear of diversion/pilferage and misuse.[5] Opium (referred to as amal) has been cultivated here for decades and consumption has social sanction for weddings, events, (reyan-funerals) Till a few years back people who were dependent on crude opium were sanctioned a small stock officially by the government. This has been discontinued after a deaddiction programme (naya savera). There are anecdotal references of opioid dependent persons abusing tramadol and buprenorphine because of opioid withdrawal.

This is also the state where "santhara" (Jain tradition in specific situations towards the end of life) has social sanction and" rudaali"(professional mourners at funerals) was a tradition!

Progress: WHO recommends three measures as a foundation for developing palliative care through the public health approach (WHO, 1996) [Table 1]:[6,7]

WHO guidelines to countries – Essential elements of palliative care development [Figure 1]:

EDUCATION AND TRAINING

The WHO recommends that when initiating a palliative care programme in a low- or middle-income country, education and training should be provided for all health workers in the target area so that priority services for most patients are in place in a relatively short time [Table 2]:

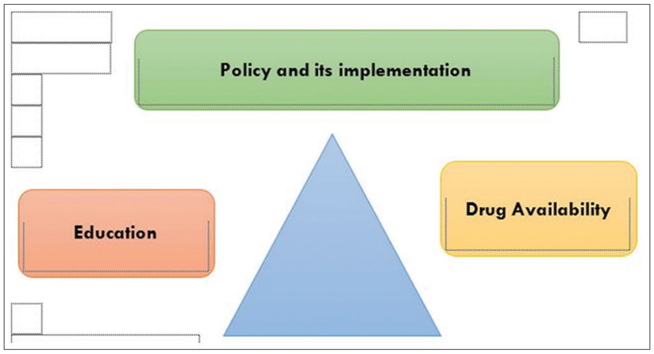


Figure 1: WHO guidelines to countries – Essential elements of palliative care development

- Working with the National Health Mission-Through the offices of the mission director, Mr Naveen Jain major steps have been taken to improve awareness, education and training across all levels of health care workers.
- The ongoing training includes an introduction to palliative care government contractual Counsellors and Social workers (90 minutes) Foundation course for all new government doctors includes a session on Palliative care (90 minutes) Sensitization of 182 doctors and nurses (8 hours) in 7 districts under the National Cancer Control Programme.

The ASHA Sahyogini workers are the community health workers who know the village families and community well. Their area of influence includes maternal health. From 2018 onwards, their training module includes sections on "identifying patients who need palliative care ",

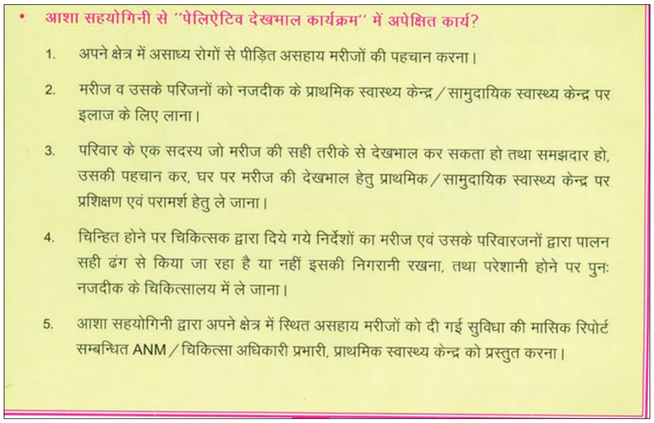
Table 1: Progress in palliative care provision in the state on basis of the WHO guidelines

Measure	Work done
A government policy to ensure the integration of palliative services into the structure and financing of the national health-care system	Concerted efforts have been made in this direction. A policy has been drafted and submitted to the National Health Mission
An educational policy to provide support for the training of health-care professionals, volunteers and the public	Sensitization, education and training has been achieved through multiple agencies at different levels
A drug policy to ensure the availability of essential drugs for the management of pain and other symptoms and psychological distress, in particular, opioid analgesics for pain relief	Morphine availability workshop with drug controller and other officials Much work is needed on this front

Table 2: WHO recommendations on Education and training-initiating a programme in a low- or middle-income country[7]

Recommendation	Achievement
Basic training (20-40 h) for the health-care providers working at the primary and community levels	IAPC supported CCEPC course 200 doctors and nurses from 2008
Intermediate-level training (60-80 h) for the physicians and nurses who are dealing with cancer patients at the secondary and tertiary levels	250 government doctors and nurses from 10 plain districts, 2 desert districts and 2 tribal districts completed a 6-day hands on competency-based curriculum supported by a grant from the National programme in Palliative Care disbursed through the National Health Mission
Proficiency (specialized) training (3-6 months) to the specialized teams or palliative care units at the secondary and tertiary levels	The Pallium India/Indo American Cancer Association has supported the training of 26 doctors and nurses (through a 6-week course) The cancer treatment centre training programme under the joint auspices of Ministry of health, AIIMS New Delhi and/ Lien Collaborative/Asia Pacific Hospice Network has trained 24 doctors and nurses working in cancer hospitals in Jodhpur, Kota, Jaipur Bikaner and Udaipur
Undergraduate training in medical and nursing schools	Is still limited to cancer departments and oncology nursing curricula

IJPC: Indian Association of Palliative Care, CCEPC



- आशा सहयोगिनी से ''पेलिऐटिव देखभाल कार्यक्रम'' में अपेक्षित कार्य?

1. अपने क्षेत्र में असाध्य रोगों से पीड़ित असहाय मरीजों की पहचान करना।
2. मरीज व उसके परिजनों को नजदीक के प्राथमिक स्वास्थ्य केन्द्र/सामुदायिक स्वास्थ्य केन्द्र पर इलाज के लिए लाना।
3. परिवार के एक सदस्य जो मरीज की सही तरीके से देखभाल कर सकता हो तथा समझदार हो, उसकी पहचान कर, घर पर मरीज की देखभाल हेतु प्राथमिक/सामुदायिक स्वास्थ्य केन्द्र पर प्रशिक्षण एवं परामर्श हेतु ले जाना।
4. चिन्हित होने पर चिकित्सक द्वारा दिये गये निर्देशों का मरीज एवं उसके परिवारजनों द्वारा पालन सही ढंग से किया जा रहा है या नहीं इसकी निगरानी रखना, तथा परेशानी होने पर पुनः नजदीक के चिकित्सालय में ले जाना।
5. आशा सहयोगिनी द्वारा अपने क्षेत्र में स्थित असहाय मरीजों को दी गई सुविधा की मासिक रिपोर्ट सम्बन्धित ANM/चिकित्सा अधिकारी प्रभारी, प्राथमिक स्वास्थ्य केन्द्र को प्रस्तुत करना।

Figure 2: Excerpt from ASHA training module: Duties of an ASHA worker in Palliative care

Figure 4: Services need to be available at the Primary care and community level to provide palliative care to the large majority (MOHFW 2012)

basic care of bedridden patients, feeding through nasogastric tubes etc An excerpt from the module [Figure 2]

Services need to be available at the Primary care and community level to provide palliative care to the large majority[7] [Figures 3 and 4].

This is in keeping with the recommendations of the Expert group (MOHFW,2012)[6] [Figure 4]. The health care professionals at the Primary Health Care centres and CHCs are the first medical service that patients will approach. So, these were targeted through our training programmes. They know the population, live in that area, are available, accessible and affordable. Unfortunately, Transfers are possible. They have multiple responsibilities-From deliveries to administrative tasks.

In the cities, specialist services are now functioning at Jodhpur (1) Bikaner (1) Jaipur (5) Jhalawar (1) Bharatpur (1) Udaipur (2) Palliative Care services are available at Medical College Hospitals at Bikaner, Jodhpur, Jaipur and Udaipur. Two cancer centres in the state have European Society Medical Oncology accreditation as designated centres of Integrated Oncology and palliative Care.

The network of PHCs, CHCs and District hospitals with palliative trained personnel [Figure 5];

But as Robert Frost said " we have promises to keep ---and miles to go before we sleep."

Per capita morphine consumption is considered the index of palliative care provision International average mg of morphine sold/population is being monitored. In Australia it is 454 mg/capita, In the UK it is 241 mg/capita, global average 6.27 mg/capita, national average 0.11

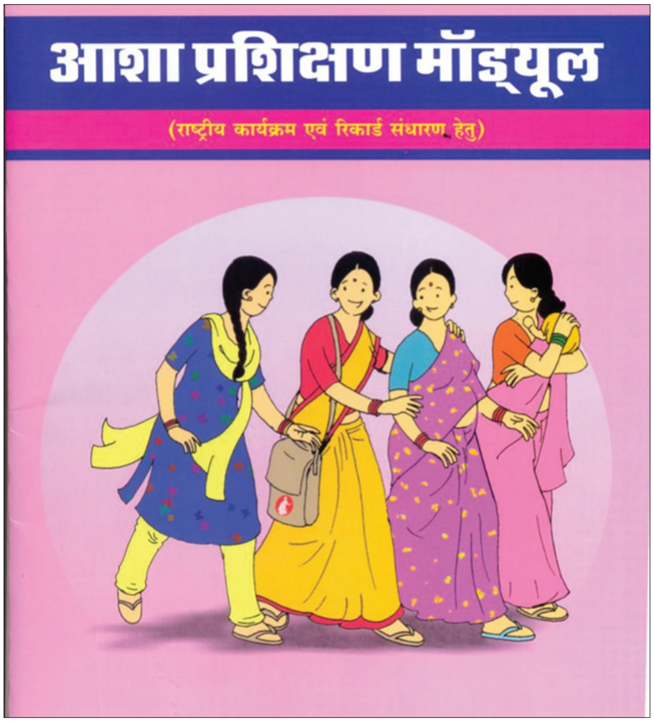


Figure 3: ASHA training module

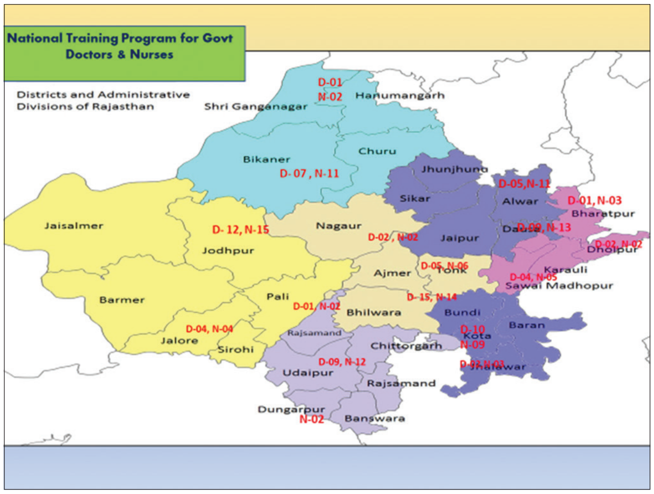


Figure 5: Map showing district wise distribution of trained doctors and nurses (through NPPC)

mg/capita. In Kerala it is 1.32 (0.49 to 2.97 mg) 2015 data[8] (M R Rajagopal, 2017). In Rajasthan crude estimates suggest that 0.05 to 0.08 mg morphine was consumed/capita in 2015. (This does not include transdermal fentanyl/buprenorphine and methadone).

The good news is that IAPCs first National Research workshop was held here in 2013. Palliative Care research is being presented at conferences of Medicine, Oncology, Anaesthesia and Palliative Care across the state and the country. Research is being done in varied fields like Sociology, Psychology and Nursing.

A network of doctors and nurses is gradually developing across the state. This WILL reach a tipping point. Small teams of committed nurses are in the field. A team in Jhalawar (Niraj and Aftab) is doing home based nursing care on a motorcycle.

Margaret Meads words are apt "Never doubt that a small group of thoughtful committed citizens can change the world, Indeed, it is the only thing that ever has".

References

1. Available from: http://www.censusindia.gov.in/vital_statistics/AHSBulletins/AHS_Factsheets_2011_12/Rajasthan_Factsheet_2011-12.pdf. [Last accessed on 2019 Feb 05].
2. Available from: http://niti.gov.in/content/maternal-mortality-ratio-mmr-100000-live-births. [Last accessed on 2019 Feb 05].
3. McDermott E, Selman L, Wright M, Clarke D. Hospice and palliative care development in India: A multimethod review of services and experiences. J Pain Symptom Manage 2008;35:583-93.
4. Krishna A, Kumar V, Yadav RP. Production and trade related issues of opium poppy cultivation with special reference to Barabanki District, Uttar Pradesh, India. Acta Hortic 2014;1036:111-8. DOI: 10.17660/actahortic.2014.1036.12.
5. Pressley L. Crossing Continents-BBC worldwide BBC Radio Rajasthan Patients severe pain due to lack of Morphine; 2011.
6. Proposal of Strategies for Palliative Care in India (Expert group report) Directorate General of Health Services Ministry of Health & Family Welfare November; 2012.
7. Planning and implementing palliative care services-a guide for programme managers WHO. Available from: https://www.who.int/cancer/palliative/en/. [Last accessed on 2019 Feb 05].
8. Rajagopal MR, Karim S, Booth CM. Oral Morphine Use in South India: A Population-Based Study JGlob Oncology 2017:720-7.

4. BREAST CANCER PATIENTS UNDERGOING TREATMENT: ARE WE LISTENING......?

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Introduction: India, located in South Asia, is the seventh-largest country in the world by area and the second-most populous country behind only China. As of 2017, it has a population around 1.32 billion people, 29 states and 7 Union territories with a total of 121 languages and 270 mother tongues. Over last ten years or so, breast cancer has been rising steadily in India and is currently the most common cancer in women in India, way ahead of cervical cancer. It accounts for 25% to 31% of all cancers in women in Indian cities. Breast cancer accounts for about one-quarter of all cancers in Indian women, about half of all cancer related deaths. The rising incidence in the developing world is thought to be due to increased life expectancy, urbanization and adoption of western lifestyles. Psychological symptoms are common in women with breast cancer. Distress may also affect treatment compliance. The easing of suffering or distress is an essential purpose of palliative care. Studies have explored the impact of cultural background on psychological distress, but there are few data from women with breast cancer in the Indian subcontinent.

Aim: To explore the experience of psychological distress in Indian women, living in India, in relation to their diagnosis and treatment of breast cancer.

Methods: In-depth interviews were conducted with 20 consenting women undergoing treatment for breast cancer. Purposive sampling was used to obtain maximum variation in socio-demographic and clinical characteristics. Interviews were verbatim transcribed, translated into English and back translated to Malayalam to ensure that the meaning had not been lost. The interview guide was developed using open-ended questions to elicit in-depth answers about their experience during cancer diagnosis and treatment, their manner of coping and how they made sense of the disease. English data were analyzed using thematic frame work analysis and synthesized to provide a deeper understanding of the individuals' experience.

Results: Majority were middle class married Hindu women with either basic education or graduate level education. The median level of distress was 3 with a range of 0-8. Three major themes emerged from the data. The first major theme was "psychological distress of patients to disease and treatment effects". This included anxiety, guilt, anger and depression in response to the disease and physical side effects of treatment and issues relating to body image, especially hair loss and sexuality. The second major theme was "getting on with life". Women tried to make sense of the disease, by actively seeking information, the role of medical professionals, and their practical adaptations. Many found a new future and a new way to live normal. The third major theme was the "influence of their support system" strongly based on family, friends, faith and the community which affect them positively as well as negatively.

Conclusion: Psychological concerns related to disease and treatment is common in Indian women with particular emphasis on body image issues associated with hair loss. Family and faith were key support systems for almost all the women although could also be causes of distress.

Keywords: Breast cancer; psychological distress

5. NARRATIVES FROM INTEGRATION OF PALLIATIVE CARE MODEL IN MENTAL HEALTH

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Introduction: Palliative psychiatry is a relatively new concept in Psychiatry and one which is fraught with many controversies. It is an approach that improves the quality of patients and their families in facing the problems associated with severe persistent mental illness (SPMI) through the prevention and relief of suffering by means of a timely assessment and treatment of associated physical, mental, social, and spiritual needs. It should also venture into end of life issues facing the mentally ill.

Palliative psychiatry can take care of the gaps in mental health care and reach those 'invisible' people who may not otherwise be reached. We share our experience in integrating the palliative care model in the course of our work in MEHAC through the narratives of our clients, partners, caregivers and the mental health team involved in providing this care.

Narratives: With the help of 2 case reports we have studied the impact of our model on the lives of patients and their caregivers. The home care, continuing support of our social workers and the rest of our team has made a huge difference in the attitude towards psychiatric treatment, improved medication compliance and helped rehabilitate many of the clients on their road to recovery. Many important issues still remain to be dealt with which include stigma and the fact that many have to be content with only a partial improvement in symptoms despite treatment. Another problem facing caregivers and clients alike is the question of long term care and end of life issues which may need further discussion.

6. "INTEGRATING PALLIATIVE CARE AND INTENSIVE CARE" – A PROACTIVE APPROACH TO EOL CARE IN AN AUSTRALIAN TEACHING HOSPITAL

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Providing a background to the Australian context is essential to provide relevance to presenting this topic in India.

As an introduction, it is noted that the Task Forces of World Federation of Societies of Intensive and Critical Care Medicine published in the Journal of Critical Care in 2016 and stated that end of life in the intensive care unit was an objective identified by the Task Forces and they set out to develop a generic statement about the current knowledge and to identify the challenges relevant to the global community that may inform local initiatives. The complexity of end of life in the ICU aand issues especially in relation to withholding and withdrawing Life sustaining treatments are recognised. The challenges presented in certain settings in this regard whilst attempting to ensure relief of suffering in the different ethical and cultural environments is recognised. This has particular relevance to India. The report encourages member societies in each country to take a lead in developing national guidelines and recommendations.

In 2012 The Indian Journal of Critical Care Medicine published the consensus Ethical Position Statement from the Indian Critical Care Society "Guidelines for end-of-life and palliative care in Indian intensive care units: ICCMS consensus Ethical Position Statement paving the way for a collaborative initiative with the Indian Palliative Care Association. Subsequently, the End of Life care policy: an integrated care plan for the dying was published in 2014 providing guidelines developed by the Indian Critical Care Society and the Indian Palliative Care Association. The pertinent factors related to difficulties with discussions at end of life are well defined in the guidelines related to patient, physician and the complex environmental factors at play. Further it is noted that end of life decision making in the Indian context or environment with its unique social, cultural, economic and legal complexities have not been adequately studied. There is also a paucity of empirical data on the frequency and the manner of foregoing life support in Indian ICUs. The Indian physician's attitude, which would appear to favor limitation of therapies is severely hampered in practice by the lack of safeguards in the form of legal guidance.

In Australia, the commonalities identified between the two disciplines include recognition of the "chronic critically ill" patient having multiple readmissions to hospital and the ICU. Additionally, there is shared recognition of the "acute" dying patient with the Medical Emergency Response Team acting as a surrogate for the Palliative Care service. Following on from this is the ICU serving as a surrogated for the Palliative care service. There are shared ethical challenges with the witnessing of the pursuit of futile or non-beneficial treatments valuing patient's autonomy over non-maleficence.

Some preliminary work around the differing perspectives of intensive care physicians regarding palliative care in the ICU shows that intensivists with qualifications in palliative medicine described as a ' foundational 'perspective, hold comprehensive knowledge of palliative care and advance care planning and will be more likely to embrace integration within their practice.

Intensivists who embrace a holistic view of care will provide a sophisticated delivery of care including ethics consultation to aid complex decisions and will be less likely to pursue aggressive therapies and futile care. Where palliative care is considered purely as comfort care, there is a more simplistic approach to integration with palliation considered separate to intensive care medicine with the perspective that Palliative care is provided after ICU care, on the ward and is for pain and symptom control. These perspectives have particular relevance when attempting to integrate the two disciplines in end of life care in the ICU.

Associate Prof Rebecca Aslakson has a 'foundational' perspective as an anaesthetist and palliative care physician and researcher. Her research interests seek ways to improve delivery of palliative care, particularly to perioperative, critically ill, and vulnerable populations. Her Ph.D. thesis concerned the integration of palliative care in intensive care units. Her hypothesis is that an individualized integrated model of palliative care can be provided with efforts related to restoring health regardless of any life-sustaining treatment in the ICU especially when the clinical outcome is uncertain. This care maybe related to the support of family as every effort is made to support the patient.[1]

Research Data on benefits of palliative care in ICU is scarce but what evidence there is demonstrates that earlier recognition of dying leads to reduced delay in appropriate care of dying patients. Transfers to lower intensity wards for appropriate patients are increased with integration of palliative care into the ICU and there is a reduction in length of adult ICU stay and hospital LOS. There is a cost saving without increased mortality by early introduction of realistic goals of care leading to reduction in the utilisation of ICU resources.

Significantly ICU staff reflect positively to the support provided by Palliative Care professionals in morally and or emotionally distressing situations.

Advance care planning discussions to support reduction of inappropriate ICU admissions in the future also demonstrated an improvement in the quality, quantity and content of communication. Palliative care in the ICU also supports continuity of care on discharge from ICU and the alleviation of symptoms and distress, including decreased anxiety of family members.[2-4]

The models of Palliative Care/Intensive Care integration have been described as *Consultative*- focusing on increasing the involvement and effectiveness of Palliative care consultations in the care of ICU patients and families especially where there is the highest risk for poor outcomes. The *Integrative* model seeks to embed palliative care principles and palliative care system processes into the ICU systems e.g. Processes of assessment and symptom control. Combining the consultative and integrative provides a *Mixed* model to meet palliative care needs of the critically ill.

Royal Brisbane and Women's Hospital is a tertiary quaternary hospital of about 1000 beds with a large catchment of Queensland, Northern NSW and some pacific islands.

The gradual integration of ICU and Palliative care service has occurred over a number of years, with some positive developments in integration of processes but failure to engage comprehensively until more recently. Changes enabling referral directly from intensivists has enabled a proactive system of engagement and development of a culture of 'business as usual'.

This presentation describes the processes of integration which included a 'Metavision' documentation project to integrate Palliative Care procedures d into ICU documentation to provide seamless electronic patient records.

Following this initiative there was an Invitation to Director Palliative and Supportive Care to provide a regular clinical round in ICU starting on a weekly basis, to provide proactive discussions for patients where there was uncertainty of clinical outcome and associated family distress or conflict in decision making around withdrawing of life sustaining treatments. This has resulted in the engagement of ICU Consultants and Registrars weekly and is now considered normal business.

There is open discussion of complex patients and anticipating Pall Care service engagement and ICU staff are reporting feeling well supported with the engagement and being provided with another layer of emotional support in their work.

There is potential for data collection and the development of research proposals to seek further evidence to support this model.

Referrals are made routinely by ICU Consultants without prior approval of referring teams as was historically the case. There has been some initial education more broadly with the provision of

'Medical Grand Round's joint presentation to discuss and promulgate the 'cultural shift'.

Since inception of a 'mixed model' of integration there is evidence of steady increase in referrals to the Palliative Care service directly from ICU.

A detailed case study is presented that demonstrates the Aslakson Model and the' duality' of care provided with Palliative Care supporting the endeavours and communication of the ICU clinicians to bring about a fundamental shift in the perspective of the family.

In summary the experience of our service in ICU has supported building trust in ICU and medical services of the hospital, has facilitated end of life discussions with evidence that the family themselves start to initiate discussions around comfort and quality of life. The engagement with the Palliative Care service can facilitate a 'shift' in thinking by the approach taken by Palliative Care clinicians especially focusing on the spiritual and cultural aspects. Patient and family goals move from long term plans and expectations to focusing instead on short term ideal goals. With a key focus on addressing patient comfort and dignity over just survival, the humanity of the individual is recognised fully.

Secondary outcomes have shown facilitation of more appropriate and earlier discharge planning from ICU.

References

1. Aslakson R, Cheng J, Vollenweider D, Galusca D, Smith TJ, Pronovost PJ, *et al*. Evidence-based palliative care in the intensive care unit: A systematic review of interventions. J Palliat Med 2014;17:219-35.
2. Hua M, Wunsch H. Integrating palliative care in the ICU. Curr Opin Crit Care 2014;20:673-80.
3. Mun E, Nakatsuka C, Umbarger L, Ruta R, Mccarty T, Machado C, *et al*. Use of improving palliative care in the ICU (Intensive care unit) guidelines for a palliative care initiative in an ICU. Perm J 2017;21:16-37.
4. Nelson JE, Bassett R, Boss RD, Brasel KJ, Campbell ML, Cortez TB, *et al*. Models for structuring a clinical initiative to enhance palliative care in the intensive care unit: A report from the IPAL-ICU project (Improving palliative care in the ICU). Crit Care Med 2010;38:1765-72.

7. Use of SPICT-LIS - A New Tool for Identifying and Managing People Needing Palliative Care in Low-Income Settings

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Worldwide including in low and middle income countries (LMIC), increasing numbers of people are living and dying from chronic illnesses, particularly non-communicable diseases (NCD). The Lancet Global Commission on Pain and Palliative Care (2017) estimated that in 2015 around 61 million people worldwide experienced Serious Health Related Suffering (SHRS).[1] As people live longer and NCD incidence increases, the level of SHRS is likely to continue to increase. Around 80% of people with SHRS live in LMIC, where access to appropriate health care is often lacking and where increasing numbers are falling into poverty through catastrophic health spending related to management of NCDs.[2]

The epidemic of NCDs occurring worldwide has led to the WHO publishing a Global Action Plan for NCD Prevention and Control,[3] which highlights the importance of achieving Universal Health Coverage (UHC) through a primary health care led approach. UHC, Sustainable Development Goal (SDG 3.8), includes health promotion, disease prevention, treatment, rehabilitation and palliation and countries of the UN have agreed to achieve this globally by 2030.

Given these developments it is clear that palliative care is an important aspect of UHC for all clinicians, but will only form a relatively small part of their work. It is therefore important to ensure that primary health care practitioners and other generalists are equipped to recognize, assess and appropriately manage people with palliative care needs as part of chronic disease management (CDM). The ability to recognize the time at which palliative care is important is particularly difficult for some non-cancer conditions where the patient's disease trajectory does not follow a clear course. For these patients it is difficult to make prognostic predictions and prognostic paralysis might ensue where people are not receiving palliative care when they need it.[4] The Supportive and Palliative Care Indicators Tool (SPICT) has been designed to enable health care practitioners to deliver palliative care to all who need it.

SPICT was developed by health care professionals from palliative care, family medicine and other medical specialties working together in Edinburgh in 2010 and has undergone iterative development, validation and evaluation since that time.[5] It has also been translated into a number of other languages. SPICT's declared aim is to help identify people whose health is deteriorating, assess them for unmet supportive and palliative care needs and to plan care. SPICT is printed on one side of A4 paper, making it portable and simple to consult and an 'app' for mobile phones is also available. The tool and app can be downloaded from www.spict.org.uk.

The health care professional is asked first to identify general indicators of deteriorating health such as: low or deteriorating performance status e.g. spending more than 50% of the day in bed, depending on others for care due to increasing physical and/or mental health problems, significant weight loss over the last few months, or persistent symptoms despite optimal treatment of underlying condition(s). General indicators also include the person having had unplanned hospital admissions – an important marker of deteriorating health at the end of life in the UK.

Next there are indicators relevant to specific clinical conditions which could indicate the person would benefit from supportive or palliative care. These include: cancer, heart/ vascular disease, respiratory disease, liver disease, kidney disease, neurological conditions and dementia/ frailty. Identifying both general indicators of deteriorating health and indicators related to specific disease, enables the healthcare professional to identify someone who would benefit from supportive or palliative care, often in addition to their ongoing disease modifying treatment.

Finally, SPICT has a section to remind the healthcare professional of the next steps to take in reviewing the person's current management and planning future care. This should include reviewing treatment to ensure the person receives optimal care and that any polypharmacy is minimised. They are advised to consider referral for specialist assessment if symptoms or problems are complex and difficult to manage and to agree a current and future care plan with the person and their family. They are encouraged to support family carers as well the patient and plan ahead particularly if loss of decision-making capacity is likely. Finally, it is suggested that they record, communicate and coordinate the care plan to ensure that others are aware of it and the person receives well-coordinated care. Further advice for using SPICT and providing high quality primary palliative care has been formulated and can be printed on the reverse side of the SPICT, providing a clear and concise resource for the busy clinician.

Using SPICT to undertake a needs assessment at a rural hospital in Nepal we found that some of the indicators were not particularly appropriate for a health facility in a low-income setting. We made some adjustments to SPICT for that setting and presented the results at IAPCON 2017.[6] Following this experience and in discussion with colleagues who had been developing SPICT in the UK, we decided to gather a group of clinicians working in low-income settings (LIS) in other parts of the world to undertake a Delphi exercise and agree appropriate changes to SPICT. The resulting version has been named SPICT-LIS. This is available at www.spict.org.uk/spict-lis along with some training videos to enable clinicians working in low-income settings to use SPICT-LIS effectively. As with all SPICT tools it is free to use and colleagues are requested to register online so that they can be informed of developments and the SPICT team is aware of where it is being used.

Some important changes for SPICT-LIS take into consideration the lack of availability of resources. For instance, rather than aiming for 'optimal treatment' SPICT-LIS suggests 'best available treatment' recognising that treatments available may be limited. It does not include 'unplanned hospital admissions' as there is no clear evidence that this is an effective marker of generally deteriorating health as it might be in higher income settings, particularly those which offer comprehensive health care to all. SPICT-LIS also recognises that it is likely that people will not be able to access some treatment because of lack of availability locally and inability to travel to another centre due to distance or cost. A number of adjustments have been made to the indicators for specific clinical conditions e.g. recognising that community based long term oxygen therapy may not be available. Finally, a number of new disease areas have been added including infections such as HIV and tuberculosis and surgical conditions, particularly highlighting burns.

SPICT-LIS is proving to be a particularly useful tool for training in palliative care for doctors, nurses and mid-level health workers in remote rural areas of LMIC. The format takes learners logically through the process of identifying, assessing and planning care for people who will benefit from a palliative care approach to their management. When used in this way, generalist clinicians are able to identify people who they are caring for or have cared for previously and reflect on how this approach might enable them to provide palliative care for such patients. SPICT-LIS can be printed out with its further advice on the reverse side, laminated and given to the trainees for them to continue using in their practice.

Following SPICT-LIS development, we plan to undertake further work to validate it and evaluate its usefulness in a variety of settings. We believe that SPICT-LIS will be a useful tool for enabling integrated chronic disease management, including palliative care and will contribute to health systems strengthening in low income settings which can make universal health coverage a reality even in places where medical resources are limited.

References

1. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, *et al.* Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: The lancet commission report. Lancet 2018;391:1391-454.
2. Anderson RE, Grant L. What is the value of palliative care provision in low-resource settings? BMJ Glob Health 2017;2:e000139.
3. World Health Organisation. Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020. Geneva: World Health Organisation; 2013.
4. Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness. BMJ 2005;330:611-2.
5. Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the supportive and palliative care indicators tool (SPICT): A mixed-methods study. BMJ Support Palliat Care 2014;4:285-90.
6. Munday D, Powys R, BK. Adapting the supportive and palliative care indicator tool (SPICT) for use in rural nepal. 24th International Congress of the Indian Association of Palliative Care. Coimbatore, Tamil Nadu. Indian J Palliative Care 2017:121-79.

8. COMMUNITY PALLIATIVE CARE IN KERALA, AND NADIA DISTRICT, WEST BENGAL: VOICES, NARRATIVES AND EXPERIENCES

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Kerala's community-based palliative care model has been recognized in global palliative care and public health discourse as a viable model for extending low-cost, resource effective care. This Kerala model is broadly characterized by a) total care including home-based care, financial, social spiritual, medical, and bereavement support and rehabilitation, b) community as the locus of care-giving, decision-making and fund-raising, and c) and integration with public health systems. Key indicators of the model's effectiveness include patient coverage of greater than 60% spanning all 14 districts, inclusion of a wide range of patient conditions, and demanding responsiveness of government bodies to communities' healthcare needs. Yet, despite 20 years of community-based provision, the model has had limited traction beyond state boundaries. This has resulted in criticisms of the approach as one configured to the Kerala's unique socio-political conditions.

The founding of Sanjeevani Palliative Care Society in Nadia district, West Bengal afforded an opportunity to examine the seeding and evolution of community-based palliative care outside Kerala. Here, I draw upon a larger study of the evolution of community palliative care in Kerala,[1,2] and on a case study of Sanjeevani,[3] to share the voices, narratives and experiences of community organizing in two distinct institutional contexts. These studies rely on a qualitative research design combining ethnographic interviews, field observations during home-care visits, trainings, and review meetings, as well as extensive use of archival sources including journal articles, technical reports, newspaper articles, organizational documents, and brochures.

Sanjeevani was founded on 22nd September 2014 by then District Magistrate Dr. P.B Salim, together with the local chapter of the Indian Medical Association, and key local stakeholders. Institute of Palliative Medicine (IPM), Kozhikode led by Dr. Suresh Kumar provided technical support during the inception and training period, commencing from March 2014. The IPM team visited Nadia monthly between May 2014 and September 2014, followed by bi-monthly visits during the first 6 months after founding. Dr. Sanghamitra Bora, then working in Kolkata, assisted weekly with doctors' home care in Nadia for the first year of operations. Sanjeevani targeted advanced cancer and chronically bed-ridden patients and provided doctors', nurses' and volunteers' home care. As of January 2016, Sanjeevani had over 1000 volunteers across 35 panchayats.

Departing from diffusion or replication perspectives, our study attended to translation processes. In other words, we recognize that social innovations are not passively adopted by recipients. Rather, innovations are 'translated' into new settings through selective interpretations by the recipients of new ideas and practices that are contextually appropriate. We recognize translation as a doubly contextualized process, reflecting both the historical and cultural conditions within which an idea emerges, and the conditions to which it is transposed.[4] The translation of a community health intervention is particularly challenging on two counts. First, it is problematic to assume the presence of a cohesive community with shared purpose as already available in a target setting. People may recognize mutual interests and a potential for shared organization, but this does not necessarily translate into coordinated, effective action. Communities need to be mobilized. Second, community forms are marked by specific organizing processes that are shaped by geographies and the histories of organizing. Communities may vary in their institutional infrastructure – such as legal infrastructure, presence of other voluntary organizations, and intra-community relations – for collective action. In Kerala, in addition to the high social development indicators (marked for instance by literacy levels, life expectancy, infant mortality rate, and maternal mortality ratio), the state government's per capita health expenditure was high. Moreover, Kerala had other constitutive elements facilitating community approaches, such as greater density of civil society organizations, deliberative planning bodies, and presence of similar other community organizations.

We found that three key moments marked the community model's translation to Nadia district. First, while Kerala's palliative care model is typically characterized by mobilization from below, Sanjeevani was seeded by the District Magistrate, a powerful officer at the district level. We contend that the symbolic power of this translator facilitated resource mobilization and helped overcome legitimacy issues in a context where palliative care was unfamiliar, and community organizing for healthcare was not a taken-for-granted idea. Second, while community mobilizing in Kerala was largely marked by horizontal relationships, we observed a hybrid of hierarchical and horizontal relationships among the teams at Sanjeevani. Third, we identified the role of occupational prestige and camaraderie among volunteers and nurses. Despite severely resource-constrained settings, and non-remunerative engagement, Sanjeevani volunteers cohered in spaces that gave them mutual comfort and conviviality, in addition to the prestige of being involved in a socially useful healthcare activity. Policy frameworks typically emphasize the strategic and rational aspects of health intervention transfers. This finding pointed to the affective component of mobilization and caregiving.

Cumulatively, these studies proffer some insights that have direct implications for organizing community health interventions. First, in both institutional contexts (Kerala, and Nadia -West Bengal), notwithstanding resource-constrained and non-remunerative settings, vulnerable actors have engaged in voluntary collective action to create transformative organizations. Second, material constraints, historical and institutional histories do present organizational challenges. Hybrid forms that combine hierarchies with decentralized participation, may be essential to overcome resource and legitimacy constraints. Whether it is through primary health centers and district hospitals in Kerala, or the top-down seeding by local stakeholders in Nadia, community-based palliative clinics are actively functioning (albeit with variations) in different geographies. The cautionary note here is that the absence of decentralized spaces may inhibit voluntary participation. The sustainability of a community health intervention may well depend on nurturing these decentralized spaces. Finally, in contrast to accounts that romanticize community participation in healthcare policies, we foreground that communities can be fragmented, with weak histories of collective action. Considered institutional analysis needs to be undertaken to identify actors who can forge solidarities and mobilize communities. Additionally, community-based care under contemporary capitalism should not imply the abdication of the government's responsibilities by shifting care for vulnerable populations to communities. This is where the third leg of Kerala's community model – that of integrating care into public health systems – gains ethical import.

References

1. Vijay D, Kulkarni M. Frame changes in social movements: A case study. Public Manage Rev 2012;14:747-70.
2. Vijay D, Monin P. Poisedness for social innovation: The genesis and propagation of community-based palliative care in Kerala (India). M@n@ gement 2018;21:???.
3. Vijay D, Zaman S, Clark D. Translation of a community palliative care intervention: Experience from West Bengal, India. Wellcome Open Res 2018;3:66.
4. Wolf M, Fukari A, editors. Constructing a Sociology of Translation. Vol. 74. Philadelphia: John Benjamins Publishing; 2007.

9. VOICES OF THE VULNERABLE: SHARING FROM A RURAL TRIBAL PERSPECTIVE

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Introduction: Emmanuel hospital Association is an NGO established in 1969, with 20 hospitals and 42 community health projects located mostly in rural North India. Chinchpada Christian Hospital is one of the 15 hospitals under Emmanuel Hospital Association that have a home based palliative care program. The palliative care project of the hospital was started in April 2016. Since then, over 295 patients and their families have been cared for, with 90 patients currently receiving care. The distribution of patients includes 62% with cancer, 37% with organ failure and 11% with HIV. The activities of the team include whole person care for the patient; family training and support; bereavement care; community awareness and networking; and volunteer training and engagement.

A study was done at the inception of this program among patients with terminal illnesses and carers for similar patients entitled "Factors Considered Important at the End of Life: A Tribal Rural Indian Perspective".

Background: Most data for end of life priorities are from Western perspectives. Even the available Indian studies are mostly urban. Little is known of the wishes, desires, and realities of life for people living with life-limiting illnesses in rural tribal India.

Aim: To explore the priorities and personal and family preferences at the end of life by people in a rural tribal community in Nandurbar District in India. A structured interview captured information from 40 subjects (20 patients and 20 carers) regarding socio-demographic profile; medical and symptom profile; and importance ascribed to various aspects at the end of life including ability to exercise autonomy, spiritual aspects, relationships, finances, and end of life care issues.

Results and Discussion: The mean age of the patients was 56 years. Half of them were illiterate. Over 90% were farmers. Over 50% had a Standard of living Index (SLI) score of less than 24. The SLI score correlated significantly with literacy. Forty percent of people had cancer; 45% had organ failure (predominantly renal failure and none were on renal replacement therapy); 15% had advanced HIV (none on ART, all on indigenous treatment). A majority (75%) had taken indigenous treatments, and 10% of patients had never seen a doctor. All patients ascribed high priority to relief of physical symptoms, particularly pain.

Financial Factors played a very important role. Most people (63%) felt they lacked financial resources in general and 85% said their treatment was suboptimal because of financial constraints. It was note-worthy that 15% in the very poor SLI group were content. One patient said, *"We don't have much, but God provides food and all that we need."*

The three HIV patients in this small cohort were not accessing ART because of various challenges including lack of affordable transport to the distant ART centre, and lack of awareness of the need for ART. There are many barriers to accessing reasonable healthcare for these tribal people of which some include lack of local health facilities and personnel, poor transport infrastructure in rural areas, illiteracy, poverty, lack of awareness, and strong belief in futile indigenous treatments.

Autonomy is highly valued in Western thought. In Indian culture, community is given priority over individualism, and shared decision-making is the norm. Deferring decision making to a trusted other is considered a valid display of autonomy. However it is important to explore the factors that lead to this deference in order to understand if true autonomy is upheld.

When importance given to patient knowledge about disease was assessed in this cohort, it was found that only 15% of patients had accurate knowledge regarding their disease; 10% had poor knowledge; while 75% had partial knowledge (knowing name of the diagnosis but expecting a cure where the disease is terminal). Only 45-50% patients expressed a desire to know details regarding their disease prognosis and the possible treatment options available. One elderly illiterate gentleman said, *"It is better to inform my son. He is educated and knows better."* However, another illiterate mother who felt that her trust had been betrayed when a pouring colostomy had been created without her knowledge lamented, *"I would never have allowed this if I had known what they were going to do to me!"* Some took a more overtly fatalistic view: *"Knowing does not change what will happen, so what is the point" "I can't afford treatment anyway, so no point knowing"* Some felt that those who are going to pay for their care have the right to make decisions.

Only about 35%of our subjects perceived themselves as being primary decision-makers; 40% perceived themselves as being completely un-involved in decision making, and 20% made decisions jointly with their families. Of the family members only 45% felt that it was very important for the patient to be aware of details regarding their illness.

The reasons given by the family to conceal the details from the patients were mostly that knowledge would cause harmful psychological distress to the patient. One of the sons said of his father: " He will not be able to understand anything: he is illiterate." Another wife said, "It is better for him to think he will improve. I keep reassuring him that he will be perfectly well."

What we know of autonomy especially in palliative care is that honest communication of information and input into improving patient insight into disease is highly valued. In India there is evidence from tertiary centres that patients exhibit a strong need for information. This need is, however, proportionate to education. In our study, literates gave more importance to knowledge, but this was not statistically significant.

Possible factors hindering autonomy could include:

- Disinclination by the patient to face the unpleasant truth,
- Underestimation of illiterate patients' capacity to understand,
- Lack of time and effort by doctors to ensure comprehension with simple and innovative explanations
- Lack of confidence and comfort of health care professionals in breaking bad news
- Injustice of money playing a central role
- Overall lack of empowerment

The importance of Relationships was almost universally affirmed by all subjects. An average of three people were involved in caring for each patient. High priority was ascribed for family's involvement in care, and reconciled relationships within the family. However, it was not considered important for the patient to be able to share their feelings with others in the family. These are some patient reflections: *"I keep my feelings to myself." "Sharing them with my family causes them distress, and they discourage it." "I don't want to burden them further by loading them with my concerns." "I would like to share, but no one listens. They immediately change the subject."*

Family members likewise, did not consider it important for the patient to be able to share their feelings. They said things like: *"Negative thinking is not good. I tell her she should think good thoughts"; "It is painful when he shares these things. It is better not to dwell on unpleasant things"; "What's the use? It only worsens the sadness for everyone. Better to focus on the positives."* Some others expressed their sense of helplessness as one wife did: *"I am unable to support him when he expresses his anguish. I feel terribly helpless and sad, and so I discourage him from talking." "His negative thinking causes his haemoglobin to go down."*

Some, however, recognized the benefits: *"Sometimes when he feels anxious and sad he comes over and we talk and pray together, and then he feels better."*

What we know is that the need to "have someone who will listen" is highly rated among the terminally ill. Factors precluding emotional support could include a prolonged state of denial, as well as a superstitious belief that talking about a negative possibility is likely to hasten its occurrence. Fear of cancer being contagious precluded care by the family and physical isolation in three patients.

Over 80% of patients considered it very important to be able to contribute to the well-being of others even while they were ill: *"I have accepted now that I am not allowed to do anything"; I can't do much, I am a burden to my family."* However only 45% of family members shared this sentiment: *"What can he do? He will use up any little energy that is remaining in him"; "We don't allow him to do anything though he wants to, because he is ill. There is no need."*

End of life issues and life prolonging treatments: A significant proportion of patients (50%) and family members (30%) felt that discussing end-of-life issues with the patient is not important. A majority of the patients said that they would feel uncomfortable discussing end of life issues with anyone in their family or with a health care professional. Over 80% of subjects had never heard about treatment options like Mechanical ventilation, Dialysis, and CPR. Artificial nutrition was better known (45%). Those who were literate were more aware.

Conclusions: Understanding of ground realities is crucial for relevant palliative care in rural India. The central role of financial factors needs acknowledging. True empowerment to exercise autonomy entails education and awareness, and a reduction in the gross inequity in health care access that plagues our country. Strong family bonds in rural families can be leveraged to strengthen physical and emotional support systems for those at the end of life. Planning for future end-of-life care is not a priority for this population that still grapples with issues that are more basic to human dignity.

10. Voices in Palliative Care for Transgender Community in India

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"Bi chuss museebata'ss ma'nz, bi chuss daq'i za'd, bi chuss pyaraan marna'ss"

"I'm facing hardships, I have been abandoned, I'm waiting for my death," says Ghulam Nabi Mir, 70, while lying on a blanket in the corridor of Shri Maharaja Hari Singh hospital in Srinagar. Mir is a transgender, who has been abandoned by her family and society too.

Transgender community is one of the most health care deprived & vulnerable section in the India. Long run legal battle to seek recognition on needs of this community was acknowledged in 2014 when Honourable Supreme Court Delhi through NALSA Judgement. It gave a directive to Indian Government to provide measures of equitable care at social, health, legal dimensions. Much is needed to be known about the discrimination been faced by this community in health care set up in our county. And so does the needs of palliative care for LGBTQI (Lesbian Gay Bisexual Transgender Queer Intersex) "rainbow", transgender section been a colour within.

Understanding healthcare needs of transgenders is important to deliver a better palliative care. Honest answers to these questions will help the palliative care professionals in India to look into palliative care needs of them.

1. Do we know the meaning of LGBTQI & The term Transgender
2. Do we know their health care needs?
3. Do we know about The health care discrimination, disparity existent in India
4. Do we know the traditional 'Hijra' culture and the community members who are not part of it?
5. Are we aware of their palliative care dimensions- physical, psychological, social & spiritual?

LGBTQI and Transgender: Getting the terminologies correct: LGBTQI is an initialism that stands for Lesbian Gay Bisexual Transgender Queer and Intersex minority and adopted as a term to use topics related to sexual orientation & gender identity. Transgender is an umbrella term used for people having a gender identity or gender expression that differs from their assigned sex.

Health care needs, Discrimination and Disparity to Transgender population in India: The Indian census 2011 counts 490000 transgender in India. This is a gross estimate. The general perception is towards 'transwomen' belonging to Hijrah or jammat system or culture. It does not include transmen and transgender individuals who do not identify with 'jammat' culture. Poor social structure lead to baffled transgender health care in India. Unaccepting 'main stream' society, lack of conventional 'family' support system, bullying at schools leading to lack of education, resorting to sex work & begging as a survival tactic are few problem to this community.

UNAID quotes 80,000 new HIV infections detected and 62000 AIDS related deaths in India (2016 data). The HIV prevalence is 7.2% in transgender population & 4.2% in gay men in India. The palliative care needs of this 'marginalised' part of society barely gets a mention in our Indian palliative care books & academic activities. The stigma associated with HIV barring the access to health care is doubled for this population. 20% of Transgender population in India suffers physical or sexual violence (2015). Access to health care and attention is a question to this section of society.

'Gender transition' is a vital step in a transgender person's life. Many of health care institutes in India are looking into this step. This essentially reduce risk of transgender community approaching unqualified persons. A safe surgery reducing postoperative morbidity and mortality at hospitals needs an organised approach. Sensitising the community about their health care needs during this time is a learning experience for both the hospital staff and the Transgender clients. Transgender persons protection of Rights bill mentions following responsibilities: 1) Separate HIV Survillance Centres; 2) Free of cost gender reassignment surgeries; 3) Counselling services; 4) Insurance Schemes to cover medical expenses; and 5) barrier free access to healthcare institutions.

Palliative Care needs of Transgender community: Inclusive Palliative Care Services: Creation of a respectful and non-discriminatory environment is a core tenet of palliative care for transgender community. Addressing transgender people with correct terminologies and pronouns that acknowledge their gender identity makes them comfortable to interact with the health care professionals. Educating ourselves as health care professionals in understanding correct terminologies relating to LGBTQI community serves this section well. Building close-knit connections with community leaders and social support organizations will help to develop palliative care delivery and monitoring systems. Training the support staff, understanding community demographics, and sensitizing providers of hospice care are essential steps to ensuring palliative care for the transgender and broader LGBTQI communities.

Understanding family structure: People belonging to LGBT community may have a different 'family' structure. Many of them establish their relationships with unique meanings. Equating these relationships and respecting them is important while caring them. A social worker should adapt to a pattern of communication with respect to this 'nonbiological' family. Making space for non-biological decision makers in health care decisions where advance directives are unavailable in India becomes a challenge the medical community needs to step up to. The tension between the biological and chosen family are also seen more clearly during the end of life. Conflict resolutions on claiming death rights, bereavement care are unique challenges to palliative care professionals for transgender clients families.

Spiritual dimension of palliative care for transgenders: As a transgender person nearing the end of life, the need in spiritual dimension is more fluid and different in the transgender community than the rest of the population. People who have undergone transition within Islam feel that they have gone against the mandates of the almighty. Award or punishment in the next life is a major concern for few whom Hindu cultural traditions prevail. Fear, guilt, hesitancy and denial to carry out death rituals from clergy men makes them to conduct their rituals in secrecy.

Psychological needs: Suicide, substance abuse and depression are major killers of transgender community. Though preventive measures are best remedy, reach out to this population is difficult. An open attitude, strict privacy maintenance and honest effort to understand their grief is essential.

Legal and financial concerns: Human rights of Transgenders in India has got recent legal recognition through NALSA judgement. The establishment of law is still a distant dream. Financially deprived status make them vulnerable to get adequate health acess. Social group supports from NGOs working in Palliative Care could make them feel included in the society. Building community leaders to do Palliative care among community is essential.

Ghulam Nabi Mir, the Kashmiri old transgender was in need of a hospice care as she is demented, old and frail. The activists from community could not help her much as there are no shelter homes in Kashmir which accepts old transgender petsons. She was denied hospital bed as she doesn't suffer from physical ailments to be looked after. She continued to be on footpath waiting for her last breaths to count. The right to live in dignity for transgender persons is conveyed to the society through various media activities and legal documents. The right to die in dignity is yet to be known to many.

11. PEDIATRIC PALLIATIVE CARE FELLOWSHIP IN INDIA

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Objectives: To understand the need and development of curriculum for Pediatric Palliative Care fellowship to meet the vast unmet palliative care needs of children in India.

Background: Pediatric palliative care in India is in its infancy and the need for capacity building is paramount. A Pediatric Palliative Care physician needs to be a researcher, advocate, mentor along with being a clinician. A well-structured program and curriculum provides the physician with the tools to be a health expert.

Description: The one-year fellowship offered at Hyderabad is a certified course by MNJIO & RCC (MNJ Institute of Oncology and Regional Cancer Center) and Two Worlds Cancer Collaboration, Canada. The course accepts applications from clinicians with MD/Diploma/DNB degree (Preferably pediatricians). The core competencies developed during the training of the expert are as a professional, scholar, collaborator, communicator, health advocate and leader.

The profile of children seen during the fellowship are those with cancer and non-cancer diagnosis. The course includes 12 month rotations in different programs- Pediatric out patient, Pediatric in patient, Hospice, Home care, Rural palliative care centres of the state of Telangana and the Adult program.

Formal training includes monthly didactic sessions with international experts through Zoom (online), Journal discussions- twice monthly, PPC ECHO-Learning mentorship support through a virtual online platform along with on-site teaching and discussions.

Assessments include workplace assessments at various fixed time periods during the year to help build skills through feedback and final (summative assessment). The fellow is expected to do a small research project or an audit. The whole training is made possible only through various partnerships including Pain Relief and Palliative Care Society (PRPCS), a local NGO in Hyderabad, University of Lund, Sweden, ECHO institute and visiting faculty from around the world.

Conclusion: A structured program aiming to train the fellow at various aspects to be a health expert is needed to build capacity for Pediatric palliative care.

Additional:

Further Details
1. Workplace assessments:
    - Mini-clinical evaluation exercise (mini-cex)- 6/year
    - Case-based discussion (cbd)- 4/year
    - Multi-source feedback (MSF)- 1/year
    - Direct observation of procedural skills- for all coreprocedures
    - Teaching observation (TO)- 2/year

2 Summative (final) assessment

The final evaluation of the trainee will be based on the combination of the above methods and a final OSCE and submission of a learning portfolio (workplace assessments, as described above) and written exam.

12. JOURNEY TOWARDS INTEGRATION OF PRIMARY PALLIATIVE CARE CURRICULUM IN FAMILY MEDICINE TRAINING IN INDIA

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Introduction: The United Nations (UN) Committee on Economic, Social and Cultural rights report that it is essential to provide "attention and care to chronically and terminally ill persons, sparing them avoidable pain, and enabling them to die with dignity." Palliative care has been endorsed as an essential health care by the National Health Policy 2017, with special recommendations to empower general practitioners in the community through distance and continuing education program. Despite the recommendations, palliative care is available to less than 2% of the 1.3 billion population of the country. Despite excellent joint work from the Indian Association of Palliative Care (IAPC) and Indian Society of Critical Care Medicine, increasing number of patients spend their last days in intensive care settings without appropriate goal setting and undergo futile and expensive interventions. The barriers to effective palliative care include lack of awareness, lack of adequately trained health care providers, inadequate access to structured health care system and limited availability of opioids. In the last decade there has been a remarkable improvement in availability of opioids to pain and palliative care services. However the accessibility continues to be a major challenge as most palliative care services exist in the tertiary centres in the urban area while a large majority of the needy patients live in the rural and tribal areas. The overwhelming need, barriers and challenges for universal palliative care in India can be addressed through an internationally recognized approach termed, "Primary palliative care". This means there is need to empower family/ general physicians in the community who then can ensure that continued quality care is accessible to patients in the community tailored to their need and choice.

With this intention, a task force comprising of both national and international palliative care specialists and family medicine physicians was formed in the year 2017. The members of the task force brainstormed on networking and integrating specialist palliative care physicians with the general physicians in the community. The IAPC and Association of Family Physicians of India (AFPI) together made recommendations to support the growth of palliative care education and services across family/ primary care physicians in India. Subsequently, a position paper was published jointly by IAPC and AFPI which clearly described the vital contribution of palliative care in achieving universal health coverage. The paper mainly focused palliative care delivery from the Indian context and the need for education and the need to develop and incorporate core competencies appropriate for provision of primary palliative care in the community.

The need for integration with primary care /family physician

1. Primary care physicians are the first point of contact for patients in the community and point for continuity of care
2. Primary care physician knows the family in the community and has built up rapport over time. The patients and family would feel comfortable to return to the community under the care of their family physician
3. Primary care physician/family physician knows the psychosocial and economic background of the family and will be able to tailor the intervention accordingly
4. They will be able to offer basic pain and symptom assessment and management
5. The physician will be able to provide holistic care, including psychosocial and spiritual care
6. The physician will be point of contact between the patient in the community and specialist palliative care physician
7. The physician is in the position to support family members in the difficult phase of their journey, prepare them for the loss of their loved ones and provide bereavement support.

Brief summary of the position paper as a way forward to developing the palliative care curriculum for family physicians[1]

The paper discussed the following:

1. Policy and Advocacy: In the country specialists works in isolation from the primary care physicians in the community. This disjointed approach to care can result in significant distress among patients and family and lot of the quality time and resources is spent in traveling to specialists for care. A concerted effort between the primary care physician and specialists with clearly defined roles will help streamline this process and will significantly improve care and quality of life and death.
2. Education: Identifying the core competencies for primary care physicians will be essential as this will guide the extent of involvement in care of patients. This will include Level 1 and 2 competencies as defined in the WHA resolution. The training should be flexible and take into account the time constraints for primary care physicians in the community, who often have overwhelming with patients. The competencies and training framework must be accredited to both the national bodies of palliative care and family physician to add credibility to their practice. As a step forward, while this collaboration gains momentum, the national bodies of palliative care and family physicians must persuade the Medical Council of India (MCI) to ensure that palliative care is made mandatory in the curricula of undergraduate (MBBS) medical training and postgraduate training in family medicine.
3. Service Development: The national bodies of palliative care and family physicians should design standard operating procedures for collaboration between the specialist and generalist physicians, define roles and responsibilities of family physicians, and agree pathways for referral to and from generalist to specialist which include other key members of the multidisciplinary team. There should be meticulous documentation of care at follow-up and cross-referrals as this will ensure seamless integration of services. Regular meetings at state and national levels will further strengthen the opportunities for better collaboration.
4. Research Collaboration: The national bodies of palliative care and family physicians should conduct audits of the work done and expand the scope for innovation and improvisation in the existing practices. Research is an integral component of service and education to ensure quality, evidence-based care that is focused on the needs of patients and families. Both the associations should collaborate to design research protocols to identify and care for patients in primary care and understand the patient and family experience, using relevant outcome measures.

Core competencies for a primary care/ family physician to be able to provide primary palliative care [Figure 1]

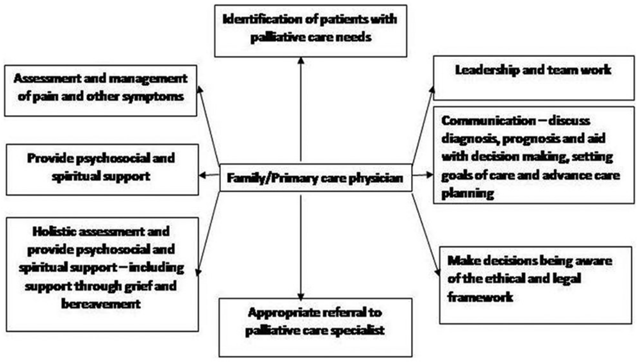

Figure 1: Core competencies for a primary care/ family physician to be able to provide primary palliative care

Way forward for empowering primary care physician: The task force had a review meeting on 08/02/2019 at the IAPCON 2019 in Kochi where the team members discussed the way forward. The members discussed the various training curricula across the country including the feasibility and practicability of introducing the curricula into the busy schedule of the family physicians and also the post graduate course of the family physician. All the curricula will be unified under the banner of IAPC and AFPI.

The members brainstormed on the competency framework for family physicians which will be published in the Journal of Family medicine and Primary Care. The competency framework will be presented to the National Board of examinations for it to be introduced into the DNB/MD curriculum for Family Medicine. The members of the task force will work on developing a training module for primary palliative care, taking insights from various national and international training modules for family physicians. We hope to complete the module by the next quarter for it to be presented to the DNB board. While the taskforce committee works on the modules, regular CMEs in primary palliative care will be conducted under the banner of IAPC and AFPI across the country. The CMEs will be accredited to the medical council of the respective states.

Reference

1. Jeba J, Atreya S, Chakraborty S, Pease N, Thyle A, Ganesh A, *et al*. Joint position statement Indian association of palliative care and academy of family physicians of India – The way forward for developing community-based palliative care program throughout India: Policy, education, and service delivery considerations. J Family Med Prim Care 2018;7:291-302.

13. FLOOD RELIEF IN ERNAKULUM DISTRICT OF KERALA- ROLE OF PALLIATIVE CARE TEAMS

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The Floods of August 2018 was the third in this era. First being in 1924, which was of the same scale and the second was in 1961, a calmer one. Kerala being the southern part of India has a long coastal belt on its west side and a Western Ghats on the east side. It is known as God's own Country for the heavy monsoon showers, green land, rivers and lagoons.

Rains were heavy during the monsoon of 2018 and the hydroelectric dams used for generating electricity as well as irrigation purposes started to fill up. The unwarranted rise in the level of the water in the dams resulted in the opening of dam shutters. The rivers which were controlled by these dams were not equipped to handle such an influx and they overflowed. The high lands didn't have the capacity to hold the water pressure and resulted in land slides. More than 30 dams were opened over night with overflowing 44 rivers. These rivers flooded 12 out of 14 districts of Kerala. Millions were evacuated and the death toll neared 500.

The district of Ernakulam was one of the worst affected among the other 12 districts. Nearly 1.5 million lives were affected. The peak recorded camp numbers amounted to 1099, accommodating nearly 0.47 million. The largest camp was at UC College, Aluva providing shelter to almost 10,000.

The RESCUE Phase: 15th to 20th of August 2018: A district control room was set up under the District Administration, it comprised of all the departments - Health, Police, Motor Vehicles, Public Relations, Wireless Services and Water Authority. Army and Navy were also part of this phase. Health systems was making sure about safety and well-being of everyone who were being rescued as well as medical needs in the camps that were being set up. To assist this venture, General Hospital, Ernakulam started a Health Control Room on 17th of August 2018 aiming at reporting health related distress and requirements via a remote call centre in the district of Kollam (which was not affected). Real time data of the requirements would be colour coded and shown in the display board at the health control room. Medical camps were conducted and monitored by the centre. Human resource management and Pharmacy was major responsibilities of the health control room during the rescue phase. Doctors from most of the private hospitals were volunteering to work, irrespective to their specialities'. Nurses were volunteering with the support of their organisations. Pharmacists were working day in and out to sort the medicines that were coming in piles from support groups from all over the country. Palliative NGO's like Thanal Palliative Care was rescuing patients as a priority. Community Palliative care nurses were well equipped to deliver health care at the camps with the available resources and also deliver primary psychological support as they are well trained in communication skills and were already a familiar member in their respective community.

The greatest strength during that period was the fact that - "Everyone came TOGETHER"

Relief activities -18th August 2018: Health Control room was mature and fully functional. The water levels started to recede, more camps became accessible, this created a window of opportunity to reach to them and provide medical care. Medicine shortage was a primary issue at the camps, especially long term medicines like anti-hypertensives, anti-epileptics etc and this was tackled by pharmacists. The corpses of animals were a huge hazard which were swiftly removed and buried in a scientific way. Enormous psychological distress due to the unforeseen incident was dealt with the help of Palliative Care nurses along with the support of NGO's like Mehac Foundation and District Mental health teams. The nurses were trained to deliver Psychological First Aid.

Rehabilitation program 20th August 2018: An awareness class symptoms and signs of Post-traumatic stress syndrome was conducted for all Palliative Care nurses in the district with the help NGO's like Mehac Foundation and Pratheeksha. Field visits were initiated, visiting every house hold with patients having any kind of long term illnesses, like, chronic kidney disease, coronary artery disease, cancer, mental illnesses etc. Palliative care training equipped them as significant enablers in the community. During the visits the nurses were given a simple survey form to fill in basic details on demography of the house, identify initial signs of post-traumatic stress syndrome, as well as to notify if any long term treatment was discontinued because of the floods.. The data was entered through google drive by each nurse. Mehac Foundation, Pallium India, NIMHANS and Pratheeksha trained many students to volunteer to support the palliative care nurses. The final data collected by our 140 Palliative nurses are given below [Table 1], though the psychological support provided by them is not reflected in it. The work was appreciated by The Lancet and it was published in their World Report, October 2018 [Figure 1].

Table 1: Data collected by Palliative Nurses

Category	Total number covered
Total number of floods affected houses visited	10,686
Number of families with long-term illness	5129
No. of children with long-term illness (below 18 years)	72
People with doubt, fear, - anger, sleeplessness, worry, anxiety	455
People already diagnosed of psychiatric illness	136
Number of people stopped procedures - like chemo, dialysis, radiation etc.	74
Number of people stopped medications of chronic diseases	160
People with communicable diseases symptoms	184

World Report

Providing psychosocial support in Kerala after the floods

When it comes to emergency response in low- and middle-income countries, psychosocial support is not usually a priority, but Kerala was prepared. Patralekha Chatterjee reports from Ernakulam.

Figure 1: The Lancet – World Report – October 2018

The follow up program has been planned by District Health Administration along with Mehac Foundation to re asses these households to assess their psychological distress as we close to 6 months after the disaster.

14. Voices for Palliative Care in Humanitarian Settings Through Partnership Intervention – Adjumani, Uganda

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Introduction: The role of palliative care as an essential part of the holistic healthcare package in humanitarian settings is being advocated for, now more than ever. Palliative care is a national priority in Uganda yet access to services is limited, particularly for those in rural and marginalized communities of refugees. These requires greater humanitarian and voices for inclusion right now.

Background:

- Uganda has been hosting refugees and asylum seekers for over 50 years.
- Ugandan refugee policies allow integration of refugees into host communities to access integrated social services e.g. health services, schools and market etc.
- 2016 United Nations Summit for Refugees declared Uganda's refugee policy a model.
- Uganda is currently hosting 1.4 M refuges and asylum seekers. (85% women/children)
- It's the highest refuges hosting country in Africa and 3rd. largest in the world. (GoU UNHCR 2017).
- The typical journey of a refugee in Uganda is characterized by an entry phase, settlement and integration phase

Who are our partners?

- Ministry of health Uganda (MOU) and other line ministries through policy issues in regards to refugees
- Adjumani District local Government for acceptance and provision of land for south Sudanese refugees
- UNHCR for logistical support and other Implementing Partners like MTI
- Cairdeas international for financial support for training and other logistical intervention for implementation of activities in refugee settlements of Adjumani District –Uganda
- Palliative care and education research consortium provided the technical support
- Peace hospice Adjumani the implementers of activities on ground

Humanitarian response/intervention Areas

- Health e.g. prevention, curative, rehabilitation but palliative omitted
- Educational facilities like rehabilitation of old structures and building new schools
- Livelihood support, through training and provision of animals for rearing e.g. goats, pigs, to reduce dependency.
- Environmental protection and mitigation measures to reduce

What challenges arose

- Increase in number of new infections like communicable and non-communicable diseases like, Hep B/HIV/AIDS, cancers and others.
- Stock out of Drugs and other essential health supplies.
- Inadequate human resource to manage the increased health demand.
- Congestion in public facilities e.g. Hospitals, schools and market places due to over population
- Land conflict due to increased demand for use land e.g. for settlement.

Methods:

- Rapid system appraisal conducted to 50 key stakeholders e.g. District Health Officer, Refugee Desk Officer, and Resident District Commander, Medical Superintendent and other health workers plus opinion leaders in Adjumani district to ascertain the need for palliative care in humanitarian setting.
- Awareness creation conducted on local radio stations of Amani FM, Aulogo FM and Usalama FM to rise voice for the voiceless.
- Assigning of the palliative care specialist as a district focal person to discuss issues of the voices less in higher platforms e.g. District Health team (DHT) and interagency meetings in Adjumani District.
- Main stream PC through integrated shared work plans with implementing partners and local government
- Work place awareness on PC to stakeholder in both refugee saving community and the District local Government through quarterly review meetings

Results:

- Communities mobilized to identify and support those with serious health related suffering / palliative care and represent their voice with key stakeholders
- Increased awareness by stakeholders of the need to build capacity and strengthen health care systems through education and training in palliative care.
- Increased political commitment by continuously rising of voices for the voiceless in higher platforms e.g. quarterly and annual review meetings, interagency meetings.

Conclusion: Voices for Palliative Care (PC) is an advocacy project seeking for legal and policy reforms, budget allocation and engagement of decision makers at regional, national, international, and humanitarian settings level to prioritize PC access to information and service by raising awareness and the profile of advocacy issues to create an environment which is more supportive towards pc service delivery.

15. Palliative Care In Humanitarian Settings; Gaza

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Humanitarian settings and palliative care: Complex humanitarian emergencies (CHE) which natural disasters such as earthquakes, epidemics such as Ebola and war and conflict affecting increasing numbers and represent an acute emergency layered over ongoing instability and need large scale humanitarian responses. Mass casualty events (MCE) such as floods occur globally and at times with little warning. Historically such events did not include palliative care as part of response interventions as the emphasis was on life saving interventions. However it is clear that such CHE and MCE carry significant palliative care needs. These include pain and symptom relief from acute injury, holistic care for those seriously ill especially if unlikely to survive or face chronic disease and prolonged rehabilitation, grief and loss support for carers and health care workers. It also includes health systems support such as volunteer and community mobilization or emergency services response. Huge MCE such as the Ebola epidemic largely neglected palliative care. For those affected by internal displacement or refugee movement they may be in temporary settings for 5-10 years. Chronic disease is therefore a huge burden to add to complex trauma, loss, poverty and at times lack of freedom and choice yet most of the focus in terms of health care remains on the acute phase. Ongoing mental health challenges are a crucial component of holistic response and is again often neglected. In addition this is an area where prior preparation and planning are essential. A review revealed a lack of evidence but clear areas of need yet relief teams are often not prepared for chronic disease management and pre-disaster training often does not include palliative care.

The 2018 WHO guideline 'Integrating palliative care and symptom relief into the response for humanitarian emergencies and crises' is an excellent overview and calls for improved planning, collaboration and research., The Humanitarian Guidebook; SPHERE, now includes chronic disease and end of life care and many Humanitarian sector UN, INGO and NGO's are beginning to consider how to incorporate palliative care. Governments are also leading these discussions in places like Uganda.

There is now an international network PALCHASE (Palliative Care in Complex Humanitarian Aid Situations and Emergencies) which is functionally linked to the IAHPC in terms of representation.

Gaza: background

This is one of the longest standing protection areas globally with no current expectation for peaceful resolution of the issues that led many hundreds of thousands to be displaced and registered as refugees in 1948 and 1967 and now is in its 50th year. A 10 year complete blockade of Gaza by air land and sea by the Israeli government accompanied by periodic increases in hostilities and political factors leave the whole population extremely vulnerable and experiencing daily challenges, trauma and hardship. An estimated 2.5 million people out of a population of 4.95 million in the Occupied Palestinian Territories are affected by humanitarian issues and in Gaza this is 1.4 m out of 1.8 million. These include protections of civilians, forced displacement, erosion of resilience and access to health care. This high level of vulnerability is revealed by stark statistics for Gaza such GDP 0.4% growth, 44% of people are unemployed with 62% of youth (15-29). Child mortality <1 yr has not declined since 2006 and 10 percent of children are stunted by malnutrition. The sole aquifer for Gaza is in very poor condition and piped water is only available 3-5 hours a day with 95% of the water is undrinkable. The United Nations has continued to report on the scale of the humanitarian challenge. It raises huge concern about the basic living conditions and suggest conditions may become unlivable by 2020 unless urgent remedial action is taken. There is severe impact on access to health including up to 30% of essential medications unavailable and medical requests to exit Gaza for further treatment such as radiotherapy are down from 90% approval to 54%. Mental health including high levels of suicidal ideation and PTSD is rising as well as NCDs. Over the past year there has been demonstrations by Gazans called 'The Great March of Return' has led to weekly casualties that very worryingly include health care workers injured and killed while trying to give aid as well as large numbers of gunshot wounds which at times overwhelm the fragile health systems. 228 Palestinians have died and a further 24,362 injured including 5,866 with live ammunition. 3 health care workers have died and 646 injured. A medical student audit showed no availability of analgesia for these patients presenting with acute and complex trauma and who will require multiple surgeries and prolonged rehabilitation.

Gaza: palliative care

At the invitation of the Islamic University of Gaza (IUG), a team from the University of Edinburgh and Cairdeas International Palliative Care

Trust carried out a scoping review in 200. Local leadership by Dr Khamis Elessi and others had carried our short training programmes and offered clinical support. One of the challenges is the huge level of need and daily challenge that makes engaging with grief and loss challenging; although the context of strong family and faith bonds form a bedrock. One senior doctor, DR Sobhi Skaik, well known as a surgeon said of palliative care '*Our people are in pain; we have no choice but to act.'*

Key issues from scoping review

- Palliative care awareness is high but as yet no recognised services developed or integrated
- Education and training capacity is strong and needs to integrate palliative care with an emphasis on accessing training within Gaza
- Access to essential medications is good with the strong exception of oral morphine. It seems the main challenges are lack of a clear regulatory framework that supports access as well as maintaining appropriate control
- Health systems strengthening regarding referral pathways and information sharing is needed with some existing platform such as cancer control forum and data management
- Health care is focused on the facilities and a home based care model is not generally well developed.

A steering group was formed with wide representation from academic, government, UN, WHO, NGO and international stakeholders. Priorities were agreed with a focus on sensitization and advocacy, developing education and training for undergraduate medical and nursing students, development of a Diploma in pain and palliative care, engaging with key hospitals and community services to have multidisciplinary teams complete the Diploma and start services and ensuring access to oral morphine.

The major achievement has been the integration of palliative care course within the undergraduate medical curriculum in the Islamic University of Gaza. Core competencies for palliative care were derived from the EAPC white paper and other documents using the Palliative Care Curriculum Toolkit. Once agreed the training was delivered and assessed using a blended learning experiential model within the 4th year clinical curriculum.

7 competencies for palliative care in IUG

1. Understand the principles of PC as part of chronic disease management and whole person medicine with an evidence based approach.
2. Identify patients who need PC and manage alongside disease modifying treatment
3. Assess and manage patients and families holistically
4. Demonstrate skills in pain assessment and management Demonstrate skills in symptom prevention, assessment and management in palliative care patients
5. Demonstrate skills and attitudes to effectively communicate with patients and their families
6. Understand and apply ethical principles and clinical judgment in managing patients and their families with PC needs
7. Work effectively within a multi-professional team

This programme has been running for 3 years with **s**tudents participating enthusiastically within a well organised curriculum with excellent collaboration from clinical and academic colleagues in IUG. Assessment includes MCQ (20 questions with 5 stems) and OSCE stations on communication. Feedback from students included evidence of learning and attitude change. "*'The course added to the clinical practice makes us feel the suffering of patients and how we can help them.' 'Patients cope better when we tell them the truth.' 'I have learned to add smile and life to days not just days to life.'*

Further developments continue with plans for the first ever Gaza national conference on palliative care in October 2019.

An outstanding issue remains access to opioids. At present this is almost zero for oral morphine. There has been a strong history of illicit use of tramadol in the community accessed via Egypt and this raises concerns in policy makers and clinicians. Rigorous systems are in place to manage controlled medications from hospital based settings and given the small geographical area this could be focal point for access. However one other significant factor is access to any medication through supply chains from Ramallah on the West Bank. The encouraging progress is that a pain and palliative care roll out led by Dr Amal Awad and Dr Rania Shahin in the MOH West Bank has developed a standard training workshops agenda for pain assessment and management. This is now being delivered to health care providers. In addition oral morphine now on essential medicines list and available alongside pain management protocols. The author wishes to applaud this endeavour as opioid availability was addressed after only one meeting with the above colleagues where the evidence was presented. Let us work together to ensure people in Gaza also have access to the pain and palliative care that is their right.

16. Using the Serious Illness Conversation Guide: Addressing the Advance Care Planning Needs of Patients and Families

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Effective communication to support decision making is a key component of care for individuals with serious illnesses throughout the illness trajectory. Since patients vary in their priorities and their individual care preferences often change over time, communication about goals of care is important to ensure that patients receive the care which they desire. The most reliable way to explore patients' priorities for care, is for health care providers to ask patients about their priorities, however, physicians often struggle to have these conversations with patients and families.

Advance Care Planning: Advance care planning is the process of reflection and communication to identify the values, wishes, and beliefs of patients related to their future health care plans. It is important for clinicians to initiate these conversations because clinicians generally identify that a patient's death is immanent an average of 100 days before the family does.[1] Advance care planning is important since aggressive or intensive care for patients with advanced illness is often harmful, and results in lower quality of life and greater physical and psychological distress.[2,3] Additionally, for many intensive treatments, there is no survival benefit for continuing treatment during the end-of-life phase.[4]

The Serious Illness Conversation Guide: Serious illness conversations are care provider-initiated discussions that ask patients about their goals and values in a structured format. The Serious Illness Conversation Guide (SICG) provides a simple guide for starting these conversations using language which has been patient-tested. The use of a guide, in the form of a checklist, bridges the gap between evidence and real-world implementation, ensuring clinicians adhere to the key steps in the process.[5] A checklist may also reduce clinician anxiety during a potentially stressful patient encounter, enhancing the clinician's ability to focus and listen to the patient and family.

Physicians routinely initiate discussions about end-of-life care very late in the course of the illness; the SICG emphasizes initiating these conversations early in the course of a serious illness.[4,6] The goals and values of patients should be revisited over time, since patients' values may shift as the disease progresses. The information shared by patients during these conversations provides a foundation for decision making, but the process of exploring these topics is valuable and therapeutic for patients even if medical decisions are not being made. Additionally, serious illness conversations can be used to share prognostic information and explore the patient's level of understanding of their disease.

Barriers to Serious Illness Conversations:

A 2014 review, described the patient, physician and system factors which impact the communication which occurs when patients are seriously ill.[4]

Patient Factors: Anxiety and denial are common in patients with serious illness and can obstruct discussions about goals of care. Health care professional may seek to reduce anxiety for patients by avoiding communication about care goals. Although avoidance and denial are common in terminal illness, and may be acceptable coping strategies, these responses can make it difficult for patients to accept the reality of their illness and plan for the future. Patients expect physicians to initiate communication about goals of care.[7]

Physician Factors: Physicians perceive a number of barriers to communication about goals of care for seriously ill patients and report feeling uncomfortable having these conversations when patients are well, do not have symptoms or have not exhausted all treatment options.[8] Additionally, physicians lack training in communicating about goals of care and most report not having been taught how tell a patient that they are dying or address patients' psychosocial concerns.[4,9] Clinicians often fail to address key elements of quality communication during their discussions with patients.[10]

System Factors: Health care systems are oriented towards providing life-sustaining or intensive treatment as the default and without the opportunity to express their values and preferences for care, however, most patients' preference is to die at home and avoid invasive treatments at end-of-life.[4,11]

Identifying Patients who Need a Serious Illness Conversation: Many clinicians are hesitant to initiate serious illness discussions as they are uncertain about the patient's prognosis.[12] One simple question which can trigger clinicians to identify patients who are seriously ill is: "Would you be surprised if this patient died in the next year?".[13] A more complete list of potential triggers can be found in the review by Bernacki and Block.[4]

Key Elements of the Serious Illness Conversation Guide: The Serious Illness Conversation Guide [Table 1] includes the following key points:

Set up the conversation: Clinicians should clarify for themselves the key details of the patient's condition. This may involve meeting with other specialty teams prior to the discussion with the patient. Depending on the patient, it may be helpful to have physicians from other specialties attending the discussion, and other health care providers including a nurse and a social worker or counsellor.

Clinicians should introduce the purpose of the discussion, ask permission to have the conversation, and provide a rationale for the discussion.

Assess Illness Understanding and Preferences for Information:

Since patients will differ in the amount of information that they want to receive, having a clear understanding of the patient's level of awareness of the illness allows the clinician to match the level of information to the patient's needs. A lack of clear information about the future is a common information gap for patients.[14]

Share Prognosis: Physicians should provide patients with clear information about prognosis to enable patients to use this information to make decisions about care plans.[15]

Using the framework of "I hope…I worry" or "I wish… I worry" communicates this information gently, but clearly. Acknowledge **uncertainty** by giving time ranges of days to weeks, weeks to months, or months to a year).

Responding to Emotion: Dealing with emotion is often a precondition for effectively addressing serious illness decisions. Allow silence and stillness immediately after giving difficult news. When strong emotions are expressed, seek clarification and express empathy. Obtain permission to proceed or offer the option to take a break from the discussion if the patient seems overwhelmed.

Explore Key Topics:

1. Hopes: a focus on hopes allows patients to feel a sense of purpose and control, which provides helps combat the hopelessness and despair which can accompany serious illness.
2. Worries: Concerns about the future are a significant component of patient anxiety in serious illness. Seeking to understand these provides clinicians with a way to show support, provide reassurance and help the patient to feel understood.
3. Strengths
4. Critical Abilities: Patients may have varying perspectives about impairments in functioning and will make choices based on their unique perspectives.
5. Trade-offs: Patient may have strong views on time in hospital and invasive treatments when these are balanced against time at home or with family. Sharing this information assists clinicians to guide informed decision making.
6. Involvement of other family members: Engaging the family is key in providing end-of-life care and this allows the clinician to understand how this can occur.

Close the conversation: Provide a brief summary and recommendations about care plans and ensure patient is in agreement. Affirm your commitment to continuing to provide care, while avoiding making promises that you cannot keep. Provide documentation about your discussion which is easily accessible to health care teams, to ensure that all clinicians are aware of the patients' values and preferences.

Conclusions: Engaging patients and families in early discussions about their goals in the setting of serious illness is key to improving end-of-life care outcomes. The serious illness conversation guide offers a structured and systematic approach, incorporating patient tested language, to explore the values and expectations of patients and their families. These conversations also allow clinicians to share prognostic information and provide support and reassurance.

Guiding Key Principles of End-of-Life Communication (adapted from[4])

Table 1: Serious illness conversation guide

Conversation flow	Patient-tested language
1. Set up the conversation Introduce purpose Prepare for future decisions Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want - is this okay?
2. Assessing understanding and preferences	"What is your understanding now of where you are with your illness?" "How much information about what is likely to be ahead with your illness would you like from me?
3. Share prognosis Share prognosis Frame as a "wish…worry"," hope…worry" statement Allow silence, explore emotion	"I want to share with you my understanding of where things are with your illness…" *Uncertain*: "It can be difficult to predict what will happen with your illness. I hope that you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time*: "I wish we were not in this situation, but I am worried that the time be as short as ____ (express as a range, e.g., days to weeks, weeks to months, months to a year)." OR *Function*: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."
4. Explore key topics Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	"What are your most important goals if your health situation worsens?" "What are your biggest fears and worries about the future with your health?" "What gives you strength as you think about the future with your illness?" "What abilities are so critical to your life that you can't imagine living without them?" "If you become sicker how much are you willing to go through for the possibility of gaining more time?" "How much does your family know about your priorities and wishes?"
5. Close the conversation Summarize Make a recommendation Check in with patient Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. Document your conversation	
7. Communicate with key clinicians	

- Patients want to know the truth about their prognosis[16]
- You will not cause the patient more anxiety or harm by talking openly about end-of-life issues[17]
- It is normal for both clinicians and patients feel anxious about these conversations[18]
- Patients and families often have values and goals beyond living longer[19]
- Learning about the patients' values and goals will empower you to provide better care

References

1. Wolfe J, Klar N, Grier HE, Duncan J, Salem-Schatz S, Emanuel EJ, *et al.* Understanding of prognosis among parents of children who died of cancer: Impact on treatment goals and integration of palliative care. JAMA 2000;284:2469-75.
2. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. J Clin Oncol 2010;28:1203-8.
3. Wright M, Wood J, Lynch T, Clark D. Mapping levels of palliative care development: A global view. J Pain Symptom Manage 2008;35:469-85.
4. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: A review and synthesis of best practices. JAMA Intern Med 2014;174:1994-2003.
5. Conley DM, Singer SJ, Edmondson L, Berry WR, Gawande AA. Effective surgical safety checklist implementation. J Am Coll Surg 2011;212:873-9.
6. Davison SN. End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. Clin J Am Soc Nephrol 2010;5:195-204.
7. Hancock K, Clayton JM, Parker SM, Wal der S, Butow PN, Carrick S, *et al.* Truth-telling in discussing prognosis in advanced life-limiting illnesses: A systematic review. Palliat Med 2007;21:507-17.
8. Keating NL, Landrum MB, Rogers SO Jr., Baum SK, Virnig BA, Huskamp HA, *et al.* Physician factors associated with discussions about end-of-life care. Cancer 2010;116:998-1006.
9. Buss MK, Lessen DS, Sullivan AM, Von Roenn J, Arnold RM, Block SD, *et al.* Hematology/oncology fellows' training in palliative care: Results of a national survey. Cancer 2011;117:4304-11.
10. Heyland DK, Allan DE, Rocker G, Dodek P, Pichora D, Gafni A, *et al.* Discussing prognosis with patients and their families near the end of life: Impact on satisfaction with end-of-life care. Open Med 2009;3:e101-10.
11. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. J Palliat Med 2000;3:287-300.
12. Clayton JM, Butow PN, Arnold RM, Tattersall MH. Discussing life expectancy with terminally ill cancer patients and their carers: A qualitative study. Support Care Cancer 2005;13:733-42.
13. Moss AH, Lunney JR, Culp S, Auber M, Kurian S, Rogers J, *et al.* Prognostic significance of the "surprise" question in cancer patients. J Palliat Med 2010;13:837-40.
14. Clayton JM, Butow PN, Tattersall MH, Devine RJ, Simpson JM, Aggarwal G, *et al.* Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. J Clin Oncol 2007;25:715-23.
15. Hagerty RG, Butow PN, Ellis PM, Lobb EA, Pendlebury SC, Leighl N,

et al. Communicating with realism and hope: Incurable cancer patients' views on the disclosure of prognosis. J Clin Oncol 2005;23:1278-88.
16. Fried TR, Bradley EH, O'Leary J. Prognosis communication in serious illness: Perceptions of older patients, caregivers, and clinicians. J Am Geriatr Soc 2003;51:1398-403.
17. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, *et al.* Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 2008;300:1665-73.
18. Block SD. Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: The art of the possible. JAMA 2001;285:2898-905.
19. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA, *et al.* Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284:2476-82.

17. E-Palliative Care Initiative of Malabar Cancer Centre

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WHO defines telehealth as "The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies, for the exchange of valid information for diagnosis, treatment, and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, in all the interests of advancing the health of individuals and their communities[1]" WHO recognizes several branches of telemedicine: teleradiology, tele dermatology, telepathology and telepsychology and so on. We, at Malabar Cancer Centre tried to use this concept to improve the service delivery of our palliative patients treated through homecare service.

Malabar Cancer Centre is an autonomous institution under Health and Family Welfare Department, Government of Kerala, It is a dedicated cancer hospital catering to the needs of Northern districts of Kerala, neighbouring parts of Karnataka, Tamil Nadu states and Mahe. Though a pain clinic was functioning in our centre since 2002, it was established as a Department in 2010.

The main objectives of the Department are
- Clinical activity- OP, IP and Homecare service
- Training of Doctors, Nurses and Healthcare workers in Palliative care
- Researches in Palliative care

All this is done by a small team comprising of a doctor and a trained nurse in the OP and one for homecare service.

Studies have shown that cost effective palliative care services can be provided by home based services. Over 50% of people prefer to be cared for and to die at home[2]. The homecare service of our centre was Started in 2009 as Physician led homecare. But gradually our OP attendance started increasing from 1024 in 2009 to the present figure of 8196 per annum. As a result, since June 2011 our homecare service has been Nurse led and Physician assisted one, where-in our home care nurse interacts with the physician over phone for any doubts regarding the management of the patients. But most of the time lack of a palliative physician in the team produces dissatisfaction among patients and care takers. This often led to hospital visits by such patients.

To overcome this problem, we introduced the concept of e-palliative care [Figure 1] from 2013 onwards. The e-Palliative, an open source web application was developed by the Health IT Division of MCC in research collaboration with Centre for Development of Imaging Technology (C-DIT), Thiruvananthapuram. E-palliative care is a form of telemedicine that uses technology to provide real-time visual and audio patient assessment. The e-palliative care system is dedicated only for the palliative and bedridden patients treated in MCC through home care service. The concept of e-palliative care is to bring the doctor to the bedside of a home care patient. The homecare team led by a palliative care trained nurse visits the patients carrying a laptop with an internet facility and a high resolution camera in it. The laptop is placed at the bedside of the patient and the nurse connects the patient to the palliative care physician sitting in the hospital through the e palliative web application, so that the patient and caregivers could see and communicate with their palliative care physician. More than 50 patients are consulted every month through e-Palliative care at our centre.

In order to know if our patients were happy with this type of service delivery, we did a study on the level of satisfaction of our home care patients and their relatives with e-palliative care. A validated e-Palliative Patient Satisfaction Questionnaire was given to the patient or to the close caregiver if the patient could not read or was not in a state to comprehend the questionnaire after the patient consulted the doctor through e palliative method. The questionnaire concentrated on six subscales namely, Patient's general satisfaction, technical quality, communication aspects, financial aspects, time spent with doctor, accessibility and convenience. It consisted of 15 statements with five response options where agreement reflects satisfaction. These subscales were measured using Likert scale of 1 to 5 with 5 representing maximum satisfaction. The mean score of response for General satisfaction was observed as 4.520. The mean score of response for Technical quality, Communication, Financial aspect, Time spent with doctor and Accessibility & convenience were observed as 3.922, 4.483, 4.550, 4.521 and 4.492 respectively. The overall satisfaction was found to be 4.394.

A search for similar studies relating to telehealth and patient satisfaction was done. We found a systematic review consisting of 44 studies showing the key results in terms of improved Outcomes, ease of use, low cost, improved communication and decreased travel time.[3]

The conclusions of our study were
- The overall satisfaction of patients receiving e-palliative homecare service from MCC is high (Mean score 4.383)

Figure 1: Palliative Consultation

- e-Palliative care is a feasible option for providing excellent palliative care in developing countries with limited resources and financial constraints.
- High Speed Internet connectivity will be the major constraint in the widespread implementation of e-Palliative care.

The highlights of e-palliative care are
- Feasible and easy to use.
- Increases patient's confidence level.
- Increases the Homecare team's confidence.
- Expert palliative care doctor's service can be made available in remote villages.
- Reduces the travel burden, waiting time of patients in the hospital
- Reduces hospital stay.
- Reduce travelling cost
- Patients can share their health details with doctor from their calm and quite home atmosphere.
- Cost effective model

The lesson we learnt by implementing this e-palliative home care service is that when a weakness or threat is identified in our work place, we should utilise our strength. Then we will be able to over come the threat. For a time we thought, we would have to compromise our OP service or the Home care program. But with the support of our Health IT division, we overcame our threat.

The challenge we faced after implementing this service was difficulty in getting high speed internet connectivity in few locations. However we overcame this challenge by implementing wireless internet connectivity of two service providers.

So now with e-palliative homecare service provided, our palliative homecare patients are able to spend their days remaining at home.

Malabar Cancer Centre had also received the Kerala state e-Governance award under the

e-Citizen Service Delivery category on 3rd January 2019 for this project.

This innovative method of e-palliative Home care service which facilitates a doctor's virtual presence and care at the patient's bedside in his home using appropriate technological expertise, is definitely a gigantic leap in the Health care delivery system.

References

1. World Health Organization. Telemedicine: Opportunities and Developments in Member States: Report on the Second Global Survey on eHealth. World Health Organization; 2010.
2. [doi: 10.1002/14651858.CD007760.pub2].
3. Kruse CS, Krowski N, Rodriguez B, Tran L, Vela J, Brooks M, *et al.* Telehealth and patient satisfaction: A systematic review and narrative analysis. BMJ Open 2017;7:e016242.

18. THE PALLIKARE APP

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Background: The Bangalore Hospice Trust (BHT) was formed some 25 years ago specifically with the intention of helping people facing progressive terminal illness, particularly cancers. The clinical work is provided through Karunashraya, a specialised palliative care unit offering 74 in-patient beds and out-patient clinics, together with associated link-centres, hospital liaison, and peripheral out-reach Home Care teams. In addition to the medical, nursing and social care, one of BHT's core values has always been a strong commitment to multi-professional education in Palliative Care. Apart from in-house training for nurses, Karunashraya has for some time contributed to other courses such as the Diploma/MSc from Cardiff University and the National Fellowship (IPM) programmes.

More recently we have been involved in developing ten-day courses on the Fundamentals of Palliative Care and have trained rural doctors and nurses from most districts of Karnataka, as well as other states such as Odisha, Manipur, and Sikkim. As part of the National Programme for Palliative Care organised by the Ministry of Health and Family Welfare, and the Training the Trainer programmes, we have also taught doctors and nurses from Uttarkhand, Chattisgarh, Assam, Puducherry, Harayana, Mizoram, and Gujrat.

The Impetus for an App: Apart from the wealth of hands-on clinical experience at Karunashrya, visiting clinicians also have a series of lectures and class-room activities. At the request of the participants all the lecture materials was made available in pdf format and uploaded to "the cloud" for reference at a later date.

Whilst this was initially appreciated, many doctors found that once back in their rural workplace, poor access to internet facilities, or very slow down-load speeds in remote areas, made this less than useful for their regular practice.

What was needed was a quick reference which could be carried with them at all times, similar to an old fashioned "Vade mecum". It was essential that this did not depend on having internet access; hence an app that could be downloaded to a smartphone.

Objectives: With help from our software developer colleagues at Digi Health Platform we set about designing a simple app with the following criteria in mind:
1. That it was to be aimed mainly at doctors (and senior nurses) with some or very limited experience of Palliative Care
2. That it was a quick reference and not meant to supplant a text book
3. Based on symptoms
4. Easy to access
5. Quick to navigate
6. That the content was congruent with the IAPC course textbook
7. It was designed specifically for the Indian subcontinent in terms of
   a. Availability of drugs
   b. Cost of medications
8. That it would be made FREE!

Development: BHT generously agreed to cover the complete costs of development and launch.

Planning started with writing simple algorithms based on a few specific symptoms/common problems, with the information available via a series of drop-down boxes and side scroll-bar, with the ability to retrace steps and look at other options.

After initial beta-testing and field work [Figure 1] involving comments from a number of seniors palliative care physicians in India, valued feed-back was collated, glitches ironed out and the navigation stream-lined. Once the amendments were incorporated and found to be satisfactory, further modules were developed so that there were eight in total, each covering one of the following:
- Nausea and Vomiting
- Constipation

- Delirium
- Breathlessness
- Neuropathic pain
- Pain
- Oral Care
- Skin problems

A further "miscellaneous box" was made with the following short topics:

- Cough
- Hiccups
- Diarrhoea
- Seizures
- Raised intra-cranial pressure
- Superior Vena Cava Obstruction
- Death rattle

The intention was to provide a basic background to the topic when first opened, with further choices for information re common causes, diagnosis, investigations that might be useful and finally management options (including general, Non-pharmacological and pharmacological options). Not every box / sub text needed to be read if not wanted and the user could skip directly to the relevant section with just three or four clicks

e.g. for the module on Delirium [Figure 1]:

Under the therapeutic section, if the first, second, third choice don't work, there is a flag to suggest "seek Specialist help".

The App: The app is called "PalliKare".

Following the primary screen, the next screen contains the various individual module options. In the top right hand corner there are either the three little dots or an Information button. Clicking on this will give details of the app, instructions on use, and a feedback option.

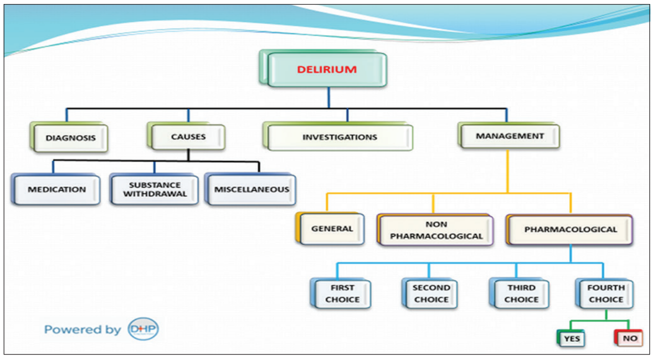

Figure 1: Module on Delirium

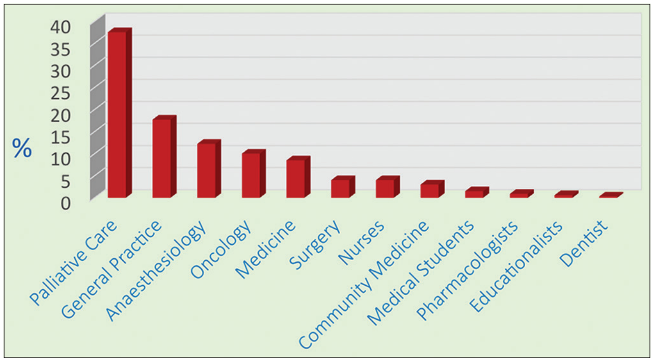

Figure 2: Professional background of App users

There is also a note indicating that the app is not a replacement for a book or more scholarly articles on the problems and there will be no liability for inappropriate use of the information contained.

Launch: The initial work was done on an Android platform and after final minor adjustments/improvements, it was "Officially" launched jointly by Padmashree Dr MR Rajagopal and Dr Robert Twycross, in the presence of Dr Nagesh Simha at the pre-conference dinner hosted by Dr Sushma Bhatnagar, during the Silver Jubilee celebrations of IAPCON 2018, in Delhi.

Work was continuing on the iOS version in parallel, but took slightly longer to finesse and complete owing to the rigorous testing, and compliance issues on the part of Apple before their giving the app a green light. The iOS version for iPhones and iPads was kindly launched by Shri Manoj Jhalani, Mission Director, NHM, on 29th April 2018, at the World Rural Health Conference in Delhi, a meeting attended by Sri M Venkaiah Naidu, Hon Vice President of India and Shri Ashwini Kumar Choubey, Minister of Health. At the same conference the app was endorsed by Dr Raman Kumar, President of Family Physicians of India and Prof John Wynn-Jones, President of Rural WONCA.

Statistics to date (end of January 2019): When initially downloading the apps, simple demography details are requested of the user, that are confidential, anonymous and generic.

There have been over 900 downloads, with 58% regular users (60% male) and predominantly in the 25 to 34 age range, (though the is representation across the whole age group up to and over 65). It regularly gets a five-star rating and any comments very positive.

There have been over 4,000 unique screen views, with an average time per screen of 1.16 minutes (range: 25 -2.24 minutes), indicating fulfilment of one of the prime objectives ie getting information quickly. The most used modules were the ones on Pain and the Miscellaneous group. There was fairly even use of all the others.

The majority of users come from Palliative Care, Primary Care or Pain backgrounds (67%) [Figure 2]:

As expected the vast majority (84%) of downloads, especially on the Android platform were from India. What was surprising was that given this was an app designed with India specifically in mind, there were a small but not insignificant number of users from other places such as Uganda, Palestine, Israel, South Africa, Germany, Colombia, Singapore and the Philippines!

Future Plans: There are plans for four or five new modules and also links to other resources, including links to directories of locally available palliative care units/provision throughout India (such as the one compiled for the recent conference).

The current app has provision for feed-back and based on what has been received so far, minor corrections are being made, with suggestions taken onboard for the content of the new modules and the provision of photos to illustrate specific points eg in wound or oral care.

We value the feed-back received and encourage users to please continue giving us comments, corrections and ideas to help improve the coverage, usefulness and usability of this app.

"PalliKare" can be downloaded free of charge from either play store or Apple Store.

19. ROLE OF INFORMATION TECHNOLOGY IN DELIVERY AND DATA MANAGEMENT IN PALLIATIVE CARE - USE OF ECHO

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Project ECHO stands for 'Extension for Community Healthcare Outcomes'. It was launched in 2003. The ECHO model makes specialized medical knowledge accessible wherever it is needed to save and improve people's lives. Project ECHO links expert specialist teams at an academic hub with primary care clinicians in local communities.

Patients need access to specialty care for their complex health conditions. In rural/remote areas, this might not be always available. Patients in rural areas have to travel to the big cities as much as 200 kms due to lack of specialists in their own communities. When it comes to palliative care, there are only a handful of specialists who are trained in treating or caring for such patients. This is where the model of telemedicine becomes much more important. Project ECHO is one such model of interaction with physicians in local communities especially in remote/rural areas.

ECHO trains primary care clinicians to provide specialty care services. This means more people can get the care they need. Patients get the right care, in the right place, at the right time. This improves outcomes and reduces costs. While the main reason for using ECHO is the fact that there are not enough specialists to treat everyone who needs care, especially in rural areas in India, ECHO also uses the model of telemedicine where participants can receive mentorship from palliative care specialists from all over the world and they can collaborate with others through case-based learning. The physicians in turn can become a local specialist in their own community.

When it comes to palliative care, there are some major barriers to provision of palliative care, the most notable among which are lack of healthcare policies and finances, lack of awareness and education, and opioid availability.

In Hyderabad, the first ECHO for Palliative care–'No Pain Too Small' - was started by Pain Relief and Palliative Care Society in collaboration with Two Worlds Cancer Collaboration, Canada. The main aim of this ECHO was connecting and involving people by training in palliative care, nationally and internationally. The second ECHO for Palliative Care, is 'Improving Access to Palliative Care in Districts of Telangana State,' which is directed at setting up palliative care centres in all 31 districts of Telangana State.

We use Zoom platform as an interface to conduct ECHO meetings. Zoom is a virtual platform which is used to connect people from all over the world. Zoom supports audio, video, chat, document sharing, etc. It is used to virtually hold in-depth discussions, host meetings, and join meetings, hold didactive and instructional sessions from any speaker at any time. Zoom is easy to join and participate, even using a mobile phone. A typical Zoom session is basically divided into 4 parts, a welcoming period, didactic presentation and questions, case presentation and discussion, and summary.

The ECHO sessions conducted at our hub in Hyderabad aim at giving some core competencies about palliative care for people who are already practicing palliative medicine. This has several advantages. ECHO can be extremely useful for the purposes of networking, giving out adequate referrals. It can be a good learning resource as we conduct real-time cased-based discussions where physicians from all over the world actively participate in sharing their experiences in their own communities and their knowledge and feedback. This gives us access to a broader view of the delivery of palliative care from other countries. We also provide access to You Tube sessions which are recorded for future references and perusal.

The main advantages of using ECHO are that the participants can learn through case studies from experts in subject matter in palliative care. They also have the chance of meeting other professionals from around the world.

Today, ECHO currently has over 120 different healthcare providers from more than 40 different locations spread all over the globe. On average, as many as 35 participants from 15 different canters are getting connected in a single Zoom-ECHO session. These participants are mainly physicians and nurses, but also various healthcare professionals can be a part of these sessions.

The main challenges we currently face are with participants dropping out while the sessions are being held. These may largely be due to connectivity problems with the network among other technical issues. Communicating over videoconference can also be a challenge for some participants if they are not fully using the functionalities of the interface.

In conclusion, Project ECHO is an innovative educational format for delivering palliative care education in resource-limited settings, which bridges the gap between experts and practitioners through an diverse online community. By using Project ECHO as the standard for teleconferencing, institutional teaching of medical trainees, nurses, and other healthcare professionals has become easy.

In the future, we expect to see continued expansion of this model to reach every Indian state and in particular to more rural communities, and also to start a Project ECHO program for paediatric residents in India.

Baseline Quality of life among patients with End Stage Kidney Disease in a resource limited setting: Uganda

20. DIGNITY CONSERVING CARE AND DIGNITY THERAPY

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Introduction: Dignity is a complex, ambiguous and multi-layered construct.[1] Despite its widespread use in philosophy, bioethics, politics and law, it is poorly defined and understood. Dignity is a central principle in palliative care and an important contributor to quality of life.[2,3] Conserving dignity of patients is a key care outcome in palliative care[4] and to do so it is important that we understand how patients with terminal illness experience dignity, what factors enhance or undermine a patient's sense of dignity, and how threats to dignity can be mitigated.

Concept of Dignity: Dignity has been defined as the "state or quality of being worthy of honour or respect". There are two basic constructs of dignity; basic dignity and personal dignity.[5,6] Basic dignity is a moral and legal construct. It is universal, i.e. emphasises the intrinsic moral worth of every human being.[7,8] It is inherent and inalienable, and is the basis for human rights. Personal dignity, on the other hand, is the personal sense of worth that is tied to an individual's personal goals and social circumstances. It is contextual, contingent, and reciprocal; i.e. affected by how one perceives oneself and by how one is perceived and treated by others.[6] When used in healthcare literature, the term dignity refers to the construct of personal dignity. In palliative care the concept of dignity in addition to ideas of self-respect and self-worth encompasses an umbrella of terms like being able to maintain physical comfort, autonomy, meaning, spiritual comfort, interpersonal connectedness, belonging and courage in the face of impending death.[9]

The Model of Dignity in the Terminally-ill: One of the commonest reasons for requests for euthanasia, and physician-assisted suicide in patients nearing end-of-life are concerns about loss of dignity.[10,11] Chronic illness opens the doorway to patienthood and its resultant bio-psycho-socio-spiritual suffering. Alterations in the body and mind, heightened dependency needs, and inability to fulfil the socially assigned roles are perceived as threats to one's identity.[12] Sense of self-worth in impacted by how one is treated by others; verbally, nonverbally or behaviourally.[13] These threats to dignity provoke powerful feelings of anxiety, humiliation, embarrassment, sadness and a desire for death, resulting in deterioration of health and quality of life. Understanding and addressing dignity-related concerns becomes imperative for the provision of good palliative care.

Qualitative studies have explored several factors that were central to the sense of dignity in terminally-ill cancer patients.[14] An empirically based model of dignity in the terminally ill was developed incorporating a broad range of physical, psychological, social, existential and spiritual issues. Three major categories that impacted patient's perception of dignity were.:[15]

a. Illness-related concerns: Patient's sense of dignity can be impacted by factors directly related to the illness experience namely:
    - *Symptom distress,*[16] either physical or psychological symptoms causing discomfort due to progression of the disease. Psychological distress is further complicated by the medical uncertainty and death anxiety[17,18] of advanced disease.
    - The impact of the disease on the *level of independence* both functional and cognitive.[19]

b. Social dignitary inventory are the environmental influences, social issues, and relationship dynamics that either erode or enhance patient's sense of dignity and include factors like:
    - *Social support network;*[20,21]
    - The extent to which one's personal environment is encroached upon during the process of receiving care/ support, i.e. *privacy boundaries*;
    - The attitude others (care providers) demonstrate while interacting with the patient, i.e. *care tenor;*[22]
    - The distress caused by a patient's belief that depending on others for personal care or illness management is a *burden to others*,
    - The worry about the impact of one's death on loved ones, i.e. *aftermath concerns.*
    - Dignity conserving repertoires: Patient's sense of dignity is influenced by their internally held psychological and spiritual landscapes.[23,24]
    - *Dignity-conserving perspectives* refer to the pre-existing personal characteristics, attributes, and worldviews of the patient that help to enhance/preserve patient dignity. Some of the perspectives emphasised are: i) the ability to remain connected to one's self despite the illness, ii) the ability to retain positive sense of self-worth, iii) the ability to function in usual social roles albeit with limitations, iv) an ability to sustain meaning and purpose in life, v) fostering a belief that one is able to leave something of value that can transcend death,[25,26] vi) having a subjective sense of choice over life despite progressive debility, vii) ability to adapt to the changing circumstances, viii) the mental fortitude to overcome illness-related concerns and optimize quality of life.
    - *Dignity-conserving practises* refer to various personal approaches or techniques used by patients to enhance or maintain their sense of dignity. These include living in the moment, maintaining normalcy by carrying out usual routine tasks despite declining health, and finding comfort in spiritual/religious beliefs.

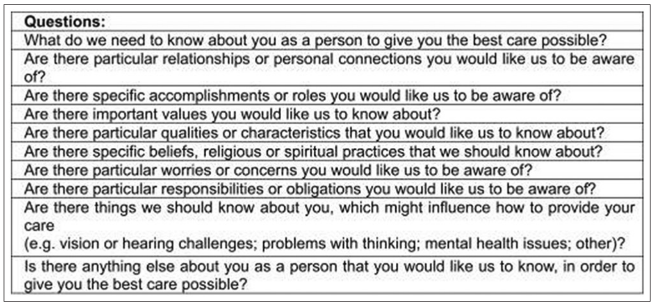
Dignity Conserving Care: The notion of dignity is dynamic, varies across individuals and circumstances. Each individual/family will ascribe varying degrees of importance to each of these components. The physician's challenge lies in understanding how a particular patient/family perceive their sense of dignity, how has it been affected by the disease, and create interventions to mitigate the threat. Dignity model provides the framework for understanding/identifying factors that influence dignity. It also offers guidance on how to provide dignity-conserving care by acknowledging and assessing what is important to the patient, addressing the individual dignity-related concerns, and enhancing empathetic connections between the patient, patient's family and the care provider.[27]

Fundamental to dignity conserving care is the care tenor. Care tenor is the tone of care that healthcare providers offer patients or the tone that patients perceive.[28] Care tenor has substantial impact on patient's sense of dignity. Healthcare providers need to ensure that the care tenor should be one that affirms patient's sense of dignity. The fundamentals of dignity conserving care can be summarized as ABCD; i.e. A) healthcare providers must be aware of and analyse their preconceived Attitudes towards patients that may affect their care tenor, B) the Behaviour of the healthcare providers must be rooted in kindness and respect, C) care tenor should be Compassionate affirming patient dignity, and D) Dialogue between the patient and the doctor should acknowledge the personhood of the patient and foster a sense of meaning, purpose and dignity.[27]

Dignity Therapy: Dignity Therapy (DT) is an individualized, brief psychotherapeutic intervention developed with the objective of relieving existential distress and enhancing end-of-life experience of terminally ill patients.[29] The process of DT engenders a sense of meaning and purpose, facilitates connection with one's core self, and enhances dignity in terminally ill patients.

For many patients the concept of dignity is connected to the need for generativity/legacy, i.e., the belief that their essence will survive beyond their death and in the pursuit of purpose and meaning. Dignity therapy provides patients with an opportunity to do this by reflecting back on their life and sharing their life stories through a legacy document.

The intervention uses 10 core questions that guide the interview, The Dignity Therapy Question Protocol [Figure 1], derived from the Dignity Model. These questions explore the values and important accomplishments of the dying patients, their hopes and dreams for their loved ones, advise and guidance for important people in their lives, and how they wish to be remembered by their loved ones. Responses are audio-recorded by a professional, trained in DT, who assists the patient in constructing and organising the narrative. This



Questions:
What do we need to know about you as a person to give you the best care possible?
Are there particular relationships or personal connections you would like us to be aware of?
Are there specific accomplishments or roles you would like us to be aware of?
Are there important values you would like us to know about?
Are there particular qualities or characteristics that you would like us to know about?
Are there specific beliefs, religious or spiritual practices that we should know about?
Are there particular worries or concerns you would like us to be aware of?
Are there particular responsibilities or obligations you would like us to be aware of?
Are there things we should know about you, which might influence how to provide your care (e.g. vision or hearing challenges; problems with thinking; mental health issues; other)?
Is there anything else about you as a person that you would like us to know, in order to give you the best care possible?

Figure 1: Dignity Therapy Question Protocolcol

is then transcribed verbatim, edited, and given back to the patient as a written legacy document. The patient reviews the edited legacy document and hands it over to family and friends.

There is clear and consistent empirical evidence supporting the acceptance of DT. Several patients expressed high levels of satisfaction and heightened sense of dignity after DT. It was beneficial to both patients and families. Though evidence for the effectiveness of DT is lacking in a large, adequately powered RCT, several other studies have shown higher levels of meaning in life, quality of life, and spiritual wellbeing after DT.[30,31] In some studies there has been significant reduction in anxiety and depression scores.[32,33]

Conclusion: A strong sense of dignity is indispensible for maintaining quality of life, especially in those who are vulnerable and dependent on others. Good palliative care acknowledges and addresses the existential distress, fosters meaning and purpose, reinforced by respect and self-esteem.

References

1. Moody HR. Why dignity in old age matters. J Gerontol Soc Work 2008.
2. Latimer E. Caring for seriously ill and dying patients: The philosophy and ethics. CMAJ 1991;144:859-64.
3. Brant JM. The art of palliative care: Living with hope, dying with dignity. Oncol Nurs Forum 1998;25:995-1004.
4. Venturato L. Dignity, dining and dialogue: Reviewing the literature on quality of life for people with dementia. Int J Older People Nurs 2010;5:228-34.
5. Albers G, Pasman HR, Rurup ML, de Vet HC, Onwuteaka-Philipsen BD. Analysis of the construct of dignity and content validity of the patient dignity inventory. Health Qual Life Outcomes 2011;9:45.
6. Pullman D. Death, dignity, and moral nonsense. J Palliat Care 2004;20:171-8.
7. Kant I. Groundwork for the metaphysic of morals (1785). Pract Philos 2005.
8. Spiegelberg H. Human dignity: A challenge to contemporary philosophy. World Futures 1971.
9. Kissane DW, Treese C, Brietbart W, McKeen NA, Chochinov HM. Ethical, existential, and spiritual issues in palliative care. In: Chochinov HM, Brietbart W, editors. Handbook of Psychiatry in Palliative Medicine. 2nd ed. Oxford University Press; 2010. p. 324-40.
10. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK, *et al.* A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998;338:1193-201.
11. Van Der Maas PJ, Van Delden JJ, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. Lancet 1991;338:669-74.
12. Jacobson N. A taxonomy of dignity: A grounded theory study. BMC Int Health Hum Rights 2009;9:3.
13. Gallagher A, Li S, Wainwright P, Jones IR, Lee D. Dignity in the care of older people – A review of the theoretical and empirical literature. BMC Nurs 2008;7:11.
14. Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, *et al.* The patient dignity inventory: A novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage 2008;36:559-71.
15. Chochinov HM. Dignity-conserving care – a new model for palliative care: Helping the patient feel valued. JAMA 2002;287:2253-60.
16. Brietbart W, Jaramillo J, Chochinov HM. Palliative and terminal care. In: Holland J, editor. Textbook of Psycho-Oncology. New York: Oxford University Press; 1998. p. 437-49.
17. Hinton J. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. Palliat Med 1999;13:19-35.
18. Hinton J. Sharing or withholding awareness of dying between husband and wife. J Psychosom Res 1981;25:337-43.
19. Miller J, Cooper J. 4.5 The contribution of occupational therapy to palliative medicine. In: Oxford Textbook of Palliative Medicine 2012.
20. Katz JS, Sidell M, Komaromy C. Dying in long-term care facilities: Support needs of other residents, relatives, and staff. Am J Hosp Palliat Care 2001;18:321-6.
21. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E. Family members' perceptions of palliative cancer care: Predictors of family functioning and family members' health. J Palliat Care 1996;12:10-20.
22. Barthow C. Negotiating realistic and mutually sustaining nurse-patient relationships in palliative care. Int J Nurs Pract 1997;3:206-10.
23. Cassell EJ. The nature of suffering and the goals of medicine. The Nature of Suffering and the Goals of Medicine 2004.
24. Byock IR. The nature of suffering and the nature of opportunity at the end of life. Clin Geriatr Med 1996;12:237-52.
25. Fisher BJ. Successful aging, life satisfaction, and generativity in later life. Int J Aging Hum Dev 1995;41:239-50.
26. Lichter I, Mooney J, Boyd M. Biography as therapy. Palliat Med 1993;7:133-7.
27. Chochinov HM. Dignity and the essence of medicine: The A, B, C, and D of dignity conserving care. BMJ 2007;335:184-7.
28. Chochinov HM. Dignity Therapy: Final Words for Final Days. Dignity Therapy: Final Words for Final Days; 2012.
29. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M, *et al.* Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. J Clin Oncol 2005;23:5520-5.
30. Hall S, Goddard C, Opio D, Speck PW, Martin P, Higginson IJ, *et al.* A novel approach to enhancing hope in patients with advanced cancer: A randomised phase II trial of dignity therapy. BMJ Support Palliat Care 2011;1:315-21.
31. Hall S, Edmonds P, Harding R, Chochinov H, Higginson IJ. Assessing the feasibility, acceptability and potential effectiveness of dignity therapy for people with advanced cancer referred to a hospital-based palliative care team: Study protocol. BMC Palliat Care 2009;8:5.
32. Julião M, Barbosa A, Oliveira F, Nunes B, Vaz Carneiro A. Efficacy of dignity therapy for depression and anxiety in terminally ill patients: Early results of a randomized controlled trial. Palliat Support Care 2013;11:481-9.
33. Julião M, Oliveira F, Nunes B, Vaz Carneiro A, Barbosa A. Efficacy of dignity therapy on depression and anxiety in portuguese terminally ill patients: A phase II randomized controlled trial. J Palliat Med 2014;17:688-95.

21. BASELINE QUALITY OF LIFE AMONG PATIENTS WITH END STAGE KIDNEY DISEASE IN A RESOURCE LIMITED SETTING: KAMPALA, UGANDA

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Introduction

The incidence of kidney disease is on the rise globally, with estimated worldwide prevalence at 8-16%.[1] The leading driver of this is the growing incidence of life style related diseases such as diabetes and hypertension.[2] In sub-Saharan Africa infectious diseases, including malaria and HIV, as well as herbal and environmental toxins also contribute significantly.[3] Complications include increased cardiovascular[4] and all-cause mortality, increased risk for acute kidney injury, progression of kidney disease, anaemia, bone and mineral disorders, fractures and cognitive decline.[5,6]

Chronic Kidney Disease (CKD) is the leading presentation of kidney disease. In resource limited settings patients often present late in the disease progression with significant morbidity limiting physical and social functioning. At this point patients have developed End Stage Kidney Disease (ESKD) and have multiple complications of kidney failure, often necessitating initiation of Renal Replacement Therapy (RRT) in the form of hemodialysis (HD) or kidney transplantation.[2]

Both of these treatment options are costly and not always offered free of charge to the patient in resource limited settings.[2,7] Consequently, the majority of patients in these settings receive Conservative Management (CM), which is holistic care including maximized symptom control and alleviation of pain as the patients approach the end of life. At this point the main goal of care is to improve the patient's Quality of Life (QoL). This is part of the burden of lack of Universal Health Coverage and affects all who have chronic disease.[8]

The World Health Organization defines QoL as the "individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns".[9] QoL is increasingly becoming an important indicator of successful chronic disease care. The Kidney Disease Quality of life instrument is one of the most frequently used tools to assess quality of life for patients with ESKD. It scores patients into 3 domains: Physical domain, Mental health domain and Kidney disease related domain. These assess, respectively, the impact of physical, mental and kidney disease related factors, such as symptom burden and hospitalizations, on the patient's QoL. Patients with lower scores are identified as having a poorer quality of life than patients with higher scores.[10]

This pilot study aimed establish a baseline review of QoL, patient outcomes and associated factors for patients with ESKD receiving hemodialysis versus conservative management in a national referral hospital.

Materials and Methods

Selection and description of participants

A pilot study was carried out on 40 consecutively recruited adult patients with ESKD receiving care in Mulago national referral hospital. Mulago hospital is the largest health care facility in Uganda with a bed capacity of 1500 beds. It offers hemodialysis at the cheapest rates in the country and receives refferals from all over the country including neighbouring countries.

Patients were recruited from the Hemodialysis unit, Inpatient wards and Outpatient clinics. All adult patients on hemodialysis were eligible for recruitment while only patients with documented evidence of end stage kidney disease defined as chronic kidney disease stage V (estimated glomerular filtration rate of 15 mls/min/1.73 m2 or less calculated using Cockcroft-Gault Formula) were recruited from the out patients clinics and in patient war.

Quantitative data was entered into a data base using EpiData version 3.1 and analysed using STATA version 12.0. Ethical approval for this pilot study was given by the School of Medicine Research and Ethics Committee.

Results

In the final analysis 38 patients were included in the study, 2 patients declined to participate due to morbidity. Majority of patients were on hemodialysis, 32 (84%) while only 6 (16%) were on conservative management. Majority were male (68%) with upto 37% acknowledgeing that they were the breadwinners in their families. More than half of the patients (52%) had 3-12 dependants and yet 22 (61%) were unemployed or retired. 27 (82%) patients were receiving dialysis at least twice weekly with a few receiving once daily hemodialysis. Only 6 patients (20%) had fistulars for hemodialysis access while permanent catheres were the most prevalent access route for hemodialysis.

On analysis of patient perceptions of their health, 19 (59%) felt their health in general was fair while 12 (32%) felt it was good and 6 (16%) felt it was poor. 21 (56%) patients felt their health did not expect their health to worsen but 14 (37%) strongly felt like a burden to their families. Majority of patients felt limited by moderate activity and felt they were spending too much time dealing with their kidney disease.

Discussion

This pilot study establishes baseline characteristics [Table 1] of patients with end stage kidney disease in a resource limited setting and explores

Table 1: Patient characteristics

Characteristic	Distribution of participants, total=38 *n* (%)
Management type	
Hemodialysis	32 (84)
Conservative management	6 (16)
Age	
19-50	18 (47)
51-78	20 (53)
Gender	
Male	26 (68)
Female	12 (32)
Family size	
0-3 dependents	13 (48)
3-12 dependents	14 (52)
Main bread winner	
Yes	9 (37)
No	15 (63)
Dialysis sessions per week	
Once weekly	4 (12.5)
Twice weekly	26 (81.0)
Thrice weekly	2 (07.0)
Type of dialysis access	
Fistula	6 (20.0)
Permanent catheter	16 (53.3)
Temporary catheter	8 (26.7)
Employment status	
Employed	14 (39)
Unemployed or retired	22 (61)
Symptom burden	
0-1 symptoms	33 (89)
2-6 symptoms	4 (11)
Patient rating of their health	
Good	12 (32)
Fair	19 (59)
Poor	6 (16)

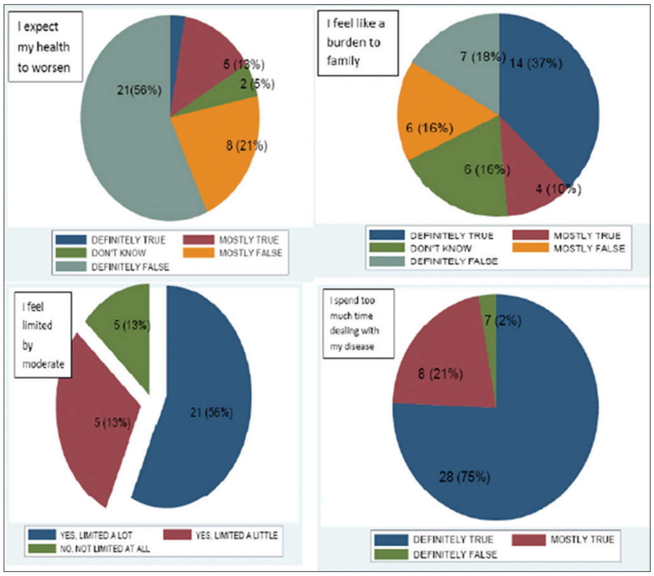

Figure 1: Patient perceptions

perceptions of patients [Figure 1] regarding their health and how it affects their lives. From this information quality of life scores will be computed and analysed to determine associations between scores and patient characteristics. We have determined that in general patient characteristics in resource limited setting don't vary significantly from those in developed setting, the older population formed a slightly bigger majority of patients as was seen by Nathan R. Hill et al in a systematic review and meta-analysis of the global Prevalence of Chronic Kidney Disease.[11] In this meta-analysis they showed that prevalence of kidney disease increased with age in all studies.

Patients perceive kidney disease as consuming a lot of their time and they feel like a burden to their families. This has been demonstrated in Malawi, another resource limited setting, by Thokozani Masina *et al*.[12] In their study they also showed a relationship between health seeking behaviour and low physical quality of life scores. Our patients similarly demonstrated limited physical activity levels, low incomes and low income generating capacity contributing to low hemodialysis frequencies since this service is a paid for service.

Unlike studies in the developed setting were average patient age was higher our patient group demonstrated less number of symptoms,[13] this may be explained by a lower age group in our study.

Conclusion

Improved QoL is a key indicator of successful chronic disease management. This baseline review informs a wider mixed methods longitudinal study. These preliminary findings suggest that patients have low perceptions of their general health, targeting this in general patient care will greatly contribute to improve care outcomes Improving this evidence base will inform renal and palliative care services with the goal of holistically improving overall patient experiences.

Acknowledgement

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Keywords: End stage kidney disease; quality of life; resource limited setting

References

1. Jha V, Garcia-Garcia G, Iseki K, Li Z, Naicker S, Plattner B, *et al.* Chronic kidney disease: Global dimension and perspectives. Lancet 2013;382:260-72.
2. Nasri H. World Kidney Day 2014; chronic kidney disease and aging: A global health alert. Iran J Public Health 2014;43:126-7.
3. Stanifer JW, Lunyera J, Boyd D, Karia F, Maro V, Omolo J, *et al.* Traditional medicine practices among community members with chronic kidney disease in Northern Tanzania: An ethnomedical survey. BMC Nephrol 2015;16:170.
4. London GM, Pannier B, Marchais SJ. Vascular calcifications, arterial aging and arterial remodeling in ESRD. Blood Purif 2013;35:16-21.
5. Meerwaldt R, Zeebregts CJ, Navis G, Hillebrands JL, Lefrandt JD, Smit AJ, *et al.* Accumulation of advanced glycation end products and chronic complications in ESRD treated by dialysis. Am J Kidney Dis 2009;53:138-50.
6. Rostand SG, Brunzell JD, Cannon RO 3rd, Victor RG. Cardiovascular complications in renal failure. J Am Soc Nephrol 1991;2:1053-62.
7. Liyanage T, Ninomiya T, Jha V, Neal B, Patrice HM, Okpechi I, *et al.* Worldwide access to treatment for end-stage kidney disease: A systematic review. Lancet 2015;385:1975-82.
8. Kieny MP, Evans DB. Universal health coverage. Eastern Mediterranean Health J 2013;19:305.
9. WHO. Available from: http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/.
10. Available from: https://www.rand.org/content/dam/rand/pubs/papers/2006/P7994.pdf.
11. Hill NR, Fatoba ST, Oke JL, Hirst JA, O'Callaghan CA, Lasserson DS, *et al.* Global prevalence of chronic kidney disease – A systematic review and meta-analysis. PLoS One 2016;11:e0158765.
12. Masina T, Chimera B, Kamponda M, Dreyer G. Health related quality of life in patients with end stage kidney disease treated with haemodialysis in Malawi: A cross sectional study. BMC Nephrol 2016;17:61.
13. Murtagh FE, Addington-Hall JM, Edmonds PM, Donohoe P, Carey I, Jenkins K, *et al.* Symptoms in advanced renal disease: A cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. J Palliat Med 2007;10:1266-76.

22. Palliative Care for Older People: Global Challenges and Advocacy

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Introduction

Palliative care is an important public health issue due to population ageing and more people are living with the effects of serious chronic illness towards the end of life. Patterns of disease in the last years of life are also changing, with more people dying from chronic debilitating conditions, such as cardiovascular disease, chronic obstructive pulmonary disease, diabetes, cancer and dementia. Unnecessary suffering of older persons for lack of pain medicines and palliative care at the end of their lives violates the basic human rights. This group frequently experiences multiple health problems and disabilities. Palliative care services urgently need to be developed to meet the complex needs of older people. These services need to be available for people with diseases other than cancer and offered based on need rather than diagnosis or prognosis. This topic is often neglected, although it is relevant to everybody.

Understanding the context

Everyone wants older people to live, comfortably and safely, in their homes for as long as possible. Palliative care focuses on improving the symptoms, dignity and quality of life of people approaching the end of their lives and on the care of and support for their families and friends. Everyone wants to see older people, with their wisdom and experience, and continue their contributions to society. Looking ahead, the challenge will be greatest in societies where care for the elderly has traditionally been provided by the extended family network. As societies have modernized, these traditional networks have been disrupted, when children in rural areas migrate to cities, they are leaving their parents behind.

Palliative care needs to be improved for older people in countries with fewer resources such as those in Africa and Asia. We have to focus on their needs and those of their families, provide hospital and home-based care models and integrates pain relief, symptom control and psychosocial care. These efforts vary from country to country and are emerging at the community, national and regional levels.

Ageing demographics

Populations worldwide are ageing, leading to a dramatic increase in the numbers of people living into seventies, eighties and nineties. The proportion of people aged 65 years and older is steadily increasing -

- Between 2015 and 2050, the proportion of the world's population over 60 years will nearly double from 12% to 22%.
- By 2020, the number of people aged 60 years and older will outnumber children younger than 5 years.
- By 2050, 80% of older people will be living in Low- and Middle-Income Countries.

In many countries, the availability of palliative care is very limited, resulting in preventable severe, health related suffering for millions of patients. In our country, according to the records - Help Age India states that among the elderly 'Our Sunset People'

- 30 Million Live alone.
- 55 Million sleep Hungry.
- 90 Million work to Survive.

Global guidelines and challenges

The rights and privileges of elderly is clearly stated in different signed documents - The Historic document adopted by UN on 1948 was the Universal Declaration of Human Rights (UDHR), A Multilateral treaty by UN on 1966- International Covenant on Economic, Social and Cultural Rights (ICESCR), A world wide plan actually provides international collaboration across countries and offers recommendations to individual countries to monitor their progress in dealing with the challenges of population ageing on 2002 - The Madrid International Plan of Action on Ageing (MIPAA), Convention on the Rights of Persons with Disabilities (CRPD) UN on 2006, The 2015 UNGASS Outcome Document, The Astana Declaration,2018 and The 2030 Agenda for Sustainable Development.

The major global challenges in connection with the elderly are Pension policy, Health and long–term policy, Employment policy, Migration and Integration policy and Infrastructure development. Some of the major issues and challenges faced by the elderly are

- Restricted Social Life.
- Mental Torture.
- Denial of Basic needs- Food, Medical Attention, clean clothes…
- Physical Harassment
- Emotional Blackmailing, Humiliation.
- Elder Abuse.
- Isolation and Loneliness.

The vast majority of elderly are both sick and financially dependent and thereby the rates of torture and abuse are very high. Around 1 in 6 people, 60 years and older experienced some form of abuse in community settings. Elder abuse can lead to serious physical injuries and long-term psychological consequences.

One among the major challenges for the poor quality of primary care especially to the elderly is Public Health System Vs Health Services System (Aligning Health Systems to the Needs of Older People).

A multi- layered and multi – skilled workforce is needed to implement health care throughout the country. But India lacks a comprehensive model in promoting quality health care. Demographic trends are outpacing current theoretical frameworks. Rising life expectancy along with the increase in population growth is one among the biggest challenge. The prime focus of Astana Declaration on Primary Care is of the good quality care available to the entire population. Even as the demand increases, there is a shortage of clinicians. Health care needs to become demand driven to satisfy the needs of citizens especially the elderly.

Data collection and analysis

Availability of socio-economic data about ageing has to be documented. In order to enable countries to assess and compare the health status, needs and unmet needs of older people, we have to link the existing surveys and collection of new population level data.

Developing national policy and strategies

Countries get the skills and tools they need to create policies that enable people to live long and healthy lives. Ageing policy tends to place older adults outside the economic and human development. Long range ageing policy requires consideration of a social contact between state and the family. In order to build or strengthen the governance capacity and mechanisms including policies, regulations and financing for ensuring a sustainable health care work force, countries will be supported to review existing strategies related to ageing and health. Thereby coordinate advocacy related activities to raise the profile of ageing and draft national strategies and their implementation. Allocate resources to priorities set by the national administration, so that national standards are adapted to meet local needs, establishing regional guidelines for palliative care for older people.

How to make health budget more sustainable?

- All Stakeholders need to discern how best to use public funds for the common good.
- Based on the social climate of each nation governments need to recognize the effects of demographic change.
- Re-visit the Policy agendas.
- Review Health care financing System.
- To address the current Unmet and growing community Needs.

Advocacy is all about taking action. In order to implement Advocacy framework, following steps are important. We have to prioritise the issues and select the most needed issue for consideration.[1]

- Step 1: Selecting your issue.
- Step 2: Understanding your political context.
- Step 3: Building your evidence base.
- Step 4: Engaging key stakeholders.
- Step 5: Developing strategic Plans.
- Step 6: Communicating messages and implementing plans.
- Step 7: Seizing opportunities.
- Step 8: Being accountable.
- Step 9: Taking a developmental approach.

Alternatives

The normative elements of a right to palliative care for older persons- Recommendations for a binding instrument Submitted in preparation for OEWGA 10 by IAHPC.[2]

- Employ the IAHPC consensus Definition
- Include access to Palliative Care in any article on the right to Health.
- Include an explicit right of Older People to the plan of Care.
- Include provisions regarding supported Decision Making.
- Include reference to palliative care in provisions on Long -term care.
- Include reference to availability of controlled essential medicines.
- Include a reference to the need for working force training in Palliative Care.

The different levels of care has to be monitored to improve the quality of life of elderly are - Improving care for older persons in hospitals, nursing and residential care homes and in resource- constrained settings. For e.g. Improving service provision for elderly people by providing separate queues and reservation of beds in all Hospitals.

Advance care planning

Integrated Care pathways[3] - Care pathways are structured multidisciplinary care plans that can promote teamwork and patient-centred care. Make available care closer to home and a future that gives older people the freedom to benefit from and to live long and healthy lives.

Developing guidance for health systems on how to develop, monitor and evaluate services in ways that can support integrated health care for older people. Training opportunities on Healthy Ageing for policy makers and other stakeholders, Ministries of Health and civil society organizations.

Developing Modern Policies along with Community based initiatives. National Budget – Increase equity in National resource allocation for primary care for the elderly. Make Health Care "inclusive" as International Health systems.

Conclusion

Global Strategy and Action Plan on Ageing and Health (WHO)

The WHO health systems approach is a holistic way of providing health care services, and it emphasizes the need to be aware of the context in which new services are being introduced.

The World Health Organization recommends every nation to uphold these commitments for the better living and dying of older people.

- Commitment to Healthy Ageing.
- Improving measurement, monitoring and understanding.
- Aligning health systems with the needs of older populations.
- Developing systems for providing long-term care.
- Creating age-friendly environments.

We have to build hospitals- without walls for having a joint venture in both public and private sectors.

We have to care for patients - without borders for having a better service to all.

We have to focus on quality- without compromise for having a better community.

So don't hurt them- without understanding, don't throw them away and let them go. But to be there for them to nurture them, to take care of them and when it's your time people will do the same.

Let me conclude with this words-

Move the '**SUNSET PEOPLE'** to the '**MOONLIGHT**'.

References

1. Promoting Health: Advocacy Guide for Health Professionals. International Council of Nurses Section 3; 2008.
2. Pettus K. Normative Elements of a right to Palliative care for Older Persons, (Prepared for Open Ended Working Group of Ageing) IAHPC; 2019.
3. Palliative Care for Older People: Better Practices.Sue Hall, HristinaPetkova, Agis D Tsouroseds WHO Regional Office for Europe; 2011. p. 44ff.

23. PALLIATIVE CARE TEAM AS CARERS

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The privilege of palliative care practice is in merging the evidence and experience of medicine with empathy and emotion. Putting together a carer team is vital to address the physical, psychosocial, emotional and spiritual needs of the patient along with supporting the caregiver. This team is expected to do "more rather than less" [1] as the care delivery planned is needs - based and person centred. Flexibility, organization, communication and cooperation are core requisites in providing effective care delivery.[1]

When palliative care is integrated early, as in our centre, patients gravitate between disease modifying therapy and supportive care needs and shift gradually into end of life care. The goal is to maintain continuity of care. For example, the core team for young Mrs S who received chemotherapy, radiotherapy and palliative care for around two years were the oncologists, palliative care physician, nurse and social worker along with the hospice staff who provided supportive and respite care when needed. When she transitioned into home care, during a visit, she was in stridor. She was moved to the hospice by the home care team with the local hospital support, counselled and then shifted for a tracheostomy which was done by our hospital surgeons. Following the episode, her care continued between home and hospice till her death. Thus, fluctuating demands and changing needs can contribute to the complexities in palliative care.

In a qualitative study by Pask *et al.*,[2] the Bronfenhemmer's Ecological system theory has been used to underpin the complexities in palliative care. The person's needs, pre-existing and cumulative complexities constitute the microsystem. The interactions with the family and the health care provider along with the dissonances and prejudices constitute the mesosystem. The ecosystem includes the availability, coordination and provision of care services. The resources for palliative care in the wider social context have been categorised as the macrosystem. The dynamic nature of the illness, changing needs and the fluctuating burdens are the chronosystem in palliative care. Keeping in mind these components of complexity is required to deliver integrated and targeted care to palliate the person as a whole.

The concept of integration goes beyond the mere presence of an outpatient palliative clinic and aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the care givers. Hui et al have identified thirty eight indicators for integration of oncology and palliative care in a systematic review. Integration is to bring together the administrative, organizational, clinical, and service aspects in order to realize continuity of care between all those involved.[3-5]

Along the trajectory of care, one needs to partner with specialists in different disciplines. When Mrs M with advanced ovarian cancer was brought unconscious to the hospice by the family with end of life care in mind, it was invaluable to have the timely support of the neurologist who helped her recover as it was a stroke that she had suffered. To ensure continuity of care, coordinating with practitioners in the vicinity of patient's homes and across cities and states is necessary. Partnering with specialists to facilitate procedures for symptom control at the earliest requires communication and organization especially in India because patients and caregivers do find navigating the health care system particularly daunting.[6] One elderly woman who had presented to our centre from the bordering state with extensive disease, ascites, severe fatigue and a very poor performance status was brought by the family because though they knew she was terminally ill, she did not have a proven diagnosis inspite of attempts having been made. They were distraught and grieving at having to put the patient through this travel but wished they could confirm the suspicion of malignancy. A sample of ascitic fluid just enough to make a cell block was drawn by the radiologist with the patient on the wheel chair. This was proven malignant by the pathologist and conveyed to the family at their home the next day. Though the patient died soon after, for the family there was a sense of closure.

Palliative rehabilitation which is delivered in partnership with other disciplines and keeping the priorities of the patients in mind has provided a high degree of satisfaction among patients in the study by Cheville et al. It is a flexible model which works towards function directed care recognizing time limited goals.[7,8] Teaming with therapists in physiotherapy, occupational therapy, art, music, nutrition, speech and language, stoma care and others can enable active living even while dying and optimise symptom control, comfort, readjustment and independence.[9-11]

Caring for special groups like children, adolescents and young adults needs dedicated resources along with specially trained carers.[12] Need based care provision as in end of life care, bereavement support, facilitating place of care, spiritual concerns is required to be coordinated by the carer team.[13,14] Our local team has coordinated eye donations when requested by the patient or the family. Though most patients express their wish to die at home,[13] in our experience, for a few, home is sacred and they prefer to die at the hospice. Everyone may not need everything, but coordinating everything possible for the one in need is the team goal.

In order to organise the team, network and coordinate care, delegate responsibilities and designate roles, there should be a leader. The role of the leader is not about doing it all but about empowering the team and creating leaders. With a goal oriented approach and interpersonal skills, the leader needs to be both flexible and strong to enable a cohesive palliative carer team. Productive team delivery is possible when the structure is defined clearly. This includes a clear purpose with designated roles and resources. Trust, knowledge and commitment is expected from the individual team members and the process of communication, coordination, cohesion, decision making, conflict management and feedback needs to be continuous.[15] For effective palliative care delivery, early integration with a flexible, individualised approach in alignment with the philosophy of palliative care is vital. A well endorsed model is the generalist plus specialist palliative care bridged by primary care physicians.[14,16-18]

Bruera and Hui[19] have described three different models of palliative care delivery and recommended the integrated model over the solo practice and the congress model. In the solo practice model, the oncologist takes care of all the disease and supportive care needs. In the congress model the primary physician refers to multiple consultants. Though interdisciplinary, this can be exhausting and result in lack of interaction, drug interactions and conflict and compromise in patient care. In the integrated model, the primary consultant focuses on the disease and the palliative/supportive care team addresses remaining concerns and coordinates specialist care when needed. In oncology, this is considered the fourth arm of comprehensive cancer care playing the supporting role for oncologists and patient's families.

Considering the public health strategy of palliative care,[20] the responsibility of the team extends into advocacy and training activities in palliative care along with promoting the safe use of opioids and ensuring its availability.

Along with care provision, evaluation and contribution to research is also the duty of the carer team. Regular Clinical and Organisational Audits, interdisciplinary teaching and research along with Quality Improvement projects have helped us promote and practice evidence based palliative care.[21-24]

The carer team also has a responsibility to itself. Self-care with a proactive approach to ensure personal health in order to support the care of others, strategies to ensure self-care and the barriers and enablers in its practice were the overarching themes in Mills' qualitative study.[25] ''Remembrance'' has been described as an opportunity for teams to come together on a regular basis to remember the patients who have died and reflect on the effect that these deaths have on the team and the ability to care in the future.[26] Empathy for the patient is a given, but empathy for the fellow clinician and team members is crucial to instill compassion and confidence in the team.

In Visakhapatnam, palliative care is provided through a tertiary cancer centre, the city hospice and a Non-Governmental Organisation supporting home care and hospice; all three of which work as a team. Supporting this team are international foundations like the Jiv Daya Foundation, Two Wolds Cancer Collaborative, Pallium India, service clubs and local donors.

It is this orchestra which plays the symphony of ensuring the best possible Quality of Life for patients as long as they live.

References

1. Gómez-Batiste X, Murray SA, Thomas K, Blay C, Boyd K, Moine S, *et al.* Comprehensive and integrated palliative care for people with advanced chronic conditions: An update from several European initiatives and recommendations for policy. J Pain Symptom Manage 2017;53:509-17.
2. Pask S, Pinto C, Bristowe K, van Vliet L, Nicholson C, Evans CJ, *et al.* A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. Palliat Med 2018;32:1078-90.
3. Aldridge MD, Hasselaar J, Garralda E, van der Eerden M, Stevenson D, McKendrick K, *et al.* Education, implementation, and policy barriers to greater integration of palliative care: A literature review. Palliat Med 2016;30:224-39.
4. Hui D, Kim YJ, Park JC, Zhang Y, Strasser F, Cherny N, *et al.* Integration of oncology and palliative care: A systematic review. Oncologist 2015;20:77-83.
5. Bruera E, Hui D. Integrating supportive and palliative care in the trajectory of cancer: Establishing goals and models of care. J Clin Oncol 2010;28:4013-7.
6. Yellapa V, Devadasan N, Krumeich A, Pant Pai N, Vadnais C, Pai M, *et al.* How patients navigate the diagnostic ecosystem in a fragmented health system: A qualitative study from India. Glob Health Action 2017;10:1350452.
7. Cheville AL, Morrow M, Smith SR, Basford JR. Integrating function-directed treatments into palliative care. PM R 2017;9:S335-46.
8. Nottelmann L, Jensen LH, Vejlgaard TB, Groenvold M. A new model of early, integrated palliative care: Palliative rehabilitation for newly diagnosed patients with non-resectable cancer. Support Care Cancer 2019.
9. Eva G, Morgan D. Mapping the scope of occupational therapy practice in palliative care: A European association for palliative care cross-sectional survey. Palliat Med 2018;32:960-8.
10. Cherny N, Fallon M, editors. The Interdisciplinary team. In: Oxford Textbook of Palliative Medicine. 5th ed. Oxford University Press; 2015. p. 139-228.
11. Olsson Möller U, Stigmar K, Beck I, Malmström M, Rasmussen BH. Bridging gaps in everyday life – A free-listing approach to explore the variety of activities performed by physiotherapists in specialized palliative care. BMC Palliat Care 2018;17:20.
12. Wiener L, Weaver MS, Bell CJ, Sansom-Daly UM. Threading the cloak: Palliative care education for care providers of adolescents and young adults with cancer. Clin Oncol Adolesc Young Adults 2015;5:1-8.
13. Johnson CE, McVey P, Rhee JJ, Senior H, Monterosso L, Williams B, *et al.* General practice palliative care: Patient and carer expectations, advance care plans and place of death-a systematic review. BMJ Support Palliat Care 2018. pii: bmjspcare-2018-001549.
14. Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AG, Hood K, *et al.* Palliative care in hospital, hospice, at home: Results from a systematic review. Ann Oncol 2002;13 Suppl 4:257-64.
15. Mickan S, Rodger S. Characteristics of effective teams: A literature review. Aust Health Rev 2000;23:201-8.
16. El-Jawahri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, *et al.* Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: A randomized clinical trial. Oncologist 2017;22:1528-34.
17. Hackett J, Ziegler L, Godfrey M, Foy R, Bennett MI. Primary palliative care team perspectives on coordinating and managing people with advanced cancer in the community: A qualitative study. BMC Fam Pract 2018;19:177.
18. Quill TE, Abernethy AP. Generalist plus specialist palliative care – creating a more sustainable model. N Engl J Med 2013;368:1173-5.
19. Bruera E, Hui D. Conceptual models for integrating palliative care at cancer centers. J Palliat Med 2012;15:1261-9.
20. Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. J Pain Symptom Manage 2007;33:486-93.
21. Haugen DF, Nauck F, Caraceni A. The Core Team and the Extended Team. In: Cherny N, Fallon M, editors. Oxford Textbook of Palliative Medicine. 5th ed. Oxford University Press; 2015. p. 139-46.
22. Brinkman-Stoppelenburg A, Witkamp FE, van Zuylen L, van der Rijt CC, van der Heide A. Palliative care team consultation and quality of death and dying in a university hospital: A secondary analysis of a prospective study. PLoS One 2018;13:e0201191.
23. Adusumilli P, Nayak L, Viswanath V, Digumarti L, Digumarti RR. Palliative care and end-of-life measure outcomes: Experience of a tertiary care institute from South India. South Asian J Cancer 2018;7:210-3.
24. Vemula SR, Dasu MR, SharmaVV, Katta N, Raju NS, Digumarti L, *et al*. Role of Social Workers and Volunteers in Improving the Quality of Home Care Services. Poster Presented at IAPCON Kochi; 2019.
25. Mills J, Wand T, Fraser JA. Exploring the meaning and practice of self-care among palliative care nurses and doctors: A qualitative study. BMC Palliat Care 2018;17:63.
26. Morris SE, Kearns JP, Moment A, Lee KA, deLima Thomas J. "Remembrance": A self-care tool for clinicians. J Palliat Med 2019;22:316-8.

24. Experiences of the Indian parents and Caregivers about Caring for a Child with Retinoblastoma: An Interpretative Phenomenological Analysis

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Background: Retinoblastoma (RB), accounts for 2.5% to 4% of all the paediatric cancers worldwide. In India 1500 new cases of retinoblastoma are diagnosed every year and 20% of the world's retinoblastoma patients live in India. Survey studies have shown that parents and caregivers of children with retinoblastoma exhibit high levels of anxiety and emotional distress. However, there are no qualitative studies that explore parental or caregiver's experience of caring for a child with retinoblastoma.

Aim: To explore the experiences of the Indian parents and caregivers about caring for a child with retinoblastoma.

Methodology: Fifteen Consenting parents or caregivers, of children with retinoblastoma, caring for at least 12 months were chosen purposively. Two groups were formed; with group 1 comprising of parents whose children did not undergo enucleation of eye and group 2 comprising parents and caregivers of children who underwent enucleation of eye. Interpretative phenomenological analysis (IPA), a variant of phenomenological research methodology was chosen as research design for the study. Data was collected using in-depth, face-to-face interview of the recruited participants using a semi-structured questionnaire. All audio recorded interviews were transcribed and interview transcripts are being currently analysed using NVIVO software. The themes were interpreted through the theoretical lense of Bronfenbrenner's ecological systems theory.

Results: Four major themes were identified during the data analysis.
Theme 1 Caregiving Expectations
Theme 2 Caregiving Experience
Theme 3 Caregiving Distress
Theme 4 Caregiving Hope

Parent's caregiving microsystem and macrosystem had both positive and negative features that balanced the experience of caregiving. However, the failure of parent's caregiving mesosystem, exosystem and chronosystem led to negative experience of caregiving.

Conclusion: The experience of caregiving was similar among parents of the enucleated and the non-enucleated children. Parents had an overall negative experience of caregiving

25. SELF-LEARNING PARTICIPATORY TRAINING FOR CARERS IN PALLIATIVE CARE, INSTITUTE OF PALLIATIVE MEDICINE EXPERIENCE

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In India, most patients who need palliative care are being cared for at home, mostly by family members.

These patients not only have physical issues but also psychological, social and spiritual problems. Often these care givers cannot meet the needs of these patients because of their lack of knowledge.

Care giving without adequate knowledge, skill, support and self care can cause harm to the patients and also increase the risk of adverse health effects on the carers. We should address the training needs of carers in the area of palliative care services. We should target the Family caregivers of those requiring PC and the community volunteers of PC clinics..

We have a handbook module. This is a self-learning participatory tool for the carers. Sessions are organised with activities in between. Aim is to impart information and knowledge to the participants through adult learning techniques.

The duration of the course is 3 days covering about 16 hours. All the important topics are covered. Highlights of this training module is that this gives guidance in establishing a community based palliative care unit and also deals with ethical principles to be followed in decision making and caring for the patient. Includes practical sessions too. Helps them in exploring and documenting physical problems apart from understanding barriers in communication and concepts of ‘active listening’.

No formal evaluation in terms of examination.

All the participants are given a participation certificate at the end of the training

Posters and Free Communication

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Poster Abstracts

Day 1

1. Prevalence of Breakthrough Cancer Pain and Its Impact on Quality of Life in Cancer Patients at Regional Cancer Centre, India: A Cross-Sectional Study (D1-201)

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Introduction: Breakthrough cancer pain is commonly seen in cancer patients with higher pain intensities and poor quality of life. Although efficacious treatment of breakthrough cancer pain is available, its clinical management remains unsatisfactory, indicating the need of proper assessment, diagnostic and treatment guidelines.

Aim of the Study: To find the prevalence rate of breakthrough cancer pain in patient coming to palliative care OPD and palliative care ward. To find the impact of breakthrough cancer pain to quality of life in cancer patients.

Methods: The cross-sectional study was done on patients whose background pain was well controlled on analgesics, receiving in-patient or out-patient treatment at the department of palliative medicine. Study subjects were assessed Breakthrough pain assessment tool and the WHOQOL-BREF questionnaire.

Results: A total of 400 patients were recruited in this study, out of which 156 (39%) patient had breakthrough cancer pain. 56% were female, maximum (65%) in age group 30-60 years of age. Breakthrough pain were common in Head and Neck cancer (17%), Gastrointestinal cancer (14%), Lung cancer (14%) and Carcinoma Breast (13%). Maximum patient were in stage I cancer (42%) followed by Stage IV (23%) Most common location of Breakthrough cancer pain was abdomen (31%) followed by low back pain (18%). 38% of patient had at least 1-2 times breakthrough pain per day. Incidental pain was the most common reason (41%) followed by spontaneous pain (37%). Overall quality of life score was 1.8, showing very poor quality of life in patients having breakthrough pain. Mean score of overall health satisfaction was 2.1, showing dissatisfaction. Quality of life domains (physical, psychological, social, environmental) showed lower scores.

Conclusion: There is a big lacuna in understanding the depth of breakthrough pain. Poor quality of life in patients with breakthrough pain necessitate some intervention and proper care plan to improve their quality of life in palliative care setting.

Keywords: Assessment; breakthrough cancer pain

2. Evaluation of the Prevalence, Type and Severity of Physical Pain in Patients Attending Geriatric Clinic and Appropriate Interventions Required (D1-202)

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Introduction: Pain is the universal symptom among the patients attending our geriatric clinic. Type and severity of pain varies, and so does the treatment options. In this study, we try to analyse the prevalence, type, site and severity of physical pain among the patients attending the geriatric clinic in a tertiary care hospital in Mangalore, and to know the appropriate corrective measures to be undertaken.

Aim of the study:

1. To analyse the prevalence of pain among the patient group
2. To assess the types, site and severity of pain (in visual analogue scoring system).
3. To know the effective treatment for each type.

Materials and Methods: Setting: geriatric clinic of a tertiary care hospital in Mangalore.
Study period: October 2017-oct 2018.
Sample size: 300.
Study design: descriptive study with convenient sampling.

Inclusion Criteria: Any patients presenting with complaints of physical pain to the geriatric clinic.

Results: Our study showed that the prevelance of radiculopathies were more common than nociceptive pain in the study population. Most of the patients had pain of knee joint (65%) and shoulder joint (26%) among the radicular pain. The most effective intervention was found to be physiotherapy and yoga, than analgesics, also the patients recruited into active ageing societies and groups were found to have better symptomatic improvement.

Conclusion: The pain in elderly are often difficult to interpret and tackle when compared to younger age group. Often they are linked to social background and mental health of the patients. And hence interventions like physiotherapy, yoga, active socializations etc are found to be more effective than analgesic therapy in this age group.

Keywords: Pain; symptoms

3. An Observational Study to Determine the Association Between Pain and Performance Status in Cancer Patients Attending Out-Patient Clinic (D1-203)

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Introduction: Multidimensional cancer pain invariably impacts patients' activities of daily living and various aspects of their quality of lives. Performance status, a fundamental prognostic indicator, has rarely been applied to monitor the association with cancer symptoms.

Aim of the Study: The study aimed to determine the association between pain and functional performance status in cancer patients attending out-patient clinic in Indian set-up.

Materials and Methods: A multicentric cross-sectional study was conducted in 261 cancer patients attending out-patient pain clinic to determine the association between pain (Numerical Rating Scale) and Eastern Cooperative Oncology Group (ECOG) score. Kruskal-Wallis test and Bonferroni correction were used to find this association. p-value <0.05 was considered significant.

Results: Mean age of patients was years 50.9 years, and 56.7 were male. The mean pain severity was 5.1. Significant association was observed for increase in pain score with increasing ECOG score (p-value-0.0001). The table below provides descriptive and association values between both variables.

Conclusion: The inverse relationship between performance status and cancer pain implies that pain is one of the strong determinants of performance status in cancer patients.

Keywords: Pain; symptoms

Acknowledgement: This study is supported by grant from pharmaceutical division (i.e. Janssen) of Johnson and Johnson Private Limited, Mumbai. There are no conflicts of interest to declare.

4. CANCER PAIN, ANXIETY AND DEPRESSION IN ADMITTED PATIENTS IN A TERTIARY CARE HOSPITAL – A PROSPECTIVE OBSERVATIONAL STUDY (D1-204)

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Introduction: Pain is the commonest symptom in admitted cancer patients. The association between severity of cancer pain and distress symptoms like depression and anxiety is a subject of research.

Aim of the Study: To study the prevalence of pain, anxiety and depression in admitted cancer patients and determine association between pain and anxiety and depression at a tertiary cancer care institute.

Materials and Methods: Prospective observational study.

We enrolled 393 cancer in-patients prospectively after written informed consent. Their disease details, presence, severity and character of pain were recorded. Numerical Pain Scale was used for pain scores, self-reporting Hospital Anxiety and Depression Scale for anxiety and depression.

Statistical Analysis Used: Normal data was analysed with Parametric, non- normal with Non-parametric methods and categorical with Chi-square test.

Results: The prevalence of moderate-severe pain was 41.5%, anxiety 20.3% and depression 24.8%. Proportion of patients with anxiety and depression was 9.2% and 17.7% in patients with no pain; 32.8% and 36.7% with severe pain respectively (p<0.000). In patients with no depression 6% had anxiety; with depression 44.9% had anxiety (p<0.000). Odd's ratio to have anxiety and depression was 4.44 (95% CI 2.0318 to 9.7024) and 2.92 (95% CI 1.5739 to 5.4186) respectively in patients with pain as compared to no pain (p<0.00). There was positive correlation between pain, anxiety and depression scores.

Conclusion: There is strong association between the presence and severity of pain and distress symptoms like anxiety and depression in admitted cancer patients.

Keywords: Pain; symptoms

5. NEUROPATHIC PAIN AND ASSOCIATED SYMPTOM BURDEN IN HEAD AND NECK CANCER PATIENTS ATTENDING SPECIALIST PALLIATIVE CARE SERVICES (D1-205)

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Introduction: Pain is a common symptom in cancer patients, affecting 40-90% of patients. The prevalence of neuropathic pain (NP) varies between 19%-39%. Head and neck (H&N) cancers constitute major cancer burden in India. Previous studies have reported prevalence of NP of 11.8% in all and 32.2% in H&N cancer patients, respectively.

Aim of the Study: To examine the prevalence of NP and associated symptom burden and its correlation with pain in H&N cancer patients referred to specialist palliative care (SPC) service.

Materials and Methods: A retrospective analysis of electronic & paper medical records of adult H&N cancer patients referred to SPC services in a tertiary care cancer centre between 1/7/ 2018 to 31/9/2018 was done. Sociodemographic, disease and treatment-related variables were noted. Pain score was recorded as documented on Edmonton Symptom Assessment Scale (ESAS) and presence of NP was noted from descriptors documented. Descriptive statistics and tests for association & correlation were done using IBM SPSSversion21.

Results: 158 patient records were analyzed. There were 130 males (82.3 %). Mean age was 50.3 years (SD 13.2). Buccal mucosa and tongue were the most common sites affected (39 patients, 24.7%). The mean pain score was 4.92 (SD 2.19) on ESAS and median was 5. NP was present in 110 (70%) patients. Fatigue and low well-being were the most common symptoms, present in approximately 49%patients. Significant correlation of pain was seen with fatigue, low well-being, anxiety &sleep (p<0.05). Tramadol was used in 74 (46.8%) patients and adjuvant pregabalin in 94 (59.5%).

Conclusion: We report that NP was present in almost 70% of H&N cancer patients referred to palliative care, with commonly associated symptom burden of fatigue and low well-being. There was statistically significant correlation between NP and fatigue, low well-being, anxiety & sleep. There is a need to conduct cross-sectional and prospective studies in the area of NP in advanced H&N cancer patients.

Keywords: Pain; symptoms

6. METHADONE - A PROMISING MEDICATION IN INDIAN PAIN AND PALLIATIVE CARE (D1-206)

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Introduction: Morphine is the strong opioid which is available to many palliative care centres in India. Usually Indian Palliative care professionals are very much experienced with usage of morphine and its titration. When the pain does not respond/poor response to Morphine, usually the patients suffer as we don't have many opioids to switch. Methadone was available in India for the last one year and only a couple of centres are using it.

Aim of the Study: To examine the prevalence of NP and associated symptom burden and its correlation with pain in H&N cancer to review the process of overcoming barriers for starting methadone

- To review the methadone use at Trivandrum Institute of Palliative Sciences from February- December 2018

Materials and Methods: Experience sharing by the TIPS physicians, how they overcame the barriers of starting methadone. We analysed the case sheets of patients who have taken methadone in the above period.

Results: TIPS-ECHO classes, talking to physicians who are experienced in using methadone, usage of social media for communication like WhatsApp and e-mails helped the physicians to start methadone. Only 8 patients were given methadone for various indications like neuropathic pain, morphine toxicities, and ischemic pain. Most of them had good pain relief and some of them had excellent pain relief. Methadone was discontinued in a few patients as they didn't have reliable caregiver.

Conclusion: Methadone is a strong opioid which needs to be used in selected group of patients which can provide good pain relief. Some of the barriers for methadone use might be due to unfamiliarity with this medication, drug interactions and various titration schedules which makes the beginner confused.

Keywords: Methadone; neuropathic pain; symptoms

7. The Ghost Pain...Phantom Pain (D1-207)

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Introduction: Phantom limb pain is the pain perceived by the region of the body no longer present was first described by Ambrose Pare, a sixteenth century French military surgeon.

Silas Weir Mitchell, a famous Civil War surgeon in the nineteenth century, coined the term "phantom limb pain". It continues to remain a poorly understood and difficult to treat medical condition. A recent study estimated that there were about 1.6 million people with limb loss in the USA in 2005 and this number was projected to increase by more than double to 3.6 million by the year 2050. Vascular problems, trauma, cancer, and congenital limb deficiency are among the common causes of limb loss.

Aim of the Study: Phantom pain is a foxing and distressing symptom and difficult to manage chronic pain for pain practitioners. Awareness of the concept its mechanisms and how it should be managed will be clinically useful to many pain practitioners.

Materials and Methods: The management of phantom limb pain in an amputated disease free patient (soft tissue sarcoma) referred from the orthopaedic department of VPS Lake shore hospital, Cochin methodology is descriptive by case detailing.

Results: Application of mirror therapy as reported by Dr Ramachandran and Rogers in 1996, in resolving visuoproprioceptive disassociation in the brain resulted in better pain control.

Conclusion: The presentation shows that there is benefit in both pharmacological and non-pharmacological methods including mirror therapy in the resolution of symptoms of this patient.

Keywords: Mirror therapy; phantom limb pain; symptoms

8. Initial Response to Morphine Administration in Opioid Naïve Patients Managed for Severe Cancer Pain (D1-208)

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Introduction: Cancer pain can be severe enough to affect activities of daily living. Morphine is commonly used in effectively managing moderate to severe pain due to cancer. However, selection of initial morphine dose to treat pain varies among physicians thereby affecting pain relief in initial 24 hours.

Aim of the Study: 1. To evaluate response to morphine in initial 24 hours with respect to pain relief. 2. To assess frequency of significant side effects.

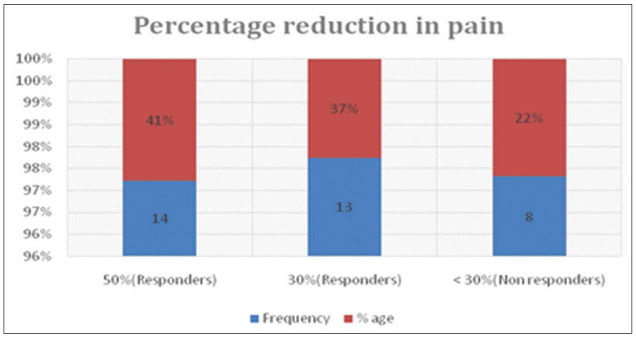
Materials and Methods: A retrospective study of 35 patient records of opioid naïve patients with metastatic cancers were analysed. Pain assessment using Numerical Rating Scale and effect on daily functionality was studied before and 24 hours after initiating morphine. Significant side effects were also analysed. Morphine doses have been presented as morphine equivalents. A 50% reduction in NRS was considered "good response", 30% "satisfactory response" and < 30% a "poor response." A correlation between dose and response will be studied.

Results: Graph 1: Percentage reduction in pain in responders and non-responders group. Graph 2: Incidence of significant side effects studied in various groups.

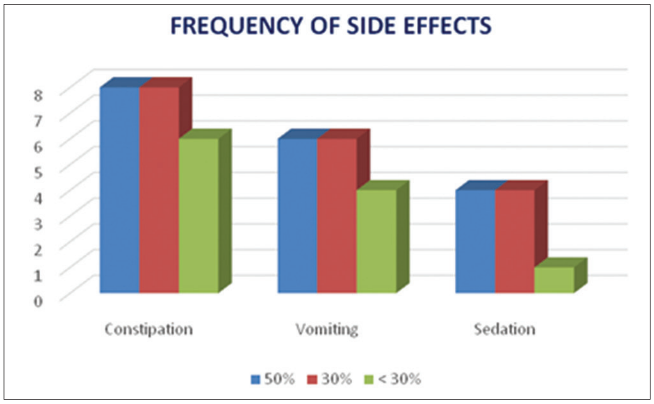
Conclusion: In the 35 patients studied, 41% had good response, 37% satisfactory response and 22% had "poor" response. The "responders" were on an oral morphine dose ranging from 25-50 mg/day [Table 1]. The side effects studied were more common in responders.

Table 1: Range of Morphine dosage in the responders and non-responders group

Mean dose of 3 groups	Mean	Range
Responders> 50%	31%	25-40 mg
Responders 30-50%	24.5%	15-40 mg
Non-responders <30%	20%	15-50 mg



Graph 1: Percentage reduction in pain in responders and non-responders group



Graph 2: Incidence of significant side effects studied in various groups

Keywords: Cancer pain; dosage; morphine

9. The Effect of TENS on Pain and QOL in Palliative Care (D1-209)

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Introduction: Cancer-related pain is complex and multi-dimensional yet the treatment protocol for the cancer pain has been medication approach. There are so many non-pharmacological and innovative pain management strategies available. Transcutaneous electrical nerve stimulation (TENS) plays a major role in pain relief in all types of pain. The aim of this study was to determine the effectiveness of TENS for cancer related pain and improving the quality of life.

Objectives:
- To find out the effectiveness of TENS on pain in cancer patients
- To find out the effectiveness of TENS on improving quality of life in cancer patients
- To find out the combine effect of TENS and Step II analgesics for pain in cancer patients.

Methods: 60 patients were selected who fulfilled the selection criteria and divided into two group.30 patients in each. Duration of the study is 8 weeks. Group A treated with TENS and Step 2 analgesics and Group B treated with Step 2 analgesics. Pre-test values were collected.

Results: The results obtained from NPRS scale shows the significant difference in pain reduction and improving quality of life, The post-test values for Group A and Group B was 4.26 at 0.05 % level of significance, which was greater than the tabulated 't' value 2.048. The result shows that there was significant difference between Group A and Group B.

Conclusions: Transcutaneous Electrical Nerve Stimulation plays major role in reducing pain and improving quality of life in the patients with cancer pain. Even though there is a significant reduce in pain and QOL in patients who only treated with Step II analgesics, but along with the TENS there is quicker and significant results in pain reduction and improvement in QOL.

10. Tramadol or Tapentadol? A Clinical Audit of Prescribing Patterns for Managing Moderate Pain in Palliative Care Patients (D1-2010)

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Introduction: 66.4% of cancer patients experience pain in advanced or terminal stages. Moderate to severe pain is reported in 38% of all cancer patients. As per World Health Organisation Step ladder for pain management, moderate intensity pain is managed by opioids like tramadol or tapentadol along with step 1 analgesics and adjuvants.

Aim of the Study: To audit the prescribing patterns of tramadol and tapentadol for management of moderate intensity pain in adult cancer patients attending specialised palliative care clinic.

Materials and Methods: Retrospective analysis of medical records and assessment charts of adult cancer patients attending palliative care clinic over a 2-month period were analysed. Patients with moderate intensity pain were included. We noted demographic variables, cancer diagnosis, type and score of pain (as recorded on Numerical Rating Scale), prescription of tramadol and tapentadol and baseline biochemical test results. Descriptive measures were used for analysis.

Results: 237 patient charts were analysed. 121 were males, the most common cancers being lung (36), gall bladder (29) and breast (24). 141 (59.4%) patients had nociceptive pain and 96 (40.5%) had neuropathic pain. Average pain score was 4.7. 149 (62.9%) patients were prescribed tramadol and 88 (37.1%) tapentadol. Among the 88 patients prescribed tapentadol, baseline liver function tests (LFT) and serum creatinine were reported to be deranged in 40 (45.5%) and 15 (17%) patients respectively. Among patients prescribed tramadol, 8 (5.3%) were reported to have baseline LFT abnormal and 9 (6%) had serum creatinine deranged. Tramadol was prescribed to 68 (70.83%) and tapentadol to 28 (29.1%) patients with neuropathic pain.

Conclusion: Our audit reports that both tramadol and tapentadol were used for moderate intensity pain in our patient population. There is a trend for prescribing tapentadol in patients with baseline LFT abnormality. The implication of this study is that prescribing patterns should focus on biochemical parameters and also take into account medication cost for the patient.

Keywords: Moderate pain; tapentadol; tramadol

11. A CASE REPORT of Pregnancy in a Young Lady with Metastatic Epithelioid Angiosarcoma - Nursing Perspectives (D1-211)

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Introduction: Epithelioid angiosarcoma is an aggressive endothelial tumour that may arise from adrenals, thyroid, skin or bone. We present a case of a young pregnant lady with metastatic epithelioid angiosarcoma arising from the right postauricular region on supportive care.

A Case Report: A 25-year-old lady, diagnosed with metastatic epithelioid angiosarcoma with lung and multiple bone metastases presented to Palliative Medicine outpatients in June 2017 with a non-healing ulcer in right postauricular and temporal region of the scalp (site of primary) with pricking pain over the ulcerated area (9/10 pain score) radiating to right shoulder and upper limb. Her pain was poorly controlled with ongoing weak opioid medications and was thus started on oral Morphine, Acetaminophen, and Amitriptyline. Her husband was empowered for doing wound dressing at home. She was on routine follow up with Palliative Medicine outpatients for over a year when she presented with ultrasound s/o 7 weeks of live intrauterine gestation in June 2018 with good general condition. Despite extensive discussions with the patient and family, she was very keen on continuing the pregnancy as she had a history of two abortions in past. Amitriptyline was stopped, and the dose of Morphine was carefully titrated but could not be stopped as she had severe pain in stopping Morphine. We started maintaining liaison with a multidisciplinary team of gynaecologist, neonatologist, anaesthesiologist, psychologist, and medical oncologist to provide optimal holistic care to the patient and family. Morphine was rotated to Buprenorphine in the third trimester of pregnancy, and a decision was taken for caesarean section at 36 weeks of gestation with extra vigilance for any opioid withdrawal symptoms in the new-born.

Conclusion: With a multidisciplinary team effort, it is possible to respect patient's choice and provide holistic care.

Keywords: Metastatic epithelioid angiosarcoma, pregnancy, pain management, opioid withdrawal

12. Development Of A Culturally And Linguistically Appropriate Version Of IPOS For Use In Nepal (D1-212)

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Introduction: Palliative care need is increasing in Nepal. A national strategy adopted by the government is in the early stages of implementation. Evaluation is vital in ensuring that high quality care is delivered as strategy implementation proceeds.

POS/IPOS (Palliative Care Outcome Scale/Integrated POS) are 10 item Patient Reported Outcome Measures (PROM) designed to measure patients' physical, psychological, emotional and spiritual symptoms/issues plus information and support needs. Developed in UK, POS/IPOS are validated PROMs translated into 18 and 8 languages respectively and used globally. Africa POS (APOS) was developed for low-income settings principally in Africa.

In 2016 a brief feasibility study successfully demonstrated the utility and acceptability of a Nepali language version of (APOS). Subsequently Africa Integrated POS (AIPOS) was made available.

Aim of the Study: To develop a culturally and linguistically appropriate version of AIPOS for use in Nepal.

Materials and Methods: Following the developer's guideline AIPOS is being culturally adapted and translated into Nepali. Led by an expert review panel the process includes: literature review and concept adaptation of AIPOS items appropriate for Nepal; testing of concepts by patient/carer and health professional focus groups; translation; back-translation; and qualitative pre-testing of the new Nepali AIPOS tool.

Results: Several challenges emerged both in the literature review and subsequent focus groups. E.g. the concept of "peace" is particularly associated with being ready for death as opposed to a feeling of "peacefulness" and "life being worthwhile" has no direct conceptual equivalent. Focus groups demonstrated the widespread reticence to talk directly with patients about their illness and prognosis even within a palliative care context. The process of translation of Nepal AIPOS is ongoing.

Conclusion: Development of Nepali AIPOS has demonstrated conceptual challenges that requiring careful consideration to ensure cultural and linguistic validity. Lessons from this project could be useful for informing development of POS into other Asian languages.

Keywords: Public health and policies

13. Communication - Best Done At Eye Level' A Nepal Hospital Initiative (D1-213)

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Introduction: Communication underpins good holistic care. Techniques to facilitate good communication are well known, but not always easy to translate into general clinical practice. One simple technique is health workers and patient/clients be at the same eye-level facilitating 2-way interaction. Green Pastures Hospital (GPH), Pokhara, provides care for leprosy, rehabilitation including of spinal cord injuries, and now palliative care (PC). The PC team facilitated a "Communication – best done at eye level" initiative, to encourage holistic care for all our patients.

Aim of the Study: To encourage staff to sit at the same eye-level as patients for clinical interactions.

Materials and Methods: The donated simple well-labelled bedside stools were distributed, and education held for doctors, nurses and other staff through normal education/clinical meetings. 5 months later, 7 x 2-hour audits were performed over a 3-week period, observing the presence and usage of stools on ward rounds and at other times when staff were involved with patient interactions. 25 Staff (20 based on wards) completed a simple questionnaire re their attitudes and practice; then 1 patient and 2 staff focus groups explored emerging issues and ways to farther encourage communication.

Results: The audit showed the median presence of stools was 88% (range 76-92) and median of clinical usage 27% (range 10-33). Questionnaires showed 96% staff (all but one non-ward staff) clearly understood the purpose, and 72% used them at least several times per week. Positive group feedback emerged from both staff and patients.

Conclusion: Ongoing education and farther initiatives based on group suggestions will be implemented to ensure stools are increasingly utilized.

Keywords: Communication, holistic care

14. Low Dose Menthol Application for Neuropathic Pain: Case Studies From A Hospital in Nepal (D1-214)

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Introduction: Managing neuropathic pain (NP) is difficult as most therapeutic agents have limited effectiveness with significant side effect profiles. A novel intervention of cold-induced analgesia elicited by low dose menthol application is currently being explored internationally. At Green Pastures Hospital (GPH), Pokhara, previous clinical audits of leprosy and spinal cord injury patients have highlighted significant burdens of neuropathic pain, impacting sleep, mood and daily function.

Aim of the Study: To undertake case studies on the effectiveness of 2%menthol in mustard oil for people with NP from various conditions referred to the GPH palliative care service.

Materials and Methods: Patients experiencing NP were identified and gave informed consent. Pain data was collected using two tools - Brief Pain Inventory (BPI) short form and Leeds Assessment Neuropathic Symptoms and Signs (LANSS) pain scale. Twice-daily application of 2%menthol in mustard oil over 6 weeks was assessed: pre-application (baseline), 2-hours post-application, at 2-week and where possible at 6-week intervals. Confounding effects of pain reduction due to underlying improvement (eg of leprosy reaction), was checked by 2%menthol initially applied to one affected limb, and pain data at the 2-week interval confirming positive difference.

Results: In 19 cases, 18/19 (95%) showed improvement and the number of responders (≥30% reduction total BPI) was 89%. The median total BPI improved from 76 (range 50-95) to 36 (range 8-68), a median total BPI improvement of 40.5 (range 12-64) and median total BPI percentage improvement 53% (range 22-83%). Median of worst pain improvement was 44%, with 84% showing ≥30% improvement. Median total LANSS improvement was 16 (range 4-21) and median LANSS percentage improvement 88% (range 25-100%).

Conclusion: 2% menthol as a novel intervention for neuropathic pain in our case studies has elicited some very encouraging results and farther research is needed.

Keywords: Interventions and neuropathic pain management

15. Evaluation of Assessment of Depression in Cancer Patients in Oncology ward in Square hospital (D1-215)

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Introduction: In Bangladesh nearly around 2 lacs patients are being diagnosed with cancer every year. Depression is a global problem, irrespective of social, economic, educational status or presence of other physical illnesses. Approximately 1 in 4 palliative care patients have some symptoms of depression which needs to be assessed for holistic care.

Aim of the Study: Whether patients are being assessed for depression
- To determine if appropriate patients are being assessed by doctors
- To ensure if depression assessment tool has been used
- To ensure alternative diagnosis of depression has been ruled out.

Materials and Methods: A retrospective data collection was done from 1st July to 31st Nov 2018 by reviewing the hospital records of patients seen in Oncology centre.

We then conducted an awareness programme amongst medical professionals regarding importance of psychological assessment in holistic care. Re-audit was done checking patients records from 1st Dec to 30th Dec 2018.

Inclusion Criteria: All cancer patients admitted in Oncology dept, square hospital.

Results: In July 2017 total number of patients admitted in Oncology ward was 75 and none of the patient were assessed for depression. But after the awareness program, in December 2018 the same audit was carried out and almost 88.8% patients were being evaluated for depression. Our study also revealed certain risk factors for depression in cancer patients.

Conclusion: The diagnosis of depression is a challenge within the cancer population and few indicators that may suggest a need for early intervention are
- A history of depression
- A weak social support system
- Poor prognosis
- Greater disability

Keywords: Depression, cancer patients

16. Impact of Patient Factors on Mental Strain of Caregivers of Head and Neck Cancer Patients Undergoing Palliative Radiotherapy (D1-216)

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Introduction: Head and neck cancers is one of the commonest cancers in India, and the incidence is rising. Caregiver is an individual who is responsible for meeting the needs of the cancer patient and helping them in performing their daily activities. However, healthcare personnel rarely take into account the burden this causes to the caregiver.

Aim of the Study: This study aims to assess the mental stress burden among caregivers of head and neck cancer patients who underwent palliative radiotherapy, and correlate them to the characteristics of the patient.

Materials and Methods: A retrospective study of caregivers of all 57 patients with head and neck cancer who completed palliative radiotherapy during September to November 2018 were assessed by the Caregiver Strain Index (CSI).Positive response to seven or more items on the Index indicate a greater level of strain. Data was collected regarding the patients' age, sex, performance status, primary site of malignancy, initial stage, use of tracheostomy tube and feeding tube, age and education level of caregiver, distance to treatment centre. Data was analysed by using SPSS v22.

Results: There was a statistically significant association ($p<0.1$) between high Caregiver Strain Index (CSI) score and use of feeding tube, tracheostomy tube, distance to treatment centre, performance status of the patient. Increased age of the caregiver also had a significant association with high CSI score. There was no significant association between education level of the caregiver and increased CSI.

Conclusion: A positive result on the CSI (7 or more items positive) indicates that more in depth assessment of the patient's caregiver is required and appropriate intervention should be applied as soon as possible. Caregivers of patients presenting with the above mentioned factors should be given priority for further assessment. However the results need to be validated further due to small sample size of the study.

Keywords: Specific pathologies and patient groups; psycho-oncology and mental health needs in palliative cares

17. STRESS IN INFORMAL WOMEN CAREGIVERS OF CANCER PATIENTS UNDER HOME-BASED-SUPPORTIVE CARE (D1-217)

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Introduction: The needs and concerns of informal caregivers of cancer patients have been neglected within cancer care services. Only recently the role of informal carers has been recognized. A carer's psychological welfare is symbiotically linked to the patients' care and wellbeing.

Aim of the Study: To identify the different stressors among the informal carers.

Materials and Methods: All the caregivers lived with their families. Most of the caregivers were living with limited resources. Observation method and unstructured interviews were conducted for six months with 5 women care givers and the stressors were identified after triangulating the findings.

Results: Many experiences were common to all participants. Levels of stress differed among them. Their main stressors were psychological which resulted in anger, guilt (could be poor symptom control), anxiety, fear of death of patient, depression, uncertainty, anticipated grief and burn out. Along with psychological stressors, it was very difficult for them to bear the stress of care-giving alone. They faced emotional and practical barriers in providing care. All of them were concerned about the future prognosis and its impact on the quality of life of the patients as well as for the future of their dependent family members, in cases where patient was the sole breadwinner of the family.

Conclusion: Primary caregivers feel lonely and have emotional and practical concerns that are overlooked by the other family members. Along with the primary care, discussion can resolve many of their issues emerging during the end-of-life care. Women carers lead poor quality of life as they ignore their own health due to stress

Keywords: Specific pathologies and patient groups; psycho-oncology and mental health needs in palliative cares

18. THE IMPACT OF A FAMILY SYSTEMS APPROACH IN ALLEVIATING PSYCHOSOCIAL DISTRESS IN PALLIATIVE CARE

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Introduction: This paper is a compendium of three specific case studies highlighting the efficacy of a family systems approach towards case conceptualisation and interventions in providing respite in psycho social distress.

Aim of the study: 1. To understand the impact of chronic progressive conditions, such as cancer, on the family system. 2. To review psychological issues in the context of the family and the interventions of family systems within the palliative setting.

Materials and Methods: Case Study

Discussion: The family and the community are important environmental factors influencing individuals. In a family system, members have a defined role that maintains equilibrium and cohesiveness. Chronic illness potentially threatens this equilibrium and gives rise to various stressors within the family system. Three case studies where family interventions were conducted by the psychologist are highlighted. The family systems approach in understanding issues regarding communication, collusion, breaking bad news, family conflict, caregiver support, respect for autonomy and bereavement within each case is reviewed. Intervention strategies such as genograms, family meetings, drawing boundaries, psychoeducation and circular questioning are highlighted.

Results: In the cases studied, the psychologists conceptualised patient's issues in the context of family systems. Using intervention techniques that involved addressing the family system as a whole, the patient and care giver's distress was addressed.

Conclusion: These case-based studies emphasise the need for a family systems approach towards cancer patients at end of life, as opposed to an individualistic approach, in order to facilitate improvement in the patient's quality of life.

Keywords: Psycho-oncology and mental health needs in palliative cares; specific pathologies and patient groups

19. TO EVALUATE THE ASSOCIATION OF RESPITE PALLIATIVE CARE ADMISSION AND SYMPTOM MANAGEMENT IN PATIENTS WITH ADVANCE CANCER (D1-219)

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Introduction: Palliative care aims to improve quality of life through better symptom control, coordination of care, and improved communication between healthcare professionals, family and caregivers in terminally ill patients. Respite Model of Palliative Care is an out-of-hospital specialist palliative care service of a tertiary care oncology centre where patients are admitted briefly for symptom control, psycho social support, empowerment of caregivers, with continuity of care being provided by liaising with local medical/palliative care centres.

Aim of the Study: To evaluate the association of respite palliative care admission and symptom management in adult patients with advanced cancer.

Materials and Methods: Medical records of all adult patient admitted to Respite palliative care facility from January 1, 2018 to September 30, 2018 were analysed. The symptom burden at the time of admission and at discharge as recorded in the ESAS [Edmonton Symptom Assessment Scale) score for each symptom was noted individually. The data was analysed using SPSS ver21. Descriptive statistics were used to analyse demographic and clinical characteristics and inferential statistics used to evaluate the difference in individual symptom burden on admission and discharge ($p<0.05$ considered as significant).

Results: The records of 397 adult patients admitted to the respite facility were screened. The mean ESAS score for each symptom at admission and at discharge was analysed. The mean duration of stay at the respite facility was seven days. There was significant improvement ($p<0.001$) in all symptoms at discharge with maximum improvement noted in symptoms of pain, anxiety and loss of well being.

Conclusion: Admission at the respite palliative care centre facilitates significant improvement in physical and psychological symptoms among patients with advanced cancer.

Keywords: Symptoms; symptoms other than pain and its management

20. PREVALENCE AND FACTORS AFFECTING DYSPNEA IN ADVANCED CANCER PATIENTS PRESENTING IN PALLIATIVE CARE UNIT AT A TERTIARY CANCER CENTRE IN INDIA (D1-220)

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Introduction: Dyspnoea is a common distressing symptom experienced by a vast majority of patients with advanced cancer. The prevalence of dyspnoea is highly variable depending on the stage of disease and ranges from 10 to 70 %. Being a multifactorial symptom difficult to manage, it is of utmost importance to gather data about this complex symptom to optimize treatment and provide better and individualized therapeutic options according to the clinical context.

Aim of the Study: The objectives of this study were to determine the prevalence of dyspnoea in patients seeking admission to the palliative care ward of a tertiary cancer hospital in northern India at the time of admission, the intensity of the symptom as perceived by the patient and the factors associated with the presence of dyspnoea.

Materials and Methods: This was a prospective observational study done over a period of 6 months from November to April 2017 at the Department of Palliative Medicine, IRCH, AIIMS, Delhi. All patients admitted in the palliative care ward were screened and recruited as per the inclusion criteria. We did a one-time assessment of the participants at their admission. It involved recording of socio-demographic information, performance score using Eastern Cooperative Oncology Group (ECOG) scale, dyspnoea by Modified Borg Scale and other disease related information.

Results: The prevalence of breathlessness was 16.6%. In these patients, the mean intensity of breathlessness was 3.4. Most common Primary tumours were Ca lung (40%) and gynaecological malignancies (26.6%). 62.5 % had pain associated with dyspnoea, 43.7% had complaints of fatigue, 37.5% had associated abdominal distention.

Conclusion: Proper clinical assessment of dyspnoea using valid tools may help to avoid underestimation of dyspnoea. Complete relief from dyspnoea is often difficult, however appropriate interventions to treat the reversible causes along with management of associated factors helps to decrease the distress, thereby improving the quality of life.

Keywords: Advanced cancer and management; dyspnoea

21. IMPACT OF A NEW HOME-BASED PALLIATIVE CARE SERVICES IN NAVI MUMBAI AND GREATER MUMBAI (D1-221)

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Introduction: Studies have shown that home based palliative care services improve physical symptoms, psychosocial issues. The Department of Palliative Medicine, Tata Memorial Centre (TMC) set up a new home-based palliative care team for advanced cancer patients residing in Navi Mumbai and adjacent areas.

Aim of the Study: To assess the impact of home-based palliative care services on patients with advanced cancer registered with TMC, residing in Navi Mumbai and adjacent areas.

Materials and Methods: Descriptive statistics at enrolment and inferential statistics to compare changes in symptom profile were calculated using IBM SPSSversion21 through an audit over a period of one year.

Results: A total of 72 patients were enrolled by the new home care team, among whom 38 were women. Mean age of all patients was 55 years. 29.2% patients had performance status 3 on ECOG. Symptoms were recorded on the ESAS scale. Most common symptom at enrolment was pain (mean score 2). We performed sequential home visits for every patient with a mean number of 4 visits and after 7-10 days on an average. Between the first 2 home visits, it was seen that most of the ESAS symptom scores, except for dyspnoea and drowsiness, decreased with a significant decrease in nausea ($p<0.05$). Procedures done in home visits were urinary catheterization and nasogastric tube insertion (8% patients). Psychosocial assessment revealed that 58% families had collusion regarding disclosure of cancer-related information to the patient. However, 90% showed good coping with advanced cancer.

Conclusion: This audit reports the annual result of a newly established homecare service in a densely populated area like Navi Mumbai and adjacent areas, who find it difficult to access service of the main hospital located in the heart of the city.

Keywords: Home based palliative care; symptom management

22. ELECTROLYTE IMBALANCE IN ADVANCED CANCER PATIENTS REFERRED TO SPECIALIST PALLIATIVE CARE CLINIC IN A TERTIARY CARE CANCER CENTRE (D1-222)

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Introduction: Advanced cancer patients often have electrolyte abnormalities, needing identification and prompt management for improving their quality of life. We aim to measure the prevalence of these abnormalities in advanced cancer patients in a specialized palliative care clinic.

Aim of the Study: To measure the prevalence of electrolyte imbalances in advanced cancer patients in a specialized palliative care clinic.

Materials and Methods: A retrospective analysis of electronic medical records and charts of adult advanced cancer patients assessed in a palliative care clinic was done. Records with documented sodium/potassium/calcium abnormalities were included and the study period was 2 months. Records with incomplete data were excluded. Socio-demography, cancer diagnoses, presenting symptoms, performance score and documented reports of sodium, potassium and calcium abnormalities were noted. The statistical analysis was done using the SPSS software.

Results: Of 900 patients seen by the service in the 2-month period, 167 (18.5%) fitted the eligibility criteria. Most were men (61.1%) and the mean age was 53.1 years (SD 14.18). The most common electrolyte abnormalities were hyponatremia (62.1%), hypokalaemia (15.6%), hypercalcemia (5.4%), and hyperkalaemia (5.4%). The abnormalities were most prevalent in patients with gall bladder (16.2%), oral cavity (13.2%) and lung (10.2%) cancers. Most of the patients had an ECOG score of 3 (46.1%) and the predominant symptoms were abdominal pain (29.9%), fatigue (8.4%) and vomiting (7.2%). The study has its own limitations as it is a retrospective analysis.

Conclusion: Electrolyte abnormalities are frequently found in advanced cancer patients referred to the palliative care clinic. It is important to identify these as they have a significant impact on the quality of life as well as the survival of the patient. Prospective studies should be done to prove the prognostic significance of electrolyte abnormalities.

Keywords: Symptoms other than pain and its management

23. Outcome of Palliative Care Consultations for Advanced Cancer Patients Attending Emergency Department in A Tertiary Care Cancer Centre (D1-223)

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Introduction: Emergency Department (ED) visits are frequent in patients with advanced cancer due to high symptom burden. Palliative care consultations and interventions in the ED lead to better outcomes and early and direct referrals to hospice. There is a paucity of literature in the area of palliative care consultations done for advanced cancer patients in ED.

Aim of the Study: To study the outcome of advanced cancer patients registered with specialist palliative care services (SPC) presenting to ED in a tertiary care oncology hospital.

Materials and Methods: This is an observational retrospective analysis of medical records maintained routinely for advanced cancer patients on palliative care attending ED over a 4 month period. Sociodemographic variables, cancer diagnoses, presenting symptoms and outcomes of the ED-based palliative care consultation were noted. Relevant statistical analysis was done using IBM SPSS v 21.

Results: 210 patient records were analysed. 154 (73.3%) patients were18-59 years of age. The most frequent cancer diagnoses was gastrointestinal (39,18.6%) and the most common presenting symptoms were pain and respiratory distress, seen in 58 (27.6%) and 47 (22.4%) respectively. 159 (75.7%) patients were advised investigations (blood and/or radiological). 16 patients (7.6%) underwent interventional procedure 47 (22.4%) patients were advised admission in the hospital or respite care or hospice. The main reasons for admission were breathlessness (in 15 patients) and pain (in 7 patients). 38 (18.1%) patients died in ED of whom 24 had presented in unresponsive state. 109 patients were advised follow-up in outpatient department or homecare.

Conclusion: Patients with gastrointestinal malignancy receiving palliative care attended ED most frequently. Pain and respiratory distress were the most common trigger symptoms leading to ED attendance. 75% patients underwent investigations. 1 in 5 patients required admission, mainly for pain and dyspnoea. Prospective studies of advanced cancer patients on oncological palliative care need to be conducted to assess outcome and impact on survival.

Keywords: Symptoms other than pain and its management

24. Rectovaginal and Vesicovaginal Fistulae in Recurrent Cervical Cancer: A Ten-Year Retrospective Study (D1-224)

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Introduction: Carcinoma Cervix is a common cancer among Indian women. Recto-vaginal fistulae (RVF) and vesico-vaginal fistulae (VVF) are among the most distressing outcomes.

Aim of the Study: To ascertain the proportion of patients developing RVF/VVF in recurrent carcinoma cervix.

Materials and Methods: The notes of local patients with recurrent carcinoma cervix seen in Palliative Care between 2007 and 2016 were retrospectively reviewed. 465 cases of carcinoma cervix were identified. 169 had been followed up until death or fistula.

Results: The median age was 48 years (Range 28 - 70). 74% had squamous cell carcinomas, 8% had adenocarcinoma, 3% had adeno-squamous carcinoma and in 12% histology was not known. 76/169 patients developed at least one fistula (50 only VVF, 9 only RVF, 17 both VVF and RVF).

Many patients had been treated in other centres. The treatment details were as follows: Patients with fistula: Chemoradiotherapy 33%, Radiation therapy 25%, Chemotherapy plus surgery 4%, RT plus surgery 5 %, Surgery alone 3%. Patients without fistula: Chemoradiotherapy 26%, Radiation therapy 42%, Chemo RT plus surgery 2%, RT plus surgery 2 %, surgery alone 0 %.

The median survivals were: Recurrence to VVF – 14.5 weeks; Recurrence to RVF -5 weeks; Recurrence to death - 33 weeks; Fistula to death – 11 weeks.

Conclusion: There is an unacceptably high occurrence of fistula - 16% of all patients and 44% of those followed up until fistula or death. Measures to prevent and palliate this problem should be a high priority.

Keywords: Carcinoma cervix; rectovaginal and vesico-vaginal fistula; symptom management

25. Nutritional Pattern in Cancer Patients Admitted to Palliative Care Ward Using Subjective Global Assessment Form (D1-226)

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Introduction: The incidence of malnutrition amongst patients with cancer has been estimated to be between 40 and 80%.The prevalence of malnutrition is dependent on various factors like the tumour type, location, stage and treatment. Subjective global assessment (SGA) is a validated method of nutritional assessment based on the features of a medical history as well as physical examination, thus overcoming the difficulties of objective assessment of nutritional status, as many non-nutritional factors can affect the results.

Aim of the Study: The aim of this study was to evaluate the use of the scored SGA as a nutrition assessment tool in hospital patients with cancer, and to determine patient outcomes in terms of nutritional status.

Materials and Methods: The study was carried out in cancer patients who were admitted in the in-patient unit of palliative care DR BRA IRCH, AIIMS, NEW DELHI. A total of 50 patients admitted at palliative care unit were assessed using SGA form cross-sectionally.

Results: A total of 50 patients were included in this study. A cross-sectional analysis was done on patients admitted to palliative care unit. Average age of participants was 48.8 years. Maximum patients (51%) had no improvement or inadequate nutritional intake in past two weeks while 30.6% had improved but not adequate. Only 10% of participants had increased weight in past two weeks while 45% had either decreased or no change in weight. Almost 65% of participants had decreased functional capacity and 60% had some progressive nutritional loss.

Conclusion: This study reports the need of nutritional assessment in palliative care patients to improve the quality of life.

Keywords: Assessment; cancer patients; nutrition

26. Unmet Need and Symptom Burden of SHS (Palliative Care) in Two Blocks of Pune District in Maharashtra (D1-227)

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Introduction: More than 80 % of people, who died with SHS in 2015 were from developing regions and the vast majority lack access to palliative care and pain relief. Lancet Commission (2017) has developed a new conceptual framework for measuring the global burden of SHS.

20 health conditions identified by Lancet Commission require palliative care intervention. Most common and severe symptoms generated by these 20 health conditions were identified by Lancet Commission.

Aim of the study:

1. To understand Symptom Burden of SHS.
2. To understand the unmet need of SHS

Materials and Methods: A cross sectional survey was carried out from 16 July 2018 to 20th November 2018 in 2 blocks (Purander & Bhor) of Pune district, Maharashtra state, India, after seeking ethical approval. A structured tool was administered which included history of symptoms and with its intensity to estimate burden of SHS [Table 1]. PNPC-sv tool with 3 point Likert scale was used to assess unmet need [Table 1]. 4935 respondents were interviewed from 1200 households. Data was analysed in SPSS version 17 software.

Results:

Conclusion: Burden of symptoms suggestive of SHS is quite high in rural Maharashtra. The unmet need of palliative care is quite high.

Keywords: Palliative care; serious health related suffering; symptom management

Table 1: Commonest symptom: Pain

Symptom	Prevalence (burden) (%)
Pain	45.8
Weakness	22.2
Fatigue	21.3
Nausea and vomiting	19.8
Shortness of breath	14
Depressed mood	9.2
Insomnia	9.4

Pain was the commonest (45.8%) symptom reported followed by weakness and fatigue

Symptom	Unmet need (%)
Pain	44
Fatigue	21.4
Pricking or numb sensation	15.8
Shortness of breath	14.7
Sleeping disorders	9.4

Unmet need of pain was 44% followed by fatigue in 21.4%

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27. Symptoms Burden in Cancer Patients During Last Week of Life in Home Based Palliative Care (D1-228)

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Introduction: Prompt and Adequate symptoms' relief is critical to Good Palliative Care. Palliative Care Teams all around the world struggle to achieve prompt and adequate symptoms' relief. In spite of a good care the patients may have to go through the disease trajectory with symptoms' load of various intensities.

Aim of the Study: The objective of this study is to find the symptom load in last week of life. We will also try to find out that which symptoms trouble the patients most during the last week of life under the Care Home Care Teams of Cansupport.

Materials and Methods: Analysis of Edmonton Symptoms Assessment charts of one Hundred former patients was done.

Results: 42% patients had fatigue, 25% had pain, 17% were Symptomless, 5% were depressed, 4% were drowsy, 2% had anxiety, 3% had nausea and 2% had shortness of breath.

Conclusion: Study of Symptoms load during last week of life is important. If the symptoms load during this period is less a good quality of death is possible. Low Symptoms load during this period is also an indicator of Good Quality of Home Based Palliative Care.

Keywords: Home care team; last week of life; symptom burden

28. Effectiveness of Complete Decongestive Therapy in Managing Lymphedema (D1-229)

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Introduction: Complete decongestive therapy (CDT), also called complex decongestive therapy, is an intensive program that combines many of the different treatment approaches including bandaging, compression garments, manual lymphatic drainage, exercise, and self-care. It is considered the gold standard of treatment for lymphedema that has progressed beyond stage 1.

Aim of the Study: To assess the role of CDT to improve quality of life of patients with lymphedema post MRM and to prevent future complications.

Materials and Methods: There are mainly two phases in CDT.

1.Reductive phase 2. Maintenance CDT

Phase I CDT is all about getting the extra lymph out of the arm, hand, or other part of the upper body to reduce visible swelling and other symptoms of lymphedema.

This involves 5 days a week session:
- Manual lymphedema drainage (MLD)
- Short stretch compression bandaging
- Exercise

Phase II CDT is about maintaining the results of the initial intensive phase on your own. Phase II includes getting fitted for and wearing compression sleeves and garments, then learning how to put them on correctly and care for them.

Results: Complete decongestive therapy was helpful in significant reduction of secondary lymphedema after MRM.

Conclusion: This shows that CDT is an effective for a cohort of patients with lymphedema. Improvements in limb volume, skin quality, and lymphedema-related QOL were improved. Valid skin and QOL measures need to be developed. Larger, blinded trials need to be conducted to determine which patients benefit from CDT.

Keywords: Complete decongestive therapy; lymphedema

29. Impact of Palliative Radiation Therapy on QoL in Patients With Painful Bone Metastases Using Eortc Qlqc30 and Qlqbm22 - Regional Cancer Centre, Jipmer Experience (D1-230)

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Introduction: In advanced cancer one of the most common site of metastasis is bone and pain is one of the most common symptoms in 70% of patients which interferes with daily activities and decreased quality of life. Bone metastases also result in debilitating complications like pathological fracture, hypercalcemia and spinal cord compression which further worsens the QOL. Henceforth QOL must be the primary outcome of interest over survival in advanced cancer patients. Radiation therapy found to be an effective method of palliating painful bone metastases and can improve function and reduce analgesic requirement.

Aim of the Study: To assess the effect of palliative radiation therapy on QOL in patients with painful bone metastases using EORTC QLQc30 and bone metastases specific QOL QLQBM22 questionnaire.

Materials and Methods: Bone metastases patients with different primary who were diagnosed in JIPMER RCC between July 2017 and December 2017 were prospectively enrolled in the study after obtaining consent. QLQc30 and QLQBM22 baseline scores and after 1 month of treatment were calculated. Descriptive statistics summarized demographics and QOL scores. The Kruskal-Wallis nonparametric test was used to compare QOL baseline scores and QOL changes after treatment (1 month).

Results: Of 91 patients enrolled, mean age was 52 years and median Karnofsky Performance Status was 50. Primary cancers of breast 21 [27.6%], prostate 17 [20.5%] and lung 16 [20.2%] were most common. Patients across all groups had similar baseline QOL scores. One month after treatment patient had significant improvements in all 4 domains of QLQBM22 (painful site, $P<.0001$; painful characteristic, $P<.0001$; functional interference, $P<.0001$, and psychosocial aspects $P<0.05$) and 13 domains of QLQC30 except constipation ($p=0.9$) and cognitive functioning ($p=0.16$).

Conclusion: Our study shows that palliative radiation therapy improves overall QOL in patients with bone metastases with significant pain relief and improved physical functioning.

Keywords: Metastatic bone pain; palliative radiotherapy

30. Communication in Palliative Care: From Patients 'and Caregivers' Perspective (D1-231)

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Introduction: Communication is no less then art. It is as vital as managing the disease itself. It is a skill that is considered to be followed by the healthcare providers irrespective of being mentioned or not regardless of the severity of the disease. But with the low doctor: population ratio, changing attitudes of both the healthcare providers and the community, this component is not given enough importance, which in turn has led to its own set of consequences. Hence the study was planned to study how is the level of satisfaction in palliative care patients and their caregivers in this matter [Table 1].

Aim of the Study: To assess the satisfaction of Palliative care patients and their caregivers towards their communication with healthcare providers [Table 1].

Materials and Methods:
- Study design: Cross sectional study.
- Study setting: a tier-2 city in Karnataka.
- Study duration: 2 months for piloting (Dec '18 to Jan '19)
- Study subjects: Patients who are receiving specialized palliative care and their caregivers.
- Sampling method:
  - The list of patients receiving home-based specialized palliative care were obtained from the organizations providing it.
  - Inclusion criteria: Patients debilitated with any chronic progressive illness who have received specialized palliative care for a minimum of 1 month & their prime caregivers.
  - Exclusion criteria: Patients
    - with communication disability
    - Less than18 years.
    - Those who do not consent

  - Homes of eligible participants were visited based on Census method.
- Study tools: Validated semi-structured questionnaire.
- Satisfaction assessed by 5 point Likert scale.

- Analysis: Microsoft Excel v2013.

Results:
- Total subjects taken for pilot study: 15.
- Indications for palliative care: Cancerous- 8, Noncancerous- 7.
- Mean age: 46.2 years.
- Gender distribution: Males- 6, Females- 9.
- Socio-economic status: Most (11) belonged to Upper middle class according to modified B.G. Prasad classification.
- Prime caregivers: Spouse- 5, Children- 10.

Recommendations:
- The area needs further research so as to develop evidence needed to plan the communication in a more effective way.
- There is lack of man-power. So recruitment and training of healthcare providers in palliative care settings need to be accelerated.

Table 1: Level of satisfaction in palliative care patients and their caregivers with respect to communication

Variables		Patients (*n*=15)	Caregivers
Overall satisfaction with regards to communication with the doctor providing palliative care	Satisfied	3	5
	Neither satisfied nor dissatisfied	11	8
	Dissatisfied	1	2
Overall satisfaction with regards to communication with the nurse providing palliative care	Very satisfied	3	4
	Satisfied	10	9
	Neither satisfied nor dissatisfied	2	2
Satisfaction regarding privacy in healthcare settings	Satisfied	3	5
Satisfaction regarding time given by the doctor	Satisfied	6	5
Satisfaction regarding time given by the nurse	Satisfied	11	9
Healthcare worker with whom comfort is more	Doctor	5	7
	Nurse	8	2
	Social worker	2	6

Keywords: Communication; healthcare providers; palliative care

31. A Pilot Survey on Confronting Own Mortality in Palliative Care Providers in A Palliative Care Setup (D1-232)

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Introduction: Palliative care brings us in touch with terminally ill patients from various domains of life. They all have one aspect in common. They are vulnerable. Caring for dying patients makes palliative care professionals face their own fear about the fragility of life. Dealing with such patients can be stressful for clinical professionals. Confronting one's mortality could mean different things to different people and also to the same person at different phases of life. Personal vulnerability not only causes stress to professionals but also may hinder the process of providing care. Through this study, we aim to understand if professionals at a Palliative Care Centre have had such experiences and reported stress due to the same.

Aim of the study:
1. To understand how many Palliative Care team members have faced their own mortality when dealing with cases in the Centre
2. To measure reported stress among palliative care professionals (PCP) when dealing with their own mortality

Materials and Methods: The Study employs survey method wherein consenting participants are handed a questionnaire that was designed in-house and comprised of 14 questions that sought to explore the experiences of professionals in a Palliative Care Centre when facing their own mortality. Responses received will be collected and analysed using basic statistics.

Results: 100% of the participants experience stress when dealing with vulnerable patients with variable severity. While stress levels in most participants are mild to moderate (95.3%) and 4.7% participants experience extreme stress.
1. 2.88% individuals thinks about their own mortality while dealing dealing with vulnerable patients and 30% thinks more often.
2. Pediatrics patients lead to experience of personal vulnerability in maximum populations. Other factors such as similar age, profession and background also significantly contribute.
3. Female professionals experienced more stress while dealing with pediatrics patients.
4. In Majority of the individuals (80.94%) thought that personal mortality affects professional efficacy and only 8% disagreed.
5. Most of the participants discuss their stress with colleague or a senior. This highlight need for regular team meetings. Sharing with family and also diversion activities were considered important deal with stress.
6. Team meetings and debriefing sessions are important way to deal with stress. Surprisingly, training for the same does not seem to appeal to the professionals. Professional counselling sessions are desirable to about third of the professionals.

Conclusion: Palliative Care Professionals often face challenges. Proximity to patients especially at End of Life can lead them to face questions related to their own mortality and cause stress. Managing this stress is imperative to ensure that the quality of care provided to patients is not impacted in anyway.

Keywords: Carer; own mortality; palliative care; stress

32. Interdisciplinary palliative intervention for family caregiver of dying patient: Does it matter? (D1-233)

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Introduction: Cancer diagnosis can profoundly impact the quality of life (QOL) for both patients and their family caregivers (FCGs). FCGs are often unprepared to carry out their role and could experience increasing levels of distress especially at the end of life, including increased psychological distress, relationship disruptions and impact on their economic well- being. FCGs receive lesser attention, within the current health care system, in which the focus is primarily on the needs of patient.

The interdisciplinary team approach central to the philosophy and practice of a specialist palliative care team, though common in developed countries, is a fresh concept in India. At our tertiary cancer centre, we have initiated this approach for FCGs of patients in advanced disease, referred for palliative care. We set out to explore the effectiveness of this interdisciplinary palliative care intervention on the QOL of FCGs in the cultural and social context of an Indian setting.

Aim of the Study: To explore the FCGs perceived usefulness of the interdisciplinary intervention on the QOL of FCGs and their preparedness regarding provision of care and outcome.

Materials and Methods: Thematic analysis is used as the research design. Purposive sampling of participants were family members of patients who had received interdisciplinary intervention. The team enlisted potential participants who fulfilled the inclusion and exclusion criteria. Of the 14 FCGs approached, 8 participated. Further recruitment was stopped due to achievement of thematic saturation.

Results: Emerged themes, indicated improvement in the psychological distress, burden of decision making, relief from social pressures and caregiver burden. Preparedness for outcome and physical QOL continued to be challenging. All participants, felt this approach is an essential part of care.

Conclusion: The intervention provided a replicable model for interdisciplinary care recommendations as a tailored approach for FCGs.

Keywords: Caregiver; interdisciplinary palliative intervention

33. Communication Challenges In A Hospice (D1-234)

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Introduction: Communication in a hospice can be very challenging starting from convincing patients and families about the need for comfort care in the end of life of a patient, to acceptance of death, with many issues on different levels in-between.

Aim of the Study: Communication plays a vital role in a hospice in maintaining a fine balance between hope and reality among family members of the patient including the patient. Not letting hope for comfort to die and keeping the hope for betterment in check, is very essential for emotional wellbeing of the patient. The objective of communication in a hospice is personalised to suit each individual case with a constant re-evaluation of the situation, if not on an hourly basis. Understanding of the condition of the patient by the family is always in a fluid state with an illusion of truth. Maintaining a sense of normalcy for the families is a challenge. That's when being in constant communication with them can avert a violent reaction at the time of death.

Materials and Methods: First, engaging in a dialogue with families constantly, understanding their emotional needs, social needs and social stigmas can make difference between the patient being comfortable without effecting his dignity to patient suffering due to issues which have no connection with his wellbeing. Second, not to judge and be accommodative even when the patients and families are indecisive. Last but not the least, be patient in explaining things repeatedly without losing our patience.

Results: Communication can result in the admission of terminally ill patients who are suffering in silence for no fault of theirs. It can translate to a dignified, comfortable and pain free death.

Conclusion: Good and effective communication in a Hospice can make difference between the family living with itself with dignity for the rest of their lives without GUILT.

Keywords: Communication; hospice

34. Role of Navigators in Cancer Treatment (D1-235)

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Introduction: When battling cancer, the challenging part is not just the disease, but it is also a burden of pain and suffering and a host of other psychological issues that are associated with it. Patients experience a lot of discomfort and fatigue during surgery, chemotherapy and radiation. Head and neck cancers patients face more challenges such as body image alterations, functional difficulties in eating and speech thus leading to disabling emotions such as anxiety and depression. Therefore, a navigators' role is to assist patients in accessing cancer care and navigating health-care systems, educating patients and caregivers on the interdisciplinary nature of cancer treatment, the roles of team members, and expectations from the health-care system. They help provide patient and caregivers evidence-based information and thereby refer them to health care professionals for adequate guidance on medical information regarding their treatment choices and potential outcomes.

Understanding and assessing barriers to care is another important role of navigators.

Aim of the Study: To provide support and guidance for cancer patients and their families throughout their treatment trajectory.

Materials and Methods: Feedback forms filled by patients and caregivers to understand and make an assessment of the support received by the navigators.

Education for patients and their families informing them about the navigators service in the hospital.

Results: Participants expressed positive feedback for the navigators' service and reported being benefited by the service. The feedback forms for patients and families were segregated separately. Aspects of quality of life, benefit from the navigator services and compliance to treatment were evaluated.

Conclusion: Navigators are cancer survivors who empower patients to communicate their preferences and priorities for treatment to their health-care team. Navigators' service is a very effective service in an oncology setting as patients and their families can relate to navigators thereby inspiring them adhere to cancer treatment.

Keywords: Cancer burden; navigators

35. Assessment of Information and Emotional Needs of Callers Using A Palliative Care Helpline (D1-236)

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Introduction: Telephone helplines play a key role in health services in terms of support for information and emotional needs. The growing burden of cancer in India created such a need and in 2004, CanSupport started a cancer-cum-palliative care helpline 3 days/week which was increased to 5 days from 2007.

Aim of the Study: The main aim of this study was to assess information and emotional needs of callers to CanSupport's helpline and to report on the response of the service to these needs.

Materials and Methods: CanSupport's telephone helpline is staffed by three counsellors who determine the need of each caller and respond accordingly. In addition to calls, the helpline is also contacted through email and during out-of-hours caller information is stored in an answering machine. The details of each call are recorded daily. For this study one year's caller data was analysed from April 2016 to March 2017.

Results: Total number of callers was 5975 of which 70% were caregivers, 7% patients and7% other family members. 66% of callers were males, unlike other studies where majority of callers were women. Only 9% of the calls were for emotional support, 91% were for information and most callers had more than one need. Most callers came to know of the helpline from hospitals followed by social media. Majority of callers wanted information about services provided by CanSupport, especially palliative homecare services. Other important needs were questions related to treatment, financial assistance for treatment and information on cancer hospitals, prosthetics, pharmacies and blood availability. The helpline was able to respond to 99% of callers' needs.

Conclusion: Telephone helplines are effective in providing support for information and emotional needs. Reviewing helpline data helps in maintaining and improving quality of service.

Keywords: Cancer patients; emotional support; telephone helpline

36. CONJUGAL INTIMACY AND ROLE OF PALLIATIVE CARE COUNSELLING (D1-237)

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Introduction: Over the years, the teams at CanSupport have counselled a number of cancer patients and their families. The counselling process involves exploring the underlying psycho-social concerns that bother the patients as they struggle with other symptoms from the disease of cancer. It is often found that unaddressed psycho-social concerns aggravate physical suffering and lead to patient distress. Patients report the lack of sexual intimacy or deprivation in sexual pleasure or satisfaction too. These thoughts often lead to hostility with the spouse. The present paper sheds light at such issues by exploring the role of palliative care counselling.

Aim of the Study: To explore and document the complexities of conjugal intimacy in the lives of cancer patients receiving palliative care.

Materials and Methods: The results of the present study are based on an extended field based interaction with the patients over 1 to 2 years. The method highlights the role of long term counselling. The findings are based on in-depth interviews and observation as two key methods. The paper discusses 5 cases from the field.

Results: The study demonstrates the patient's as well as spouse's perspective towards intimacy and make us understand the complexities involved in addressing these issues.

Conclusion: The study shows that the interventions may not meet patient's expectation yet it assesses the measures taken in order to develop a healthy communication around the issue.

Keywords: Cancer patient; counseling; lack of sexual intimacy

37. IMPACT OF AUDIT ON MONITORING SYRINGE DRIVER RECORD CHARTS OF PATIENTS REQUIRING CONTINUOUS SUBCUTANEOUS INFUSIONS (D1-238)

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Introduction: The purpose of this audit was to establish the standard of practice in hospice in-patients where syringe drivers are being used for continuous sub-cutaneous infusions of medications. It is important to monitor the Syringe Drivers because unregulated practice may lead to: poor symptom control, inadequate dosing, delayed treatment response and machine error.

Aim of the Study: (1) To monitor whether the subcutaneous infusions are being administered and recorded appropriately according to the chart prescribed by the Hospice Medical Team. (2) To analyse the data collected. (3) To identify the reasons for not completing the record charts as per the established standards.

Setting the Standards: The standard was set at 85% accuracy of monitoring, every four hours, with respect to the following items: a) Site of injection, b) rate of infusion, c) volume dispensed, d) flashing light.

Methods: Data was collected from 30 random charts during the initial four-month phase.

Following training, a further 30 charts were subjected to re-audit during a similar period.

Results:

Items	September – December 2017 (Phase 1: pre-audit)	February – May 2018 (Phase2: post-audit)
Total Patient records	30	30
Monitored Patients	10	27
Unable to Monitored	20	3
Standard Met	33%	90%

Conclusion: A target of 90 % was achieved after training, compared to only 33% previously.

This audit helped to raise the knowledge and awareness of the nursing teams, leading to a considerable improvement in symptom control, accuracy and the quality of service.

Keywords: Symptom control; syringe driver; training

38. ASPECTS OF "ISOLATION" SEEN IN PATIENTS WITH PROGRESSIVE, ADVANCED CANCERS (D1-239)

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Introduction: Terminal illness can be an extremely lonely and isolating experience and be incredibly restrictive.

Aim of the Study: To highlight various aspects of "isolation" described by our patients and their families.

Materials and Methods: Examples taken from a review of recent case-note records of in-depth counselling sessions to illustrate different areas that may lead to feelings of isolation.

Results: Common themes to emerge include:
- Physical isolation by family and / or village community
- Exclusion from workplace
- Social isolation: being shunned,
- Emotional isolation: diminished or non-existent interaction
- Difficulty in finding accommodation
- Being judged / blamed (often associated with feelings of guilt)
- Lack of access to professional medical help (eg preventing Home Care team from visiting)
- Repercussion on family
- Finding employment
- No marriage proposals
- Being excluded by society
- Denial of last rites or access to burial ground / crematorium

Many of these were related to poor education and ignorance eg the firm belief that cancer is contagious, is genetic, is associated with bad Karma or Papas, particularly in rural areas.

At other times, related to altered body image, or presence of fungating, malodorous, bleeding wounds, or disturbed mental state.

Conclusion: Specific examples will be presented to illustrate some of these issues and emphasis put on the paramount need to give patients and families time and space to have their voices heard with respect to these issues and help allay their fears.

Keywords: Cancer patients and families; isolation

39. Listening to the Voices of Bed-Bound Patients at Home: Helping to Affect Change (D1-240)

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Introduction: Several complications attend the bed-bound patient, not just physical issues, but also psychological, social and spiritual ones. Compared to constant attention when admitted to the hospice, patients feel more vulnerable at home as the access to medical and nursing assistance is diminished with a consequent increasing burden of care falling on both the family and patient.

Aim of the Study: To understand the impact of being bed-bound at home and the extra challenges this entails.

Materials and Methods: Notes from ten randomly selected home-care patients were chosen and the semi-structured counselling notes reviewed, looking for common themes and any issues of particular significance.

Results: Caring for bed-bound patients in the hospice may be challenging. However, it is even more demanding when the patient has to be cared for at home.

Common areas of great difficulty and concern, in a domiciliary setting, were found to include:
- Feeding and drinking
- Issues with elimination
- Maintaining personal hygiene
- Moving and lifting
- Maintaining dignity
- Being a burden / loss of independence
- Financial worries

Apart from these more practical issues, psycho-social and existential worries that have been brought up are:
- Distress of suffering, particularly if prolonged
- Feelings of hopelessness
- Confusion
- Fear of night-time and fear of death
- Distancing in relationships

Conclusion: listening attentively to the voices of these patients and their families, enables them to share their worries and helps us to be responsive and develop strategies that are appropriate to their individual needs.

Keywords: Caring; voices of bed-bound patients

40. Challenging Discussions with Informal Care Givers When Implementing an End of Life Care Plan (D1-241)

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Introduction: For over two years, in our hospice, we have regularly used a validated Care Plan for patients entering the terminal phase of life. Central to implementing this are meaningful discussions with the patient and family members about what this entails.

Aim of the Study: To enumerate key issues that affect family members in discussing the End of Life Care Plan.

Materials and Methods: Based on a review of the counselling notes and a focus group discussion, notable issues were compiled and categorized.

Results: Dealing with the practical aspects of death and dying were found to be fairly straightforward. However, despite detailed explanation about the care plan, backed by written information, family members frequently found it difficult to comprehend the physical changes taking place, together with the ongoing social and emotional withdrawal of the patient. This was exacerbated when they failed to understand the reasons for these changes or had unrealistic expectations.

Particularly challenging issues encountered by counsellors included:
- Feeling of helplessness among family members
- Fluctuations in the general condition of the patient
- Mistrust of the clinical team
- Frustration towards being out of control of the situation
- Anxiety and uncertainty about the future
- Inability to bring closure

Conclusion: Giving a voice to relatives at this difficult time and for their concerns to be heard is part of good counselling. Drawing on recent experiences, examples of such concerns, and their impact, will be presented and discussed.

Keywords: Communication; end of life care plan; family

41. MOTIVATION BEHIND STARTING A CHARITABLE PALLIATIVE HOME CARE SERVICE IN A PRIVATE/ CORPORATE HOSPITAL: A CASE STUDY AT RAJAGIRI HOSPITAL, ALUVA, KERALA (D1-242)

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Introduction: Even though India has a National Program for Palliative Care, it is estimated that the present system in India is able to cater to only about 2% of the total need which traditionally has been on the outer spectrum of funding priorities. Hence most Palliative Care services in India are run by NGOs/Charitable Trusts.

To cater to an estimated 5.4 million new patients each year who need Palliative Care, it has to come into the private sector which takes care of the majority of health care burden.

Aim: What will it take for Palliative Care to be accepted into the private sector where financial imperatives and branding of the organization matters?

Presently we at Rajagiri Hospital a Private-Corporate Hospital run by the CMI congregation (A Catholic religious order for men) created a new model that can effectively merge charitable activities with paid services. On one hand the Hospital runs a paid Pain & Palliative Medicine OP and IP services within the hospital and on the other hand runs a charitable (fully free) Palliative Home Care program.

Methods: A questionnaire was prepared to find out what motivated the members of the management council to support a Charitable Palliative Home Care service.

Results: The questionnaire revealed that majority of the members supported because of their 'Personal Belief/Religious Conviction', however along with this some of them were also convinced about the 'Good will generation/ Increase in Brand value such a service would bring about. A few members also felt that it will be beneficial as a business strategy/revenue generation in the long run.

Conclusion: Motivation and reasons for starting Palliative Care at our institution can be a model for other organizations.

Keywords: Motivation; Palliative home care; private hospital

42. JOINING HANDS FOR CELEBRATION OF LIFE (D1-243)

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Aim: To create innovative and humanitarian solutions to EOLC patients and later to their bereaved families.

Materials and Methods: Creating solutions for persons in their end of life and for the bereaved families to live as close to normalcy as possible. Establishing normalcy to facilitate a sense of wellbeing in terminally ill patients. Needs of a person fighting with a terminal illness cannot be categorised into small, big, irrelevant or unnecessary. A unique solution can be arrived at, for each type of need with a prime motive to add life to his remaining days. Many opportunities can be explored that can help the patient celebrate his life. Like.,

Coffee-date,
Birthday/Wedding day celebration,
Festival celebrations,
Singer-of-the-day,
Facilitating alternate livelihood,
Story book Reading,
Educational opportunities,
Patient's day out,
An evening at a park,
Couple candle light dinner,
Colourful Mehndi,
Playing board games,
Group watching of cricket matches on TV,
Unexpected guest visiting,
Religious reading,
Job opportunity,
Video calling far off children,
Lending medical bed, wheel chair, walker, air bed to a patient at a far off place,
New clothes on festival days,
Movie going,
Going to a beauty salon,
Bringing favourite homemade food,
Flag hoisting on national days,
Dancing,
Organising a music concert,
Making the patient guest of honour on a special day/ festival

Results: The above said activities can not only bring solace to the patient but also reduce the emotional distress to the families before and after the patient. Affection with objectivity is the key to care.

Conclusion: Need of the patient is the need of the day.

Keywords: EOL care; humanitarian solutions

43. IMPACT OF BEREAVEMENT COUNSELLING IN PALLIATIVE CARE (D1-244)

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Introduction: The loss of a loved one is life's most stressful event and can cause a major emotional crisis in a caregiver's life. Some people are at special risk during the period of bereavement and these risk factors can give rise to complicated forms of grief that can culminate in to mental illness. A clear understanding of these factors through bereavement counselling will often enable us to prevent major psychosomatic and psychiatric disorder in bereaved people.

Aim of the Study: (1) To understand the need and acceptance of bereavement counselling by the deceased family. (2) To voice out few caregiver's discernments towards bereavement counselling about how it helped them coming back to reconciliation.

Materials and Methods: 51 bereaving caregivers, irrespective of their age, gender and relationship with patients were given feedback forms, which included their suggestions on bereavement counselling. Consent was taken from the participants who were interviewed in depth.

Results: It was noticed that 74.5% of caregivers were benefited by counselling, 7.8 % caregivers it did not play a vital role. 17.64 % preferred not to comment.

Conclusion: Bereavement counselling is an important aspect of palliative care and a deep subject in itself to be studied and researched further. Though the sample size is small due to time limitations, the study shows the relevance of counselling to support the bereaved family.

Keywords: Bereavement counseling; palliative care

44. ADMINISTRATIVE PERSPECTIVE FOR BETTER PATIENT SATISFACTION IN PALLIATIVE CARE (D1-245)

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Objective:
- To analyse the area or domains where dissatisfaction is experienced by patients and relatives.
- To bring various validated feedbacks.
- Good Communication is key for patient's satisfaction.
- To overcome changes in all aspects to bring out better outcome.
- Look at it not only at medical perspective but also at an administrative perspective to bring out satisfaction in services.
- Sensitization of hospital to handle palliative care patients to give quality palliative care services & Treatment.

Materials and Methods: Casual Interview of 20 palliative care patients during hospitalization to understand all aspects that could affect their satisfaction.

Results: Our interview revealed that the following factors influenced patient satisfaction
- Humane interaction
- Lack of patient's awareness of their disease status and denial
- Poor interaction between specialists
- Advance care plans
- Social stigma
- Time management.

Conclusion: Good communication and a holistic approach are key to improving satisfaction of Palliative Care Patients admitted to Hospital.

Keywords: Administration; palliative care; patient feedback

45. PALLIATIVE CARE IN NICU: TABULA RASA! (D1-246)

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Introduction: Recent advances in medical care have improved the survival of new-born babies born with various problems. Despite this death in the NICU is an inevitable reality. For babies who are not "going to get better", the health care team still has a duty to alleviate the physical suffering of the baby and to support the family.

Palliative care is a multidisciplinary approach to relieve the physical, psychosocial & spiritual suffering of patients and their families.

Aim of the study:
- To "build a case" for palliative care in the Indian NICU setting as it is almost non-existent at present.
- Focus on the holistic care of baby and family.

Materials and Methods: Here we describe 4 cases each one being consequential in itself.

Case 1 PT (30)/B.wt.1 kg was on ventilator support for 31 days diagnosed as Non-Immune hydrops with sepsis with CHF and ARF died after 31 days.

Case 2 Term baby (previous sibling K/C/O IEM) Kept on ventilator and ionotropic supports. NH3 >5000, Peritoneal dialysis (PD) done, ultimately went home after NICU stay of 5 days.

Case 3 Term baby with Hyperammonaemia (Sr.NH3>1500), PD done, took LAMA and went to home after NICU stay of 7 days.

Case 4 PT (28)/B.wt. 0.76 kg kept on ventilator support and was in shock with HMD grade III, took LAMA.

Results: Above 4 cases directs that palliative care consultation may enhance end of life care for new-borns through better control of pain and other distressing symptoms and by avoiding futile treatments whose burden outweigh benefits.

Conclusion: At present there are no such clinical practice guidelines recommended in India. The overall benefits of palliative care provision in the NICU in the Indian setting may improve management of symptoms and support for decision making for babies "who are not going to get better".

Keywords: New-born; palliative care

46. PAEDIATRIC PATIENTS PROFILE IN DISTRICT LEVEL (D1-247)

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Introduction: Pain relief and palliative care society is a registered charity organization and the largest palliative care provider for children with incurable illnesses. PRPCS has signed an MOU with Telangana government to start palliative care units in each district. Eight units have been opened between 2017 to 2018.

Aim of the Study: Identifying children suffering with incurable illnesses and providing quality care and control of suffering.

Materials and Methods: Mass survey in district level with the help of 8 palliative care trained ANMS.

Results: All the 8 palliative care units have identified paediatric patients in a category wise with age, diagnosis, village and district.

Conclusion: Our study identified significant number of children with Palliative Care needs. Early identification and management of such children is essential in providing good care. Public awareness and educations also played an important role in identifying such children with Palliative Care needs.

Keywords: Paediatric palliative care

47. FAMILY FUTURE CARE WISHES - EMPOWERING THE CHILD AND FAMILY TO HAVE A VOICE THROUGHOUT THEIR PALLIATIVE CARE JOURNEY YVONNE RILEY (D1-248)

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Introduction: Hope House Children's Hospices developed the 'Family Future Care Wishes' document in 2001. In 2016 it formed an additional module in the All - Wales Paediatric Advanced Care Plan (PAC-Plan).

Aim of the Study: The Family Future Care Wishes document was developed to support the family in making decisions about their child's future care. It provides the opportunity to discuss in a timely manner areas where the family need further information and ultimately end-of-life care.

It avoids the situation whereby Intensivists have no time to explore these issues in the last few hours of life, and parents are reluctant to 'let go'.

Materials and Methods: The document is divided into 3 sections:

Section A: Completed early in the child's illness. Looks at how the family view the illness and their understanding of the hospice.

Section B: Completed as the child's illness progresses and focuses on end-of -life. It explores working in collaboration with other Health / Social Care professionals. At this stage it may be incorporated into the All-Wales PAC-Plan.

Section C: documents care after death, memory making and bereavement support.

Results: Parents comments:

'It was good to complete while my child was still relatively well…. I felt no pressure at that time'.

'It was difficult to do …...but at the end of my child's life all the issues had been addressed'.

Conclusion: Family Future Care Wishes document provides the family with a voice, choices and support. The end-of-life journey fulfils the family's expectations. A positive experience is created for all involved.

Keywords: Paediatric advance care plan

48. Creating A Compassionate Community to Support Care for Children with Chronic Diseases in A Urban Informal Settlement in Bangladesh (D1-249)

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Introduction: Paediatric Palliative care (PPC) in resource limited settings is a key component for care. Globally, 98% of children who are in need of palliative care services live in low or middle income countries (1). In Bangladesh specifically, only 1-2% of the 29 000 children in need receive PPC (2). Community based palliative care is becoming the front line approach in non-urban settings in order to address the need. The Korail slum project revolves around providing such care.

Aim of the Study: The primary aim of this study was to evaluate the Korail Slum Children's palliative care project, a project based on providing community based palliative care services to children living within the Korail slum in Bangladesh.

Materials and Methods: Surveys were conducted to assess the quality of life of the children receiving PPC using a Paediatric Quality of life tool periodically, every 6 months.

Results: We interviewed 18 children initially at their time of enrolment into the Korail Slum Children palliative Care Project. These children were identified to have the following life-threatening conditions: Developmental disability (33%), Physical disability (22%), feeding problems (18%), incontinence (13%), seizures (9%), visual impairment (2%), and hearing impairment (2%). A follow up survey was conducted 6 months later and we noticed an overall increase in the quality of life of the children.

Conclusion: There is a significant need for paediatric palliative care services in the Korail slums of Bangladesh. There is a lack of adequate pain treatment and management of children living with life-limiting and chronic illnesses in Korail specifically. Community based palliative care programs, are a cost-effective way to reduce the burden of preventable suffering in children living with life-threatening illnesses.

Keywords: Bereavement care; end of life care

49. Evaluation of A Project Echo on Paediatric Palliative Care Targeting Health Professionals in South Asia (D1-250)

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Introduction: Project ECHO Paediatric Palliative Care is an online educational program developed to train healthcare professionals in South Asia to provide palliative care for seriously ill children in their communities. Regular 90-minute sessions hosted every 2 weeks over multipoint videoconference provide didactic and case-based teaching. Launched in March 2018, this is the first ECHO program globally to specifically provide training in paediatric palliative care.

Aim of the Study: The goal of this study is to describe the program, including the key characteristics of participants and sessions and the satisfaction and the perceived strengths and weaknesses of the program.

Materials and Methods: Participant and session characteristics were recorded for each session, including the number of participants, time duration of each portion of the session, number of questions, and time that participants and facilitators spoke. Web-based surveys were used to assess participants' experiences with the program.

Results: There were 118 healthcare providers from over 40 centres across South Asia who participated in the program. On average, 35 participants from 15 different centres attend each session. The majority of participants were physicians (54%) or nurses (32%). Most participating health centres were hospitals (35%) or palliative care hospices/centres (33%). The majority of participants have rated their experiences with the ECHO Program very positively. The highlighted strengths of the program include multidisciplinary global participation, sharing of valuable learning and experiences by participants during case discussion, and the additional learning resources which are provided to participants after each session. Weaknesses included poor internet network connectivity and limited access to the technology needed to participate in the program.

Conclusion: In its first year, Project ECHO PPC has received positive reviews by participants, with new participants continuing to join from across South Asia. Future surveys and focus groups are planned to further explore the effect of the program on the learning experiences of participants.

Keywords: Education; paediatric palliative care

50. ILLNESS PERCEPTION IN A PAEDIATRIC CANCER POPULATION AT A TERTIARY CANCER CENTRE (D1-251)

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Introduction: Diagnosis of cancer and its treatment course is a stressful experience for both the child and family. In a child this experience may cause a change in the child's perceptions about the illness, about himself/herself, his family and the world around him. Illness perceptions among the paediatric cancer population are still a relatively unexplored area.

Aim of the Study: To find out the illness perceptions in paediatric cancer population as well as their parents using the Malayalam translated "Revised –illness Perception questionnaire (IPQ-R)".

Materials and Methods: This was a prospective observational study. Children between 8 and 18 years of age with a primary diagnosis of cancer and on active treatment at Malabar Cancer Centre, were enrolled in the study after getting informed consent from their parents. Both the child and the caregiver were asked to complete the Malayalam translated questionnaire (IPQ-R).

Results: 10 children (all boys) with median age 15 years and mean treatment duration of 4.3 months were analysed. 60% of them had haematological malignancies. All of them were aware of cancer diagnosis. Scores signifying negative perceptions of the illness were found to be low except that related to the consequences of the disease (Child -147/300, Parent – 156/300). High scores were found on the positive perceptions related to disease like personal control (Child -194/300, Parent – 196/300) and Treatment control (Child -190/250, Parent – 183/250). A high score for personal understanding of the disease was also noted. Scores for emotional representation regarding the illness was high and it was comparably higher in parents.

Conclusion: Although positive perceptions are there among both children and parents regarding the illness, there are many negative perceptions which needs to be identified and resolved for both these groups.

Keywords: Paediatric cancer; perception

51. RELATIONSHIP BETWEEN DOMAINS OF HEALTH RELATED QUALITY OF LIFE AND CANCER RELATED FATIGUE IN CERVICAL CANCER PATIENTS WITH ADVANCED DISEASE (D1-252)

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Introduction: Cancer-related fatigue (CRF) is a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer. Cervical Cancer patients who have the advanced disease experience CRF. Though studies report functional disability in fatigued cancer patients, the correlation between CRF and domains of health-related quality of life is still unclear.

Aim of the study: (1) To determine the functional assessment and CRF of cervical cancer patients with advanced disease as measured by Functional Assessment of Cancer Therapy-Cervix (FACT-Cx) and Cancer fatigue scale. (2) To determine the relationship between CRF and the different domains of FACT-Cx.

Materials and Methods: The study was a cross-sectional, correlational study, using a quantitative approach. The study population consisted of all patients who were diagnosed with advanced cervical cancer. All patients visited and were treated in a tertiary referral hospital and underwent radiotherapy (high dose rate teletherapy or brachytherapy) exclusively, adjuvant or concomitantly with chemotherapy. The data were collected through interviews after the ethical committee approval and after obtaining written informed consent, at one point of time, from a non-probability purposive sampling who met the eligibility criteria.

Results: Among the 60 patients interviewed, a majority (80%) were Hindus, with age ranging between 45 to 75 years. Among them, twenty patients had metastatic disease and the remaining had locally advanced disease. The scores obtained on the different domains of health-related quality of life measured using FACT-Cx had average scores closer to the maximum obtainable scores. The lowest scores were obtained in the domains of 'emotional wellbeing, social/familial wellbeing and also in the domain of 'additional concerns'. Significant correlations were found between CRF and the domains of health-related quality of life measured using FACT-Cx in cervical cancer patients with advanced disease ($p<0.05$).

Conclusion: CRF influences health-related quality of life in cervical cancer patients very negatively.

Keywords: Cancer related fatigue, cervical cancer, quality of life

52. PROBLEMS OF PATIENTS WITH CHRONIC KIDNEY DISEASE ON DIALYSIS IN A TERTIARY CARE HOSPITAL, PONDICHERRY (D1-253)

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Introduction: The Palliative care Unit under the Department of Community Medicine is working in collaboration with the Nephrology Department to develop a palliative care program for patients with Chronic Kidney Disease (CKD) on dialysis at Sri Manakula Vinayagar Medical College and Hospital (SMVMCH). As a first step, we tried to identify the problems faced by CKD patients.

Aim of the Study: To identify the problems of CKD patients on dialysis in a tertiary care hospital at Pondicherry.

Materials and Methods: The Nephrology Unit at SMVMCH was the study setting. Ten patients with CKD on dialysis were interviewed using a semi structured questionnaire by trained medical students to know the problems faced by them due to the disease. The data was gathered during the regular visits of the patients for dialysis. Informed consent was obtained from the patients before the interview. Manual content analysis of the qualitative data was done.

Results: The problems identified were categorised into physical, financial, psychological and health care service related problems. Chronic pain at the puncture site and breathlessness were the common physical problems reported by the patients. Psychological problems included disfigurement due to fistula in the neck and fear of death. Financial burden were due to loss of wages for family caregivers during hospital visit and cost for transportation. Long waiting time and limited transport facilities to reach hospital were some of the health care service related problems.

Conclusion: We were able to identify the problems of CKD patients on dialysis at SMVMCH. These problems will help us sdevelop a program plan for providing comprehensive care for CKD patients through an interprofessional approach.

Keywords: CKD; dialysis; palliative care

53. ENHANCING QUALITY AND QUANTITY OF LIFE: 13-YEAR SURVIVAL WITH RECURRENT ENDOMETRIAL STROMAL SARCOMA (D1-254)

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Introduction: Targeted and hormonal treatments have an increasing role in improving QOL and survival with acceptable toxicity and cost.

Aim of the Study: To review the clinical course of a long term survivor (13 years) who received hormonal therapy in palliative care clinic.

Materials and Methods: Retrospective chart review.

Results: A thirty-year-old mother of three school going children presented with a 19x15 cm solid pelvic mass that had recurred after three surgeries done in another centre over the past two years (1. Hysterectomy and Right Salpingoopherectomy for an adherent lesion, 2. Inoperable disease at laparotomy, 3. Biopsy and cyst wall drainage.) The biopsy had been reported as a low-grade endometrial stromal sarcoma from uterus/ovary. She was referred for palliative care.

After reviewing literature which suggested favourable outcomes with adjuvant Letrozole, a senior surgeon was consulted. Laparotomy with palliative intent was performed and 30x30 cm solid mass was resected. The fields were deemed too large for postop RT.

The patient was referred back to Palliative Care and we started on Letrozole 2.5 mg OD, which she has now continued for 13 years, with no adverse effects. Bisphosphonates and Calcium supplements have been given.

Conclusion: The patient has been asymptomatic and disease free for 13 years.

Keywords: Endometrial stromal sarcoma, hormonal therapy, quality of life

54. COMPONENTS OF A COMMUNITY CARE MODEL FOR PERSON WITH A NEURODEGENERATIVE CONDITION AT BENGALURU (D1-255)

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Introduction: Motor Neuron Disease (MND) is a progressive neuromuscular disorder that can have significant and debilitating impact on the affected patient and families. Person with MND are largely been cared for at home. With the dynamic care needs, minimal resources and lack of adequate training and support, care for persons with MND at home becomes challenging.

Aim of the Study: To propose a comprehensive model of care for persons diagnosed with Motor Neuron Disease (MND) through a narrative case analysis.

Materials and Methods: The life and experience of a person diagnosed with MND was analysed through his spouse's perspective. Spouse of person diagnosed with MND was asked to narrate her perception of her husband's life with MND. This was audio recorded and transcribed by the researcher. Later those narratives were re-storied to make a meaningful framework.

Results: The main themes derived from the narrative were the journey of the person diagnosed with MND across the illness trajectory; the support sought; facing the crisis- death; family's emotional state and challenges; the bereavement phase and the life without the loved one. This frame helped the researcher to propose a comprehensive community model for care of persons with MND.

Conclusion: Through a single case based on the struggles they faced, and the positive aspects they felt in the process, the support they received; a comprehensive community care model for persons with MND and their family members involving different stakeholders can be suggested. Components of this model need to be further expanded based on similar case studies.

Keywords: Care model; MND

55. YOGA AND PALLIATIVE CARE (D1-256)

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Introduction: Palliative care is a specialty care for persons suffering from potentially fatal diseases or terminally ill conditions. Mostly, these conditions are associated with severe anxiety and depression, along with the acute pain and physical symptoms of the disease. Yoga is being practiced since ancient time, yoga as therapy is still a moderately novel and evolving trend in the healthcare field. Yoga is a mind-body intervention that is gaining popularity among terminally ill patients and it can improve the overall quality of life of patients with life-limiting conditions.

Aim of the Study: The Objective of the review is to assess the effect of yoga on palliative care.

Materials and Methods: Original research articles and systematic reviews from 2000-2018 were selected and studied using the following keywords Yoga, palliative care, yoga in life limiting illness.

Results: Literature shows that in palliative care, yoga can offer a holistic approach in which the 'individual' as a whole is focused on and not just the disease. It comprises patient-centred interventions concentrating on symptoms such as pain, physical difficulties, mental stress of illness, and mainly concentrating on improving the quality of life. The adverse effects of yoga are stated to be negligible when yoga is practiced under guidance in a systematic way. Some of the literatures points out that misapprehensions about yoga is also prevalent among public and professionals. Literature also discussed about the fact that cultural and social barriers about yoga is also a concern in accepting and practicing yoga in palliative care settings.

Conclusion: Incorporating yoga and spirituality in the conservative palliative care setting seems to be a, cost-effective, and reliable holistic approach posing a complete wellness plan for patients.

Keywords: Spiritual care and yoga

56. IMPROVING SLEEP QUALITY THROUGH PRANAYAMA DURING CHEMOTHERAPY (D1-257)

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Introduction: Insomnia and sleep quality impairment are among the most prevalent and distressing problems reported by cancer patients and survivors. Almost 15 to 90 percent of the patients report some form of insomnia or sleep quality impairment (Mustian K M, 2013). Causes can be due to hot flashes, night sweats, excessive daytime napping, difficulty falling asleep, and waking up too early. Research suggests pranayama is a well-tolerated exercise intervention with promising evidence for its efficacy in treating insomnia among cancer patients during chemotherapy.

Aim of the Study: To evaluate the effects of pranayama for treating insomnia among cancer patients during chemotherapy.

Materials and Methods: A prospective cohort study was conducted to evaluate the effect of Pranayama on the sleep quality among cancer patients receiving chemotherapy (n=30).

The effect on their quality of sleep was assessed using the Pittsburg Sleep Quality Index.

Out of the 30 patients screened, 16 of them met the inclusion criteria and were included in the study. The intervention consisted of five Pranayama's that were to be practiced at home for a period of 3 months.

A pre- assessment, mid (after 1 month) and a post assessment at the end of 3 months was made to evaluate improvement in sleep quality using the Pittsburg Sleep Quality Index.

Results: The 16 patients at the end of 3 months who had received Pranayama were found to have improved quality of sleep.

Conclusion: Pranayama is an effective intervention among cancer patients receiving chemotherapy, suffering from Insomnia. Improved sleep quality through pranayama is a holistic approach. Mind body service is a much needed intervention for cancer treatment along with conventional treatment for improved quality of life.

Keywords: Cancer patients; insomnia; pranayama

57. THE IMPORTANCE OF COMMUNICATION TO THE PATIENTS IN THE HOSPITAL (D1-258)

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Introduction: Good communication in healthcare improves patients experience to treatment. Not all doctors, nurses and volunteers are trained in communicating effectively. Different communication techniques are needed to engage with the elderly, children and terminally ill patients. More needs to be done to improve communications skills of healthcare professionals in our country.

Aim of the Study: To create communication module scientifically to suit the needs of the cancer patient. All healthcare professionals including hospital staffs need to be trained to communicate effectively.

Materials and Methods: 10 volunteers, 5 doctors, 5 nurses, 5 Hospital staffs were randomly interviewed about their training in communication and their comfort zones in connecting with the patients.

Results: Junior Doctors felt uncomfortable in openly communicating with the dying patients as they feared off letting down on patient's hope and trust in the system. Many wanted training to improve their communication skills. Nurses: 50% of nurses were comfortable in having EOL communications with patients. 80% wanted training in effective communication skills. Volunteers: 90% felt that they were poorly equipped with good communication skills. 70% had no knowledge of when and how to communicate. 40% felt that there was no necessity for training to improve communication.

Conclusion: All healthcare professionals and hospital staffs should have adequate training in communication skills.

Keywords: Cancer hospitals; communication; training

58. CONVERSATIONS OF A LIFETIME: DEVELOPING PRIMARY PALLIATIVE CARE SKILLS THROUGH SIMULATION-BASED TRAINING (D1-259)

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Introduction: The communication skills required to integrate complex medical issues with patient-centred values go beyond the basic interviewing skills taught in medical school. As the US population ages, the number of patients with advanced, chronic, life-limiting illness will only grow, many of whom will have multiple comorbid conditions. Resident physicians are often at the front lines caring for these patients. Therefore, it is critical that residents learn to engage patients in conversations about their goals and values while also informing them of their disease trajectory and the burdens and benefits of their treatment options.

Materials and Methods: Half-day workshop using didactics and skills practice with standardized patients trained by Hospice of Cincinnati. Content focused on breaking bad news, responding to emotion, eliciting patients' goals, discussing uncertainty, transitioning from curative to comfort care, and discussing death and dying. Participants were internal medicine residents of TriHealth (N =28). Surveys measured prior training, pre-course self-assessment, immediate post-course perceived changes, and long-term changes in communication skills and clinical practice using open- and closed-ended questions.

Results: Response rate was 100% (pre- and post-course) and 93% (at follow-up). Participants reported improvement in all domains and sustained improvement at follow-up ($p < 0.05$). Participants also described detailed changes to their daily clinical practice.

Conclusion: An interactive communication skills-building course can have a meaningful impact on residents' perceived preparedness and attitudes in having goals of care conversations with patients. Our findings highlight the need for structured education on communication skills with direct observation and feedback in residency training.

Keywords: Breaking bad news; communication; doctors

59. METHADONE IN CHILDREN IN INDIA- EXPERIENCE AT A TERTIARY CANCER REFERRAL CENTRE (D1-261)

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Introduction: MNJ Institute of Oncology & Regional Cancer Centre is a tertiary referral centre for cancer treatment. MNJIO alone registers around 1000 new children suffering with cancer each year. Pain and Palliative Care is integrated right from the beginning of the treatment, even before the confirmation of the diagnosis. We see around 15 out patients and 30 in-patients who require palliative care on a daily basis for high symptom load like pain, breathlessness, oral mucositis etc during their primary cancer treatment.

Aim of the Study: Safety and demographic profile of Methadone used as a part of opioid rotation for severe pain in children with cancer in Indian population.

Materials and Methods: Based on WHO ladder, Step 3 medication includes strong opioids for pain. When morphine was not effective for good pain control, methadone was tried in paediatric age group at a tertiary cancer referral centre as a part of opioid rotation.

Results: Methadone is a safe drug like morphine and can be used in children with proper drug dosage and titration for severe pain in cancer.

Conclusion: Methadone can be used in children when pain is poorly responding to morphine.

Keywords: Cancer; children; methadone; pain management

60. DEVELOPING AND IMPLEMENTING A PROJECT ECHO FOR PAEDIATRIC PALLIATIVE CARE IN SOUTH ASIA (D1-262)

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Introduction: More than 98% of children who need palliative care live in low- or middle-income countries where access to palliative care is very limited. Project ECHO uses web-based videoconference sessions to train healthcare professionals, through a virtual learning community where participants can reflect to deepen their knowledge. We develop Project ECHO Paediatric Palliative Care (PPC) to train health professionals to care for children with serious illnesses in South Asia.

Aim of the Study: This study describes the key considerations from our experiences in developing and implementing Project ECHO PPC. These are first steps in designing and evaluating a program to teach paediatric palliative care, which we hope will serve as a useful guide for others who develop a similar Project ECHO program.

Materials and Methods: Project ECHO PPC was developed using a mixed-methods approach which involved (1) literature review, (2) a survey of stakeholders, and (3) establishing consensus using an expert panel. The program consists of a 90-minute session occurring regularly every two weeks over videoconferencing software, which includes a didactic teaching session (40 minutes), followed by a case presentation with discussion (40 mins).

Results: We identified the primary themes regarding PPC training from a review of the (1) scientific and gray literature and (2) training objectives from relevant professional bodies and existing training courses. We then conducted an online survey of stakeholders, followed by review by an expert panel to establish consensus about content and desired format. Ongoing improvements to the program are facilitated by regular meetings of our leadership and management teams to debrief the sessions. Ensuring that sessions run smoothly and meet the learning needs of participants are the most significant challenges encountered.

Conclusion: Project ECHO PPC is an innovative educational format for delivering paediatric palliative care education in resource limited settings, which bridges the gap between experts, and practitioners, through a collaborative online community.

Keywords: Education; paediatric palliative care

DAY 2

61. REASONS FOR COLLUSION AMONG INDIAN FAMILY CAREGIVERS OF PATIENTS WITH CANCER (D2-301)

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Introduction: Collusion is often faced by health care professionals, especially in oncology and palliative care, where family members of patients secretly request them not to share important medical information with the patient. Literature has shown that patients want to know about their disease condition, up to 95% in India. However, many are not aware of their diagnosis. One of the reasons for this is collusion. A few studies have been conducted to understand the reasons for collusion, mostly in Asia. However, none have explored factors influencing the decision to collude specifically in India.

Aim of the Study: This study set out to explore reasons Indian family caregivers of patients with cancer collude with health care professionals regarding the patient's diagnosis and/or prognosis, highlighting reasons exclusive to the Indian setting. It also explored demographic factors influencing collusion.

Materials and Methods: Qualitative methodology was used with in-depth semi-structured face-to-face interviews of ten participants. Demographic details of patients and caregivers were also analysed.

Results: The character, perceptions and concerns of caregivers governed the decision for collusion. The most common reasons for collusion were feared outcomes of disclosure, strong family responsibility and to prevent suffering. Factors which were dependent on individual patient or family circumstances also affected the decision for, types and degree of collusion. Among female patients, especially older women, collusion was more prevalent.

Conclusion: Collusion appears to be a socio-cultural "defence mechanism" used to "protect" patients and caregivers. The decision for collusion among caregivers of Indian patients with cancer is governed by many factors. The context and reasons for collusion need to be explored carefully with caregivers. When these reasons have been understood, careful empathetic provision of knowledge and counselling can be done to facilitate a mutually agreed upon mode of disclosure to the patient.

Keywords: Cancer patients; caregivers; collusion

62. PALLIATIVE CARE NEEDS IN GERIATRIC AGE GROUP SUFFERING FROM MALIGNANCIES IN TERTIARY CARE HOSPITAL (D2-302)

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Introduction: Cancer patients may experience multiple symptoms due to the disease itself, cancer treatment or combination of both. It is more enhanced in elderly age group. There is a need of study to assess various health care issues and later plan to address them.

Aim of the Study: Listing all the issues classified into domains and subdomains that are faced during the care of elderly patients with malignancies.

Materials and Methods: Cross sectional study done at Yenepoya medical college hospital, Mangalore. Among 62 elderly enrolled for study.

Results: Multiple issues experienced by elderly suffering from malignancies had been clustered together, psychological and physical issues were dominant. Among physical issues pain was predominant issue. Among psychological issues depression was predominant. Most of the elderly were having monetary issues regarding treatment.

Conclusion: Knowledge obtained from this study could be beneficial for better understanding, assessment and management of symptom clusters in elderly with malignancies. The information can be used to plan ahead and seek treatment in a timely manner.

Keywords: Palliative care in elderly

63. CHALLENGES AND MOTIVATION OF PALLIATIVE CARE ASSISTANTS IN PROVIDING CARE FOR ELDERLY PEOPLE IN AN URBAN SLUM (D2-303)

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Introduction: Palliative care has been acknowledged as an essential component of Universal Health Coverage (UHC) for all who are in need of it. In developing and densely populated country like Bangladesh it is not evident in main stream health care where formally trained health care providers are mostly trained in prevention and cure oriented approach to provide this care. The gap is attempted to be filled in by ‘Palliative Care Assistant’ to providing basic palliative care in the community after completing a structured purposeful target oriented training program.

Aim of the Study: The aim of this study is explore challenges and identify the motivation of Palliative Care Assistants (PCAs) who provide care of elderly people in an urban slum in a city.

Materials and Methods: It is a qualitative study analyzing in depth interviews of six PCAs who have minimum 2-year experience of providing care of elderly people in slum.

Results: The PCAs identified 4 major challenging areas 1) Inability to educate patients and caregivers because of their unavailability 2) dependency on PCAs for all nursing issues 3) Inability to follow advice due to aging related incompetency, household conflict between patient and caregiver 4) unmet expectations of patients and caregivers for free medications, investigation costs, regular food supply etc. To overcome challenges, PCAs developed several realistic approaches in their work settings, include an attempt to show respect by fulfilling minimum most essential needs by addressing these, honest open communication with patients & families regarding their abilities and limitations, increasing team efficiencies, motivating caregivers and neighbours to take care of patients. In spite of all the challenges, PCAs get encouraged when patients and family members ultimately accept & welcome them and look forward to their home visits & often share their personal issues with them.

Conclusion: Although there are challenges and barriers in providing care, PCAs find their own jobs satisfactory and respectful.

Keywords: Palliative care in elderly

64. ENHANCING QUALITY AND QUANTITY OF LIFE: EIGHT-YEAR SURVIVAL WITH LUNG SECONDARIES USING HORMONAL TREATMENT IN PALLIATIVE CARE (D2-304)

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Introduction: Hormonal treatment can improve survival and symptoms in gynaecologic, breast and prostate cancers with acceptable toxicity and cost.

Aim of the Study: To review the clinical course of a long term survivor with multiple lung secondaries.

Methods: A postmenopausal lady who was afraid of hospitals and had defaulted treatment for early endometrial cancer. She presented to palliative care with cough and dyspnoea caused by extensive lung metastases. She was started on megestrol 80 mg twice daily with which her lung secondaries resolved within two years. Her appetite improved significantly but due to increase in weight and hyperglycaemia, she was shifted to letrozole and subsequently back to megestrol. She has no recurrence of cough and dyspnoea for the past six years.

Conclusion: Appropriate hormonal treatments can reduce the need for symptom control medication and improve quality of life and survival.

Keywords: Hormonal treatment; lung secondaries; quality of life

65. CAREGIVER BURDEN IN CAREGIVERS OF OLDER ADULTS WITH LONG TERM CONDITIONS (D2-305)

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Introduction: Many families caring for terminally ill older adults report making major life changes and personal sacrifices to care for their relative. It is also known that caregiver burden affects the overall morbidity and QOL of the older adults who is been taken care.

Aim of the Study: The purpose of this study was to understand the characteristic of caregiver and the patients associated with caregiver burden.

Materials and Methods: Data was collected from 50 caregivers who were taking care of older adults for more than 4 months. Caregiver burden was assessed with Zarit Burden Inventory (22 item scale). Beck Depression Inventory was used to assess the depression in caregivers. Katz index of ADLs and Lawton Brody index of IADLs were used to assess the functional dependency of the patient. Descriptive and analytical variables included patient and caregiver socio-demographic and health characteristics and caregiver psychosocial characteristics.

Results: 45 percent of the caregivers had severe caregiver burden whereas 10 percent reported no or little burden. There was a significant relationship between intensity of assistance in ADL and caregiver burden (odds ratio [OR] = 23.13). Although scores increased modestly over time, the association between time and burden was not significant. Caregiver burden was greater associated with patients with dementia and having bowel incontinence. Depression is common in caregivers especially in older caregivers (40 percent in carers above age of 50 years).

Conclusion: Caregiver burden was common among caregivers of patients with dementia and with high functional dependence. Depression is high among older caregivers especially females. Caregiver burden is a major determinant of the QOL of both the caregivers and patient. Lack of skilled nursing care at home for chronically bedridden patients is one major reason for increasing caregiver burden.

Keywords: Caregiver burden; long term condition

66. Spiritual and Psychosocial Aspects of the Quality of Death in A Selected Geriatric Population (D2-306)

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Introduction: Quality of death is a measure of quality of palliative care. Unlike physical dimensions, spiritual and psychosocial dimensions of death vary across cultures, religions, subjectivity and other factors. There is a dearth of research, examining spiritual and psychosocial dimensions in the context of these factors. This study aims to understand spiritual and psychosocial dimensions of quality of death, in an Indian context. A geriatric cohort was chosen, as they may be able to speak of the quality of death more meaningfully as compared to younger age groups.

Aim of the Study: To identify and explore psychosocial and spiritual dimensions of quality of death amongst a selected geriatric population in Bangalore city.

Materials and Methods: Ten participants were recruited from Guanella-Aged Home and Bangalore Baptist Hospital. In depth face to face interviews were conducted using a semi-structured interview schedule, recorded, transcribed and analysed to look for themes.

Results: Eight themes and twenty-two categories were generated. The themes were: role of God, life completion, lack of purpose, preparedness, individual perceptions of death, hope for the future, process of dying and miscellaneous. The categories were: sovereignty of God, accountability to God, fatherhood of God, characteristics of God, death as undesirable, death as a law of nature, death as a journey, death as a divine curse or blessing, faith-based hope, lack of fear of death, hope encouraged by spiritual practices, peaceful death, lingering, unnatural deaths, spiritual preparedness, psychosocial preparedness, financial preparedness, physical preparedness, death bed visions, dearth of spiritual conversation, need for honest conversations and coping with suffering.

Conclusion: Lack of purpose that individuals experience after life completion, with no hope for further purpose in life, contributes to psychosocial lingering. Hope for the future dispels fear of death. Belief in a loving and forgiving God and a surrender to His will gave meaning and helped cope with suffering.

Keywords: Hope; psychological and spiritual care; quality of death

67. Comparison of Two Cases of Acute Upper Airway Obstruction at the End of Life in Terminally Ill Cancer Patients (D2-307)

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Introduction: Acute upper airway obstruction is an emergency. It's a distressing symptom for patient & to care giver also. This paper highlights the role of multi-disciplinary team providing care during End of Life emergencies.

Aim of the Study: (1) Describe two cases of acute upper airway obstruction in the last few hours of life. (2) To compare differences & in approach to management.

Materials and Methods: We are presenting two cases with acute upper airway obstruction with different presenting symptoms.

Case I: A 55 years old female, farmer by profession, case of Carcinoma Left Alveolus Post treatment was admitted with moderate dyspnoea & severe submandibular pain since past 2 days. Doctors had discussion about need of tracheostomy. Patient being full aware of prognosis refused to undergo tracheostomy. On the last day her dyspnoea increased. She developed stridor & became unconscious.

Case II: A 60 Years old man, driver by profession, Ca- Right Alveolus Post treatment. He was admitted with mild dyspnoea & severe headache since past 6 days. Need of Tracheostomy & further prognosis explained to patient & relatives. Patient refused to undergo the same. On last day patient started complaining of severe cough, dyspnoea. Became restless, developed stridor.

Results: Case 1 - Goal of care was to provide comfort care. Multidisciplinary team already had discussion about disease prognosis with patient & family. Patient died without any restlessness with her family at bedside. Case 2 - Goal of care was to reduce restlessness & provide comfort care. Doctrine of double effect explained to relatives. To relieve distress Inj. Midazolam was given with titration of dose. Patient died after few hours with family at his bedside.

Conclusion: This comparison highlights that a multidisciplinary approach, appropriate medicinal use & good communication play important role in care of patient & their family in need of End of Life care.

Keywords: Airway obstruction; end of life care

68. End of Life care practice at a Tertiary Cancer Centre in India: An Initial experience (D2-308)

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Introduction: In India, almost 80% of the cancer cases presents to a hospital in stage III and IV and requires end of life care (EOLC). Improving quality of life of these patients is challenging because of lack of understanding of palliative care and various barriers.

Aim of the Study: To assess the current EOLC practices and the magnitude of futile care in a tertiary cancer centre. To find out the barriers in the provision of good EOLC in cancer patients.

Materials and Methods: A cross-sectional study was done on 18 patients. Patients who were diagnosed end of life by using palliative prognostic index (PPI) were enrolled in this study. Socio-demographic and clinical details were recorded using hospital record. Information regarding counselling by treating or palliative care physician were recorded. Various barriers encountered for EOLC was explored from the palliative care physician.

Results: In this study initial experience of 18 patients were analysed. PPI score was >6 (survival shorter than 3 weeks) in 66.6% patients, while 22.2% patients had score >4 (survival shorter than 6 weeks). Maximum (56%) patients preferred home as their place for EOLC while 33% preferred hospital and 11% preferred hospice. Most common barrier in provision of EOLC was found to be family member's related barrier because lack of understanding and clear communication among family members followed by physician himself who don't feel confident.

Conclusion: EOLC is a least studied part of patient care with various barriers and with proper communication and palliative care, futile treatment can be avoided. With healthy communication we can empower family members and patients for good death.

Keywords: Communication; end of life care; futility

69. FAMILY DYNAMICS IN PSYCHOSOCIAL ASSESSMENT A CHALLENGE IN PAEDIATRIC PALLIATIVE CARE – A CASE STUDY (D2-309)

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Introduction: Psychosocial assessment is the main tool to help plan interventions that help the family. Children are not involved for all treatment or care related decisions. They are dependent on parents. Different issues within family dynamics such as interpersonal discord, differences of opinion etc. can affect decision making regarding availing healthcare services.

Aim of the Study: (1) To address family dynamics as a challenge in paediatric palliative care. (2) Impact of family dynamics on decision making. (3) To address the psycho-social issues of single parent. (4) To facilitate access to healthcare facilities.

Materials and Methods: With the consent of family, we describe this case, 9-year-old girl with pre-B ALL diagnosed 8 months prior to referral to our palliative care centre (PCC), she received chemotherapy but due to issues faced by her mother, a single parent, she could not complete her whole treatment. The mother was dependent on extended family, however due to lack of family and financial support, she was helpless. The challenge for the MSW team was to bring the family together and explain the need for cancer treatment and palliative care.

Results: Extensive counselling sessions were conducted with the mother and extended family to help them understand the prognosis and value of supportive care for the patient.

Goals of Care for the Mother included

- Acceptance of change in child's behaviour
- Encouraging mother to take decision in the interest of child's wellbeing
- Providing Closure
- Reinforcing the importance of Palliative Care to provide comfort to the patient.

Conclusion: The sessions helped the mother feel supported in her decisions regarding her child's treatment and reduced her feelings of guilt. It also helped the mother to cope with impending loss and motivated her to move ahead in life. This case study helps us to understand the family dynamics and address the challenges in providing overall support.

Keywords: Paediatric palliative care; psychological assessment

70. NURSES' PERCEPTIONS OF END-OF-LIFE CARE AFTER AN IN-SERVICE EDUCATIONAL INTERVENTION (D2-310)

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Introduction: Nurses working in a palliative care unit are well aware of the concept of a "good death" than most other health care professionals. Most of the dying patients do not receive terminal care from specialist palliative care professionals since expert hands in EOL care lack in the health care delivery system. Health care delivery system cannot function without empathy. The scope for palliative care is limited in a nursing curriculum in diploma and UG program. EOL care demands professional who can able to handle challenges with competence, commitment, and human compassion.

Aim of the Study: (1) To identify the perception level of end of life care among nurses. (2) To find an association between perception level with demographic variables.

Materials and Methods: Pre-Experimental Design, One-shot case study method was used to collect the data. The convenient sampling method was used to select 68 participants after informed written consent. After an in-service educational session, the perception level of nurses assessed with the help of 5 points Likert scale.

Results: Data analysed descriptive and inferential statistics. Majority of them have completed a diploma program in nursing. Around 45 (66%) of them were in the age group of 21 to 25 years. Half of them 40 (59%) family members had suffered in their end of life. Majority of nurses 53 (78%) felt it had changed the outlook on EOL care. The overall perception was good among 63 (93%) nurses and no significant association found with the demographic variables.

Conclusion: Most of the nurses are witnesses to painful events during EOL care. Adequate training and knowledge in EOL care can help them overcome many of the obstacles in caring for terminally ill patients. Our nursing curriculum should also focus on palliative and EOL care.

Keywords: Education; EOL care; nurses perception

71. IMPACT OF DISTRESS AND PAIN IN ADVANCED CANCER PATIENTS DURING HOME VISITS IN CHENNAI, TAMIL NADU (D2-311)

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Introduction: Distress is an integral part of advance stage of cancer. Palliative care plays an important role in improving quality of life by relieving distress. Results of Home based palliative care services give a positive feedback.

Aim of the Study: The aim of the study was to assess the impacts of distress & pain in advanced cancer patients in response to home visits.

Materials and Methods: All the patients were registered in the department of pain and palliative care, for home visits in the tertiary care institute. A total of 118 patients participated in the study in the year of 2017. The patients were prospectively studied to assess the impact of home care visits using distress thermometer and visual analogue pain scale.

Results: Out of the 118 patients participated, after the first home visit, the percentage of patients with Mild Distress 43.1%, Moderate Distress-41.5%. Moderate Pain-59.3% and Severe-33.9%. During subsequent home visits (Distress: No distress-30.5%, Mild-55.9% and Moderate-13.6%; Pain: No pain-52.5%, Mild-11.9%, Moderate-16.1% and severe-19.5%) were reported by the patients. There was a significant decrease in the distress level in response to a home visit by our team.

Conclusion: Repeated home visit improved the symptom control and psychological well-being. Impacts of distress were changed over the period. From this study, it is understood that repeated home visit brings down the pain & distress in patients & caregivers.

Keywords: Advanced cancer; distress; home visits; pain

72. MEMORIAL SERVICE AS BEREAVEMENT CARE (D2-312)

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Introduction: Palliative care includes the care of families of persons facing life-limiting illness and their bereavement support. The psychological and emotional needs of families are often neglected.

As part of bereavement care, the Palliative Care department in Bangalore Baptist Hospital has been conducting a memorial service annually, for families of their patients who had passed away in the previous year. The program is usually attended by 150-200 people, 60% of the families invited. The program included a time of sharing of experiences by families, an encouraging word by a counsellor and concluded with a candle lighting ceremony.

This poignant program allowed families to experience closure, while lighting a candle and placing it in the pot of sand. Families also felt comforted while sharing their sorrow with others with similar experiences.

Aim of the Study: To determine the value of memorial service as care for bereaved families.

Materials and Methods: A questionnaire, in English and Kannada (the local language) with simple questions asking if people felt comforted by the service, the need for further assistance in coping and if people would like to volunteer, was distributed at the end of the service. The data collected from the questionnaire was analysed.

Results: Out of 47 people, 43 (91.5%) were comforted while 4 did not answer the question (possibly due to the layout of the questionnaire). Most people (41, 87%) found the lighting of candles meaningful while 76% indicated the sharing of experiences. 29 (61.7%) were touched by the counsellor's talk. Under "suggestions", many used the opportunity to express gratitude to the palliative care team for their service.

11 admitted to needing medical help while 10 required spiritual support. 31 (65%) were willing to volunteer in palliative care work.

Conclusion: Memorial service was found to be meaningful to most bereaved families and can be used effectively in bereavement support.

Keywords: Bereavement care; memorial service

73. COLLABORATIVE APPROACH: COMBINED CLINICS AND JOINT ICU CONSULTATIONS FOR COMPREHENSIVE AND SEAMLESS CARE OF OLDER PEOPLE APPROACHING END OF LIFE (D2-313)

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Introduction: According to WHO, Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life. However, in India patients are often referred late and are unable to benefit much due to the short period of support through palliative care. To address this, a combined clinic was initiated in January 2018 for people 60 years and above, with life limiting conditions who were approaching end of life. Palliative care interface in ICU was also improved.

Aim of the Study: To facilitate early referral and seamless transfer to palliative care for older people approaching their end of life and support them with whole person care including home care.

Materials and Methods: Doctors were trained to identify people approaching the End-of-Life using the Proactive Identification Guidance (PIG) of the Gold Standards Framework, U.K. The clinic was planned for Friday afternoons from 2.00 to 4.30 pm and each specialty was given a half hour slot. Doctors could bring their selected patients by appointment to this combined clinic for joint discussion and making further care plans and facilitation of their wishes. On other days referrals for palliative care continued as before. Also, in the ICU, joint patient consultations and joint family counselling were done.

Results: Analysis of a year's experience is presented.

Conclusion: Combined clinics and joint ICU consultations resulted in continuity of wholistic palliative and end of life care and finally a good death in hospital or home for older people approaching their end of life.

Keywords: Collaborative approach; ICU

74. DELIVERING QUALITY, RESULT ORIENTED, PALLIATIVE CARE IN A HOME SETTING (D2-314)

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Introduction: The Jimmy S Bilimoria Foundation launched PALCARE in December 2015, as one of the first multi-disciplinary, professionally run, home-based, palliative care services in the city of Mumbai.

Aim of the Study: To provide patients, residing in and around Greater Mumbai, with life limiting conditions, primarily cancer patients, a much needed palliative care, in the comfort of their homes, through a service which embraces the highest standards of professionalism, integrity and a humane approach. Such palliative care must ensure a comfortable, pain-controlled and dignified life for the patient till the very end.

Materials and Methods: To begin with 4 strategy goals were determined:

1. Develop a robust palliative care service and a sound business plan, to deliver the organization's mission; constantly fine-tuned and upgraded to meet changing needs.
2. Lay emphasis on professional development through:
    - setting up active advisory committees to share their expertise
    - developing thoroughly researched clinical guidelines for a home setting
    - training, educating and mentoring the team
    - discussing case studies for future learnings
3. Deliver advocacy to onco-specialists, hospitals, local GPs by sharing data, success stories and commendations from satisfied patient families.

Patient data over 3 years, two specific stories and one family feedback letter are shared to highlight PALCARE's contention that patients may be afforded a peaceful, happy, dignified end at home.

Results: Driven by a passion for excellence in delivering quality and compassionate care in the home, PALCARE has seen the emergence of an extremely satisfied client base. It has managed 739 patients in the first 3 years. 80% of demises have been at home.

Conclusion: Quality home-based palliative care requires both mind and heart.

Keywords: Bereavement care; end of life care

75. THE NURSES' KNOWLEDGE AND ATTITUDE REGARDING END OF LIFE CARE (D2-315)

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Introduction: The end of life care or palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, perfect assessment, treatment of pain and other physical, psychosocial and spiritual problems. The goal of palliative care is to have interventions in place to ensure that the patient is safe and comfortable throughout the disease process and will experience a peaceful death. Providing adequate pain management requires the use of evidence-based interventions to provide pain relief and avoid unnecessary suffering at end of life.

Aim of the Study: To assess the level of knowledge and attitude of staff nurses regarding end of life care, to identify the association between knowledge and attitude regarding end of life care with selected socio-personal variables and to determine the correlation between knowledge and attitude regarding palliative care or end of life care.

Materials and Methods: The research approach used in this study is Quantitative with descriptive design. Sample includes the staff nurses working in Srilanka and sample size was 100. Sampling Technique used was convenient sampling. Tools include a socio-personal Performa, a semi- structured questionnaire to assess the knowledge and FATCOD attitude scale to assess the attitude. Data collection technique was self-reporting.

Results: The study finding revealed that 22% of nurses have adequate or good knowledge while 60% moderate knowledge and 18% poor knowledge. 56% were having moderate attitude regarding end of life care, 16% were having adequate attitude while 28% were having poor attitude.

Conclusion: The nurses had fair knowledge, also their attitude regarding end of life care was moderate. Recommendations are that integration of the national health policy related to end of life care in the national curriculum of nurse education and provide training related to end of life.

Keywords: Attitude; EOL care; nurses knowledge

76. HOW TO WRITE A "LIVING WILL" - A CAMPAIGN TO ENSURE SUCCESSFUL DYING (D2-316)

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Introduction: Recent Supreme court judgement allowing ``passive euthanasia`` in India is a revolutionary step in ensuring dignified death to its citizens which was welcomed by all. But few further steps were taken by palliative care organisations to teach the public on how to write a ``living will``. Alpha palliative care is an organisation functioning in central Kerala since 2005 which actively engages in end of life care. This project of Alpha palliative care is to empower the community to take right end of life care decisions which will ensure a dignified end to all.

Objectives: (1) To provide necessary insight on the recent law on passive euthanasia. (2) To present a template from which people can select, modify and draft a "living will". (3) To open doors of discussion for framing end of life care policies in our health care system.

Materials and Methods: This project was conducted public meetings on ``good death`` and distributing -templates- of living will to the participants. Complex formalities of the new law and norms of registration are also discussed. Monthly follow up meetings are also planned.

Results: As this is an ongoing project we need to wait for at least a year to assess the impact. Impact could be assessed by number of people writing and registering their living will, framing of end of life care policies in hospitals, number of patients achieving good death etc.

Conclusion: This project envisages to kick-start discussion on death and dying in our death denying society and an attitudinal change in the way society see death. Palliative care organisations all over the country need to involve in this campaign to empower the society in the matters of death and dying.

Keywords: Bereavement care; end of life care

77. AN AUDIT ON IMPLEMENTING END OF LIFE CARE POLICY IN MEDICAL INTENSIVE CARE UNIT OF A QUATERNARY CARE CENTRE IN INDIA (D2-317)

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Introduction: The intensive care unit (ICU) is a setting where the focus is on sustaining life but also a setting where death is common and the delivery of high-quality end of life care (EOLC) can be challenging. As per Indian Association of Palliative Care (IAPC) there are recommendations on EOLC.

Aim of the Study: Our hospital had implemented a functional EOLC policy since 01st March 2018. Our aim was to assess the adherence of current practices in patients admitted to medical ICU to EOLC policy of the hospital.

Materials and Methods: A retrospective review of hospital inpatient deaths in medical ICU from 01st August 2018 to 30th October 2018 was done using electronic medical records. All deaths with an admission duration of >3 days and with an advanced, progressive, incurable or life limiting illness were included and all those with <3 days admission and sudden deaths and death from other causes were excluded.

Results: Out of 42 expired patients 28 were eligible. EOLC adherence was documented in 9 patients (32.14%). The terminal nature of illness and futility of care was communicated to 24 patients (85.7%). An EOLC referral was given for 5 patients (17.8%). Active symptom control medications were given for 8 patients (28.5%). Optimization of medications and invasive treatment was documented for 7 patients (25%). Psychosocial, emotional, cultural, and spiritual needs, regarding dying and grieving was documented for 12 patients (42.8%).

Conclusion: There is a scope for improvement in terms of adherence to the policy particularly with initiation of EOLC as the most important area. This also highlights the need for Quality improvement projects in EOLC.

Keywords: Intensive care unit; end of life care policy

78. COMFORT AT END-OF-LIFE: CAN BISPECTRAL INDEX MONITORING ADD TO OUR UNDERSTANDING? (D2-318)

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Introduction: Unresponsiveness preceding death is often managed in palliative care with subcutaneous infusion of an opioid and sedative. Dose adjustments are based on clinical assessment and observational measures of comfort and sedation. Following research suggesting unresponsiveness does not equate to unconsciousness, this study compares their validity against an objective measure of sedation, the Bispectral (BIS) Index score.

Objective: Determining the validity of the Richmond Agitation-Sedation Scale (RASS) and Patient Comfort Score (PCS) in assessing sedation and comfort in unresponsive patients.

Materials and Methods: BIS monitor connection via a sensor applied to fronto-temporal region when a patient became unresponsive. Nurses recorded 4th hourly measurements of sedation (RASS) and comfort (PCS). Correlation coefficients examined their relationship with time-matched BIS, using the Bland and Altman method.

Results: Forty consenting patients were monitored from the time of unresponsiveness until death. Mean age was 74 years, with 25 males. Mean duration of subcutaneous sedation was 3.7 days. Mean duration of monitoring was 22.4 hours. The relation between BIS and RASS was highly significant, $p<0.0004$. The relation between BIS and PCS was weaker, but also significant, $p=0.003$. However, detailed analysis of 17 patients monitored for a full 24 hours before death showed wide variations in BIS scores (level of awareness), when RASS and PCS suggested they were deeply sedated and pain-free.

Conclusion: Clinically unresponsive patients may be more aware than observational measures suggest. RASS and PCS appear to be relatively blunt instruments at the lower end of their respective scales. Further research is required to guide clinical practice.

Keywords: End of life care; patient comfort score; Richmond agitation-sedation scale

79. EMPOWERMENT OF FAMILY CAREGIVERS BY COMMUNITY NURSES (D2-319)

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Introduction: Community nurses in Kerala performs a dual role. One is active patient care in the home care setting and the other is to educate the family caregivers in patient care. This empowerment of the family caregivers with knowledge and information is very crucial in the management of patients with long term illnesses.

Aim of the Study: (1) To assess the level of empowerment gained by the family caregivers. (2) Assess the significance of demographic variables in the empowerment.

Materials and Methods: This is a prospective study by collecting data from the family caregivers through a structured interview using a standard questionnaire. Apart from the basic demographic data the questionnaire explored the level of knowledge and information the caregiver had gained from the community nurses and the level of confidence they have achieved in managing the patient. The demographic variables studied were relationship of the caregiver to the patient, education status of the caregiver and socioeconomic status of the family.

Results: We interviewed 33 family caregivers providing care for catheter, pressure ulcer, colostomy, tracheostomy and Morphine administration. We found that the average score of empowerment for caring the patients was 80.6% and that of the perceived psychosocial support was 83.6%.

Conclusion: The family caregivers were empowered by the education received from Community nurses. The level of empowerment directly correlated with the sense of confidence and satisfaction of the caregiver. It would be better if we can incorporate family empowerment as a topic in the curriculum of Community Nurses.

Keywords: Empowerment; family caregivers

80. Evaluating the Effectiveness of Progressive Rehabilitation Therapy among Women with Breast Cancer-Related Lymphedema: A Pilot Study Report (D2-320)

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Introduction: Breast cancer-related lymphedema (BCRL) is a progressive, debilitating chronic disease that affects millions of cancer survivors and primarily results from the surgical lymphatic vessel / node removal and radiation therapy. There is no cure for this condition but requires lifelong self-management.

Aim of the Study: The aim of this study is to improve QoL through PRT among breast cancer-related lymphedema women in their maintenance phase.

1. Evaluate the impact of PRT on QoL among women with BCRL.
2. Assess the effectiveness of PRT on self-care activities among women with BCRL.
3. Determine the effectiveness of PRT on limb functioning among women with BCRL.

Research Design: Quantitative, Randomized control trial.

- The setting of study: Urban / Semi-urban community in Bangalore
- Population: BCRL women – post-mastectomy surgery
- Sample: 16 BCRL women patients (8 Experimental and 8 Control; 2 blocks in each group)
- Sampling technique: Patients who fulfill the inclusion criteria were included

Results:

- Mean age group of the subjects was 59.5 years
- Nearly two-thirds (62.5%) of the subjects had their left arm affected with lymphedema
- All the subjects had undergone axillary lymph node dissection, and 75% had undergone radiation therapy.
- The self-care practices improved from 38% (pre-intervention) to 63% (post-intervention) in the experimental group.
- The upper limb functioning (QUICK DASH) score improved from 37 to 8; post-PRT whereas in control group it reduced from 24 to 22.
- The health-related QoL using LYMQOL arm score improved from 5.26 to 8.13; post-PRT whereas it remained same (6.63).
- The subjects in the experimental group maintained their arm volume with an average variation of -4.3% between Day 1 and Day 60.

Conclusion: The study revealed that self-care practices resulted in improvement in affected arm functioning for most of the subjects thereby leading to a better QoL.

Keywords: Breast cancer; lymphedema; rehabilitation

81. Significance of Multidisciplinary Team in Management of Complex Patient Care (D2-321)

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Introduction: A Multidisciplinary team is a group of healthcare professionals from varied disciplines and roles, working together towards a common goal of providing optimal care for a patient. Palliative care lends itself particularly well to this approach due to multiple dimensions involved in caring for patients.

Aim of the study: (1) To describe the management of TOTAL PAIN. (2) To highlight the importance of multidisciplinary approach to pain management.

One case report which helped the patient and the family to cope complex physical & psychosocial pain.

Mrs. SG is a 47 yrs. Old, wife of migrant labourer diagnosed with Right sided Ca breast, recurrent with axillary mass. The patient had undergone 4 cycles of chemotherapy and then approached palliative care for pain and other symptoms.

Pain: Severe neuropathic pain related to rt. brachial plexus involvement.

Management: Along with Opioids and Adjuvants, Right upper limb brachial plexopathy with Inj. Lignocaine and Inj. Ketamine (Inj. Xylocard 5 ml + Inj. Ketamine 2 ml + 43 ml Normal saline) @ 30 ml/hr. under monitoring of vitals parameters.

Pain reduced to 3/10 and patient comfortable.

Physiotherapy: For the management of lymphedema Transcutaneous Electrical nerve stimulator was used which reduced the pain.

Management: Medications, pain medication, physiotherapy and social work together

Social issues: Lower socio-economic migrant background, two children and husband having contractual job with no support, temporary House. Major concerns were anxiety about the daughters, patient's attention seeking behaviour and no social support. Due to these, her pain threshold decreased. Family meeting was planned which facilitated relocation back to their hometown with family along with referral note to seek healthcare intervention.

Results: The Multidisciplinary team helped her and the family to achieve the goal of good pain relief.

Conclusion: This case helped us understand the importance of multidisciplinary teamwork for the patient and family care.

Keywords: Complex neuropathic pain, multidisciplinary team

82. Occupational Therapy - A Holistic Approach: A Case Study (D2-322)

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This is a case report of a 53 year old married, school teacher who had recently undergone modified radical mastectomy and the role of occupational therapist in providing a holistic care.

Aim of the report is to demonstrate the use of Occupational Performance Model to assess the following in this patient.

1) Activities of daily living, self-care, work & leisure
2) Motor, Sensory, Cognitive, Psychological & Social
3) Temporal & Environmental
4) Pain: Physical / Social / Psychological / Spiritual
5) QOL

Occupational therapist was involved 4th day post op whilst drain was still present. We initially built a rapport with the subject and did an in depth history taking, asking subject to express areas of difficulty. Assessed was made using ROM, WHO QOL bref scale. Patient was taught deep breathing exercises, skin care do's and don'ts, exercises for shoulder and she was followed up twice a week.

Since subject was from out of the country, prescription of breast prosthesis with donning and doffing explained, for later use. Subject was to receive chemotherapy and provision of a wig was also discussed. Being a primary school teacher and needing to use her hand for writing on the board, she was encouraged to try using the non-dominant hand when fatigued. She was advised to contact a certified Lymphedema Therapist in her hometown.

Results: Patient was discharged after 3 weeks. Subject and husband satisfaction improved with the involvement of an Occupational Therapist.

Conclusion: Occupational therapy practitioners play an important role in Palliative and hospice care teams. They can be instrumental in identifying life roles and activities that are meaningful to clients and addressing barriers to performing these activities. They consider both the physical and psychosocial/ behavioural health needs of the clients. The focus is on what is important to him or her to accomplish their goals using available resources, support systems and the environment in which the client is able to participate. It is holistic and client-centric approach that fosters a sense of independence and self-efficacy amidst the challenges of living with symptoms that can be debilitating.

Keywords: Breast cancer; occupational therapy; QOL

83. Impact of Half Way Home – A Rehabilitation Project for Spinal Cord Injured (Sci) Patients by Pallium India (D2-323)

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Introduction: Spinal cord injury causes serious disability among people. Improvements in the management of spinal cord injuries have come not only from the novel surgical techniques and tools or drugs but also from a holistic approach to the patient. Half way home is a rehabilitation model, where these patients are trained so as to help them to lead an improved quality of life, with very less dependence on family and community. The physical, functional, psycho-social, and spiritual rehabilitation will be done in the specially designed facility.

Aim of the Study: To assess the impact of psycho-social support and rehabilitation model among spinal cord injured patients in half way home.

Materials and Methods: By a case study method, data was collected using interviews, measurement scale (FIM), case sheets and questionnaire during the time of hospitalization.

Results: The study among 53 patients (from March 2015 to December 2018), showed that before our interventions, patient's activities of daily living needed maximum external assistance (FIM score 40 to 60) and post rehabilitation, they were able to do their daily activities with minimal assistance and supervision (FIM Score 61 to 115). This model helped us to understand the psychosocial and rehabilitative support made significant changes in these patients life. This has a positive impact towards life with better self-esteem, improved social interaction, confidence and reduced compassion fatigue of their family members too.

Conclusion: The idea of half way home by Pallium India is an intensive rehabilitation programme, which provides a better platform for differently abled to lead a better life.

Keywords: Rehabilitation, spinal cord injury

84. Invisibility of Health Crisis - Plight of Women Caregivers in Palliative Care (D2-324)

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Introduction: Globally, gender norms expect women to be caregivers of the elderly and those with chronic diseases within the family. India is no exception. Palliative care reaches less than 1% of India's population regardless that 10 million Indians undergo serious health related sufferings (SHS). While 55 million are pulled down below poverty line by catastrophic health expenditure, the heavy burden on caregivers affects their quality of life. This would be devastating on female caregivers as they do not seek to share care giving unlike men. It is in this context, we tried to explore problems of women caregivers in serious health related sufferings.

Aim of the Study: To understand the coping strategies of women in health crisis.

Materials and Methods: Caregivers were selected based on psycho-social assessment made by a multi-disciplinary team. Our project team tried to implement the best possible intervention to enhance quality of life of women caregivers. They were given opportunities to interact with policy makers and activists to strengthen their support system. These works are collated to a case study.

Results: Women irrespective of their age were drowning in health crisis. Besides issues related to health expenditure, lack of a strong psycho-social support system was apparent. They were solely taking care of their spouse, child or parent (sometimes more than one) in serious health related suffering.

Conclusion: To lessen caregivers burden and achieve health for all, we should try to empower community, engage civil society as called by the recent Astana Declaration and spread interventions like respite care.

Keywords: Coping; palliative care; women caregivers

85. Impact of Physiotherapy in Palliative Care Experience from Pain and Palliative Care Society, Thrissur (D2-325)

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Introduction: Functionality has an important role in improving quality of life of patients needing Palliative Care. Incorporating physiotherapy services to Palliative Care will improve functionality of patients. The Pain and Palliative Care Society, Thrissur functioning since 1997 started a physiotherapy unit in 2011. It caters to the physiotherapy needs of the patients and extends its services in outpatient, inpatient and home care domains.

Aim of the Study: (1) To evaluate efficacy of physiotherapy in improving functionality of patients needing Palliative Care. (2) To identify demographic variables associated with improvement in functionality.

Materials and Methods: It is a prospective study involving the patients registered with the Pain and Palliative Care Society since 2016. The inclusion criteria are the patients of both genders above 10 years and below 65 years. The patients registered one year after the trauma or incidents are excluded. The spectrum of patients includes both cancer and non-cancer patients. Functional Independent Measurement Scale (FIM scale) is used to assess the functionality of patients before and after commencing physiotherapy. These scores are compared to assess the efficacy of physiotherapy.

Results: We have found that 25 patients out of 45 patients registered with the physiotherapy unit have recorded an improvement in FIM score. The demographic variables which had a bearing on the outcome were age, co morbidities, education status, regularity of physiotherapy intervention, proper usage of orthoses, caregiver support and bladder functions.

Conclusion: Patients with long term illnesses need physiotherapy to improve and sustain functionality.

Keywords: Palliative care; physiotherapy

86. ROAD TO SUCCESS (D2-326)

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Introduction: We have around 25 colostomy patient under Pazhayannur block panchayath palliative care unit. Due to physical constraints and superstitious believes, most of them are isolated and were downtrodden. To uplift them, interactive sessions were arranged to help them to understand various problems faced by the patients as well as their families.

Aim of the study:

1. To identify beneficiaries and conduct family get-together.
2. To discuss and solve the various physical, mental, social, financial, emotional and ethical problems.
3. To ensure financial assistance to the patients undergoing colostomy surgery
4. To plan & implement innovative activities for their independent life and wellbeing and henceforth improve the quality of life.
5. To take steps to enable the organization in getting financial aid from governmental and nongovernmental organization.
6. Mobilize resources like physiotherapy for improving the physical limitations of the patients.
7. To actively involved in general welfare of the public.

Materials and Methods:

1. A charitable society was formed and a workshop was conducted by the block panchayath for the welfare of colostomy patients.
2. Patients were trained for self-irrigation at home.
3. Irrigation set and colostomy bags were distributed freely under government and nongovernmental organization.
4. A charitable society of their own was set up. With the help of block panchayath few self-employment schemes were launched.

Results: The programme resulted in

1. Improvement in Quality of life of patients.
2. A Self-supporting and self-sufficient community was created.
3. Interpersonal relationship and self-respect improved.

Conclusion: All the beneficiaries are motivated in improving their quality of life and upgrading their standard of living.

Keywords: Colostomy; quality of life; training

87. PALLIATIVE CARE IN HUMANITARIAN CRISIS (D2-327)

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Introduction: The flood disaster in Kerala affected many, but those with pre-existing serious illness, with disabilities, the elderly and children were particularly more vulnerable. The aftermath of floods to such patients with serious health conditions will be next to disaster. Palliative care can have a huge role to play during such humanitarian crisis.

Aim of the Study: To demonstrate the role of Palliative care in flood affected areas.

Methods: In collaboration with Government agencies and NGOs Palliative care nurses and Medical Psychiatry social workers were deployed to the affected areas.

Results: It was observed that there was a huge need for Palliative care in disaster management. As part of 3636 home visits in Alappuzha, Pathanamthitta and Ernakulam districts we were able to reach out to 115 palliative patients in the affected areas. The medical issues of the flood victims were identified and addressed appropriately.

Conclusion: Need for palliative care and its relevance in disaster management is well understood during natural disasters like the recent Kerala floods. Palliative Care providers can collaborate with primary health centres and other NGOs in community level to address the needs of patients with serious illnesses.

Keywords: Humanitarian crisis; palliative care

88. FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP AFTER INITIAL VISIT AMONG PATIENTS VISITING PALLIATIVE CARE CLINIC IN A RURAL HOSPITAL (D2-328)

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Introduction: In chronic illnesses, patients are often exhausted with treatment part- physically, emotionally, socially and spiritually. In our palliative care department, we come across patients who didn't turn up for follow up after the first out-door patient services consultation. Follow up visits and treatment adherence are crucial for palliative care to achieve the ultimate goal of better quality of life of patients.

Aim of the Study: To identify factors responsible for loss to follow up to improve treatment compliance and adherence.

Materials and Methods: Among the data of patients maintained in our department, we found 81 out of approximately 1200 OPD visits who didn't turn up for follow up after the first O.P.D visit in one year period which we wanted to study. After taking the institutional ethical committee approval we did telephonic interview of those patients or their relatives, took their consent to participate after explaining the study in brief. Talking to them with empathy considering emotional aspects, we noted the reason of not coming for follow up in our questionnaire. Out of 81, 61 patients (36 Male/ 25 Female) (57 Cancer/ 4 non-cancer) could be contacted on phone.

Results:

No Palliative care awareness	0
Financial	0
Difficulty in bringing patients	1
Alternate medicine	7
Exhausted with treatment	3
Not benefited	0
Death after the first visit	31
Others	19

Conclusion: Almost 50% are related to death after the first visit. We noted date of death and found majority were within one month of the visit. Early referral of those could have helped us to serve the purpose better.

Keywords: Loss to follow up; palliative care clinic

89. Challenges in Palliative Care Settings – A Qualitative Study among Nurses in Puducherry (D2-329)

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Introduction: Palliative care need is increasing in low and middle income countries where 80% of global non communicable diseases like cancer and cardiovascular diseases are reported. Palliative Care is a right of patients with chronic life-limiting illnesses. Various challenges exist in the delivery of effective palliative services in resource poor settings.

Aim of the Study: This study focuses on challenges faced by nurses in provision of holistic services to cancer patients.

Materials and Methods: Two Focus Group discussions were conducted among nurses working in a tertiary care hospital in Puducherry. Purposive sampling technique was adopted. Nurses trained and untrained in palliative care nursing participated in the discussions.

Results: Lack of training, difficulty in communication skills, non - conducive environment, lack of privacy, failure in control of intractable physical symptoms, multiple responsibilities in the wards and low nurse to patient ratio were identified as the major challenges.

Conclusion: We recommend to strengthen the existing nursing curriculum by including modules to improve knowledge and skills of nurses in Palliative Care. Hospital administrators should identify the lacunae and difficulties encountered by nurses in providing palliative care and address those issues to improve the standard of care.

Keywords: Challenges; nursing; palliative care

90. Strengths, Opportunities and Challenges of Establishing A Palliative Care Unit in A Non-oncology Multi Specialty Government Hospital (D2-330)

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A Palliative Care unit was started as an outpatient Department with inpatient referrals at a non-Oncology multi-specialty Government Hospital in a metropolitan city in April 2017. The setting up of the Palliative Unit was conceptualized as a result of personal experience by the top management which had recently been sensitized to the concept of Palliative Care.

There were many challenges and opportunities faced while following the principles of Palliative Care to provide relief from physical and psychological suffering to patients suffering from chronic and life limiting conditions as they were foreign concepts to the conventional environment that needed gentle gradual promotion.

Strengths and opportunities

i) The hierarchy of the institution helped the acceptance of Palliative Care across different settings;

ii) The continuum of care is maintained as health care facilities are availed across the lifespan of all the members and their dependents;

iii) The support to patients in the form of medicines and interventions eliminates the cost factor;

iv) Consultation space could be easily identified and made available due to the available infrastructure;

v) Regular ongoing academic activities provide a platform for spreading the concepts of Palliative Care.

The principles of Palliative Care are slowly but steadily being accepted in the conventional environment, thus providing solace to all those who need it and also providing opportunities to other consultants to practice it in their own domains.

Conclusion: The PC services are slowly expanding and impacting different patient care domains, including patients in the intensive care unit.

Keywords: Establishing palliative care; Hospital; opportunity

91. A Community Based Need Assessment Survey of Patients Requiring Palliative Care (D2-331)

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Introduction: Palliative care is aimed at improving the quality of life, by employing what is called "active total care", treating pain and other symptoms, at the same time offering social, emotional and spiritual support. People living in low-income and middle-income countries (LMICs) have little or no access to pain relief or palliative care.

Aim of the Study: The objective was to identify the patients in the need of palliative care services and study their socio-demographic details.

Materials and Methods: A community-based cross sectional study was conducted in a municipality ward of Mysuru city, Karnataka covering 3191 households with the help of 87 nursing volunteers. A pretested questionnaire was used to collect data on sociodemographic characteristics and health seeking behaviour.

Results: A total of 75 participants that needed palliative care. Majority of them are between the ages of 51-60 years, 55% were males and 45% were females. The most common diagnosis among the participants was stroke, followed by cancer and diabetes.

Conclusion: There is an increasing need for palliative care services. The integration of palliative care into both public and private health systems will help to fulfil the palliative care needs in the community.

Keywords: Community; Mysore; need assessment survey

92. A DESCRIPTIVE REPORT OF COMPETENCIES PROVIDED BY THE SIX WEEKS PALLIATIVE CARE TRAINING PROGRAM AND THE PRACTICAL COMPETENCIES REQUIRED TO SET UP A NEW PALLIATIVE CARE UNIT, AT A GOVERNMENT MEDICAL COLLEGE HOSPITAL D2-232

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Introduction: After the 6 weeks of training in Palliative Care (PC) I felt confident in my role as PC nurse. I was equipped to provide i) Good clinical care, ii) counselling patients and families, iii) do PC procedures, iv) administer PC drugs v) maintaining records of opioid medications vi) educating patients and families on personal care and medications vii) ensuring documentation viii) ensuring continuity of care. Once posted at the GMCH the expected competencies were i) introducing concept of PC to unaware personnel ii) explaining rationale of PC to colleagues/students, iii) setting up the OPD, iv) gathering required equipment and instruments, v) preparing forms for documentation, and vi) performing procedures.

The high-level order from the Director of Medical Education to the administration provided the helpful thrust. The team applied to the different departments for the necessary equipment, drugs/ consumables list. A pharmacy that stocked tablet Morphine was identified. Documents and templates for records were developed. Once the room for OPD was sanctioned we immediately had it set up to provide basic Palliative Care.

On an average our PC unit is now seeing around 6-7 patients/day since its inception in 22nd of November 2018. From inauguration till date we have treated 110 patients. Support from mentoring groups and funding made this possible. There is an immense sense of achievement in setting up this unit with the over whelming support from the Government and the public.

Conclusion: As the Palliative Care is relatively new in our country, the challenges faced are likely to be unique. The 6 weeks Palliative care training curriculum had prepared me with basic competencies to run a PC unit. Incorporating knowledge to set up a Palliative Care unit – space, drugs, consumables, equipment, advocacy and networking etc. in the curriculum will be beneficial to many who want to start from the scratch.

Keywords: Competencies; palliative care training

93. ROAD MAP TO INTEGRATED PAEDIATRIC ONCOLOGY PALLIATIVE CARE SERVICES (D2-233)

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Introduction: The motivation for this study is from two newspaper reports pertaining to children with cancers', where parents had approached a local court to grant Euthanasia to their children in severe pain.

Aim of the study: (1) To Formulate a Comprehensive Childhood Cancer Management policy which includes Shared Care Model and Integrated Palliative Care Services. (2) To Identify National Health Programme/s to implement the above policy.

Materials and Methods: (1) A Communication was sent To Government of India (GoI) as to what is the Programme to Implement Early Diagnosis of Childhood Cancer Module. (2) A Focused Group Discussion was held among the Faculty and Staff of Departments of Paediatric Oncology, Pain and Palliative Medicine, Kidwai Memorial Institute of Oncology, Bengaluru to draw in a pathway of a Shared Care Model Integrating Palliative Care Services into Paediatric Oncology.

Results: In reply to the communication sent to GoI a letter was received clarifying Rashtriya Bal Swasthya Karyakram (RBSK) is the Programme through which the Module of Early Diagnosis of Childhood Cancers can be Implemented. The Focused Group Discussion resulted in a Shared care Pathway with Integrated Paediatric Oncology Palliative Care throughout the continuum of care and at all levels of Public Health Delivery System. The Tertiary Oncology Center functions as the Core Provider Group. Nearest Medical College Hospital's Paediatric Medicine Department provides District Level Services. RBSK Mobile Health Team Provides Community Level care and arranges transport for Respite care to the District level Hospital or the Tertiary Level Hospital. A United Platform would facilitate Civil Society Organizations' participation.

Conclusion: Providing Paediatric Palliative Care services is in the best interest of a child and upholds their rights. An Interface for all the stakeholders can be achieved by using state of art Information & Technology Tools like Internet of things.

Keywords: Integration; paediatric oncology; palliative care

94. DEVELOPMENT OF PALLIATIVE CARE SERVICES IN DISTRICT HOSPITALS OF UTTARAKHAND UNDER THE PALLIUM – GANGA PREM PROJECT (D2-334)

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Introduction: Ganga Prem Hospice is the only hospice in Uttarakhand that provides inpatient palliative care service in Rishikesh, home care in Rishikesh, Dehradun and Haridwar, and oncological outpatient service to patients from all over Uttarakhand.

Aim and Objectives:

- To work with government and non-government bodies to scale up Palliative Care services, and improve access to controlled medicines for pain relief.

- To Work with the government for implementation of NDPS Amendment Act to remove regulatory barriers to opioid access.
- To Ensure training to all healthcare professionals and members of the community to deliver Palliative Care effectively.
- Encourage and support the opening of Palliative Care units / OPDs through expert guidance.

Methods:

- Sensitization of officials and public about the need for palliative care and palliative care policies.
- Sensitization of the concerned departments namely Drug Controller, Director of Health Services, Excise Department and Director of Medical Education.
- Facilitate opening of Palliative Care OPD's in district hospitals and medical schools with the aid of the DM, CMO, PMS and other concerned officials.
- Volunteer Support for community outreach and advocacy of Palliative Care.

Results: We visited and sensitized approximately 200 medical professionals / 650 students and volunteers in Rishikesh, Dehradun, Pauri, Srinagar, Nainital, Almora, Rudrapur and Tehri. A Palliative Care OPD was inaugurated in Uttarkashi on 14th April, 2018 under the jurisdiction of DM – Mr. Ashish Chauhan. A Palliative Care ward is being planned at Uddham Singh Nagar district. We have been instrumental in creating a District wise active volunteers what's app groups which ensures community participation and prompt communication to seek help for home bound patients.

Conclusion: This project has aided Government sector in Uttarakhand to set up and expand Palliative Care services. Those who were trained need regular inputs to remain motivated, and this remains a challenge with the terrain and distance involved. It is our sincere endeavour to widen our network to improve access to Palliative Care in Uttarakhand.

Keywords: District hospital; palliative care service

95. STRENGTHENING THE PALLIATIVE CARE SERVICES IN THE STATE OF ASSAM A ONE YEAR REVIEW OF THE TATA TRUSTS PROGRAMME (D2-335)

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Introduction: Tata Trusts Cancer Care program [TTCCP] aims to develop access to quality cancer care centres where it is needed most, with initial focus on Assam. Palliative Care [PC] is an integral component to TTCCP.

Aim of the Study: Working through three pillars of policy on services, education and opioid availability, PC is getting integrated into several levels of the public healthcare systems in the state.

Materials and Methods: A longitudinal qualitative descriptive study (implementation research).

Results: TTCCP facilitated participation of senior state level health secretary and three prescribers in the IAHPC opioid availability workshop held in AIIMS-Delhi, in Feb-2018. With this began the process of implementing the narcotic drug policy in the state, with two applications for RMI status from government institutions, which are under the perusal at the SDC office. The State Cancer Institute [SCI] hosted the IAPC Certificate Course for the first time, with 10 doctors from district hospitals attending it. Funds were mobilised from the National Programme for Palliative care [NPPC] for 2018-2019. Through a national faculty workshop, TTCCP has developed the 1-year Fellowship incorporating a hybrid structure to ensure a mentored rigorous training. The ongoing PC services at SCI, BBCI and Cachar cancer Hospital are getting strengthened and new services have begun at Assam Medical College, Dibrugarh and to a minimal extent at government institutions at district levels. The PEP project has been successfully piloted.

Conclusion: Challenges still remain in the areas of training, human resources, program management and implementation of the Amended NDPS Act. The key learnings also include impact of local culture.

Keywords: Assam; palliative care; Tata Trusts

96. SYMPTOMATIC PALLIATION AND QUALITY OF LIFE IMPROVEMENT IN MULTIPLE MYELOMA (D2-336)

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Introduction: Multiple myeloma patients can have numerous physical, social, functional and emotional issues. AIIMS is a tertiary care referral centre for multiple myeloma with patients for specialized treatment.

Aim of the Study: To evaluate symptom burden and quality of life in multiple myeloma patients visiting AIIMS. To assess change in quality of life and symptoms on follow up after one and three months from the first encounter.

Materials and Methods: After ethical clearance, multiple myeloma patients were enrolled. Clinical and treatment related details were entered in a predesigned proforma. Myeloma Palliative Outcome Scale (MyPOS) was administered and pain assessment using Brief Pain Inventory (BPI) was performed at baseline, 1 and 3 months. The data from these patients were analysed using SPSS v21.

Results: Eighty two multiple myeloma patients consented for recruitment (Mean age- 52 + 9 yrs; Male 55%). Mean duration of the disease since diagnosis was <1 year (0.86 yrs), with a mean International staging (ISS) stage of 2. Up to half (37/82, 45%) of the patients had received bone marrow transplantation (BMT). The baseline MyPOS Score was 58 + 8.8 while the mean Pain severity (MPS) and interference (MPI) scores were 25+8 and 43+10 respectively. The most painful region was the back. There was no significant effect of prior treatment on baseline scores. Tramadol was sufficient for only a small minority (6/82, 7.4%) while all the rest received oral morphine. There was significant interval improvement in all pain and QOL scores with a p statistic of <0.01 on follow-up (MyPOS at 1 month and 3 months were 81+6 and 78+5, MPS were 21+13 and 17+1.1, MPI were 38+2.2 and 37+2.1 respectively).

Conclusion: Follow-up with a standardised questionnaire model is an essential clinical tool for the Palliative specialist to assess successful patient management.

Keywords: Clinical tool; Multiple myeloma; symptoms

97. INITIATING PALLIATIVE CARE SERVICE IN A GOVERNMENT MEDICAL COLLEGE IN ASSAM (AMCH), FACILITATORS AND CHALLENGES (D2-337)

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Introduction: Palliative Care (PC) services in the Government Medical College and Hospital was made possible because of the policy decision by the Govt. of Assam to collaborate with an established NGO and to make cancer care with quality PC available across identified institutions in the health care system.

Aim: To start a PC service in a Government Medical College Hospital.

Methods: The following actions were instrumental in achieving the goals we set for

- The facilitators were directed by the Director of Medical Education, specifying the contents of collaboration in terms of space and services.
- PC sensitization seminars were conducted, followed by interaction with the Principal, Faculty and the Administrative Officials of the institution
- Intensive training was provided for medical and nursing personals
- Core committee members were identified from within the AMCH faculty
- Adequate support was provided from Principal's office to disseminate information on the new program
- Access to governance structure to escalate and address challenges.

The specific challenges at ground level were i) pending access and availability to essential narcotic drugs (pending RMI) ii) lack of awareness about the scope of the field among the professionals and public iii) the advocacy and networking efforts required to get the concepts into a running PC unit, and iv) bureaucratic delays.

Results: PC unit started functioning on 22/11/2018.

Conclusion: Setting up a PC unit in Medical College and Hospital has several advantages. Moving forward, the continued growth of this PC unit will influence the way clinical medicine is learnt by the medical students and will also bring PC services closer to the citizens of Assam.

Keywords: Assam; Government Medical College; palliative care

98. PALLIATIVE CARE AND THE NATIONAL HEALTH POLICY IN INDIA (D2-338)

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Introduction: The concept of Palliative care in India is spreading slowly since two and a half decades. Awareness and availability of treatment in this field differs from state to state and this depends on the conviction and commitment of professionals and volunteers in taking the message to the policy makers and other stake holders.

Aim of the Study: The goal of Palliative Care (PC) is to improve the quality of life of both patients and families by responding to pain and other distressing physical symptoms. PC also involves providing good psycho-social and spiritual support.

Materials and Methods: The main focus in our National Health Policy 2017 was "to improve health status through concerted policy action in all sectors and expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality." However there were many challenges to take it forward to the needy community.

RMD Pain and Palliative Care Trust as pioneers in this field are working on the following areas:

a. Creating awareness among the policy makers on the features of palliative care to plan implementation strategies across educational and health institutions.
b. Conducting research studies to identify the patients in need of palliative care across the state.
c. Promoting volunteers and professionals as practitioners in the field of palliative care
d. Advocacy and lobby to include palliative care as part of curriculum in health education.
e. Building awareness to the public on Palliative care.

We are presenting a case report were our efforts had helped a patient and family to get access to high quality PC.

Keywords: National health policy; palliative care

99. PALLIATIVE CARE NEED ASSESSMENT IN SONITPUR DISTRICT OF ASSAM, INDIA (D2-339)

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Aim: A survey was planned to find out the palliative care needs of the population and to develop a care model.

Objectives: (i) To estimate the proportion of the population which needs palliative care. (ii) To identify types of diseases for which palliative care is needed in the local community.

Materials and Methods: A community-based cross-sectional survey was conducted in selected subcentres of the chosen five villages between August to October 2018. Two subcentres were selected randomly from Sonitpur District. A house-to-house survey was conducted using a structured questionnaire by a trained team. The available member of the households was interviewed about the morbidity profile and need for Palliative Care in the family.

Results: A total of 1035 household was surveyed in Sonitpur District. The need of palliative care in this community was 1.35/100 household. The mean age of people requiring palliative care was 75 years. The most common disease condition in need of palliative care was stroke (42.8%) and majority of them were women (57%).

Conclusion: There is the need for palliative care services among elderly people. This data would be used for planning and implementing community-based palliative care services in Sonitpur and other districts of Assam.

Keywords: Assam; needs assessment; palliative care; survey

100. CHALLENGES OF INTEGRATING NEW PALLIATIVE CARE UNIT WITHIN PUBLIC HEALTH SYSTEM IN TELANGANA (D2-340)

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Introduction: Government of Telangana is rolling out palliative care programme in each District as a part of the National Health Mission (NHM) programme. Funding for human resources, infrastructure and other consumables is through the NHM. Government of Telangana has established this programme in every district with the help of a NGO called Pain Relief and Palliative Care Society. The Society started this project in 2017 and by the end of 2018, 8 palliative care units were started.

Aim of the Presentation: To share all the challenges faced in establishing palliative care units in 8 Districts.

The following were the challenges faced
- Getting people to share resources
- Time required for negotiation between various Departments
- Lack of Palliative Care awareness
- Training the team of doctor, nurses, physiotherapist, ANMs and housekeeping staff

Results: All the Palliative care units in 8 districts are now up and running successfully.

Conclusion: To setup district based palliative care unit within the public health system which requires lot of awareness, sensitization, and negotiation among human resources by setting an example.

Keywords: Challenges; palliative care unit; setting up

101. Role of Palliative Care in Patients with Advanced Neuroendocrine Carcinomas Undergoing Radiopeptide 177 Lu-Octreotate Therapy (D2-341)

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Introduction: Radiopeptide 177 Lu- Octreotate is a recent treatment modality for inoperable and disseminated neuroendocrine carcinomas with significant improvement in overall outcome. The integration of palliative care in patients undergoing anticancer treatment improves the quality of life of patients. The 5-year survival rate now for advanced metastatic NETs is ~25%.

Aim of the Study: To assess change in symptom burden in patients with Advanced Neuroendocrine carcinomas undergoing Radiopeptide 177 Lu-Octreotate therapy after integration of palliative care.

Patients and Methods: Five patients diagnosed with Neuroendocrine carcinoma with metastasis, who were planned for 177 Lutetium Octreotate was enrolled for the study. All age groups were included. Patients with first line treatment and multiple recurrences were included. All patients were screened with the Edmonton Symptom Assessment System-revised version (ESAS-r) prior to the therapy and the scored was assessed. Those patients with less 20/90 score were excluded. The repeat score was assessed after 6 weeks to measure the impact of integration of palliative treatment.

Results: All five patients showed an improvement in symptom burden. There was a difference of 32%, 27%, 44%, 31% and 24% recorded in the scores.

Conclusion: Unrelieved symptoms may worsen the quality of life of patients and pose a negative impact on survival. Patients with disseminated neuroendocrine carcinomas often present with high burden disease. The integration of palliative care in radionucleotide therapy is rewarding.

Keywords: Neuroendocrine carcinoma; palliative care

102. An Analysis of Patients with Carcinoma of the Cervix Admitted to an in-Patient Hospice (D2-342)

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Introduction: Carcinoma of the Cervix accounts 9% of all cancer patients admitted to Karunashraya and 60% of gynaecological cancer started on end of life care.

Aim of the Study: To examine the demography of patients, the common symptoms, reasons for re-admission and the counselling issues involved.

Methods: A retrospective data analysis of all patients admitted between 1st January 2017 and 30th June 2018 was undertaken.

Results:
- 112 new patients with cervical cancer were admitted during this period,

The average age was 54 years; mode 47 range: 25 to 92 years
- 21 patients required multiple re-admissions. Of the remainder, approximately half died in the hospice, the rest being discharged to family, home care teams or lost to follow-up.
- The main reasons for admission were for symptom control (particularly pain), distressing vaginal discharge and/or bleeding and obstructive uropathy.
- Associated urinary problems included dysuria, incontinence and haematuria often as a result of vagino-vesical fistulae.
- Difficulty in caring for these distressing symptoms at home, together with anxiety were reasons for frequent re-admissions.
- Although patients were happy to discuss social issues with the counsellors, there was a distinct reluctance to refer to sexual or psychological problems. Of the latter, particularly amongst the younger patients, the main concerns were with regard to the family, and fear for their own future.

Conclusion: Significant issues will be discussed in greater detail together with their relevance to service delivery and quality improvement.

Keywords: Carcinoma cervix; symptoms

103. Perceptions About Meaning in Life and Death Among Doctors in A Medical College in Puducherry (D2-343)

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Introduction: Hospitals are recognized as one of the environments of mortality. Attitude towards death influence the behaviour of doctors with respect to communication and care of terminally ill patients.

Aim of the Study: The objective of this study was to assess the concept of meaning in life and attitude towards death among doctors.

Materials and Methods: A cross sectional study was carried out among 30 married doctors in a Medical College in Puducherry. A Questionnaire with Death Attitude Scale statements was administered. The responses were scored between strongly agree (7) and strongly disagree (1) [Table 1].

Results: The mean age of the participants was 47.4 + 14.5 years. About 70% were males. The median years after post-graduation was 10.5 years. About 40% said that being a part of family and fulfilling their responsibilities gives meaning to their life. About 90% of them felt their end of life to be at home in presence of their family members. While dealing with terminally ill patients, about 40% were not comfortable in talking end of life issues with the patients. There was no significant difference ($p>0.05$) between male and female doctors on the dimensions of death attitude [Table 1].

Conclusion: Communication skills development training for dealing with end of life care issues will improve the confidence of doctors in managing palliative care patients. Internalization within oneself the concepts of death and life may aid a doctor in providing holistic care to terminally ill patients.

Table 1: Attitude towards death

Dimensions (max score for strongly agree)	Mean			
	Male	Female	*t*-test	*P*
Fear of death (49)	24.0	28.6	0.92	0.38
Death avoidance (35)	17.7	17.3	0.06	0.95
Neutral (35)	32.8	30.6	1.06	0.31
Escape (35)	12.3	16.3	0.68	0.51

Keywords: Death; doctors; perception

104. Service Improvement Measures in Palliative Care in-Patient Unit in A Teaching Hospital in UK – Current Perspectives And Future Plans (D2-344)

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Introduction: Service improvement can streamline services, improve provision of health care, make cost savings and might reduce clinical errors. Service improvement is a challenge given the complexity of healthcare.[1] Whether service improvement initiatives is adequate to improve patient outcomes and quality of care is a question that all healthcare professionals need to answer.

Objectives: (1) To understand the perspectives of health care professionals in the in-patient unit regarding the current service improvement initiatives. (2) To obtain suggestions for further improvement of service provision.

Methods:

Design – Qualitative study

Population – Health care professionals in the unit

Sample size – Till data saturation

Data collection – Interview using an interview guide. Individual interviews recorded and transcribed verbatim. Opinion on Measures undertaken for Service Improvement

Data analysis - Two independent reviewers coded themes and subthemes

Measures undertaken for service improvement:

1. Changes in E-white board policy, and language used under doctors, nursing, pharmacy, PT/OT, social worker columns
2. Daily referral meeting and handover venue change and fixed timings
3. Implementation of new multidisciplinary team (MDT) proforma sheet
4. Rescheduling MDT meeting time to morning from afternoon
5. Introduction of safety huddle
6. Consultant ward round sticker changes and patient charts in a single folder
7. Huddle, late afternoon between nurses and doctors
8. Bi-monthly meetings with the entire team on the unit
9. Any suggestions for further improvement of service

Results: Sample size – 10, Doctors – 2, Nurses – 3, Pharmacist – 1, Occupational therapist – 1, Ward clerk – 1, Social worker -1, Advance Nurse Practitioner -1

Themes and subthemes-

Measures indirectly influencing patient outcomes
- E-white board changes
- MDT (Multi-disciplinary team) changes
- Ward function changes
- Handover changes

Measures indirectly influencing patient outcome
- Safety huddles

Future plans
- Discharge proforma
- Appreciation of day to day activities

All participants welcomed the e-white board changes. Education about e- white board updating is necessary and is underway. Most participants shared the view that more nurses should attend the fortnightly meeting which will ensure changes. Everyone appreciated the MDT proforma and the shifting of MDT time from afternoon to morning. Most participants agreed that safety huddles are beneficial. Pharmacists and doctors were of the opinion that syringe driver charts in the folder by the bed side is difficult to access and make changes. Nurses loved the patient charts in one folder by the bed side. Late afternoon huddles are seen as beneficial by most, but some disagreed about the timing of 4.00 pm. Most participants liked the idea of a future discharge proforma.

Conclusions: Service improvement measures under taken in the in-patient unit has been largely welcomed and most participants are of the opinion that clinical care processes are getting clearer. Most of the participants were of the opinion that a discharge proforma might be helpful to streamline discharges, thereby ensuring good patient centred care and good patient turn over.

Reference

1 Craig L. Service improvement in health care: A literature review. Br J Nurs 2018;27:893-6.

105. Retrospective Analysis of Palliative Care Referral Trends in Patients with Metastatic Breast Cancer (D2-345)

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Introduction: Patients with metastatic breast cancer show variability in presentation and time of palliative care referral in terms of tumour behaviour depending upon the tumour subtype. This study aims to compare time of initiation of palliative care with age, symptoms and tumour subtype.

Aim of the Study: Primary objective: To assess the trend of first palliative care referral from the time of diagnosis of metastatic breast cancer (MBC) depending upon the tumour subtype.

Secondary Objective: To assess the trend of symptoms and age group which receives early palliative care.

Materials and Methods: Patients with MBC who were admitted in the palliative care ward between January 2018 to June 2018 (total n=50) were identified from the archives of medical record section of Dr.B.R.A IRCH, AIIMS, New Delhi and relevant information was abstracted from their clinical charts. Metastatic disease was classified as per AJCC 8th edition TNM classification. Patients were classified based on their age groups, ECOG PS, palliative care referral time, symptoms at first referral, and tumour subtype.

Results: A total of 50 patients were analysed, 54.3% of them were in age group of 40-60 years. Majority (45.7%) patients belonged to ECOG PS 3. Among patients with Triple Negative Breast Cancer (TNBC) 63.15% received early palliative care compared to 56% of those with hormone positive status. Pain was the most common reason followed by concomitant pain and respiratory symptoms. Patient aged >60 years were referred to palliative care earlier than younger counterparts (p value =0.72).

Conclusion: Patients with TNBC tend to develop visceral metastasis early in the course of illness and hence most of such patients receive early palliative care referral. Hormone Receptor positive patients despite developing skeletal metastasis, do not become symptomatic early after metastatic illness diagnosis and hence receive a later palliative care referral. However, the difference among the two was found to be insignificant.

Keywords: Metastatic breast cancer; palliative care referral

106. Students Initiative in Palliative Care, Thrissur District (D2-346)

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Introduction: Involvement of students in palliative care projects is being implemented throughout Kerala and has become an immediate necessity. This SIPC project was initiated by the Pazhayannur block panchayath and followed by other schools and panchayaths.

Aim of the Projects:
- To strengthen the ongoing palliative care activities through students.
- To teach students basic nursing and to support them to continue this practice it in their community.
- To students actively participated in the rehabilitation of bereaved families.
- To students were trained to render assistance to palliative care patients and families to help them with government and non-governmental financial aid and to mobilize resources from the society.

Methods: Initially students, teachers and received training in Palliative Care. Students were then involved in
- Home based care done by government and nongovernmental agencies.
- Assisting healthcare staffs during Community Palliative Care OPs
- Planning, organising and Implementing rehabilitation activities.
- Help mobilise resources in the community.
- Conducting seminars, discussions, debates and cultural activities for Palliative Care patients with a view to improve their quality of life.

Results: The project helped students to develop a caring attitude towards the elderly and patients with serious illnesses. The actions of students were valued by family and society members which motivated them to achieve more.

Conclusion: Students developed an empathetic attitude towards elderly and sick people through this project.

Keywords: Palliative care; students

107. Effectiveness of Training Program For Social Workers and Volunteers in Palliative Care (D2-347)

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Introduction: Palliative care social workers and volunteers work with patients with advanced or chronic life-limiting illnesses and their families. They need education in knowledge, attitude and skills in the area of generalist/specialist palliative care to help them practice competently. Our Palliative Medicine department has been conducting an annual training programme for social workers and volunteers working or interested in palliative care since last 10 years.

Aim of the Study: This study reports on the effectiveness of a training program conducted for social workers and volunteers.

Materials and Methods: Questionnaire survey was done for the participants prior to and after completion of the training, to assess their knowledge about palliative and end of life care and communication skills. Data collection was done with consent from the participants and data was anonymized.

Results: 25 people participated in the training program, out of whom 8 were men. 5 were social workers and 20 were volunteers. The mean age was 51.12 yrs. 19 participants had no previous knowledge or experience in palliative care. The average marks for the pre-test questionnaire was 14.2 and post-test was 15.28. Prior to the training, participants scored maximum on item related to team approach, aim of palliative care and concept of total pain. The post-test items answered correctly in addition to the above by majority of participants were about communication skills. There was no statistically significant difference between pre and post-test average scores.

Conclusion: Our study participants had good knowledge about palliative care prior to the training programme, which improved after the course. However there was no statistical significance, which could be due to limited number. Participants' knowledge improved on information related to aim of palliative care and communication skills. There is a need to conduct studies evaluating competency-based skills of social workers and volunteers in future.

Keywords: Palliative care; social workers and volunteers; training

108. Online Continuing Medical Education for Home-Based Palliative Care in Kerala, India (D2-348)

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Introduction: Pallium India is a Kerala-based charitable organization that facilitates the delivery and integration of palliative care across India, conducting 7,325 home visits in 2017. However, these team members have lacked continuing medical education (CME) in palliative care beyond an initial 16-hour orientation program.

Aim of the Study: To assess interest and applicability of an online CME curriculum for home-based palliative care in Kerala, India.

Materials and Methods: In February 2018, an online training curriculum developed by the Center to Advance Palliative Care (New York, NY, United States) was made available to interdisciplinary team members (n=38) at one Pallium India site in Thiruvananthapuram, India. Primary outcomes consisted of engagement rates based on voluntary course completion. Secondary outcomes consisted of responses to a qualitative feedback survey administered to all site members, including those who chose not to register for the courses.

Results: 24 (14 nurses, 7 social workers, 3 physicians) of 38 total Pallium India site members registered for the online training program. Among those who registered, a mean of 13.1 (SD=13.4) courses was completed per participant (nurses: $\bar{x}$=15.9, SD=13.6; social workers: $\bar{x}$=5.29, SD=3.77; physicians: $\bar{x}$=18.0, SD=22.5). The most popular courses completed were focused on knowledge and skills related to pain management.

Conclusion: Interdisciplinary team members showed strong interest and engagement in an online palliative care CME program. Notably, a considerable number of participants became "super-users", with half (12 of 24) completing more than 10 courses each and one quarter (6 of 24) completing more than 20 was each. The online format served to enable a unique, global collaboration, which addressed a local need and which demonstrated the relevance of core palliative care concepts despite cultural differences.

Keywords: Home-based palliative care; online training

109. Improving Transition of Palliative-Care Beyond Hospital to Community - Training Needs Analysis of Community Teams (D2-349)

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Introduction: Patients requiring end-of-life care are discharged from hospital to home/hospice for improved quality of life and cost control. However, they may continue to require advanced treatment modalities. Hence, skills of community palliative-care teams need honing.

Aim of the study: (1) To identify skills gaps in community palliative-care teams hampering smooth transition of care of terminally ill patients requiring advanced treatment modalities. (2) To use results for planning focussed training programme.

Materials and Methods: Focus group discussions among hospital and community palliative-care teams were conducted to ascertain care issues. Retrospective audit of 8 patients discharged with specialised analgesia modality- implanted intrathecal/spinal catheters (ITC), was conducted. A google survey ascertaining confidence level (5-point Linkert scale) of palliative-care teams for managing patients with oral opioids, chest drains, fungating cancer and ITC was emailed to 3 palliative care teams involved in community care. Open ended suggestions were also collected.

Results: Focus group discussions involving community and hospital teams revealed inadequate confidence particularly for ITC. Retrospective audit of patients discharged with ITC revealed unnecessary hospital visits in all, catheter damage in 1 and dissatisfaction expressed by 2. These were deemed avoidable with training of community teams. Subsequently, 37 doctors and nurses from 3 palliative-care teams managing community patients responded to a survey. The mean (median) confidence level for managing oral opioids, chest drains, fungating cancer and ITC in the community were 4.5±0.6 (5), 3.58± 0.81 (4), 3.9 ± 0.84 (4) and 1.82±0.84 (2) respectively. Hence, community teams competent in various advanced care modalities had significantly lower confidence level for ITC. Open ended responses from teams revealed a desire for 'hands-on' or simulation-based training for ITC.

Conclusion: This study revealed significant skills gap of community palliative-care teams in management of intrathecal catheters which directed resources for an appropriate focussed simulation-based education. Management of chest drains and fungating cancers need re-enforcement.

Keywords: Community; palliative care; transition

110. Improving the Assessment and Documentation of Pain in Patients with Communication Difficulties in a Cancer Hospital in Northeast India: An Audit Report (D2-350)

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Introduction: There is evidence that pain is under detected and under treated for people with communication difficulties (C.D). A number of behavioural pain assessment tools exist but they are under used.

Aim of the Study: This audit was conducted to look at the ways, the palliative care team assess pain in patients with communication difficulties with a view to improve its assessment and documentation.

Materials and Methods: All cancer patients with C.Ds for symptom control were analysed in pre and post educational session. Local standards were set. Deficiency in assessing pain in patients with C.D was found in pre-interventional audit. A clinical audit was conducted for the nurses before and after the educational session on "pain in non-communicative patients" and "Bolton pain assessment tool". Analysis of the following factors were done following pre and post-educational session: Pain assessment, pain scoring tool, use of pain medication and their effects. The outcomes were compared with the standards.

Results: Pre-intervention audit identified 10 patients admitted during three months period, who cannot self-report pain and 90% (9) were assessed for pain. And out of which, 66.66% patient had pain assessed by NRS scale and the remaining had pain assessed by VRS scale. All this assessment were done intuitively by observing behaviour associated with pain and discomfort. While re-audit following the educational session showed that 100% were assessed for pain by using the Bolton assessment Scale, the average pain score at initial assessment was 4.8 and after using analgesics pain came down to an average of 4.4.

Conclusion: This audit demonstrates educational sessions do improve the quality of care.It was found that pain could be deciphered and documented in patients who could not communicate, by using the behavioural pain assessment tools. It is important to have a behavioural pain assessment tool in our setup when we assess pain in patients who cannot verbalize.

Keywords: Assessment of pain; communication difficulties

111. ROLE OF SOCIAL WORKERS AND VOLUNTEERS IN IMPROVING THE QUALITY OF HOME CARE SERVICES (D2-351)

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Introduction: A Quality Improvement initiative in Organising Home Care Services was taken up by a Government Cancer Hospital providing integrated outpatient services in oncology and palliative care. Continuity of patient care is maintained by the coordination between this unit, the city hospice and the local NGO supporting home care.

Aim of the Study: To highlight the role of social workers and volunteers in improving the quality of home care services.

Materials and Methods: This is part of the Stanford PC-PAICE Quality Improvement Project in Organising Home Care Services using the A3 Methodology through dialogue and consensus done between November 2017 and May 2018.

The Root cause analysis for the disorganized home care services revealed lacunae in data collection of patients needing home care as one of the problem areas. Social workers and volunteers plan the visits for patients identified with home care needs. They, along with the help of the Information Technology Department and the electronic medical records categorized the patients registered in palliative care and those needing home care could be listed.

Results: The coordinated effort helped to identify the list of patients who needed home care in the defined radius from the hospital. The Social workers and volunteers could transfer this information to the Master list of the city NGO coordinating home care. The responsibility of planning, scheduling and documentation of the visits was also taken by them. A home care id was created to help access and exchange of information to maintain continuity of care.

Conclusion: This data coordination initiative improved the planning, organising and frequency of home care visits. This intervention was impactful in setting the foundation for an organised and sustainable home care service in teaming with teams and facilitating the continuity of care. All this is possible due to the continued involvement of social workers and volunteers.

Keywords: Date coordination; homecare services; social workers and volunteers

Acknowledgements: Director, HBCHRC, Stanford PC-PAICE Team

112. NURSING STUDENTS' KNOWLEDGE OF PALLIATIVE CARE: SIGNIFICANT IMPROVEMENT AFTER TWO HOURS TRAINING (D2-353)

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Introduction: Cancer care, including palliative care and end of life care (EOLC), is in the curriculum of nursing courses, both General Nursing and Midwifery (GNM) and Bachelor of Science (BSc) Nursing. The need for training on palliative care was realized when nursing students doing their clinical posting in the palliative care department were mostly unaware of the concepts and principles of palliative care. It was then decided that the department would coordinate with the school of nursing to conduct classes for the same.

Aim of the Study: To measure the increase of knowledge on the concepts of palliative care and EOLC among nursing students, after a two hour training.

Materials and Methods: A questionnaire, consisting of twenty true/false questions, was framed after a brief literature review, covering concepts, coverage and delivery of palliative care, pain management (including Morphine) and EOLC.

2 one hour classes were conducted separately for two batches of nursing students (second year GNM and final year BSc). Introduction to palliative care (its concepts and principles) and pain management were covered in the first hour. The second hour class was on EOLC the following day. Pre and post tests using the questionnaire were conducted before and after the training. The questionnaires were marked and the data collected from these was analysed.

Results: A total of four hours of training was conducted for 62 students (29 GNM and 33 BSc) in October 2018. There was significant improvement in the knowledge overall ($p<0.001$), seen in 18 of 20 questions. Significant improvement as high as 69% was seen in some topics, like on the use of the subcutaneous route for EOLC.

Conclusion: Knowledge in palliative care can significantly improve with training as short as 2 hours.

Keywords: Nursing students; palliative care; training

113. DEVELOPING CLINICAL GUIDELINES TOWARDS DELIVERY OF EVIDENCE BASED PALLIATIVE CARE IN THE HOME SETTING (D2-354)

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Introduction: The Jimmy S Bilimoria Foundation launched its PALCARE service in December 2015. The growth of the service prompted the need for guidelines to help deliver standardized and good care across the team. Hence PALCARE constituted a Clinical Consultative Committee (CCC) comprising experienced and reputed medical professionals in palliative care, to develop robust, evidence based guidelines, which are relevant for the care of patients at home in India. Members of the committee comprise Dr. R. Akhileswaran, Dr. Jeremy Johnson, Dr. Jenifer Jeba and PALCARE's CMO, Dr. P. Jayarajan. In addition, Sr. Anu Thelly was brought in to bring in the nursing perspective.

Aim of the Study: To develop evidence based clinical guidelines in palliative care which are reliable, effective, and robust and which fulfil the delivery of good palliative care in a home care setting in India.

Materials and Methods: The committee identified 9 broad categories comprising 41 specific guidelines. The initial draft of each guideline was subjected to detailed literature review and intensive study of different available guidelines. This was followed by rigorous discussion and debate through monthly Skype conferences. Thereafter, the final customised guideline was approved, but not before it was put through a further round of scrutiny.

Results: Thirty-four guidelines have now been developed; the other seven will be completed shortly. Many of these guidelines have been discussed with the PALCARE home care team and they have found them very useful.

Conclusion: There is a need for well-researched, robust palliative care guidelines that benchmark practice in home based palliative care in India. The PALCARE guidelines fulfil this need. They are good teaching aids. Though not measured, use of such guidelines will eventually translate to better patient and health care outcomes.

Keywords: Evidence based palliative care; home setting

114. NURSE COORDINATED OUT OF HOUR SERVICE FOR PALLIATIVE CARE PATIENTS (D2-355)

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Introduction: Home based palliative care is an integral model of palliative care service delivery. The existing home-based palliative care service run by Department of Palliative Medicine caters to app 450 patients in regular working hours. The existing regular hours home care does not address the inconsistent provision of out of hours care through local general practitioners (LGPs). In order to address this gap, a nurse coordinated home care services facilitated through LGPs, for emergency and out of hours care was developed.

Aim of the Study: Objective of this paper is to report the impact of this service in terms of number of patients assessed, number of doctor visits coordinated and impact of such visits.

Materials and Methods: Retrospective Analysis of prospectively maintained data base of patient's medical records (electronic & chart) by the department of palliative medicine over a period of six months.

Variables considered as socio demography, previously registered with LGPs, monthly income, disease & treatment details, number of LGP visits facilitated and costs. (LGPs professional fees).

Results: 135 patients were identified of this service. Over a period of 7 months, 99 homecare patients received out of hours services through local PCP coordinated by a nurse. Reasons for referral to PCP during out of hours varied from symptoms management, nursing issues and for procedures like NG tube insertion.

Conclusion: Our model of nurse co-ordinated and local PCP facilitated home based Palliative Care service is feasible. Consolidation of this model is required to the designated target which will help in comprehensive care of advanced cancer patients requiring home based Palliative Care.

Keywords: Nurses; out of hours; palliative care

115. CLINICAL PREVALENCE OF "CHRONIC BREATHLESSNESS" IN LUNG CANCER PATIENTS AND DEVELOPMENT OF A COMPLEX INTERVENTION FOR PATIENTS AND CAREGIVERS: A MIXED METHODS OBSERVATIONAL STUDY (PROTOCOL) (D2-356)

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Introduction: Chronic breathlessness, is defined as "breathlessness that persists despite optimal treatment of the underlying pathophysiology and that results in disability." Clinical prevalence of breathlessness is 44% of advanced cancer patients in India. However, breathlessness in lung cancer patients is commonly considered 'inevitable' and goes untreated. Self-management techniques developed in western settings, are not currently in use in India.

Aim of the study: To:

1) assess clinical prevalence of CB in lung cancer patients,

2) develop a chronic breathlessness complex intervention for patients with lung cancer and their carers.

Materials and Methods: Observational, mixed methods study at a major national referral centre in India. Patients will be identified through the Thoracic Multi-Disciplinary Team and consenting participants asked to complete the Cancer Dyspnoea scale. Clinico-demographic data will be collected. Descriptive statistics will be used and prevalence will be presented with confidence intervals.

Results: Patients completing the Cancer Dyspnoea scale and their family carers will be invited to participate in a semi-structured interview and clinical team members to a focus group. Participants will provide informed consent and asked about their views about how breathlessness is currently managed. We will explore the appropriateness and acceptability of breathlessness self-management techniques to identify the best approach for the Indian context. Data will be subjected to thematic analysis and used to develop an intervention appropriate for Indian context for future testing.

Conclusion: Self-management techniques breathlessness are relatively inexpensive. Implementation of effective approaches may improve quality of life of patients and carers and reduce health care costs.

Keywords: Chronic breathlessness; intervention; lung cancer

116. Impact of Educational Training in Improving Skills, Practice, Attitude, and Knowledge of Healthcare Workers in Paediatric Palliative Care: Children's Palliative Care Project in the Indian State of Maharashtra (D2-357)

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Aim of the Study: The "Children's Palliative Care Project" was initiated in October 2010 in the Indian state of Maharashtra with a view to improving the quality of life of children with life-limiting conditions. This study evaluates its education and training component through a questionnaire.

Materials and Methods: A cross-sectional survey was carried out pre-/post-training among 258 doctors, nurses, social workers, and counsellors at three sites in Maharashtra in March 2015. Descriptive statistics were used for data analysis.

Results: Sixty-two participants responded. Post training, doctors and the nurses had a better level of knowledge, skill set, and attitude; whereas social workers and counsellors fared better with prevailing care practices. Participants advocated using morphine only when other analgesics had failed and suggested ways for better service delivery of care.

Conclusion: The study gives a rough idea of the prevailing practice of paediatric palliative care among the health-care workers (who participated in the survey) and suggests practical ways to improve it.

Keywords: Education; healthcare workers; paediatric palliative care

117. Development of Compassionate Community for Care by PALLIUM India (D2-358)

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Introduction: The concept of Compassionate Community Care comprises of variety of support services to the person with life limiting diseases and their families at times of suffering. It provides complete circle of compassionate care that recognizes and respects the physical, social, psychological and spiritual needs of those involved.

Neighbourhood network is providing the care for a larger community, whereas compassionate community concentrates on smaller communities like residence associations, welfare groups, pensioners etc.

Aim of the Programme:

- To train volunteers to provide non-medical support services to persons in their locality.
- To provide non-medical support services for persons with life limiting illness,
- To educate the public about Palliative Care, end-of-life issues

Methods:

- Identifying the community
- Giving orientation to the identified community
- Detecting the appropriate people to join the workforce
- Giving the workforce specialized training (Basic care & Communication)
- Formation of different committees for care (Admin, Survey, Physical, Psychosocial Support, Fundraising, etc.)
- Identify the needs and resources for the community
- Provide care to the people by Compassionate Community

Results: Ranigiri Compassionate Community for Care was one such programme successfully implemented by Pallium India. The programme started identifying needy persons (19 patients from September 2018).

We are planning to develop 15 more similar units before 2020.

Conclusion: Compassionate Community Care aims to provide complete care as much as possible for the people with life limiting diseases by empowering a particular community.

Keywords: Compassionate community; empowerment; palliative care

118. Overcoming Reticence in Hospice Nurses in Caring for HIV+ Patients, through Targeted Education (D2-359)

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Introduction: Despite regular training with regards to universal precautions, when decisions are made to admit cancer patients with HIV/AIDS to our hospice, there was always some apprehension and reluctance amongst many nursing staffs.

Objective: To determine the impact of an education programme to care for HIV patients.

Materials and Methods: Focus groups were convened to elicit particular areas of concern. These were then addressed. A short series of teaching sessions were then formulated to specifically address these issues. Topics included:

- How to care for patients with HIV
- Mode of transmission
- Handling patients during nursing procedures
- Confidentiality
- Support to family members
- Practical procedures following death

A pre and post- education survey was undertaken with a sample of 30 nurses to assess the impact of the training. Domains included:

- Knowledge
- Fear
- Self-confidence
- Quality of care
- Challenges
- Comfort
- Dealing with care-givers

Results: There was a dramatic improvement in all areas, especially with regard to self-confidence (15 to 96%) and fear (20 to 90%).

Conclusion: Education led to a willingness to take on caring for patients with HIV and improved self-confidence, knowledge and the ability to handle relatives.

This in turn enabled the Hospice to give better service to a wider range of patients needing care.

Keywords: Education; HIV; Hospice; Patients

119. Establishing a Palliative Care Unit In a Private Medical School: A Novel NGO-Private Model (D2-360)

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Introduction: The Unit of Pain and Palliative Care in Pushpagiri Medical College was started in the year 2002 and provides out-patient, in-patient and home care facilities. The hospital provides the infrastructure and the staff, while the general ward and the out-patient medications of the poor patients are subsidized by the NGO, Pain and Palliative Care Society, Pushpagiri. Other activities include free supply of opioids, volunteer home visits, food grain and construction of houses for patients' family, children's education and marriage support and also advocacy programs. The Unit is also involved in the academic activities of the medical and allied health sciences and started conducting prize exams among medical undergraduates since last year.

Materials and Methods: Key informant interviews were conducted among founding members who were involved in the activities of Pain & Palliative Care Society, Pushpagiri. The interviews were entered using N Vivo 11 and analysed to identify the emerging themes.

Results: The following three themes were identified; establishment of Unit as the philanthropic face of the hospital, identification of an influential figure as the face of palliative care society, which helped in creating robust funds; high levels of motivation among the members.

Conclusion: Private medical schools play a vital role in health care delivery in India. It is important that palliative care movement make considerable in-roads into this area as the reach it can create, both among the medical fraternity and lay people, will be immense.

Keywords: Palliative care unit, Private Medical School

120. Analysis of Spectrum of Diseases in A Palliative Care Unit in North India (D2-361)

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Introduction: WHO states that all life threatening illness requires palliative care. In 2017, WHO stressed that majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Broadwell Christian Hospital, is in Fatehpur, Uttar Pradesh, one of India's 100 aspirational districts (NITI Aayog, 2018) and set up one of UP's first home based palliative care programs.

Aim of the study:

- To understand the trends of patient population registered in our care
- To understand the various non-cancer diseases under Palliative Care
- To know whether the case trends registered under our Palliative care program reflects WHO estimations.

Materials and Methods: A retrospective analysis of case sheets of patients registered from September 1rst 2012 – March 31rst 2017 and segregated them into cancer and non-cancer diseases.

Results:

- Total patients registered – 315
- Total cancer patients registered-281 (89.2%)
- Total non-cancer patients registered – 34 (10.8 %)
- There were 203 male patients and 112 female patients.
- Based on the findings from the Table 1, It is seen that almost 50% of the patients were suffering from oral cancer
- The top 5 cancers grouped in other cancers were- Sarcoma, haematological cancers, brain cancer and bladder cancer
- The non-neurological illnesses requiring Palliative care were- HIV, Renal failure, Chronic pancreatitis, Stroke, Hip fracture in the elderly, Spinal cord injury and Tuberculosis.

Conclusion: The non-cancer patients seen by us are less compared to the estimated need by WHO. This could be due to lack of awareness regarding Palliative Care among the public. More information needs to be given to the Public and professionals about the scope of Palliative care.

Table 1: Types of Illnesses

Type of illness	Number (%)
Oral cancer	138 (49.1)
Gastrointestinal cancer	50 (17.7)
Breast cancer	26 (9.2)
Cervical cancer	17 (6.0)
Lung cancer	13 (4.6)
Other cancers	37 (13.2)
Other noncancers excluding neurological	23 (67.6)
Neurological illnesses	11 (32.4)

Keywords: Spectrum of diseases, Non-communicable disease, Palliative care in rural health

121. Impact of Home Based Palliative Care Services in Mumbai Metropolitan Region (D2-362)

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Introduction: Studies have shown that home based palliative care services improves physical symptoms, psychosocial issues and quality of life in patients with advanced Cancer. Home death is viewed as a dignified and comfortable experience as compared to hospital deaths. The Department of Palliative Medicine, conducts regular home based palliative care for patients residing in Mumbai Metropolitan Region. A home care team consists of a doctor, nurse and social worker. The team makes ardent effort to maintain liaison with local family physicians to ensure continuity of care particularly after office hours and in cases of emergency.

Aim of the Study: Audit on patients with advanced cancer registered with TMC, through an audit over a period of one year (To know the impact of home based palliative care services January to December 2018).

Materials and Methods: Audit of patients from Jan-Dec 2019.

Results: A total of 693 patients were registered for home care, among them 411 were women. Mean age of all patients was 62 years. 67% patients were of ECOG status 1 or 2. Symptoms were recorded on an ESAS scale. Common symptoms were pain and fatigue with a mean score of 2. Major interventions done in home visits were Foley's catheter (8%) and Naso-Gastric Tube insertion (9%). Psychosocial assessment revealed that 5% families had collusion regarding disclosure of cancer related information to the patient, however 69% showed good coping with advanced cancer and 95% had accepted such information. We could gather death data for 201 patients. 66% deaths were expected - 38% died at home, 29% died in hospital, and 17% died in hospice.

Conclusion: This audit reports the annual results of an urban homecare service in Mumbai. Though majority of the patients died at home as compared to hospital, we can achieve greater success with systematic service delivery improvement initiatives in future.

Keywords: Home based palliative care; impact; Mumbai

122. An Assessment of Chronic Illness and Palliative Care Need In A South Sudanese Refugee Population Within Uganda (D2-364)

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Introduction: Palliative care (PC) is recognised as an essential component of healthcare provision in humanitarian settings but little is known about the palliative care needs of refugee populations who are vulnerable at so many levels. Uganda hosts the largest refugee population in Africa and is committed to PC as a national priority. Adjumani District has 250,000 refugees mostly from South Sudan in over 18 settlements which are further divided into clusters of 100 households, supported by a Village Health Team (VHT).

Objectives: To determine the prevalence of chronic illness and PC need amongst refugees in Adjumani.

Methods: Purposive sampling of VHTs, supported by health centres with PC trained Health Care Workers, who then received training in PC including patient identification for chronic illness. These trained VHTs supported a household case finding survey to refugees over the age of 8 eligible and willing to participate. The survey tool included the APCA-POS, POS-S, ECOG and social demographics.

Results: Preliminary results (27 interviews) are shared. Musculoskeletal and neurological conditions highest prevalence. 89% lived with their condition > 1 year, 52% ECOG of 3-4. Significant symptom burden with 73% pain scores 4-5/5, and median number of symptoms 6. 15% previously received PC but only 1 currently access to oral morphine. The median total APCA-POS score was 19; reflecting the holistic palliative care needs of participants. Social demographics revealed the huge challenges including access to running water, indoor toilet facilities, sufficient food and paid employment.

Conclusion: Understanding the chronic disease and palliative care prevalence and need will guide the development and implementation of palliative care services for this underserved community for governmental and NGO sector planning. This has wide relevance and such situational analyses are requested in the WHO guideline

Keywords: Chronic illness; palliative care; refugee; Uganda

123. To Study and Analyse the Pattern of Symptoms in Head and Neck Cancer Patients Presenting In Palliative Care Ward At A Tertiary Cancer Centre of India: A Cross Sectional Study (D2-365)

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Background: Knowledge of the prevalence of symptoms is essential for the medical care of all patients. Identification of symptoms is prerequisite for making diagnoses and therefore formulating management plans. Awareness of the relative prevalence of symptoms contributes to the identification of patients' needs in terms of symptom control, and therefore to the rational provision and planning of cancer treatment and Palliative care.

Objective: To assess the pattern of symptoms in Head and Neck Cancer patients in patients presenting to the Palliative Care Unit, Dr. BRAIRCH, All India Institute of Medical Sciences (AIIMS), New Delhi, India, a Tertiary Cancer Institute.

Methods: Our study is an observational cross-sectional study of 71 Head and Neck cancer patients admitted in Palliative Care Unit. 71 patients were screened out of 502 cancer patients. The patients included in the study were provided with the Participation Information sheet. Patients diagnosed with cancer and giving consent were assessed using the modified Edmonton Symptom Assessment Scale (ESAS).

Results: Assessment of symptoms was done using ESAS in 71 Head and Neck cancer patients. Pain in 68 (95.77%) patients was the most common symptom, followed by loss of appetite in 46 (64.78%) patients, dysphagia in 35 (49.29%), dry mouth in 30 (42.25%), constipation in 21 (29.57%), anxiety in 19 (26.76%) nausea and vomiting in 16 (22.53%) patients, breathlessness in 15 (21.12 %), depression in 10 (14.08%), abdominal distension in 3 (4.22%) patients and fever in 2 (2.81%) patients.

Conclusion: Using our results, a comprehensive care plan for pain and other symptom can be formulated for Head and Neck cancer patients, to give them the best possible supportive and palliative care. Prognosis and survival pattern in cancer patients admitted to palliative care ward using Palliative performance scale and palliative prognostic index form.

Keywords: Head and neck cancer; palliative care ward; symptoms

124. Prognosis and Survival Pattern in Cancer Patients Admitted to Palliative Care Ward using Palliative Performance Scale and Palliative Prognostic Index Form (D2-363)

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Background: Most of the patients presenting to Palliative Care units have advanced disease, so the assessment of their prognosis is very important to decide further management. Palliative performance scale (PPS) and palliative prognostic index (PPI) is a validated tool to assess their performance status and their survival.

Objective: To assess the prognosis and survival of patients admitted in Palliative Care Unit, Dr. BRAIRCH, All India Institute of Medical Sciences (AIIMS), New Delhi, INDIA, a Tertiary Cancer Institute.

Methods: The study was carried out in cancer patients who were admitted in the in-patient unit of Palliative care DR BRA IRCH, AIIMS, NEW DELHI. A total of 50 patients admitted at palliative care unit were assessed using Palliative performance scale and Palliative Prognostic Index.

Results: A total of 50 patients were included in this study. A cross-sectional analysis was done on patients admitted to palliative care unit. Average age of participants was 48.8 years. Females were 27 (54%) and males were 23 (46%). Assessment of prognosis was done using the Palliative performance scale and Palliative Prognostic Index. PPI greater than six was in 9 (18%) patients with survival shorter than 3 weeks, PPI greater than four was in 6 (12 %) patients with survival shorter than 6 weeks and PPI with less than or equal to four was in 35 (70%), with survival more than 6 weeks. Palliative performance scale (PPS) of more than 80 were seen in 6 (12%) patients, 39 (78%) patients had PPS score ranging from 40-70, while 5 (10%) had PPI ranging from 0-30.

Conclusions: Using the results above a comprehensive care plan can be formulated to provide appropriate treatment to our Palliative Care patients.

FREE COMMUNICATION ABSTRACTS

DAY 1

1. CREATING SOLUTIONS AND STRENGTHENING VOICES: ICPCN SHAPING THE PAST AND THE FUTURE FOR CHILDREN'S PALLIATIVE CARE (D1-A-101)

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Introduction: Creating solutions and strengthening voices through collaboration and networking are key to the implementation of the WHA Resolution on palliative care. A global network was set up in 2005 to raise awareness of children palliative care (CPC), advocating for global CPC development, speaking up for children and their families, sharing expertise, skills and knowledge.

Aim of the Study: To review the impact of the network and inform its new strategy.

Materials and Methods: Mixed methods review: 1) of the 2015-2018 strategic plan; 2) of current activities: 3) consultation - 37 stakeholder and 102 member surveys, and 11 interviews.

Results: The network has: developed a strong global reputation; a unique role; a high level of expertise; committed staff; a clear vision; >2,000 individual members and >350 organisations. It made significant progress towards its previous strategy. Achievements include: Communication: e.g.: >11,000 Facebook followers, 1,900 Twitter and 200 Instagram; the International Children's edition of e-hospice has >700 users monthly, #hatson4cpc events in >25 countries, reaching >1.4 million Twitter impressions; a regular newsletter. Advocacy: representing the global voice of CPC including global influencing with the WHO and Multilateral Agencies, along with regional and national impact. Research: developing, implementing and supporting global CPC research, with >250 conference presentations & 65 papers published. Education: 3,200 individuals from 124 countries accessing 7 e-learning courses in 11 languages; Face-to-face training to >1,000 participants from 22 countries. Strategic development: The network has contributed to the development of CPC globally, along with in-country development in a variety of countries.

Conclusion: Measuring the impact of a global network is challenging. However, the review demonstrated its impact with networking being pivotal to the ongoing development of CPC. The network is the only global organisation working towards the global provision of CPC and is in a great position to continue to create solutions and shape the future of global CPC.

Keywords: Palliative care in children; specific pathologies and patient groups

2. ASSESSMENT OF COPING OF HAEMATOLOGICAL CHILDHOOD CANCER PATIENTS (CURATIVE AND PALLIATIVE) (D1-A-102)

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Introduction: Children with curative and palliative cancer face many physical and emotional stressors. Patients' use certain coping strategies that can affect their desire for information about their disease, their self-efficacy, and how they adjust to the disease and its treatment. But little is known about their coping strategies or the association between their coping strategies, impact of diagnosis and emotional status.

Aim of the Study: To assess the coping strategies of haematological childhood cancer patients (curative and palliative).

Materials and Methods: The study is part of ongoing study; the study assessed the coping of children, impact of event and alexithymia in paediatric cancer patients. For assessment we have used Kidcope, Cries 13 and Toronto alexithymia scale in patients within 8 weeks of a diagnosis of haematological cancer. To examine associations between coping strategies, Impact of event and alexithymia, we used person correlation, adjusting for patient's age and sex and cancer type.

Results: The mean age of children was 12.27Â±2. 91, Male patients were 47% and rest female. Male patients showed difficulty in identifying and describing difficulty of feelings than female. Intrusion and avoidance showed significant association (r = 0.811 and 0.819 p 0.05) with problem solving coping among male, while female showed significant association (r =0.971 and 0.927 p 0.01) with distraction coping. No significant association observed in curative and palliative cancer as the study is in infant state (15 cases).

Conclusion: So use of certain coping strategies may impact patient's perceptions of their illness and influence their decisions, which can have a lasting impact on their treatment course. On the basis of complete result a tailor made intervention can be designed to counsel children with cancer for the healthy coping.

Keywords: Assessment; children; coping; haematological cancer

3. Developing Access to Neonatal Palliative Care in India (D1-A-103)

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Introduction: A UNICEF report, 2017 on new-born mortality rate (number of deaths per 1,000 live births) has ranked India the 12th worst country to be born in among 52 lower middle-income nations. India with 25.4 deaths per 1,000 births ranks below Sri Lanka, Bangladesh, Nepal and Bhutan. Palliative care is appropriate for neonates with severe prematurity, complex congenital anomalies and for conditions that may result in death during first few hours of life or after several years. It's a team approach to relieve physical, psychological, social, emotional, and spiritual suffering of the dying infant and the family.

Aim of the Study: Sensitisation of health care workers and other stakeholders about the need of Neonatal Palliative Care in India.

Objectives:

1. Create guidelines in caring for new-borns who may need to have technological support withheld or withdrawn. The protocol will assist providers for withdrawing or withholding life-sustaining interventions from dying or critically ill new-borns.
2. Capacity building of health care workers: Specific skills are needed by the staff to provide palliative care. Nurses and other health care staff needs to be trained in providing the family a meaningful experience while caring for the family's psychosocial needs including bereavement support.
3. Create institutional policies that will allow staff flexibility to respond to parental wishes.
4. Assist parents in making plans for a memorial service, burial, etc.

Results: The guidelines and protocol can allow for consistency in the approach to caring for new-borns with life-limiting conditions and provide a model useful for teaching palliative care to medical and nursing trainees.

Conclusion: With increasing survival of neonates with complex congenital abnormalities and extreme prematurity, neonatal palliative care is emerging as a speciality in itself. Multidisciplinary working that incorporates parental perspectives is vital to provide support and manage neonates during this distressing time for the parents.

Keywords: Guidelines; life sustaining treatment; neonatal palliative care

4. Validity and Reliability of Pain Assessment Tool for Bangladeshi Children (D1-A-104)

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Introduction: The Faces Pain Scale- Revised (FPS-R) is the most commonly used self- report measure of pain intensity scale to assess pain in children. Little evidence exists about the Bengali version of this scale [Table 1].

Aim of the Study: To assess the validity and reliability of the Bengali version of the FPS-R for Bangladeshi children.

Materials and Methods: A methodological study design was conducted. Sample comprised 84 children with cancer and 84 family caregivers. A FPS-R was used by children to measure their pain and Numeric Rating Scale (NRS) was used for the parents to validate their child's pain status. Descriptive statistics, t-test, ANOVA, Pearson's correlation coefficient, were used for data analysis.

Results: The age of the child with cancer was 4-8 years. The mean age of children was 5.73 years with SD Â± 1.60. Majority 64.3% of the child's current diagnosis was Acute Lymphoblastic Leukaemia and only 1.2% was Ewing sarcoma. The highest 77.7 % of the child received oral pain medications, among them 71.4% child had received non-opioids and 8.3% received strong opioid (morphine) for their pain management.

Conclusion: FPS-R is a valid and reliable tool for the child with cancer to assess pain. Dissemination and broader application of the FPS-R tool in Bangladesh could improve paediatric pain evaluation and in relieving their pain suffering.

Table 1: Validity and reliability of Faces Pain Scale-Revised with Numeric Rating Scale (n=84)

Variable
1st test of child face pain scale: r (p)
1st numeric rating scale by caregiver: (<0.001) (validity)
2nd face pain scale-revised by child with cancer: 0.93** (<0.001) (reliability); 0.77**
FPS-R scores correlated with parent scores using NRS (r=0.77, P<0.001) suggested good validity. Test-retest reliability of FPS-R was supported by strong correlations (r=0.93, P=<0.001) suggested excellent reliability

FPS-R: Faces Pain Scale-Revised, NRS: Numeric Rating Scale

Keywords: Bangladesh; children; pain assessment tools

5. Adolescents and Young Adults With Bone and Soft Tissue Sarcoma- Efficacy of Psychosocial Interventions for Patients and Their Siblings (D1-A-105)

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Introduction: Quality of life of cancer patients and their caregivers is greatly impacted and compromised by cancer diagnosis and treatment. This is often under reported. Need for psycho-social support is vast.

Aim of the Study: To investigate the role of psychosocial interventions in relieving distress among (AYAs) patients and their healthy AYA siblings.

Materials and Methods: 40 AYA patients, age- 14 yrs. to 29 yrs., on active treatment, their healthy AYA siblings enrolled for the study; 20 patient-sibling dyads in each, Experimental group (EG) and Control (waitlisted) group (CG). Pre-test post-test quasi experimental design was used to study the change in Depression, Anxiety among the patients and siblings after psychosocial interventions. Body image was studied only in patients. Six home-based intervention sessions for patients and siblings in the EG over 3 months included arts based therapy, CBT, psycho-education, family therapy and supportive therapy. Interview and feedback were obtained from patients-siblings dyads in EG and qualitatively analysed.

Results: Post test scores of both AYA patients in the EG and CG and post test scores of healthy AYA siblings in the EG and CG on above mentioned variables analysed using independent t-test. Results revealed statistically significant difference between the two groups of AYA patients (EG and CG) on Depression (t=4.68; p<0.001*), State Anxiety (t=4.13; p<0.01*), Trait Anxiety (t=3.29; p<0.01*) and Body Image (t=3.65; p<0.01*) and between the two groups of healthy AYA siblings (Experimental and Control) on Depression (t=7.64; p<0.001*), State Anxiety (t=6.89; p<0.001*) and Trait Anxiety (t=4.20; p<0.001*). Results report healthy siblings experience equal distress as patients.

Conclusion: Mental health is one of the main pillars of comprehensive health care. A step in the direction of making mental health care available to the larger population will benefit the society at large, enhance quality of life and help reduce the disease burden.

Keywords: Adolescents and young adults; psychological interventions; quality of life

6. SLEEP DISTURBANCE AND ASSOCIATED SYMPTOM PROFILE IN ADVANCED LUNG CANCER PATIENTS REFERRED TO SPECIALIST PALLIATIVE CARE - A CLINICAL AUDIT (D1-B-106)

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Introduction: Sleep disturbance is common in cancer patients ranging from 24-95% and can be related to disease and treatment variables. Literature reports approximately 62% advanced cancer patients report sleep disturbances. There is paucity of literature in sleep problems in advanced lung cancer in India.

Aim of the Study: To examine prevalence of sleep disturbance and associated symptom profile in advanced lung cancer patents in specialist palliative care clinic.

Materials and Methods: We retrospectively analysed medical records of adult advanced lung cancer patients referred to specialist palliative care clinic in our tertiary care cancer from January to June 2018. Sociodemography, current treatment, performance status and sleep and other symptoms (as documented on Edmonton symptom assessment scale) were noted. Relevant statistical analysis was done using IBM SPSS 22.

Results: 100 patients' records were analysed of whom 66 were men, and 59 were on Early Palliative Care (EPC). 63 patients had performance status of 2 (Eastern Cooperative Oncology Group). Sleep disturbance was found in 55 patients (moderate to severe in 10, mild in 45). 39 patients who had any grade of sleep disturbance were on opioid (30 mild, 6 moderate, 3 severe). There was a statistically significant association of sleep disturbance with pain, lack of appetite, anxiety, fatigue and dyspnoea ($p < 0.05$). In EPC group, cough was significantly associated with sleep problems. In multivariate regression model, the 2 significant factors were loss of appetite and anxiety ($R2 = 0.531$).

Conclusion: 55% of our study population had sleep disturbance, 10 % with moderate or severe grade. Sleep disturbance was significantly associated with pain, lack of appetite, anxiety, fatigue and dyspnoea. Proper identification and management of sleep problems are essential to reduce symptom related distress in patients with advanced lung cancer.

Keywords: Advanced lung cancer; sleep disturbance

7. ASSESSMENT OF DISTRESS AMONG PATIENTS AND PRIMARY CAREGIVERS: FINDINGS FROM A CHEMOTHERAPY OUT-PATIENT UNIT (D1-B-107)

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Introduction: Chemotherapy is an intense and cyclic treatment unlike surgery and has several side effect such as hair loss, nausea, vomiting. Long periods of treatment, repeated hospitalizations and side effects of chemotherapy beside the knowledge of having cancer can have an effect on the psyche of patients and their caregivers. On such aspect is distress which are unpleasant emotions that range from normal feelings of vulnerability to anxiety or depression.

Aim of the Study: To understand distress among patients undergoing chemotherapy and their primary caregivers.

Materials and Methods: A cross-sectional study design was used. Patients (n=61) undergoing chemotherapy and their accompanying primary caregivers (n=60) were screened for distress using the NCCN Distress thermometer and the problem list. Data was analysed using descriptive and inferential statistics.

Results: Patients (21.5%) and their caregivers (18.2%) reported experiencing moderate levels of distress. Higher levels of distress were found among patients (42.1%) than caregivers (38.8%) based on the domains of practical, family and physical problems (p<0.05). There was no significant difference in emotional, spiritual and religious problems. Further, patients reported increased distress on physical problems like fatigue (p=0.000) and pain (p=0.005), followed by emotional problems of worry (p=0.05) and sadness (p=0.04). Similarly, caregivers reported increased distress on family problems such as family health issues (p=0.000), practical problems of housing and transportation (p=0.005) and emotional problems of fear (p=0.04). There was a positive correlation between physical, family and emotional problems (r =0.342, p=0.001). Majority (80.2%) of patients and caregivers showed interest to avail psycho-oncology services.

Conclusion: Psychological distress is prevalent among patients with cancer undergoing chemotherapy and their caregivers. Clinical implications could include physician referrals to psycho-oncology services for patients based on the screening scores which could be a channel to understand caregiver distress. Future research warrants understanding of various psychological interventions that could reduce distress and improve overall quality of life.

Keywords: Psycho-oncology and mental health needs in palliative care

8. Impact of Palliative Homecare on Quality-of-Life of Head and Neck Cancer Patients (D1-B-108)

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Introduction: Head and neck cancers account for one-third of all cancers in India. These patients endure both physical and psychosocial pain due to the disease and adverse effects of cancer treatment. This study investigates the effect of home-based palliative care on head and neck cancer patients.

Aim of the Study: The main objective of the study was to determine the symptoms in advanced head and neck cancer patients and how effectively they were managed by a palliative homecare service.

Materials and Methods: Forty consecutive adult, head and neck cancer patients of both genders were enrolled from those registered for the palliative homecare service. Patients had completed chemotherapy and or radiotherapy and had Karnofsky Performance Score of 60. Patients were followed up every 10 days for 2 months and for a minimum of 4 visits. The EORTC QLQ PAL-15 and a modified version of the EORTC QLQ H&N-35 were completed on each visit. Scoring of the data was completed in accordance with EORTC scoring manual.

Results: 40 patients were enrolled for the study of which 80% were males. Patients' age ranged from 25 to 82 years and mean age was 50.7 years. Majority of patients were from lower income group and unemployed. 60% patients had history of tobacco and or alcohol use. The top four symptoms in these patients were pain (95%), fatigue (92.5%), insomnia (82.55) and appetite loss (80%). The top four symptoms related specifically to head and neck cancer were dysphagia, trismus, oral secretions and bleeding.

EORTC QLQ PAL-15 quality of life scores improved in 45% patients. Physical functioning scores improved in 50% patients and emotional functioning scores improved in 67% patients.

Conclusion: Advanced head and neck patients have a large symptom burden. However good palliative care can improve the quality of life of these patients.

Keywords: Head and neck cancer; palliative homecare; symptom burden

9. Psycho-Social Issues of Caregivers of Palliative Care Patients with Advanced Head and Neck Cancers – A Mixed Method Study (D1-B-109)

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Introduction: Caregiving, while it is an important aspect which determines the wellbeing of patients with advanced cancer, compromises the quality of life of caregivers.

Aim of the Study: This study using mixed method aims to explore the psychosocial issues faced by caregivers of advanced head and neck cancers patients and to quantify their burden and quality of life (QOL).

Materials and Methods: Burden and quality of life of (n=15) caregivers were quantified using Zarit burden interview (ZBI) and Caregiver quality of life index for cancer (CQOLC) respectively and ten primary caregivers were interviewed using semi-structured interview schedule and the session was audio recorded. Thematic analysis was employed to analyse the qualitative data.

Results: Care giver details are in Table 1.

Analysis revealed that 73% had QOL < 100. Mean CQOLC was 73.07% (maximum score being 140). Majority (46.7%) revealed mild to moderate burden [Figure 1].

Qualitative analysis [Figure 2] showed that care givers were affected in the physical dimension in the form of decreased sleep, eating and overall health, in the psychological dimension as Guilt, anger, anxiety and fear.

The hospital cost was the major financial constraint with social dimension affected in the form of inability to visit religious or social activities. Care givers perceived support in the financial and emotional domain from their friends and relatives.

Caregivers perception of illness while being devastating was accepted as something to be endured, almost all care givers had a wishful expectation of a miracle.

Conclusion: Caring for patients with advanced cancer impacts the physical, emotional, financial and social aspects of primary caregiver. Family acts as a major source of strength to manage the emotional and financial constraints. Majority of caregivers experienced only mild to moderate burden but scored low on QOL. This can be interpreted as accepting the decreased QOL as a part of caregiving and not considering it as burden.

Table 1: Care giver (*n*=15) details

No of females	11 (73.3%)
Mean age	46.1 (19 – 65)
No of spouses	11 (73.3%)
No with income < Rs 5000	12 (80%)
Marital status.	11 (73.3%)
Duration of caregiving >16hrs	9 (60%)
Financial support.	8 (53%)
ZBI (Mean)	32.4 (SD 18.2)
CQOLC (mean)	73.07 (SD 24.17; 60% scored below mean)

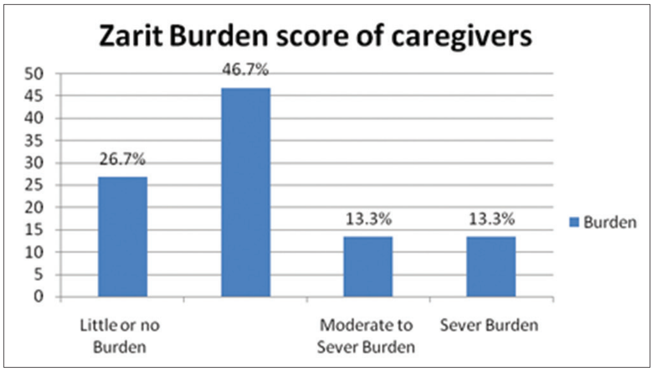

Figure 1: Zarit Burden Interview of Caregivers

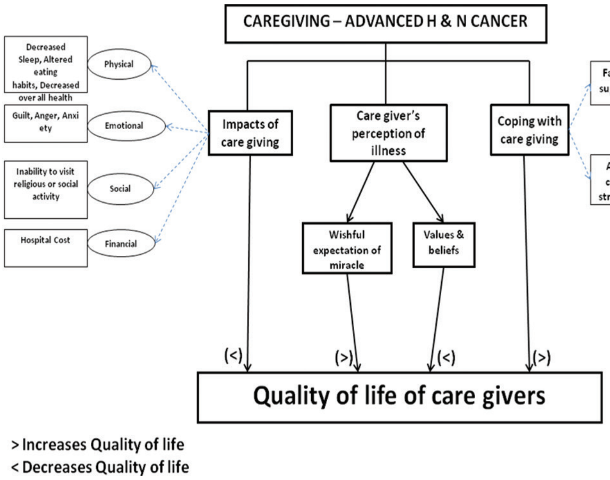

Figure 2: Qualitative analysis of Psycho-social issues of caregivers of advanced head & neck cancer patients

Keywords: Psycho-oncology and mental health needs in palliative care

10. A Systematic Review of Body Image Dysfunction in Head and Neck Cancer Patients (D1-B-110)

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Introduction: Body image is a critical psycho-social issue in the field of Head and neck cancer (HNC). Patients with HNC are at an elevated risk of experiencing body image difficulties due to illness and its treatment causing significant changes to physical appearance and normal functioning of the body. Therefore, there is a vital need to address body image difficulties when delivering care to patients with HNC. Research on Body Image issues in HNC is still in its infancy and literature on its prevalence is scant.

Aim of the study: (1) To explore the prevalence of body image dysfunction in HNC and, (2) To assess its impact on mood and quality of life and perceived barriers.

Materials and Methods: A search in multiple electronic databases was conducted (PubMed, CINAHL, PsycINFO) to locate articles in English from 2000 to present. The search terms used were body image, body dysmorphic syndrome, carcinoma, cancer, head and neck. The studies included met the following criteria: 1) Described body image dysfunction 2) Focused exclusively on HNC patients. Methodological quality was reviewed using study objectives, study designs, key findings.

Results: The search yielded 576 articles of which 564 abstracts were screened. 41 studies met eligibility criteria and full texts were reviewed. 23 were qualitative, 14 quantitative, 2 mixed method and 2 were quasi-experimental studies. Quantitative studies reported increased prevalence in females, post-operative patients and in patients with lack of social supports. Qualitative studies explored quality of life, associated depression, social withdrawal and contextual barriers.

Conclusion: The findings from this systematic review indicate that there is a high prevalence of Body Image dysfunction in HNC, which is inadequately addressed and associated with poor quality of life, depression and social withdrawal. Proper assessment of Body Image disturbance is not regularly done in patients causing significant distress in HNC patients.

Keywords: Body image dysfunction; head and neck cancer; quality of life

11. Analysis of Association of Demographic Variables with Awareness of Diagnosis, Prognosis and Distress in Palliative Patients with Cancer- Retrospective Study (D1-C-111)

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Introduction: Incidence of advanced cancer is increasing in lower- & middle-income countries but patients are often much distressed and are not aware of diagnosis or prognosis. Knowledge of diagnosis and prognosis can empower patients in making end of life decisions.

Aim of the Study: This study is aimed at assessing the relationship between the demographic variables and the awareness about the diagnosis, prognosis and the level of distress among palliative patients with cancer.

Materials and Methods: Retrospective analysis of palliative cancer patients registered from January to June 2018 was carried out in a tertiary care institute. Demographic data was collected with special emphasis on income groups, rural urban divide and educational level. The awareness of diagnosis, prognosis and the level of distress using the distress thermometer was analysed in this subset using Chi square test.

Results: There were a total of 764 patients. There were 406 (531%) males and 358 (46.9%) females. Education level was less than middle school in 83.9%. Over 59.2% presented in 5th decade of life. On looking for knowledge of diagnosis and prognosis in this subset, it was found that more males were aware of diagnosis, compare to females ($p<0.002$), but there was no gender difference in prognosis or distress level. Education level was an indicator of awareness of both diagnosis and prognosis ($p< 0.000$). A higher income >Rs 8000 translated to being aware of diagnosis and prognosis ($p<0.003$). Age and rural urban divide were not predictors of awareness of either diagnosis or prognosis. 76.9% complained of moderate distress. There was a significant association between greater level of distress with lesser education level ($p=0.019$) and stay in rural areas ($p=0.08$).

Conclusion: Male gender, education and financial status were indicators of better awareness of diagnosis and prognosis. Most demographic factors are non-modifiable, but patients' education is a modifiable factor that can decrease distress.

Keywords: Awareness; cancer; patient distress

12. Symptom Burden and Quality of Life Assessment in Patients of Gastrointestinal Malignancies Attending the Palliative Care Clinic of A Tertiary Care Center, India (D1-C-112)

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Introduction: Gastrointestinal cancer has recently been recognized to be the cancer with maximum symptom burden. Pain and treatment steps bring lots of stress in patient's life. Palliative treatments are used to ease pain, improve quality of life and at times, prolong life when full recovery from gastrointestinal cancer is not possible.

Aim of the Study: To assess symptom burden and quality of life of patient suffering from gastrointestinal malignancies attending the palliative care clinic of a tertiary care center, India.

Materials and Methods: 62 patients of gastrointestinal malignancy attending the palliative care clinic were included in the study. Demographic data like age, gender, educational status, histopathological diagnosis and stages, treatment history, previous admissions, duration of disease, adverse effects of analgesics like constipation, dyspepsia, sedation were recorded. Symptom burden was assessed using the scale ESAS-R (Edmonton symptom assessment system-revised) and quality of life with the EORTC QOL-C30 questionnaires.

Results: The mean age was 48.64 Â± 13.17 years. Most common symptom according to ESAS-R scale in the group was fatigue (mean (SD) 7.41 Â±1.06) followed by pain (7.33 Â±1.67), depression (6.46 Â±0.86), lack of appetite (6.43 Â±1.36), anxiety (6.27 Â±1.59), well-being (5.67 Â±1.25), nausea (4.5 Â±2.7), drowsiness (3.20 Â±1.8), shortness of breath (2.82 Â±1.8). Mean score of Global health according to EORTC scale was 41.26%. EORTC scale was divided in physical, role functioning, emotional, cognitive and social functioning and mean (SD) scores for these subscales were 53.54%(10.86), 50.80%(9.74), 55.54%(9.67), 55.64%(14.13), 42.74%(14.35) respectively. Maximum mean scores using EORTC symptoms scale were of appetite loss (68.27% Â±15.30) followed by pain (66.39Â±18.47), insomnia (62.90% Â± 18.21), and constipation (60.75%Â± 19.58).

Conclusion: Symptom burden is very high in patients with gastrointestinal malignancies and they have poor quality of life. A comprehensive holistic assessment is required to address symptom burden in such group of patients.

Keywords: Gastrointestinal malignancy; palliative care clinic; quality of life; symptom burden

13. COPING STYLES – IMPACT ON QUALITY OF LIFE OF PALLIATIVE CARE PATIENTS (D1-C-113)

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Aim of the Study: Limited research has been done to explore the relationship between QOL and coping styles in advanced cancer.

To observe the relationship of coping styles with the QOL in advanced cancer.

Materials and Methods: A sample of 100 advanced cancer patients was taken from BMCH&RC, Dept. of Palliative Care. WHOQOL-BREF was used to assess the QOL and brief -COPE was used to assess the coping styles.

Results: Social QOL of the patients is better than the physical, psychological and environmental.

Mostly used healthy coping techniques are venting, acceptance and religion while unhealthy techniques are self-blaming and behavioural disengagement.

Overall QOL of patients with breast lung cancer is better than the head neck disease. Denial is higher in patients with lung & head neck cancer as compared to breast cancer. Whereas acceptance is high in patients with breast cancer.

Physical QOL of female patients is better than male patients. Behavioural disengagement is used more by female patients while acceptance is more in female patients than males.

Patients living in joint families have better social and environmental QOL as compared to patients living in nuclear families. Active coping, venting, and use of instrumental support are high in joint families while behavioural disengagement is high in nuclear families. Unhealthy coping like behavioural disengagement and self-blaming are used more by patients undergoing treatment for 0-2 yrs.

Conclusion: Gender difference, domicile, family structure, types of disease all are directly associated with coping styles of the patients which has an impact on QOL.

Keywords: Advanced cancer; coping styles; quality of life

14. EXPLORING PALLIATIVE CARE NEEDS OF TRANSGENDERS IN SOUTH INDIA (D1-C-114)

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Introduction: Total population of transgenders in India is 4.88 lakh in 20111,2. The risk of HIV, mental health issues, suicide and substance abuse is higher among transgenders than in general population. A 2016 study published in The Lancet attributes the increased mental suffering to the discrimination, stigma, abuse and exclusion by the transgenders. In 2014, Supreme Court of India recognized "transgender" as "third gender" in order to protect their fundamental rights3,4. Universal health coverage ensues that all people and communities have equal access to quality health services and calls to "ensure right to health: leaving no one behind"6. The Lancet Report on Palliative Care in 2017 has proposed a broader vision for palliative care focusing on both averting and alleviating serious health-related suffering and promoting dignity, both in life and in death5. Thus it is imperative that we acknowledge and address the healthcare needs of LGBTQI community, in order to achieve universal health coverage.

Aim of the Study: To explore the palliative care needs of transgenders and the barriers to accessing healthcare.

Materials and Methods: A two-day workshop for transgender's was organized in collaboration with Sahodaran Community Oriented Health Development, Puducherry. The first group consisted of 22 young adults below 40 years and the second group consisted of 38 older adults above 40 years. Focus group discussion was conducted in a non-intimidating environment to elicit the physical, social, legal, and psychological care needs. Narratives from this workshop was analysed on various axis of health equity with a reflection on existing policies and ethics.

Results: Transgenders are exploited mainly because of their gender orientation through denial of opportunities and discrimination from society irrespective health status. Findings includes unmet physical, psycho-social and spiritual needs and reveals the fact that mental health is ignored.

Conclusion: Findings throws light to inequity in health care apart from questioning the policies and law of the land.

Keywords: Palliative care; South India; transgenders

15. PALLIATIVE CARE NEEDS OF PERSONS WITH NEURODEGENERATIVE DISORDERS (D1-C-115)

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Introduction: People facing the life-threatening disease require some degree of compassionate care in addition to the treatment they are receiving. Hence, palliative care is of paramount importance. People with chronic, debilitating, and life-limiting neurodegenerative diseases are today living longer and as a result, have significant care needs. Care of the neurological patients poses greater challenges as they may have multiple disabilities often progressive. In India, direct care giving takes place in the family context.

Aim of the Study: To understand the palliative care needs and care giving dimensions in neurodegenerative disorders.

Materials and Methods: A Cross-sectional descriptive study design was used to collect information among patients suffering from Neurodegenerative Diseases. The study was conducted among patients diagnosed with Motor Neuron Disease (MND) and Parkinson's Disease (PD) to understand patient's functionality, palliative care needs, quality of life and burden faced by the caregiver. Sixty patients and their caregivers receiving treatment from Dept. of Neurology, NIMHANS were recruited for the study. All the patients were evaluated for their complaints and clinical diagnosis was established. Patients and caregivers were interviewed and assessed using standardized scales involving Functional Independence Measure, Palliative Care Outcome Scale, The World Health Organization Quality of Life (BREF) and the Zarit Burden Interview scale.

Results: Functional independence measure in both MND and PD has shown an impact on the functionality of the patient. Quality of life was higher in social relationship domain in MND and environment domain in PD. Caregivers reported mild to moderate burden in taking care of the patient's needs in both disorders. The palliative care needs were similar in both the disorders. There was agreement in the nature of palliative care needs between the patients and carers. Women in both disease groups had significantly higher palliative care needs as compared to men.

Conclusion: The understanding gained from the study aided in developing multidisciplinary management plans for patients suffering from Neurodegenerative diseases. Social workers trained to provide psychological support can have a vital role in management of such patients.

Keywords: Caregiver burden; functionality; neurodegenerative disorders; palliative care needs; quality of life

DAY 2

16. PALLIATIVE CARE: PART OF INTEGRATED MANAGEMENT FOR NON-COMMUNICABLE DISEASES - A MODEL FOR LOW INCOME COMMUNITIES (D2-C-116)

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Aim of the Study: The rapid rise in non-communicable diseases (NCD) globally disproportionately impacts low and middle-income countries (LMIC) with 80% of NCDs occurring in countries least able to deliver comprehensive Universal Health Coverage (UHC). UHC for NCDs should include: health promotion, disease prevention and management, rehabilitation and palliative care.

Objective is to integrate all aspects of NCD management including palliative care into a model of UHC

Materials and Methods: In 2017 the Duncan Hospital (Raxaul, Bihar) Community Health Team Integrated NCD Programme was established, providing home based palliative care and screening for diabetes, hypertension and oral cancer. Other aspects include health education for cancer recognition and healthy lifestyles and engaging with local community groups. Individuals identified through screening are referred for appropriate management and follow up. Primary care providers are trained to provide integrated NCD management. Data collected is used to determine the local prevalence of NCDs.

Results: 996 villagers screened; 198 (20%) referred for further management. 64 received home palliative care (57 advanced cancer 7 non-cancer). 2 community wellness structures established, 16 community groups (157 volunteers) trained to provide health promotion advice with a few also providing palliative care. 251 primary care staff received training in NCD management. Support of 13 local officials achieved through advocacy. Evidence is emerging that compassionate palliative care encourages communities to engage with integrated NCD management and effectively models essential patient centred approaches for primary health staff.

Conclusion: Palliative care as part of integrated NCD management in rural communities could provide an enhanced UHC model for low incomes settings.

Keywords: Integrated management; low income communities; non-communicable diseases; palliative care

17. EXPERIENCES AND ATTITUDES TOWARDS DISCLOSURE VERSUS NONDISCLOSURE OF A POOR PROGNOSIS TO ADVANCED CANCER PATIENTS: INDIAN ONCOLOGISTS PERSPECTIVES (D2-C-117)

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Introduction: Nondisclosure of advanced cancer prognosis is commonly practiced in some Asian cultures. Oncologists cite reasons for nondisclosure such as cultural factors, not wanting to upset patients, family reasons, and desire to protect oneself from harm. However, no research has explored the experiences of oncologists in India about prognosis (non) disclosure.

Aim of the Study: To explore experiences of and attitudes of Indian Oncologists towards disclosure versus nondisclosure of a poor prognosis to advanced cancer patients.

Materials and Methods: Thirty oncologists (n =10 medical, 12 radiation, 4 surgical, 4 palliative care) practicing in India were recruited for a semi-structured interview, exploring their experiences and attitudes towards disclosure versus nondisclosure of a poor prognosis to advanced cancer patients. Interviews were analysed using Interpretative Phenomenological Analysis.

Results: Three superordinate themes emerged from the analysis: (i) barriers to communication comprising of lack of resources, white coat syndrome, multidisciplinary teams (ii) role of the family comprising of family comes first (oncologist discloses prognosis to family first), arbitrary disclosure, role of education, stigma taboo of cancer, socio-cultural beliefs about cancer, understanding patient needs, understanding internal family needs and (iii) building a relationship with the patient consisting of understanding the patient, using layman's language (metaphors), gaining the patients trust, partial or selective disclosure, balancing families wishes with their own beliefs, not giving false hopes, being honest and sometimes not telling the patient is the best.

Conclusion: Revealing prognosis was a delicate balancing act for Indian oncologists, i.e., managing patient and family emotions while providing them relevant information and maintaining hope. Additional work is needed to explore Indian patients and family's needs and perceptions of cancer care. Clinical implications include understanding patient-family beliefs, expectations of care, introducing skills in sharing serious news and providing oncologists with appropriate resources to aid better patient care in India.

Keywords: Oncologists, Nondisclosure, Prognosis, Advance cancer

18. Palliative Care for Dementia: A Social Work Model (D2-C-118)

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Introduction: Dementia is a life limiting disorder, and the demographic shift towards aging, many people will die with or from Dementia. Palliative care can help to mitigate patients' and families' concerns and needs. Palliative Care needs in Dementia, though increasingly being recognized, have received limited attention in India especially from social work professionals.

Aim of the Study: The paper aims to assess the palliative care needs in Dementia and to propose a psychosocial care model based on the needs from social work perspective.

Materials and Methods: A cross sectional descriptive study was performed among thirty patients diagnosed with Dementia and their caregivers who were receiving treatment from a national tertiary referral centre for Neurological disorders. All the patients were diagnosed as Dementia based on clinical evaluation and radiological findings. Functionality, Palliative care needs and caregiver burden were assessed with standardized scales including sociodemographic schedule, Schedule to assess Palliative care Needs in Dementia, Clinical Dementia Rating Scale (CDR), Integrated Palliative Care Outcome Scale â€“ Dementia (IPOS-Dem) and Zarit Burden Interview.

Results: Mean age of patients was 65 with 73% of them being male. 63% of the patients were 61 yrs. and above. Fronto-temporal dementia was the most common type of Dementia. Palliative care needs emerged as an important concern. Applicability of palliative care, person centred communication, shared decision making, setting care goals and advanced care planning, prognostication and timely recognition of dying, avoiding overly aggressive treatment, optimal treatment of symptom and providing comfort, family, psychosocial and spiritual support and ethical issues emerged. The theoretical framework and model in social work perspective provides a useful intervention model aiming at optimizing quality of life of the patient and alleviating caregiver burden.

Conclusion: Further research on feasibility and effectiveness of the intervention is needed. Palliative care social work approach in neurodegenerative disorders like dementia needs to receive more attention and needs to be initiated early.

Keywords: Care giver burden; dementia; palliative care; quality of life

19. Surviving the 2015 Earthquakes in Nepal: The Experiences of People with Life Limiting Conditions in Two Rural Districts (D2-C-119)

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Introduction: In 2015 two large earthquakes devastated large areas of Nepal with 10,000 deaths, 22,000 serious injuries and extensive damage to property and infrastructure. Some of the worst affected place were remote rural areas where access to healthcare even before the earthquakes was restricted. Studies of natural disasters in low income settings demonstrate that those with chronic illness, old people and those with disabilities suffer disproportionately and are frequently poorly served in recovery and rebuilding efforts.

Aim of the Study: To explore experiences of people with advanced chronic illness, severe disability or old and frail affected by the Nepal earthquakes.

Materials and Methods: A convenience sample of people within the target group was recruited in two rural districts. Semi-structured interviews explored participants' experiences of the immediate effects of the earthquakes and their subsequent lives. Interviews particularly focused on access to healthcare and how this had changed following the earthquake. Interviews were conducted in Nepali, recorded verbatim, translated into English and analysed thematically.

Results: 19 people provided vivid descriptions of their experiences of the earthquake; many escaped falling buildings or needed to be dug out. Some described how others were crushed and died. The immediate aftermath included fear of returning to homes and building temporary structures or living in out-houses. 20 months after, most still lived in temporary dwellings. Participants often relied financially on family members living in Kathmandu or abroad before and after the quake. Subsistence farming continued as before. Access to healthcare was limited before the quake and changed little following it. Few participants received comprehensive chronic disease management (CDM) and many relied on medication being sent from towns and cities.

Conclusion: The earthquake caused widespread damage to homes and increased the hardship face by these vulnerable people. Access to CDM was severely limited. Integrated CDM including palliative care should be a focus of post-earthquake development.

Keywords: Chronic disease management; Nepal earthquake; palliative care-integrated care

20. DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF PALLIATIVE CARE EDUCATION FOR HEALTH CARE WORKERS, VILLAGE HEALTH TEAMS AND FAMILY CAREGIVERS PROVIDING HEALTHCARE FOR SOUTH SUDANESE REFUGEES IN ADJUMANI DISTRICT, UGANDA: (D2-A-120)

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Introduction: Adjumani district has 260,000 refugees, with 240,000 host community. A PC integration programme supported by a rapid system appraisal revealed significant gaps in service provision & need for capacity building.

Aim of the Study: To address training & capacity needs within refugee settlements by developing PC education pathways for Health Care Workers (HCW), Village Health Teams (VHT) and Family Caregivers (FC).

Materials and Methods: Training for 30 HCW (5 days), 75 VHT (3 days) and 150 FC (1 day) was developed & delivered. Evaluation comprised pre & post course knowledge testing, pre & post course confidence ratings, plus post course evaluation & sample interviews and 3 month post course follow-up including qualitative evaluation for the VHTs.

Results: Initial evaluation reveals an increase in knowledge & confidence for HCW by 2 out of 5 VAS scale points. VHTs identified improvements including the belief they can now identify PC patients, and communicate more effectively. HCWs interviewed revealed new skills, improved ability to care for patients and families and increased satisfaction. It modelled my character, my behaviour is quite different from before I had the knowledge. FC reported significant health promotion support. Full comprehensive qualitative and quantitative results will be presented including impact on practice.

Conclusion: In order to adopt a universal health coverage approach for chronic disease care in in humanitarian situations strengthening capacity is crucial. This work is being done in partnership with key stakeholders including humanitarian agencies, the Ministry of Health and should also have wider relevance in fragile contexts. A baseline needs assessment & health systems review is also in process to offer further evidence.

Keywords: Education; palliative care integration programme; refugee settlements

21. CREATING SOLUTIONS THROUGH DEVELOPING LEADERS IN PALLIATIVE CARE: EVALUATION OF TWO COHORTS OF LEADERSHIP TRAINING IN UGANDA (D2-A-122)

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Introduction: The WHA resolution on Palliative Care (PC) promotes the integration of PC into health systems – key to this is national leadership. The Ugandan Palliative Care Leadership Fellowship (PCLF) Programme was developed to improve leadership skills & increase access to PC services in Uganda. 2 cohorts of Fellows have been trained, 20 from Aug 2015-Jan 2017 & 20 from Jan-Nov 2018. Teaching was delivered on a modular basis with three 1-week taught modules interspersed with mentorship & supervision.

Aim of the Study: To evaluate the impact of the PCLF.

Materials and Methods: An evaluation was undertaken at the end of each of the programmes. Mixed methods included: (1) utilising existing sources of M&E e.g. course reports, action plans, etc.; &, (2) interviews with at least: 20 fellows, 4 link nurses, 3 project leads, & 10 UK mentors. Data was triangulated to confirm findings & draw conclusions.

Results: The PCLF is effective and well-delivered. Fellows demonstrate improved knowledge, skills & self-confidence & give examples of increased leadership roles. The combination of the training format, action plans & national projects, supported by mentors, was effective in ensuring knowledge transfer into skills. 40 PC Fellows trained over 300 individuals thus consolidating their skills & providing ongoing mentorship & supervision, with Cohort 1 Fellows supporting those in Cohort 2. 8 national research projects were undertaken, strengthening research capacity of fellows & having both national & international impact. Fellows have been recognised as leaders & invited to participate in national & international meetings, as well as submitting abstracts & presenting papers.

Conclusion: Training of PC leaders in Uganda is strengthening the health system workforce, with leaders taking on increased roles & responsibilities within local, national & international PC contexts. Leaders are embedded within the existing health system, building on existing resources and enabling sustainability.

Keywords: Health system; integration of palliative care; training; Uganda

22. GENERAL PRACTITIONER TRAINING, EXPERIENCE AND VIEWS CONCERNING NON-COMMUNICABLE DISEASE MANAGEMENT AND PALLIATIVE CARE IN NEPAL: ONLINE SURVEY (D2-A-123)

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Introduction: Nepal's NCD prevalence is increasing with increasing need for palliative care (PC) in cancer and non-cancer illnesses. Nepal's multi-sectoral action plan for NCDs promotes an integrated primary and secondary care approach for NCD prevention and control including cancer and PC. General practitioners (GP) with MD (GP) work at all levels, often leading services in rural district hospitals (DH).

Aim of the Study: Survey of MD (GP)s training, experience and views concerning NCD management, including PC.

Materials and Methods: Online survey covering: diabetes, hypertension, asthma COPD, cancer and PC. All GPs with known emails were invited to participate. The survey was publicized via a GP conference and social media. Questions included: background, workplace, experience and training in NCDs; views on MDGPs role, facilitators and barriers to NCD management.

Results: 64138 (47%) invited plus additional 15 completed survey. 4579 (56%) had worked in government DH. NCDs formed minimum 30% workload for 39 (49%). 60 (76%) – 67 (85%) reported ability to manage most cases and 67 (85%)-73 (92%) believed MDGP training prepared them well in COPD, asthma, hypertension or diabetes. Only 16 (20%) were confident and 24 (30%) claimed adequate preparation in PC. 42 (54%) had undertaken post-MDGP training in diabetes, 28 (35%) in COPD, asthma, only 22 (28%) in PC, although 67 (86%) expressed the desire for it.

Most agreed: communication skills, patient-centred approach and GP-led management were essential for effective NCD management.

Conclusion: Nepal's MD (GP)s are mostly confident in NCD management but report lower confidence and inadequate preparation in PC. They desire further PC training. Ongoing work needs to ensure MD (GP)s are trained in PC and equipped with necessary skills.

Keywords: General practitioner; NCD; Nepal; palliative care

23. Impact of Arogyakeralam Palliative Care Programme for Infirm in Kerala - Looking Through the Lens of State Palliative Care Policy (D2-A-124)

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Introduction: Kerala was the first state in India and first government in the developing world that perceived the fact that power of healing is not only in prescribing drugs but essential care of the patient and family. Every primary health centre in the state now has one nurse with training in palliative care providing home visits to non-ambulant/bedridden patients.

Aim of the Study: To evaluate the performance of existing state palliative care programme run by the Government of Kerala in terms of coverage, type of services provided, utilisation pattern, and to understand the extent to which the policy succeeded and the gaps that need to be resolved.

Materials and Methods: The study employed mixed method design with secondary data analysis and in-depth interviews among policy makers, stakeholders and health care workers. Policy analysis triangle is used as a framework to evaluate the policy.

Results: More than 400 Gramapanchaytas have established home care programmes with the involvement of local self-governments. The policy succeeded in strategizing and channelizing resources and in reaching out through the primary care network. But it has touched only the fringe of the problem as indicated by per capita opioid consumption, inadequate participation professionals, poor implementation of proposed monitoring machinery, and inequity in care to vulnerable populations.

Conclusion: Arogyakeralam palliative care programme has been a giant step in access to palliative care and a sagacious decision to tackle suffering of millions, but needs to implement an effective monitoring mechanism as envisaged in the policy and take remedial action to address the current gaps.

Keywords: Kerala; state palliative care policy

24. Piloting A Mobile Application Developed by World Health Organisation – Report from the Site in India in A Multi Country Study (Uganda, Zimbabwe And India) D2-B-125

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Aim of the Study: To develop, implement and explore the usage of an app for caregivers of PC patients and a web-based dashboard for PC clinical teams.

Materials and Methods: Study design: Mixed-methods longitudinal study. An advisory group consisting of IT professionals, clinic staff interacting with family members and patients was involved in the design of: 1) an app, to collect information about patient and family symptoms; 2) a web-based backend application (dashboard), to collect the information sent by caregivers through the app.

Study setting, participants and sample size:
Conducted in Institute of Palliative Medicine, Kerala, 25 family caregivers and 25 community caregivers (total n=50) and 3 clinical staff (doctor, 2 nurses).

Data collection and analysis: The app and the dashboard were implemented and used by carers and clinical staff for 6 weeks. A quantitative descriptive analysis of its use and a qualitative evaluation, by nine semi structured interviews, were conducted

Results: The app includes: 1) recommendations for the use of the app; 2) information about PC; 3) information about the symptoms to be reported; 4) nine questions to be answered using Likert scales. The web-based dashboard allows to sort the information by each item (patient, level of pain, feelings, etc.), Clinical staff interacting with the caregivers during the implementation found the app and the dashboard useful and feasible to be integrated in their practice.

Conclusion: The development of this tool demonstrated the information to be provided to caregivers and the IT functions requested to support the communication between caregivers and clinical team.

Keywords: Caregivers; clinical staffs; IT tool; WHO

25. DEVELOPING A PURPOSE BUILT ELECTRONIC MEDICAL RECORD SYSTEM FOR PALLIATIVE CARE IN INDIA (D2-B-126)

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Aim of the study:

1. To develop comprehensive purpose built electronic patient record retrievable database
2. Attempt to improve quality of care by embedding processes around multi-disciplinary team (MDT) assessments, risk assessment, patient-professional communication, care planning, anticipatory care planning
3. Emphasize MDT approach and improve clinical inputs of non-physician team members
4. EMR portability on tablet computer device

Methods:

- The EMR was developed by a specialized vendor, with inputs from our MDT, over 18 months.
- A generic framework included- assessment with standardized tools, care plan and follow up. Patient safety assessment and care plans included key areas e.g. fall risk, medication reconciliation.
- Documentation of patient family communication with care providers emphasized Goals of Care and MDT discussions.
- Physician treatment plans include Symptom Management plans with anticipatory symptom management.
- Psychosocial care workflows include subjective assessments and management. Specialized pain intervention, physiotherapy and dietitian workflows were included.
- Home care workflow captured relevant aspects like access to local medical care, resource mapping.
- The EMR is hosted in a secure cloud-based environment ensuring safety and remote availability.

Results:

Challenges

- Perceived as detailed and time consuming
- Comfort with technology variable for staff
- Technical problems during development
- Internet connectivity

Benefits

- Truly encourages MDT approach to care
- Supports systematic assessments and care planning
- Improves documentation and patient safety

Conclusion: We believe that this is the first purpose built Palliative Care EMR in India. Further analysis will be required to evaluate the actual impact on patient care.

Keywords: palliative care; patient records

26. PREVALENCE OF PAIN DUE TO NON-ADHERENCE TO ORAL MORPHINE AND REASONS FOR THE SAME IN ADULT PATIENTS WITH ADVANCED CANCER (D2-B-127)

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Introduction: Pain is one of the most feared symptoms in cancer patients and more than two-thirds may have pain in advanced disease. The WHO analgesic ladder provides good pain relief in 70-90% patients with strong opioids like morphine being prescribed for severe pain. However many patients may be non-adherent to oral morphine which may lead to poor pain relief.

Aim of the Study: The aim of this study was to determine the prevalence of pain due to non-adherence to oral morphine in Indian cancer patients followed at home and also to find the reasons for non-adherence.

Materials and Methods: A mixed methodology was used. Pain prevalence was determined in 86 advanced cancer patients by first recording pain scores using the numeric rating scale. Adherence was determined in patients with a pain score â‰¥5 using patient self report and residual pill counting. Reasons for non-adherence were determined qualitatively through semi-structured interviews in 10 patients and 2 caregivers. Interviews were transcribed verbatim and then read and reread to find emerging themes which were color-coded.

Results: 24 patients had moderate or severe pain, a pain prevalence of 28%. 16 of these were non-adherent to oral morphine so pain prevalence due to non-adherence was 18.6%. Non-adherence was more in the lower socio-economic group and in those who were on morphine for more than a year. The reasons for non-adherence were grouped under three major themes, patient factors, medication factors and health delivery-related factors.

Conclusion: Non-adherence to oral morphine may be a cause of significant pain in advanced cancer patients. It is dependent on number of factors related to the patient, professionals, availability and misconceptions about morphine. Non-adherence may be improved by patient education, improving health professionals' knowledge on opioids and cancer pain management and by making patients a partner in the management of their disease.

Keywords: Morphine; non-adherence; pain

27. GETTING MORPHINE IN THE DISTRICTS HOSPITALS-RULE BOOK VERSUS REALITY (D2-B-128)

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Introduction: Pain Relief and Palliative Care Society, PRPCS is a registered charity organization and one of the largest palliative care providers to take care of patients living with incurable illnesses. PRPCS signed an MOU with Government of Telangana to start Palliative Care Centres in public hospital system like District Hospital/ PHC/ CHC under National Program for Palliative Care. In the first phase 8 such centres were opened which have a 8-10 bedded in-patient facility and home care.

Aim of the Study: One of the objectives of the program was to improve access to pain relief even in the most remote regions of the state by means of making available opioid medications like injection and oral morphine in all the districts palliative care centres of Telangana.

Materials and Methods: To meet the above-mentioned objective, both MNJ Institute of Oncology and PRPCS worked closely with Department of Health and Family Welfare, Department of Drug controller, Management and Pharmacists of Public Hospitals, local Drug Controller offices, pharmaceutical companies and District Collectors. The process involved getting the Recognised Medical Institutions (RMI) or its equivalent status in each palliative care centres, necessary training of Doctors to get the Recognised Medical Practitioner (RMP) status, allocation of funding to procure opioid medications and procurement of medications from the pharmaceutical companies. It required creation of an official check issued by the Drug Controller Office for the processing of the application, several meetings, sensitization and advocacy efforts, personal interactions, writing letters and phone follow-ups.

Results: All the 8 Palliative care centres are officially approved as Recognized Medical Institutions. They have procured Tablet and injection morphine. Today patients in those regions have access to pain relief in their Government hospitals without having to travel all the way to Hyderabad.

Conclusion: The ground reality is different and it requires effort at various levels for an effective implementation.

Keywords: Public health and policies

28. Do we Need Step 2 of the WHO Pain Ladder; an EAPC Research Network Study (D2-B-129)

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Introduction: The need for step 2 of the WHO analgesic ladder has been questioned and in some LMIC settings including Uganda a 2 step rather than a 3 step approach is already used. A pilot study supported a multicentre RCT.

Aim of the Study: To establish if a 2 step approach to cancer pain control achieves stable pain more quickly without increased side effects and with improved health economics.

Materials and Methods: An international, multicentre, open randomised parallel group trial comparing a 2 versus 3 step approach of the WHO ladder in patients with cancer with moderate pain severity. Study duration 20 days. Primary outcome: time to stable pain control (first day of 3 consecutive days with average pain score <3). Secondary outcomes: mean of average daily pain scores, % days with average and worst score >6, pain intensity, pain relief, pain interference and distress. Tools used; Patient Diaries, Worst/Average pain in last 24 hours, Brief Pain Inventory, NCCN Distress Thermometer, Analgesic and non-analgesic use, Opioid Toxicity and Side-effects Questionnaire, EQ-5D, QALY.

Results: 2164 patients screened 153 randomised over 36 months from European, Latin American and African participant centres. Uganda contributed 27. Time to pain control was similar in both arms but 36/76 (48%) of patients who were commenced on a weak opioid required a switch to a strong opioid to achieve pain control. No difference in side effects ($p>0.05$). Cost analysis shows economic outcomes strongly in favour of the 2 step arm.

Conclusion: Patients with cancer who have moderately severe pain commencing a strong opioid de novo achieve pain control at least as quickly with no greater likelihood of side-effects. However to achieve pain control 1 in 2 patients who commence with a weak opioid will need to switch to a strong opioid. The 2 step approach is cheaper, even without factoring in cost of extra visit(s) to deal with uncontrolled pain in 3 step arm. This has significant implications for WHO analgesic ladder and clinical care.

Keywords: Weak and strong opioids; WHO pain scale ladder

29. Universal Health Coverage and Palliative Care – The Way Forward (D2-C-130)

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Introduction: World observed Universal Health Coverage Day on 12 December 2018. Proactively, Government Medical College, Thiruvananthapuram and Pallium India Trust organized a workshop on "Universal Health Coverage & Palliative Care in Kerala- The Way Forward, Call for Action Based on Astana Declaration on Primary Health Care".

Aim of the Study: The objective of the workshop is to involve stakeholders to evolve strategies that helps to practically implement palliative care at ground level through universal health coverage.

Materials and Methods: Through a series of sensitization sessions and one on one meetings which concluded with a meeting declaration through the participation of all the stakeholders including subject experts.

Results: The discussion pointed to the followings

- Review the implementation of the Kerala State Palliative Care Policy with a view to improving coverage and quality of palliative care delivered with possible adaptation by other state governments,
- Implement the amended Narcotic Drugs and Psychotropic Substances Amendment (NDPS) Act of 20143 throughout the country and ensure the availability of Essential Narcotic Drugs (ENDs) at affordable cost and
- Initiate undergraduate palliative care education by the Medical Council of India, Indian Nursing Council, and in allied health sciences. It is important to make education altruistic compassionate and gender sensitive. Palliative Care should be included in broad specialties and super specialties.
- Implement the Clinical Establishment Act and adhere to ethical practices when it comes to the end of life care at the minimum

Conclusion: The meeting declaration was submitted to the state governments to make sure that the palliative care services are reaching people in all age groups with serious health-related sufferings by overcoming the barriers of accessibility, affordability, and availability.

Keywords: Public health and policies

30. Integrating Palliative Care, End of Life Consultations with the ICU Care (D2-C-131)

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Introduction: For everyone, ICU care and palliative Care are poles apart but in real, their goals are the same: Alleviation of Sufferings, Introduction of Palliative care consultations early with families in patients rounds, making a effective communication with them, results in better symptomatic management of patients, with clear demarcated goals of care, alignment of treatment with patient's values and preferences, support for both patient and families during the stressful period.

Aim of the Study: To study Effect of Introducing Palliative Care Consultations with patients and families and to study what difference it makes on the number of DNRs orders, usage of Inotropes, number of dialysis or other non-fruitful interventions, median survival time and overall Quality of life in terms of family satisfaction level.

Materials & Methods: A prospective study was conducted with patients admitted under ICU from July 2018 to December 2018 with APACHE 2 score of more than 35. Data of numbers of DNRs, refusal of Dialysis and other interventions, Mortality Benefits, Satisfaction level of patients and families. Family Communication Sheet.

Results: We counselled 100 % of patients who are admitted in the ICU from July 2018 to December 2018. There was 30 % reduction in life sustaining procedures which include ventilatory support, Dialysis etc. ICU length of stay was shorter for patients who opted for Palliative care. There was no mortality benefit for those who continued with ICU care.

Cost of care in last week of life was reduced by 45 % in those who opted for Palliative Care.

There was better use of ICU resources and improved family satisfaction.

Conclusion: Palliative Care Is not a mutually exclusive alternative, nor simply a failure of ICU care when attempts for life prolongation has failed. It is an integral component of comprehensive care for critically ill patient, regardless of diagnosis or prognosis, from time of ICU admission to ICU discharge or Death.

Keywords: ICU; integrating palliative care

31. Baseline Quality of Life Among Patients with End Stage Kidney Disease in A Resource Limited Setting (D2-C-132)

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Introduction: At 23% the prevalence of chronic kidney disease in sub-Saharan Africa is higher than the global prevalence of 16%. With no national healthcare coverage for haemodialysis or kidney transplant, Ugandan patients struggle to pay driving communities into poverty. Studies in developed countries show that patients on haemodialysis may prioritize quality of life (QoL) over survival time. There is a dearth of information about QoL of patients with End Stage Kidney Disease (ESKD) in LMIC.

Aim of the Study: Establish a baseline review of QoL, patient outcomes and associated factors for patients with ESKD receiving haemodialysis versus conservative management in a national referral hospital.

Materials and Methods: A mixed methods analytical study using the Kidney Disease Quality of Life Short Form, African APCA POS and Renal POS. Clinical, demographic and micro-financial information is collected and patient experiences explored using semi-structured interviews.

Results: 40 patients completed with 6 interviewed. Full evaluation will be presented with scores grouped into mental health, physical health and kidney disease related composite scores. Summary; QoL 91% felt kidney disease interfered too much with their life. 37% felt they were a burden to their family, 61% felt very frustrated with their lives. Average pain score (POS) was 2.4 with 27% reporting severe or overwhelming pain. Most had only 1 additional symptom with breathlessness highest prevalence (16%). Extensive co-morbidities present; 90% hypertension & 50% diabetes. Key themes; disease burden and comorbidities, importance of spirituality, loss of hope and financial constraints 'I wish God could take me before I deplete my family's resources'.

Conclusion: Improved QoL is a key indicator of successful chronic disease management. This baseline review will inform a wider mixed methods longitudinal study. Improving this evidence base will inform renal and palliative care services with the aim of improving patient experience.

Keywords: End stage renal disease, quality of life

32. Starting A Home Palliative Service for End Stage Organ Failure Patients – Challenges and Solutions (D2-C-133)

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Aim of the Study: In the last two decades, end stage organ failure (ESOF) patients have also been seen in specialist palliative care services. But the growth of home palliative services for ESOF patients has been slow in Asia. Holistic care for medically advanced patients started in 2008 as a pilot programme in Singapore for advanced COPD and end-stage heart failure patients. 550 patients benefited it. It was then extended to more public hospitals and by 2016, up to 3000 patients had benefitted. In 2018, programme IMPACT started as a home palliative programme for ESOF patients with end-stage kidney, lung or heart disease.

Objectives: To plan and implement programme IMPACT (Integrated Management & Palliative Care for the Terminally-Ill Non-Cancer patients) in a public hospital in Singapore.

Materials and Methods: Systemic, Professional, Patient-related and Cultural causes for apparent reluctance to use such a service were studied. Collaboration between the organ specialists and palliative care specialists was the starting point. Funding models were studied, and Ministry of Health support was obtained. The programme is now in the implementation phase of year 1 of the 5-year programme.

Results: Despite the challenges faced, solutions found during the implementation of IMPACT have been encouraging. Creating awareness and getting the buy-in from the organ specialists has been key. Ongoing training of doctors, nurses and other staff who are not palliative care trained is essential.

Conclusion: Lessons learnt from IMPACT will help sustain, grow and mainstream the programme.

Keywords: Innovations

33. Effect of Cognitive Behavioural Therapy on Quality of Life Among Patients Undergoing Haemodialysis (D2-C-134)

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Aim of the Study: Introduction: Research studies have reported that patients undergoing Haemodialysis (HD) have poor Quality of Life (QOL) which is associated with increased risk of mortality and hospitalizations. Cognitive Behavioural Therapy (CBT) the most widely used psychological intervention is found to enhance QOL among patients undergoing dialysis.

Objectives: To evaluate the effect of CBT on QOL among patients undergoing HD in selected Hospitals, Kerala.

Materials and Methods: A quantitative research approach was used with true experimental: pre-test post-test control group time series design [Table 1]. Sample size was 138 (69 each in experimental and control group). Pre-test was conducted using socio-demographic data and Ferrans and Powers Quality of Life Index (Dialysis version). Experimental group received six sessions of CBT while the control group received the routine care. Post-tests were done thrice (2, 6 and 10 weeks after the intervention).

Results: CBT was found to be effective in making a statistically significant difference in the total and the subscale scores of QOL (P< 0.001) of dialysis patients.

Conclusion: Patient counselling is found to play an important role in improving the QOL of dialysis patients.

Keywords: Palliative care in chronic illnesses (includes non-malignant conditions)

Table 1: Summary of repeated measures between subjects ANOVA of quality of life score in the experimental and control group

QOL components	Between periods (time) *F*	Between groups (group) *F*	Period group interaction *F*
Total QOL score@	481.87***	713.52***	582.46***
Health/function@	495.22***	630.29***	542.44***
Socio economic@	452.99***	561.44***	515.13***
Psychological/spiritual@	388.08***	539.75***	436.01***
Family@	165.83***	507.38***	360.92***

QOL: Quality of life

Day 3

34. Palliative Care for Children with Duchene Muscular Dystrophy- A Contextual Understanding (D3-A-135)

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Introduction: Duchene Muscular Dystrophy (DMD) is a genetic disorder characterized by progressive muscle degeneration and weakness. Although the process of transition is predictable in DMD, readiness to accept the condition is minimal among children and families. Adopting a palliative approach for DMD affected children and their families from the time of diagnosis will be beneficial. However, the palliative care for children with DMD is a less explored area in India and is complex due to diverse issues. The present paper attempts to revisit the concept of palliation for a paediatric neurodegenerative disorder like DMD.

Aim of the Study: The aim of the study is to explore the family's understanding of palliative care services for children with DMD, services available, accessed and challenges in utilising them.

Materials and Methods: A cross sectional qualitative exploratory study was performed among the five families of boys diagnosed with DMD. Semi structured in-depth interviews were used to elicit information from the family and professionals. Questions were used as a guide, but actual interview questions developed from the statements and responses made by the families as the interviews progressed. Thematic analysis was done to identify the pattern or themes from the interviews.

Results: Most families never heard of the term palliative care and not clear where to access it. Those who were familiar with the term tended to associate palliative care with death and was wary about it. An external intervention and support could address the emotional and psychological wellbeing of the families. Major issue themes emerged from the interviews were transition issues and acceptance. Children in life limiting conditions require more intense care and their needs vary as they grow.

Conclusion: The present study findings suggest a need for improved awareness of palliative care and related services among families of children with DMD.

Keywords: Duchene muscular dystrophy; family; palliative care

35. Palliative Care and Rehabilitation during Natural Disasters - 2018 Kerala Floods Context; Thrissur Pain and Palliative Care Society Experience (D3-A-136)

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Introduction: Natural Disasters push health care to identify strategy for emergency response. The affected people require medical, psycho-social support to come to terms with losses and prevent/fight health issues.

Aim of the study:

- Identify immediate need for rescue and relief in our area and reach out to them in collaboration with District Administration
- Identify and reach out to our patient needs. - Find sponsors for supply of essential items

Methods:

- Form a team
- Attend training to take precautions and provide psychological support
- Contact Visit affected areas with relief measures
- Draft a Survey form to assess the Total loss incurred by our patients and try to mobilise help.

Outcome:

- Formed a Rescue Team comprising of our young volunteers at District Collector Control Room.
- Extra shifts by staff and volunteers at OP and IP Units provided services without much hindrances.
- Visited 9 rescue shelters and provided relief items in 5 camps.
- Packing and forwarding relief measures at camps.
- Prepare and distribute leaflets with instructions to chlorinate wells. - Clean and Chlorinate 21 houses in 2 localities joining local Health Inspector.
- Phone calls to 100 Kidney dialysis patients and survey conducted. - Home care visits to affected homes and survey conducted.
- 30 patients were provided social support in cash and kind through sponsors.

Conclusion: Extending palliative care approach into management of patients and public affected by natural disasters can improve the quality and outcome of the care we provide.

Keywords: Kerala floods; palliative care; rehabilitation

36. Integration of Palliative Care into Healthcare Provision for South Sudanese Refugees in Adjumani District, Uganda; A Rapid Systems Appraisal Evaluation (D3-A-137)

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Introduction: In humanitarian settings palliative care (PC) is rarely prioritised. Situational analyses are needed to enable integration as part of a health system strengthening approach. Uganda hosts one of the largest refugee populations and in Adjumani District the 240,000 population hosts 260,000 refugees.

Aim of the Study: To evaluate the setting and systems affecting chronic disease and health related suffering for refugees and host populations in Adjumani District.

Materials and Methods: Using Rapid Systems Appraisal we reviewed documentation & mapped key stakeholders, Interviews conducted with 4 groups: leaders in the refugee & host community, Ministry of Health, Peace Hospice and humanitarian stakeholders; those living with chronic disease including mental health issues; PC providers & those who refer or interact with PC, alongside field observations.

Results: From 69 qualitative interviews in five refugee communities the following themes emerged: PC is missing in almost all communities and recognised by stakeholders. It has been a key lacking point; challenges in coordination, and integrating resources within the fragile health systems integration is the way forward; cultural barriers to care; significant stigma and effects of trauma, limited PC education, need and impact of PC. It is like losing hope then hope appears suddenly like the sun.

Conclusion: At all levels PC service integration and training are needed including MOH and humanitarian stakeholders. Refugee communities must have empowerment and ownership to ensure issues of culture and stigma are understood and host communities included to avoid a 2 tier system. Further evidence on the palliative care need will be collected, alongside comprehensive education package for health care workers, village health teams and family caregivers.

Keywords: Health system; integration of palliative care; refugee community

37. Mentorship - A New Dimension in Education Support by Pallium India (D3-A-138)

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Aim of the Study: Pallium India envisions each child fulfilling his/her potential to become models of success against adversity, which can motivate children from similar backgrounds.

Materials and Methods:

a. Applications for educational support are accepted throughout the academic year.
b. Based on the detailed socioeconomic assessment done by the volunteers' team for rehabilitation, educational support is given to each applicant.
c. Children studying in 9th, 10th, 11th and 12th standard are selected for mentoring and counselling.
d. Volunteers are selected to act as mentors to these children and each person is allotted four to five children from different classes, continuous interaction with children, parents and class teachers during the academic year.
e. Based on the feedback from mentors Career guidance program of one-day duration has been conducted in a centralized location closer to their home (4 programs in 2017-18).
f. Special needs like fees for tuition classes cost towards additional books guides for study are taken care of, by the mentors with support from Pallium India.

4. Pallium India Kuttikootam Summer Camp: Since 2011, Pallium India has organized a three-day summer camp in Trivandrum for children aged 12-18 years, who are beneficiaries of the educational support. Mentors play a key role in it.

Results: Reduction in school dropout cases, improvement in studies, change in outlook and clarity on aspirations were noticed in the last seven years of mentorship. 13 children have completed professional courses and obtained jobs.

Conclusion: Interaction during home care visits, testimonials, children and their parents show that mentorship has brought about a positive impact on their lives.

Keywords: Children; mentorship

38. Palliative Care for People with Dementia (D3-B-139)

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Introduction: Dementia is a major public health challenge. In Kerala, about 4% of ≥55 years and 5% ≥65 years of aged people have dementia. Dementia is mostly neglected by family members and people with dementia may be denied access to palliative care services.

Aim of the Study: The Objective of the review is to assess the existing palliative care services for people with dementia in the hospitals and within the home environment.

Materials and Methods: Original research articles and systematic reviews from 2000-2018 were selected and studied using the following keywords dementia, palliative care, palliative care in elderly.

Results: Palliative care needs of patients with dementia are often poorly addressed; symptoms such as pain are undertreated and these patients are over subjected to burdensome interventions. Despite the wish of the majority of dementia patients (and their families) to die in their own home, most will die in hospital in acute wards where staff may be poorly trained or have insufficient time to manage their individual needs, or in care homes where there may be inadequate staff training in palliative care, poor symptom control and lack of psychological and emotional support. It has been consistently pointed out by the literatures that pain is under-recognized and undertreated in dementia patients. Impaired communication (particularly difficulties with recall, interpretation of sensations and verbal expression) reduces the ability to express pain and for attendants to recognize it. Impaired communication (particularly difficulties with recall, interpretation of sensations and verbal expression) reduces the ability to express pain and for attendants to recognize it.

Conclusion: It is important that healthcare professionals should have the option to refer dementia patients to specialist palliative care when appropriate. Family and health professionals also need to be prepared for symptoms associated with dementia, so unnecessary admission to hospitals can be avoided.

Keywords: Dementia; palliative care

39. An Update and Comprehensive Analysis of Patients Started on an End of Life Care Plan (D3-B-141)

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Introduction: For the last two and a half years a structured Care Plan has been implemented, in Karunashraya, for patients entering the terminal stage of their illness. This has been based on the ten essential principles described by the International Collaborative for Best care of the Dying Person.

Objective: To present a comprehensive analysis of patients looked after using a Care Plan for End of Life (EOLC) and critically examine areas that may require re-evaluation and further training or improvement.

Results: Period under consideration: May 2016 to 31st October 2018 (30 months).

Population: In-patients with advanced cancers deemed, by consensus of the multi-disciplinary clinical team, to have met specified criteria indicating their needing EOLC.

Number of Patients: 776 (male: 237; Female: 539); mean age: 64, mode: 67 years

Length of time on care plan: average: 6.6 days, mode: 2 days, range 1 to 53 days

Commonest cancers:
Males: Head & neck, gastro-intestinal, lung
Females: gynaecological, breast, GIT, head & neck

Points for consideration:

- Variable periods on care plan
- Staff and relatives coping with extended periods on EOLC ï,§ Difficulty in prognostication
- Those patients not starting on the care plan
- Uncertainty of relatives
- Variability between wards and teams in implementation
- Training issues for new staff

Conclusion: Despite an overall considerable improvement in care and confidence as a result of previous training, some areas remain challenging.

Keywords: End of life care plan; improvement; training

40. Understanding Spiritual Competence in Cancer Care- the Health-Care Providers' Perspective (D3-B-142)

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Introduction: Spirituality concerns a sense of connecting with others, transcendence and finding meaning and purpose in life. Studies showed that cancer patients' spiritual needs were under-addressed due to time constraints, lack of confidence in effectiveness, and role uncertainty. There is also growing awareness towards addressing patients' spiritual needs while in the hospital setting and ought to be supported across the healthcare team rather than solely being the responsibility of chaplaincy services.

Aim of the Study: To understand healthcare providers competence in providing spiritual care from diverse oncology settings.

Materials and Methods: Healthcare providers including doctors, nurses and allied healthcare professional working in oncology settings in South India completed the Spiritual Care Competence Scale after obtaining informed consent. The demographic details were collected and analysed using descriptive and inferential statistics.

Results: The overall spiritual competence among healthcare providers (n=103) was found to be average (50.5%) and high (45.6%), among which allied healthcare providers (20.4%) and nurses (18.4%) had better spiritual competence respectively. These groups did well on areas of competence like Communication, Referral and Professionalization and improving quality of spiritual care. Overall spiritual care competence correlated significantly with areas of competencies. No significant correlation was observed between overall competence in spiritual care with age, gender, healthcare professional group and professional experience (r=.030, p=.763).

Conclusion: rrespective of age, gender, healthcare professional group, years of experience Indian healthcare providers exhibit more than average spiritual competence. Nurses and Allied healthcare professionals showed better competency when compared to Physicians. Although healthcare providers show spiritual competence they lack in certain areas of competence - attitude towards patients spirituality, assessment and implementation of spiritual care and personal support and patient counselling which could be the result of limited awareness and training.

Keywords: Healthcare providers; South India; spirituality

41. Clinical Nurse Specialist Led Multi-Speciality Clinics – Perspective of Patient and Carer (D3-C-143)

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Introduction: The Clinical nurse specialist (CNS) plays a vital role as a team member in the management of patients with complex palliative care needs. CNS provide education and holistic patient assessment and care to patients and their families. Moving from a multidisciplinary approach to an interdisciplinary approach, the CNS at Cytecare hospitals have started the multi-speciality clinic, in a hospital setting, to address the distressing symptoms faced by patients. This has streamlined the patient care, reduced the waiting time for patients and facilitates meeting with the interdisciplinary team.

Aim of the Study: To determine the level of satisfaction among patient and carer regrading care and acceptance of multi-specialty clinic at a tertiary cancer centre.

Materials and Methods: These clinic functions as part of an interdisciplinary team and is run by the CNS. Health professionals and patients are made aware of the clinic and the CNS contact number. Patients are seen based on referrals from various specialities in oncology or self-referrals. Following the assessment, the case is discussed with the interdisciplinary team and care plan drawn out by the CNS.

A survey was conducted using a modified version of Dr. Laschinger's patient satisfaction with nursing Care Quality questionnaire with additional qualitative questions to assess the usefulness of the clinics and its effect on the quality of life of patient and relatives.

Results: The results show that the CNS led multi-speciality clinics are potentially beneficial for patients and relatives, in the fields of symptom control, psychological support and as being an advocate for them, providing a sense of being holistically cared for.

Conclusion: In a cultural Indian setting, where judicial use of the available resources is required, the clinical nurse led multi-speciality clinics in an inter-disciplinary setting is the way to ensure holistic care for patient and carer.

Keywords: Holistic care; nurse specialist; palliative care; patient satisfaction

42. Debriefing Sessions - An Intervention to Support Nurses in When Caring for Patients at End of Life (D3-C-144)

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Introduction: Health care professionals especially nurses experience grief when caring for patients with cancer at the end of life. The time involved in caring and responding to patients and relatives can be emotionally exhausting thus affecting the quality of care and lead to personal burnout. As our tertiary care cancer centre, we initiated an intervention to support nurses - the debriefing session. The objective is to provide emotional support, answer queries regarding decisions taken, and improve communication skills while interacting with patients and relatives of patients at end of life and increasing one's ability to manage grief.

Aim of the Study: To explore the views of nurses who attended debrief sessions regarding the usefulness and meaning of debriefing sessions.

Materials and Methods: As a pilot a total of 12 debriefing sessions were conducted in an Oncology ward for nurses caring for EOLC patients. Sessions were facilitated by the psycho-Oncology team. Once a week, nurses involved in the care of a patient who had passed away are invited via email to attend the sessions at a mutually convenient time. Open ended questions are used as prompters for participants to express their responses to the death.

26 nursing staff, who attended the debriefing sessions, were divided into three groups -naive, those who attended < 6 and those who attended >6 debriefing sessions. A cross-sectional survey method was used to rate how helpful, informative and meaningful they found the debriefing sessions.

Results: Debriefing sessions was found to helpful and meaningful. They reported improvement in communication skills, ability to handle patients and anxious relatives, greater ability to manage their grief.

Conclusion: Debriefing sessions is a required opportunity to express grief while reflecting on the experience of caring for a patient at the end of life. It allows nurses to manage their own grief and continue to serve patients and families needing their support.

Keywords: EOL care; grief; intervention; nurses

43. Self - Care Practices And Professional Quality of Life of Oncology Professionals in A Tertiary Care Hospital (D3-C-145)

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Aim of the Study: Oncology professionals experience significant work related stress due to nature of patients they deal with on daily basis. Self-care practices (SCP) to alleviate this are not given priority. We aim to explore SCP and Professional quality of life (ProQOL); compassion satisfaction (CS), burnout (BO), secondary traumatic stress (STS) among Oncology professionals and identify any correlation to SCP.

Materials and Methods: This descriptive cross-sectional study was done among doctors and nurses in oncology (n=120). Participants filled the ProQOL scale (version 5), Self-care and Lifestyle Balance Inventory and demographic details. Associations between ProQOL, demographic characteristics and SCP were studied using Chi-square and Fisher exact test.

Results: Response rate was 74.2%. Majority (75%) were female and nurses (60.5%). High proportion (59.2%) were between 20-35 years, and 43.2% had >10 years' experience.

High CS was present in 27.4%, 59.5% had average STS scores. None had high BO scores, 61.9% scored average. Trainees had significantly higher average BO scores (p=.03). BO was significantly higher with physical illness in self family (p=.04). STS was significantly higher among nurses (p=0.04) and when spouses worked outside healthcare (p=.03).

Only 57.3% had good SCP. SCP was significantly better among nurses (p=.001); 50 work hours week (p=.002); living as nuclear families (p=.04); with absent emotional interpersonal stressors (p=.01).

There were no correlations between SCP and ProQOL.

Conclusion: There is a need to provide support to trainees, nurses and professionals with physical ailments (self-family member) and when spouse is not in health care. Favourable work hours, family setting and reduced stress promote SCP.

Keywords: Burnout; oncology professionals; self-care; stress

44. Prospective Observational Study on Caregiving Burden and Quality of Life of Family Caregivers of Cancer Patients on Chemotherapy (D3-C-146)

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Introduction: Informal caregivers of cancer patients have extensive burdens and are prone for poor quality of life (QOL).

Aim of the Study: To assess burden and quality of life of family caregivers of cancer patients receiving chemotherapy admitted in ward ICUHDU.

Materials and Methods: This prospective observational study including 178 caregivers was carried out in Dr BRA IRCH, AIIMS, Delhi. The assessment of caregiving burden was done using Zarit-burden interview, and its impact on QOL using WHO BREF QOL questionnaire.

Results: Mean age and mean Zarit-burden score of caregivers were 38.98 Â± 10.53 and 30.697 Â± 8.96 respectively. Of the total 70.22% caregivers reported mild to moderate burden but 21.38% reported moderate to severe burden.

Upon assessment of QOL WHO BREF mean general score was 5.79 Â± 1.84, physical health score was 49.65 Â± 16.07, psychological health 51.85 Â± 20.43, social relations 59.38 Â± 21.43 and environmental 58.73 Â± 17.51. The QOL scores were slightly better in mild to moderate burden compared to moderate to severe burden but not statistically significant except for social relations (p value = 0.053). We didn’t find any difference in burden scores or QOL between male to female caregivers.

Conclusion: Mild to moderate burden was seen in 70.22% caregivers and 21.38% had moderate to severe burden.

Keywords: Cancer patients; caregiver burden; chemotherapy; quality of life