

Keynote Forum September 23, 2019

Palliative Care 2019 Clinical Trials 2019











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Eric G Bush

Hospice of the Chesapeake, USA

Community based palliative care, opportunities and challenges

ommunity based palliative care has been instrumental in providing patients and families high quality patient centered care. The opportunity to grow these patient centered services is enticing. While this can provide great improvement in quality of life and decrease hospital admissions, there are concomitant challenges in growing this service line. These challenges include but are not limited to areas such as: personnel, regulatory and financing. This presentation will explore this topic from all aspects with the goal of stimulating thought in optimizing what, when and how to provide high quality patient centered care to patients in the community. What is the best way to provide this care given the current resources? Are we optimizing utilization of the current infrastructure in place? How do we best provide quality of life focused care given changing global demographics and population growth?.

Speaker Biography

Eric G Bush is board certified in internal medicine, addiction medicine and hospice & palliative medicine, practicing for 15 years. He graduated from State University of New York at Buffalo in 2004, with an MD. Prior education: BS Pharmacy 1994 and MBA 1996 from Buffalo; starting as a medic (& later LPN) in the US Army Reserve in 1988. Post-residency Fellowship at National Institutes of Health. Prior medical director for Frederick Memorial Hospital Pain and Supportive Care Services & Hospice of Frederick County (obtaining Joint Commission Certification for Inpatient Palliative Care Service), received US national recognition in 2015 with Circle of Life Citation of Honor for Excellence in Hospice and Palliative Care. Currently he is an academic editor and palliative care section chief for the online journal medicine. Since 2016, he has been chief medical officer for Hospice of the Chesapeake & Chesapeake Palliative Medicine. He is the CEO for Hospiceandpalliativeboardreview.com.

e: egbush@yahoo.com

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Donna M Wilson

University of Alberta, Canada

Moving and moving again as death draws near

Avery clear trend in end-of-life care is emerging and becoming evident worldwide. This trend is for home-based death and dying, and therefore also home-based end-of-life care. Many countries have already realized a major shift from hospital-based deaths to deaths in the home such as the dying person's own home or a family member's home and also nursing homes since these are now the last home for many people.

There are laudable reasons for this shift out of hospital. The chief reason is that death is rarely unexpected now, with terminally ill people and their families having time to accept the inevitability of death and plan for death. A wish to die at home is often a major focus for these plans. However, death and dying at home is not always easily accomplished. End-of-life care can be emotionally and physically taxing, changes in health and supportive care needs are common as death nears, and many other factors contribute to the need for frequent care setting transitions as death nears.

This presentation will highlight existing evidence in an attempt to understand why dying people and their families

want home deaths, review worldwide trends in location of death, and present new research on the contemporary problem of frequent moves from place to place as death nears. This presentation will focus on what must be done to better support home dying to reduce or eliminate the need for moving and moving again as death nears.

Speaker Biography

Donna M Wilson is a professor in the Faculty of Nursing at the University of Alberta, with appointments in the Faculty of Medicine and University of Limerick. She has worked as a staff nurse, nursing supervisor, senior hospital administrator, media commentator, educator, researcher, and professor in Alberta, British Columbia, New Zealand, Texas and Ireland. Her research program focuses on health services and health policy; primarily in relation to aging, ageism and end-of-life care. Her work is oriented to myth busting, to ensure effective and accessible healthcare services for older and younger people. Her investigations often involve population data and mixed-methods research. She has over 300 articles, books, book chapters, and other peer-reviewed communications in print. She is frequently and widely consulted for expert commentary on aging, end-of-life care, health policy, healthcare services and health system trends and issues.

e: donna.wilson@ualberta.ca





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Dee Sissons

Rainbows Hospice for Children and Young People, UK

The changing face of children and young people's palliative care: Safe staffing the missing link

The numbers of children with life-limiting or life-threatening conditions is rising. Palliative Care for these children is complex, it begins with diagnosis and continues through a child's life. At one end of the spectrum palliative care has extended into antenatal, new-born and perinatal care, whilst at the same time we are seeing the life expectancy of our young people increase with many livings into adulthood and transitioning into adult palliative care services.

We have seen a four-fold increase in the number of children dying in the hospice, alongside an increasing acuity, complexity and case mix. In addition, we are experiencing an increased demand for outreach and community services, alongside a resduction in community pediatric teams.

Our workforce comes from a range of disciplines including health visiting, pediatrics and learning disabilities. Whilst this diversity has been invaluable in bringing together a range of skills, many of our staff's core skills are rooted in the traditional short break/respite model of care. Using a validated tool, we have interrogated our activity, reviewed our dependency tool and looked at the impact of professional judgement on keeping our staffing levels safe while we develop the workforce's skills and competencies in response to a changing model of care.

Speaker Biography

Dee Sissons joined Rainbows Hospice as CEO in June 2018, after working as Director of nursing for Marie Curie Cancer Care for five years. Her career that spans commissioning acute services and the independent sector and she has represented nursing and end-of-life care at the board and national levels across the UK. She continues to play a key role in nursing leadership and is an active council member at the Royal College of Nursing. She is passionate about developing others and brings a wealth of knowledge about practice development and professional standards. Unafraid of a challenge, she has recently embarked on a professional doctorate bringing the nursing voice to the debate on excellence and nursing care in the palliative care sector. She is also a Florence Nightingale leadership scholar.

e: dee.sissons@rainbows.co.uk





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Danica Rotar Pavlic

Network of Primary Health care, Slovenia

Bridging primary palliative care in South Eastern Europe

Background: Exposure to death and dying had a strong influence on the present life of every citizen. Primary care workers value palliative part of their work. Most of the time, patients appreciate the contribution of the GPs, district nurses, social workers, hospices and lay support, especially if they accessible, take time to listen, allow patient and carers to ventilate their feelings, and make efforts made regarding symptom relief. While providing palliative care to patients, primary care workers often have to overcome barriers and myths.

Aim: The workshop seeks to facilitate the changes in service models, policy, education and research in primary care. It provides a backdrop for debate on the development of palliative care in primary care in South Eastern Europe.

Methods: When primary health care team start with palliative approach, it faces problems of transition from regular care to palliative care. Patient, relatives and team workers meet several problems. Usual approach to patients SOAP (subjective S = O = objective, A = Assessment, P = plan), is expected to be replaced by other protocols. The doctor and his colleagues also face a bunch of different questionnaires and rating scales, which are intended to assess the state of palliative patients. There are multiple wishes expressed by relatives. However, one should always put the patient's feelings and expectations in the first plan. Barriers, opportunities, examples of good and bad practices will be discussed at the workshop, which were focused on palliative care in primary care.

Results: Effective palliative care services should be integrated into the existing health system, especially community and home-based care. The non-specialist palliative care needs should be considered by the staff delivering the on-going care, with initial guidance and support from specialists in hospitals and specialized palliative care teams. Caring for the caregivers is an essential area of palliative care in primary care.

Conclusion: Implementation of interdisciplinary care that focuses on effective communication, individualized care plans and care coordination should be established.

Speaker Biography

Danica Rotar Pavlič was granted, on 20 April 1998 the title of Assistant for the subject Family Medicine. In 2000, she became project coordinator of IMPROVE (Improvement of older patient involvement in medical care, http://baserv.uci.kun.nl/~improve/) for Slovenia. This is an international project performed under the auspices of the European Community, involving 11 countries. In 2003, She became co-ordinator of the international project called PREDICT with the following participating countries: Great Britain, the Netherlands, Portugal, Spain, Estonia and Slovenia. She is and main coordinator of working group on palliative care of the Association of general practice/family medicine of South-East Europe AGP/FM SEE. She was the Vice chair of European Forum for Primary care 2010-2018. She is the President of Slovenian Association of Family Doctors for the period 2013–2017.

e: danica.rotar@gmail.com





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Charmaine Attard

Hilltop Gardens Naxxar, Malta

Palliative care provided within a care home- A SWOT analysis of the introduction of an innovative service offered through the private sector in Malta

Just under 2000 persons are diagnosed with cancer every year in Malta, with the figure expected to shoot up to over 2,100 by 2020. At present, Hospice Malta offers a wide range of services for terminally ill patients and their families, including day care and home care however no residential or inpatient palliative care is provided in the country to date. Our only oncology hospital on the island constitutes of 24 beds which falls short of demand and supply when this caters for the whole population of Malta.

As a result of this a number of palliative clients find themselves on acute hospital wards which are not able to cater for their specific needs during this period. Simblija Care Home is a privately-run nursing home in Malta which seeks to address the needs of persons who need palliative care, including respite for their careers or end of life care. Within our model of care, we adopt a holistic approach to both the individual and the respective family and the existent network of support. We hope to address physical needs, like pain control and also to their psychological needs which often involves counselling services. Our services extend further and encompass spiritual assistance when requested. Different professionals are brought in the care cycles, as are occupational therapists and physiotherapists. In this way we

assist the person achieve better quality of life and their families to find support and assistance. This is a new residential service offered by a care home for elderly in the palliative stages.

The paper provides a critical SWOT analysis of the introduction and roll out of this innovative much needed service in Malta. It is believed that the reflective evaluation of this service is of interest to other parties who are gauging need or planning such services in other contexts.

Speaker Biography

Charmaine Attard achieved her BSc in Nursing in 1994; MSc in Nursing at the University of Manchester in 2006; Post Graduate Diploma in Business Administration in University of Leicester in 2016. After graduation she worked for a number of years in the acute areas of care within St. Luke's Hospital and Capua Palace Hospital. In 1999 she went on into long term care, where she managed a private home for the elderly. She went on to become Operations Manager in 2006; left long term care and took up the post of Director of nursing and midwifery at Mater Dei Hospital in 2009 and so on. She is currently working as the general manager of Hilltop Gardens, an appointment given to her in 2017. She holds a part time assistant senior lecturer post at the University of Malta where she teaches nursing students within the Faculty of Health sciences.

e: Charmaine.attard@axcare.mt





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Donna M Wilson

University of Alberta, Canada

Bereavement Care - Current and needed evidence

For every death, it is estimated that 4 to 10 people will be significantly grief stricken, with many more experiencing some mourning or other emotional reactions. Over the years, a wide range of bereavement care services have come to exist in Canada and most other countries. This range of services is highly relevant, as the care or support needs of bereaved people can differ considerably. For instance, the bereavement care needs of a young child who has lost a parent or sibling will differ from those of a teen or young adult who similarly has lost a parent or sibling. Moreover, the bereavement care needs of older women or men who suffer the loss of a long-time beloved spouse will differ from the bereavement care needs of young women and men who have lost a child through stillbirth or through cancer, an accident, or suicide. Moreover, some people are more able to manage their grief as they have strong personal or other resources, helpful support from family and friends, and past experiences of recovering from grief. Only a small proportion of mourning people seek out or use bereavement support services; often those at risk of or who are already experiencing complicated or chronic grief. What is not clearly evident is which bereavement care services are more effective than others for helping people

who are seriously grieving. No government requirements appear to exist to mandate bereavement service evaluations or to regulate how bereavement programs are designed or formatted. To that end, a series of studies are being conducted by the lead author to begin to understand bereavement and bereavement support. Existing evidence-based practice and research needs in relation to bereavement care will be the focus of this presentation.

Speaker Biography

Donna M Wilson is a Professor in the Faculty of Nursing at the University of Alberta, with appointments in the Faculty of Medicine and University of Limerick. She has worked as a staff nurse, nursing supervisor, senior nospital administrator, media commentator, educator, researcher, and professor in Alberta, British Columbia, New Zealand, Texas and Ireland. Her research program focuses on health services and health policy; primarily in relation to aging, ageism and end-of-life care. Her work is oriented to myth busting, to ensure effective and accessible healthcare services for older and younger people. Her investigations often involve population data and mixed-methods research. She has over 300 articles, books, book chapters, and other peer-reviewed communications in print. She is frequently and widely consulted for expert commentary on aging, end-of-life care, health policy, healthcare services and health system trends and issues.

e: donna.wilson@ualberta.ca





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Els M L Verschuur¹

van der Sande R¹ and Francke A L²

¹HAN University of Applied Sciences, The Netherlands ²Nivel, Utrecht & Amsterdam UMC, The Netherlands

Palliative care in a home care setting; the development of a guideline for district nurses and nurse assistants

Background: In the Netherlands district nurses and nurse assistants have a pivotal role in palliative care at home. Partly due to aging of society, an increase of palliative care is expected. Related to this, we developed a guideline Palliative Care at Home for district nurses and nurse assistants.

Methods: This guideline is developed following the standard of the Dutch AQUA-Advisory and Expert Group. To assess the bottlenecks in daily practice, face to face and online focus groups with district nurses and nurse assistants were performed. Seven predefined questions were answered by a systematic international literature review of existing systematic literature reviews and evidence-based guidelines in the field of palliative care at home. The AMSTAR and AGREE II criteria were used to assess the methodological quality.

Results: The 41 recommendations covered four themes: support of self-management among patients; identification of the palliative phase and needs assessment; advance care planning and competences of district nurses and nurse assistants. All four themes are structured as follows: predefined questions, recommendations, results of the literature review and other considerations. To obtain overall agreement on each recommendation, all recommendations were thoroughly discussed in the multidisciplinary project group and advisory group with representatives of key

stakeholders in palliative care. This resulted in both evidence-based and consensus-based recommendations. Two examples of recommendations are: 1) District nurses and nurse assistants plan patient centered palliative care, taking into account the values, wishes, needs and expectations of patients and those of their relatives, and 2) District nurses and nurse assistants discuss the outcome of the 'surprise question' with the general practitioner if the answer to that question is: 'No, I would not be surprised'.

Conclusions: This guideline provide recommendations concerning key aspects of palliative care at home by district nurses and nurse assistants. They should serve as a reference standard for providing palliative nursing care and for collaboration with the interdisciplinary team around patients, in particular with the general practitioner.

Speaker Biography

Els M L Verschuur has a background in nursing. She is a Bachelor Nurse (not practicing) and studied Nursing Sciences at the University of Utrecht, The Netherlands. She has completed her PhD in 2007 from Erasmus University Medical Center, The Netherlands. She has over 50 publications and is serving as an editorial member of the Dutch Flemish Scientific Journal Verpleegkunde'. She is a member of Sigma Theta Tau at Large chapter Rho Chi. She is working at HAN University of Applied Sciences in Nijmegen The Netherlands as a Lecturer Advisor and Senior Researcher.

e: Els.Verschuur@han.nl



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Mari Salminen-Tuomaala

Seinäjoki University of Applied Sciences, Finland

Learning palliative care by means of simulation

The study is part of an ESF-funded research and development project, whose purpose was to use simulation to support socissal and healthcare staff's competence development in small and medium-sized enterprises. The project partners were a vocational education institution and a university of applied sciences. The participants represented 20 SMEs engaged in old people's care, child welfare, mental health and disability services. Based on a learning needs assessment, they were offered simulation-based coaching in their own contexts.

The staff in enterprises offering care for old people (n=5) participated in simulation coaching designed to influence their attitudes and theoretical and practical palliative care competence. The aims were to help staff recognise clients' physical, psychological and social palliative care needs, increase staff's sensitivity and preparedness for holistic care and practise interaction supporting family members. One Lecturer assumed the role of a dying person/family member, while another facilitated the simulation process and feedback discussion. The participants, 6-10 employees per enterprise, were divided to actors working in pairs and observers instructed to focus on certain areas of the performance. Following the intervention, the participants were asked to

evaluate the usefulness of the coaching for their competence development and the suitability of simulation for learning palliative care. Their responses to the 5 Likert-type items and 3 open questions were analysed using SPSS for Windows 25 and inductive content analysis. Simulation coaching was found to be well suited for learning palliative care; it allows experiencing near-authentic scenarios in a safe and confidential atmosphere and encourages deep reflection. Profound discussion, built on the near-genuine scenario and shared action and interaction, was appreciated as the most important yield of the coaching. Participants had an opportunity to discuss challenging care situation, ethics and coping in a safe environment. Simulation-based coaching could be considered a form of clinical supervision.

Speaker Biography

Mari Salminen-Tuomaala, completed her PhD in Health Sciences. Currently she is a Principal Lecturer in Nursing and Advanced Practice Nursing, the Responsible Lecturer for the Master Programme in Advanced Practice Nursing and a Senior Lecturer in Acute Nursing at Seinäjoki University of Applied Sciences, School of Health Care and Social Work. She is also the Responsible Lecturer for the national R & D Coaching Programme. She has authored or co-authored 68 scientific articles and has been a key note speaker and presenter in several national and international conferences.

e: mari.salminen-tuomaala@seamk.fi





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Gebhard Mathis

Praxis Internal Medicine, Austria

Medical coordination in the nurse home improves the treatment of residents and contentment of the staff

Background: In crisis situations, comprehensive palliative care in care homes is frequently hindered by the absence of a doctor.

Aim: To improve advanced care planning in care homes by the establishment of medical coordination.

Methods: Medical coordination facilities were established in three care homes housing a total of 266 residents. The effect was compared with three care homes without medical coordination. Formative evaluation: In two focus groups, at the start and around the end of the twelve-month period the involved persons in the test and reference care homes as well as practicing doctors and health experts exchanged their views on the subject. 16 experts provided detailed information about specific aspects of the model project in the course of qualitative interviews. Furthermore, in a summative evaluation the following aspects were investigated: emergency plans, the registration of presumed will, emergency doctors' missions, the number of ambulance services, and the provision of emergency medication. Statistics: Mann-Whitney U-test, Box-Ljung.

Results: Representatives of the test care homes reported their

positive views concerning the model project: the expansion of consciousness and the introduction of structures for palliative work in homes for the aged, optimized coordination between nurses and doctors, the systematic documentation of helpful emergency plans, stores of on-demand medication in care homes, uninterrupted care, improvement of quality, and reduction of costs. The time curves for the five care-home-related parameters revealed significantly positive changes compared to reference care homes: 74%:48% and 61%:39%.

Conclusion: Medical coordination in the care home improves the quality of care for the residents. The economic evaluation shows that undignified ambulance services and unnecessary emergency doctors' missions can be considerably reduced by medical coordination.

Speaker Biography

Gebhard Mathis studied at the Medical University of Medicine in Vienna. He received the MD there at 2019. He worked on palliative medicine since in different fields: Foundation of Palliative Courses in Austria 1999, the Palliative Care Station in LKH Hohenems 2003, He also has more than 100 publications.

e: Gebhard.mathis@cable.vol.at





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Mohammed Abduh Alshaqi

Prince Sultan Military Medical City, Saudi Arabia

Palliative care for elderly with Dementia

Dementia is a progressive terminal illness for which there is currently no cure. The prognosis may range from 2 to more than 15 years, with the end-stage lasting as long as 2–3 years. Although the frequency of dementia in low- and middle-income countries is uncertain due to few studies and varying estimates, most people with dementia live there (60% in 2001, rising to 71% by 2040).

The care of older people with dementia is widely inadequate on the continuum from prevention to the end of life. At the end of life, this inadequacy has been summarized as: too much intervention with little benefit such as tube feeding or too little (poor pain control, dehydration and malnutrition). There are many reasons why people with dementia do not receive adequate palliative care, including health care professional's not perceiving people with dementia as having a terminal condition and difficulty in prognosis.

The number of symptoms is similar to that of people with cancer, but people with dementia experience them for longer. People with dementia have cognitive, functional and physical impairment, which gets progressively more severe, often over a prolonged period of time. The most frequent symptoms in the last year of life are cognitive impairment, urinary incontinence, pain, low mood, constipation and

loss of appetite. Palliative care for people with dementia urgently needs to be improved. Approaches could include interventions for agitation, constipation and pain, which may improve the quality of life, decrease the number of unnecessary investigations and reduce costs.

Speaker Biography

Mohammed Abduh Alshagi is a Consultant and Head of Palliative Medicine in division of Oncology Department at Prince Sultan Military Medical City at Riyadh, Saudi Arabia. He completed his MBBS from King Saudi University 1992/1993. He served as an Arab Board of Family Medicine in 2001, then Palliative Care from Canada and King Faisal Specialist Hospital & Research Center at 2006 and 2008. He is a member of many affiliations and societies like American Academy of Family Physicians and Saudi Society of Family and Community Medicine since 2001. In addition to that, he is a Member of Middle East Academy of Medicine of Aging (MEAMA) since 2003, Member of International Association for Hospice and Palliative care since 2006, Member of Saudi Oncology Society since 2008, member of Saudi Pain Society since 2009, Member of Group on Educational Affairs (GEA) for Medical Education Research Program (MERC) since 2011, and Member of Arab Society of palliative care since 2014 till present. He is a trainer and external examiner of Palliative Medicine of Saudi Commission for Health Specialties and Acting director of Saudi Society of Palliative Care since 2013 till present.

e: shaqimmman43@gmail.com





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Blazenka Eror Matic

La Verna, Croatia

The role of volunteers in palliative care

Volunteers are recognized as the third resource for palliative patients alongside with professional care and family care. They do not replace them. Volunteers have their own special place and their specific role in that care.

What can volunteers do for a patient and family? Volunteers can be with the patient and the family and help in way they need it. The importance of this "being there" needs to be revealed. Terminal patients in the last moments of life feel no pain just because of the nearness of physical death, but rather the pain of "social death". Mother Theresa also said that there were no more serious illness in human life than being "unwanted, unhappy, isolated and left out".

Besides the volunteers who will be directly with the patient and the family, volunteers who are involved in organizing, fundraising, promotion and various other roles are also important. In order to help volunteers to play their role and to make this assistance sustainable, it is important to have volunteer organizator (manager) that links all three care resources (family, professionals and volunteers).

How to attract volunteers? We can do that by developing a variety of volunteering programs for palliative care that need

to be tailored to the target group (kindergartens, schools, students, employees, retirees, etc.). Programs should also be adapted to modern ways of communication. It is not easy to promote volunteers in palliative care because it is always associated with death and dying. So when we talk to the community it is better to send positive messages, talk personal stories, emphasize values of volunteering.

Speaker Biography

Blazenka Eror Matic obtained her Master's degree at the Faculty of Economics in Zagreb and has 33 years of working experience in financial sector. She has long term volunteering experience as a member of the Secular Franciscan Order (since1996). In palliative care she had been included as project manager since 2009 when the Mobile Team of volunteers were organized. Ten-year project management of the Mobile Team of volunteers in palliative care has contributed to the acquisition of knowledge and experience on the organization of palliative care in Croatia and in the world, especially the place and role of volunteers in the palliative team to provide comprehensive palliative care for patients and their families. Considering that these activities are financed by donations, rich experience in writing and implementing projects was accumulated.

e: blazenkae@gmail.com





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Rukhadze T^{1,2,3}

Lekashvili T1

¹Iv. Javakhishvili Tbilisi State University (TSU), Georgia ²Research Institute of Clinical Medicine, Acad. F. Todua Medical Centre,

³Georgian National Association for Palliative Care, Georgia

Evaluation of medical needs and available medical services of end-of-life cancer patients – Georgian experience

Goal of the study - Practical guidelines development for palliative care current model improvement in Georgia through evaluation of palliative patients medical needs and provided medical services, based on analysis of patients' incurable status definition in the country.

Questionnaire survey, analysis of medical documentation and histories were applied in the study. Based on duration of medical service provided to the patients, three groups were assigned. Social and psychological problems of patients, problems associated with caregivers and difficulties with respect to clinical groups, problems of opioids prescription, dose selection, availability of tablets were assessed and included in data base along with medical problems.

In accordance with the obtained material, three groups of patients were assigned, comparative analysis of them was performed and study results reliability was evaluated based thereof, wherein p value indicator was considered to be statistically reliable. Considering study tasks and goals, 161 patients were selected. The 119 patients (73.9%) had diagnosis of solid tumors, 27 (16.8%) oncology hematological diseases, 15 (9.3%) diagnosis of primary tumors of central nervous system. Number of patients due to age and sex was as follows: group of patients aged 25-40 included 16 (9,9%) patients; group of patients aged 41-60 included 35 (21,7%) patients, 60-74 included 66 (40,9%) patients, and 75-80 included 44 (27,3%) patients.

Conclusions: Needs of incurable patients and current medical services are based mainly on medical needs and non-medical aspects are often ignored; Provided medical services are mainly based on minimal needs of patient and don't include internationally acknowledged model of palliative care;

It is not fair to request that duration of incurable patients' palliative care shall be some 3 or 6 months, that infringes main concept of palliative care: care till the end of life and improvement/retention of quality of life.

Speaker Biography

Rukhadze T is a Medical Oncologist and Professor at Tbilisi State University. Also, she serves as International Expert of Palliative Medicine and completed her Postgraduate Fellowship in Clinical Oncology at Karolisnka Hospital, Stockholm, Sweden and PhD at the age of 30 years from TSMU, Georgia. She has completed international Fellowship program at the Institute of Palliative Medicine, San Diego University, San Diego, USA. She has over 50 publications that have been cited over 37 times and her publication H-index is 3,5 and has been serving as an editorial board member of EPMA Journal.

e: tamar.rukhadze@tsu.ge