



2nd International Conference on Neurodegenerative Disorders

26[™] & 27[™] November 2024

PROCEEDINGS

"Expanding the Horizon for Neurocare in Sri Lanka"

Organized by the

Faculty of Nursing | University of Colombo | Sri Lanka



2nd International Conference on Neurodegenerative Disorders

"Expanding the Horizon for nEUROcare in Sri Lanka"

PROCEEDINGS

FACULTY OF NURSING
UNIVERSITY OF COLOMBO
2024

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Organizing Committee

Chairperson : Prof. SSP Warnakulasuriya – University of Colombo

Secretary : Ms. MGAS Malkanthi – University of Colombo

Co-secretaries : Ms. HMCM Herath - University of Colombo

Dr. AMSD Pathiranage – University of Peradeniya

Dr. SMTD Sundaraperuma – University of Ruhuna

Dr. Dinithi Vidanage – General Sir John Kotelawala Defense

University

Main Committee Members: Prof. SSP Warnakulasuriya

Prof. G Kisokanth

Ms. WARP Menike

Ms. MGAS Malkanthi

Ms. HMCM Herath

Programme Outline

Programme of the Inauguration – 26 th November 2024			
Time			
8:30 am - 9:00 am	Registration		
9:00 am - 9:10 am	Inauguration and the Lighting of the traditional oil lamp		
9:10 am - 9:15 am	Faculty Song - Faculty of Nursing		
9:15 am - 9:20 am	Traditional cultural Pooja dance		
9:20 am - 9:30 am	Welcome address by Prof. S.S.P. Warnakulasuriya, Dean, Faculty		
	of Nursing - University of Colombo		
9:30 am - 9:40 am	Introduction to nEUROcare project by Prof. Martin Persson,		
	University of Kristianstad, Sweden		
9:40 am - 9:50 am	Speech by Senior Prof. H.D. Karunarathne, Vice-Chancellor,		
9.40 am - 9.30 am	University of Colombo		
9:50 am – 10:00 am	Speech by Prof. Hakan Pihil, Vice-Chancellor - University of		
	Kristianstad		
10:00 am – 10:10 am	Speech by the Chief Guest, H.E. David Gregory Pine,		
	High Commissioner of New Zealand to Sri Lanka		
10:10 am – 10:40 am	Keynote Speech by Dr Barana Millawithana on 'Expanding the		
	Horizon for Neurodegenerative Diseases Care in Sri Lanka'		
10:40 am - 10:50 am	Vote of thanks by Ms. Shiroma Malkanthi – University of		
	Colombo		
10:50 am -11:20 am	REFRESHMENTS		

Programme of the Technical Session – Day 1			
Time	Session	Speakers	
11:20 - 11:40	Person-centered care	Ms. Emma Edberg Matei University of Kristianstad, Sweden	
11:40 - 12.00	Clinical assessment and outcome measurement	Ms. D.A.R.K. Dasanayaka University of Peradeniya, Sri Lanka	
12.00 - 12:20	Oral Health and Neurodegenerative diseases	Dr. Riina Runnel University of Tartu, Estonia	
12:20 - 12:40	Comprehensive Care Approach for Patients with Neurodegenerative Disorders	Prof. Nirmala Rathnayake University of Ruhuna, Sri Lanka	
12:40 - 13:00	Neurology and medical care of neurodegenerative disorders	Mrs. WARP Menike University of Colombo, Sri Lanka	
13:00 - 13:20	Oral Health	Dr. Andres Köster University of Tartu, Estonia	
13:20 - 13:40	Prevention of neurodegenerative disorders - is it possible?	Dr. Ülle Krikmann, MD Tartu University Hospital University of Tartu, Estonia	
13:40 - 14:00	Palliative Care in Neurodegenerative Disorders	Dr Dinithi Vidanage General Sir John Kotelawala Defense University	
14:00 - 14:40	LUNCH		
14:40 -15:00	Comprehensive Care Approach for people with Neurodegenerative disorders	Prof Steve Smith Triskelion	
15:00 -15:20	Neurology and medical care of neurodegenerative disorders	Prof Gorazd Drevenšek University of Ljubljana, Slovenia	
15:20 - 15:40	Neurology and medical care of neurodegenerative disorders	Ms. HMCM Herth University of Colombo, Sri Lanka	
15:40 - 16:00	Person centered care	Dr. A.M.S.D.Pathiranage University of Peradeniya, Sri Lanka	



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16:00 - 16:20	Psychology	Dr. Elly Anastasiades Neapolis University Pafos
16:20 - 16:40	Rehabilitation of Communication Abilities in Patients with Neurodegenerative Disorders	Dr Pramuditha Kariyawasam University of Ruhuna, Sri Lanka
16:40 - 17:00	Family and societal perspectives	Dr Maliga Wijesisri General Sir John Kotelawala Defence University, Sri Lanka
17:00 - 17:05	Wrap up - day 1	Prof. Martin Persson University of Kristianstad, Sweden
17:05	Evening Coffee	

Programme of the Technical Session – Day 2 (27th November 2024) Time Session **Speakers Prof. Martin Persson** 8:30 - 8:40 Introduction to the day Kristianstad University, Sweden **Prof Steve Smith** 8:40 - 9:10 Keynote speech Triskelion Address by representative Representative 9:10 - 9:30 Alzhimers international Alzhimers International Ms. PACL Dayarathna 9:30 - 9:40 Address by a Geriatric Nurse Sri Jayewardenepura General Hospital Dr. Marilena Mousoulidou 9:40 - 10:00 Psychology Neapolis University Pafos Prof. Zvezdan Neurology and medical care of 10:00 - 10:20 neurodegenerative disorders University of Ljubljana, Slovenia Prof. Martin Persson 10:20 - 10:30 Implementation and Evaluation Kristianstad University, Sweden 10:30 - 11:00 REFRESHMENTS 11:00 - 13:00 Technical session - nEUROcare abstract presentations 13.00 - 14.00**LUNCH Experts in Medical /NDD** 14:00 - 15:00 Scenario Based Discussion Geriatric Medical Association **Experts from Sri Lanka and** 15:00 - 16:00 Panel discussion Europe **Prof. Martin Persson** Kristianstad University, Sweden 16:00 - 16.20 Wrap up Prof. SSP Warnakulasuriya University of Colombo, Sri Lanka 16:20 - 16:25 National Anthem 16.25 REFRESHMENTS

Message from the Vice Chancellor - University of Colombo



Senior Prof. H.D. Karunaratne
Vice Chancellor
University of Colombo
Sri Lanka

It is with great pleasure that I welcome you to the 2nd International Conference on Neurodegerative Disorders 2024, a momentous event organized by the Faculty of Nursing, University of Colombo. This conference stands at the forefront of innovation and collaboration in the field of neurology and mental health, bringing together thought leaders, researchers, and practitioners from diverse backgrounds. The Faculty of Nursing is proudly organizing this conference for the second time under the theme of 'Expanding the Horizon for Neurocare in Sri Lanka' with the collaboration of the nEUROcare Project - a European initiative for capacity building to meet the challenges of caring for people with Neurodegenerative Disorders in Sri Lanka.

We have a unique opportunity to share insights, explore groundbreaking research, and discuss the latest advancements in Neurodegenerative Disorders. The challenges we face in mental health and neurological disorders require a concerted effort, and events like this foster the type of cross-disciplinary dialogue that can lead to meaningful solutions. I am sure that this conference would be the best platform to enhance knowledge and skill concerning the care and rehabilitation of patients with Neurodegenerative Disorders. It will also be beneficial for healthcare professionals and caregivers. I encourage each of you to engage actively in the discussions and workshops throughout this conference. Your contributions, shared experiences, and networking are vital in advancing our understanding and treatment of neurological conditions.

I take this opportunity to express my gratitude to Neurosurgeons, Neurologists, Psychologists, and neurocare experts from our European partner universities and local universities including the University of Peradeniya, University of Ruhuna, and General Sir John Kotelawala Defense University for their immense contributions to making this conference a success. Let us embrace this opportunity to learn from one another and to inspire hope for those affected by these challenges. Together, we can pave the way for a brighter future in neurocare.

I would also like to extend my heartfelt gratitude to our chief guest, H.E. David Gregory Pine, High Commissioner of New Zealand to Sri Lanka, and to our two keynote speakers, Prof. Steve Smith and Dr. Baran Millavithana, for their invaluable contributions to this important event. I would like to thank the organizing committee of the nEUROcare project team, led by the project manager and the coordinator of the local partner universities, Professor S.S.P. Warnakulasuriya, Dean of the Faculty of Nursing, for their tireless efforts in making this conference a success.

Thank you for being a part of this important gathering.

Message from the Vice Chancellor - Kristianstad University



Prof. Håkan PihlVice Chancellor
Kristianstad University
Sweden

At Kristianstad University, we are delighted to support and celebrate the success of this project. Global challenges like NDD demand cross-disciplinary, cross-institutional, and international collaborations. Expanding our involvement in such impactful initiatives aligns with our university's strategic goals and mission. This project has been an invaluable opportunity for us to grow, learn, and forge critical new relationships, strengthening our future capacity to make meaningful contributions.

As we reach the conclusion of this project, we are thrilled by the remarkable results and outcomes achieved. We are delighted to join our partners at the final conference to celebrate the project's success and to reflect on our shared accomplishments. It has been a privilege to be part of this impactful journey, and we look forward to building on this success with our project partners and continuing these fruitful collaborations in the future. The knowledge gained and partnerships formed have strengthened our commitment to advancing societal and global health, and we are excited about the possibilities for further impactful work together.

Message from the Vice Chancellor - University of Peradeniya



Prof Terrence Madujith
Vice-Chancellor
University of Peradeniya
Sri Lanka

I am delighted to send this congratulatory message to the 2nd International Conference on Neurodegenerative Disorders 2024, organized by the Faculty of Nursing, University of Colombo in collaboration with the University of Peradeniya. This is the last conference for the nEUROcare project, a European initiative for capacity building in Higher Education to address the challenges of caring for people with neurodegenerative disorders in Sri Lanka. The project is coordinated by Kristianstad University (Sweden) with partner Universities in Europe and Sri Lanka.

Neurodegenerative disorders impact millions, driving the need for innovative treatment and support. This conference is a vital platform for sharing research, discussing new strategies, and fostering collaborations. As responsible researchers, we recognize the profound impact of these disorders and the urgent need for comprehensive research to better understand mechanisms, develop treatments, and improve quality of life.

Neurodegenerative disorders such as Alzheimer's, Parkinson's, and Huntington's disease are a growing global health challenge. Over 55 million people worldwide suffer from dementia, and this number is expected to reach 139 million by 2050, with an economic burden exceeding \$1.3 trillion annually. Asia, home to over 60% of the world's elderly population, is seeing a rapid increase in dementia cases, projected to reach 71 million by 2050. Sri Lanka, with one of the fastest-aging populations in South Asia, is also expecting a significant rise in neurodegenerative conditions, with an estimated 147,000 people already living with dementia.

The conference aims to advance research in neurodegenerative disorders by bringing together experts from various fields to share their latest findings, discuss innovative therapeutic approaches, and promote interdisciplinary collaboratively, by the University of Colombo and the University of Peradeniya. I appreciate the tireless effort of the organizing committee and all involved parties to showcase the nEUROcare project's outcome.

I wish all the best for a fruitful conference that ensures an elevated patients' quality of life, and more effective healthcare systems locally and beyond.

Message from the Vice Chancellor – University of Ruhuna



Senior Prof. Sujeewa Amarasena
Vice Chancellor
University of Ruhuna
Sri Lanka

It is with immense pride and heartfelt appreciation that I commend the organizing committee of the 2nd nEUROcare Conference, hosted by the nEUROcare project. The remarkable progress and achievements of this initiative have deeply impressed me and reaffirmed the importance of international collaboration in advancing higher education and healthcare in Sri Lanka.

Under the exceptional leadership of Prof. Martin Persson, the nEUROcare team has laid a robust foundation for sustainable growth across both academic and healthcare sectors in Sri Lanka. Through capacity-building efforts, the development of a master's program, and a range of academic initiatives—alongside the professional development of healthcare professionals—the project is driving meaningful improvements in healthcare services and enhancing our educational frameworks.

As we look to the future, the sustainability of these efforts becomes ever more critical, especially with the expected rise in neurodegenerative diseases linked to Sri Lanka's aging population. The work carried out by the nEUROcare project is not only addressing present needs but also preparing us for future healthcare challenges. Ensuring the continuity and further expansion of these efforts will be essential to delivering effective care for this vulnerable population.

I extend my deepest gratitude to the entire nEUROcare team, and especially to the project implementation team from the University of Ruhuna. Your dedication and tireless efforts have been pivotal in driving this project forward, bringing great honor to our institution and the nation. Your work sets a high standard for future collaborative ventures, inspiring us all. The impact of this project promises to extend well beyond the present, contributing to a brighter future in higher education and healthcare. I look forward to seeing the continued success and lasting influence of these efforts on Sri Lanka and beyond.

Message from the Vice Chancellor – General Sir John Kotelawala Defense University



Rear Admiral HGU Dammika Kumara

Vice Chancellor

General Sir John Kotelawala Defence University

Sri Lanka

As Vice Chancellor of General Sir John Kotelawala Defence University (KDU), it is my privilege to extend heartfelt congratulations on organizing of this distinguished conference, marking the culmination of a successful series of meetings and workshops under our Capacity Building in Higher Education (CBHE) project focused on neurodegenerative disorders. This gathering stands as both a significant achievement and a stepping stone toward future advancements in Neurodegenerative disorders.

Neurodegenerative disorders (NDDs) are a growing public health concern and a leading cause of disability and dependency, particularly as Sri Lanka faces the challenge of being the fastest-aging society in South Asia. Disorders such as Alzheimer's and Parkinson's disease progressively impair fundamental abilities like motor skills, speech, and cognition, placing an increasing strain on the healthcare of the country and economic systems. As family structures change and urban migration increases, the demand for trained caregivers and a comprehensive approach to managing neurodegenerative disorders has become more critical than ever.

Through this collaborative effort, we have enriched our academic foundation, most notably by establishing an M.Sc degree programme dedicated to neurodegenerative care. This initiative embodies our commitment to integrating pioneering research and therapies within our educational offerings, ensuring that future healthcare professionals are equipped with advanced competencies to address these critical challenges. The knowledge exchange fostered here has provided invaluable insights, forming a robust basis for future neuro-care strategies. As we move forward, the partnerships and innovations sparked by this series will undoubtedly drive

continued progress and excellence in the field. KDU is committed to exploring every possible avenue to effectively implement the objectives of the nEUROcare project.

My sincere appreciation goes to all those whose dedication has brought this endeavor to fruition. Special thanks are extended to the Erasmus+ programme for its invaluable support in providing this opportunity to KDU and other Sri Lankan universities, fostering growth and collaboration in higher education.

Message from the Conference Chair



Prof. SSP Warnakulasuriya

Dean, Faculty of Nursing

Sri Lankan Coordinator of the Neurocare Project

University of Colombo

Sri Lanka

It is a great pleasure to write this message as the chair of the conference on the occasion of International Conference ,2024 on Neuro Degenerative Disorders organized by the Faculty of Nursing, University of Colombo under the theme of "Expanding the Horizon for Neuro-care in Sri Lanka". This is the second conference organized under the nEUROcare capacity building European project of the Faculty of Nursing to showcase the capacity development work and research that have been carried out by the nEUROcare team during the past three years.

According to the agenda, a large number of experts in Europe as well as in Sri Lanka in the field of neurodegenerative disorders and care will attend this conference. The special feature of this conference is that many stakeholders in the health care system from all parts of Sri Lanka are invited to attend this conference, including multidisciplinary health professionals and undergraduate students in BSc Nursing Degree programs. The renowned keynote speakers Professor Steve Smith Triskelion Norway and Dr Barana Millawithana, consultant in medical gerontology will offer a thought-provoking framework for neurodegenerative disorders. In addition, the module presenters of Master of Nursing in Neurodegenerative care program will enlighten the audience on various educational components of neurodegenerative disorders-related theory and care management. Further, research abstract presenters from the area of neurodegenerative disorders will share their findings and create an effective scientific discussion. The panel discussion on the second day of the conference with the participation of Sri Lankan experts in Neurodegenerative diseases will create an effective dialogue to discuss the current situation of neurodegenerative diseases and care

management in Sri Lanka and the future challenges and possible alternatives regarding preparation of the health care workforce for future challenges in neurocare.

I believe that the second International Conference on Neurodegenerative Disorders 2024 will continue to attract healthcare professionals who are interested in neurodegenerative disorders, leaders from multiple disciplines, undergraduates in the healthcare discipline, researchers, scientists, advocators, policy experts, and other key stakeholders from across Sri Lanka. As organizers of the conference, we are committed to providing informative, innovative, and accessible content through main speakers and presenters of various neuro-care educational modules, oral and poster sessions as well as panel discussions.

In response to this call to action, I hope the conference will serve as a forum to recognize the individual work that is occurring within the neurocare team of four Sri Lankan Universities and four European universities, celebrate accomplishments, engage in meaningful dialogue on what it will take to achieve, set objectives during the coming years and define the role of the neurocare team in leading the way.

The proceedings of the conference consist of 8 abstracts presented by researchers in the Neurocare field and a synopsis of 16 module presenters in partner universities. The quality of the abstracts has been maintained by reviewing them thoroughly and assessed by a panel of university academics in relevant fields.

I would like to express my sincere gratitude to the organizing committee of the Nurocare conference, 2024 including the Nurocare team of the Faculty of Nursing and other partner universities for their commitment, hard work, and all efforts to make this event a reality.

As the chair of the conference, I also wish to convey my sincere gratitude to the heads of the departments, academic staff, Senior Assistant Registrar, Assistant librarian and the students, and the non-academic staff of the Faculty of Nursing for extending their fullest support and cooperation to show up the second international neurocare conference a great success. I also congratulate all the abstract and module presenters who are presenting their research and module contents at the conference. Special thanks to Professor Steve Smith and Dr Baran Millawithana the Keynote speakers, H . E David Gregory Pine, High Commissioner of New Zealand, our Chief guest, and all the guest speakers of the neurocare conference 2024. I would

like to place a special remark to Senior Professor H.D. Karunarathne, Vice Chancellor University of Colombo for his moral support, visionary leadership, correct guidance and inspirations to make this event a success. Also, I would like to make special acknowledgement to Professor Martin Persson, project manager at Kristianstad University Sweden for his brilliant coordination of the Neurocare European team and for facilitating this conference. I hope all the participants enjoy the glamor of the Nurocare Conference 2024 which was organized by the Faculty of Nursing, University of Colombo. I wish the 2nd International Conference Nuerodegenerative Disorders 2024 would be a great success!

Message from the Conference Secretary



Ms. MGAS Malkanthi

Senior Lecturer

Department of Fundamental of Nursing
Faculty of Nursing
University of Colombo

Sri Lanka

It is a great pleasure to write this message as the secretary of the 2nd International neurocare conference, 2024 organized by the Faculty of Nursing, University of Colombo under the theme of "Expanding the Horizon for Neuro-care in Sri Lanka" with the collaboration of the nEUROcare Project- European initiative for capacity building to meet the challenges of caring for people with Neurodegenerative Disorders in Sri Lanka. I consider this remarkable scientific conference will enhance the quality of nursing education and research on neurodegenerative disorders in Sri Lanka.

I believe that this International Conference would be the best platform to enhance the knowledge, skills and practice among nurses and nursing students about caring and rehabilitation of patients with neurodegenerative disorders using new strategies and technologies in future. I sincerely thank the Dean/nEUROcare project manager, Faculty of Nursing, University of Colombo, Prof SSP Warnakulasuriya for initiating, encouraging and guiding to organize this conference in corroboration with nEUROcare Project.

Furthermore, I would like to extend my gratitude to all the members of the organizing committee, faculty of Nursing and the neurocare team members of other Universities for their great support and dedication to make this conference success.

We, the organizing committee hope that this conference will be a memorable event for you and look forward to seeing you all soon.

Message from the Project Manager



Prof. Martin Persson
Professor of Health Science
Faculty of Health Sciences
Kristianstad University
Sweden

Developing Capacity in Neurodegenerative Disease Care in Sri Lanka: The nEUROcare Initiative

Neurodegenerative diseases (NDD) represent one of the world's foremost medical and societal challenges, with an estimated 50 million people globally affected by Alzheimer's disease and related disorders. Sri Lanka, a multi-ethnic nation with one of the fastest ageing populations in South Asia, is experiencing a rapid rise in NDD prevalence. Despite this, no universities or educational institutions in Sri Lanka currently offer training programs focused on NDD care. This lack of trained professionals has significant consequences, particularly for informal caregivers—family, friends, and neighbours who provide unpaid care—who often experience reduced quality of life, health challenges, and financial burdens. Thus, developing a trained workforce to care for those with NDD and support their caregivers is a pressing need for the country.

Neurodegenerative diseases (NDDs) represent one of the most challenging categories of medical conditions, placing a significant burden on society. As Sri Lanka's population ages, this burden is expected to intensify, with dementia emerging as the most common NDD. Meeting the complex physical, cognitive, and psychological needs of individuals affected by these conditions is a challenge for healthcare systems worldwide, requiring comprehensive, high-quality care for a particularly vulnerable population. In response, the nEUROcare project

aims to address this need by developing a robust curriculum to train caregivers and healthcare professionals, equipping them to provide effective support for those impacted by NDDs.

The European Union's Erasmus+ Capacity Building in Higher Education program has generously supported this effort through the nEUORcare project, which brings together a consortium of five European and four Sri Lankan institutions. This collaboration has yielded substantial outcomes, including:

- Development of courses comprising over 30 credits (1,500 hours) aligned with the Sri
 Lanka Qualifications Framework (SLQF). These courses will enable the creation of an
 accredited program, offered as a postgraduate certificate, postgraduate diploma, or
 master's by coursework at four Sri Lankan universities.
- Design and implementation of multiple continuous professional development (CPD) training modules.
- Dissemination efforts to raise awareness, including published research and promotion via global media, TV, radio, and newspapers.

Beyond these tangible outputs, the nEUORcare project's intangible achievements are foundational. More than forty dedicated professionals have overcome cultural and structural challenges to work collaboratively for the benefit of patients and families affected by NDD. The recent years have been turbulent, with global disruptions due to the COVID-19 pandemic followed by Sri Lanka's financial crisis. Yet, through these challenges, the project has moved forward thanks to the commitment and professionalism of everyone involved.

Looking ahead, I am confident that the project's impact will endure. By enhancing the capacity of Sri Lanka's healthcare education system, the project will enable the country to independently train healthcare students and professionals in NDD care, without further reliance on EU support. However, while we have laid the groundwork, it is you—the attendees of this conference, future students, and healthcare professionals via the nEUORcare project—who will drive the improvement of NDD healthcare. Ultimately, the fundamental legacy of this project will be to strengthen and support Sri Lanka's already compassionate and capable healthcare workforce, providing an enduring foundation to further elevate care for patients with NDD and their families.

An introduction to nEUROcare project

nEurocare project is the European initiative capacity-building project for nursing education in Sri Lanka while meeting the challenges of caring for people with Neurodegenerative Disorders in Sri Lanka. This project was established as the first international grant project in the Faculty of Nursing in 2022. This project aims to develop new and innovative courses and methodologies in healthcare to develop human capacities in the field of Neurodegenerative disorders within the four, selected higher education institutions in Sri Lanka.

This timely significant project is mainly coordinated by the Faculty of Nursing, University of Colombo the main partner University from Sri Lanka with Kristianstad University Sweden, the main partner university from Europe. Other partner European universities that are involved in this project include the University of Ljubljana in Slovenia, the University of Tartu in Estonia, and Neapolis University Pafos in Cyprus and Triskelion - Norway. On the other hand, the other partner universities invited from Sri Lanka include the University of Peradeniya, the University of Ruhuna, and General Sir John Kotelawala Defence University.

Under this project, there are a series of international workshops and conferences that have been scheduled to develop postgraduate-level course modules in nursing care education specializing in Neurodegenerative disorders. The second international workshop was held at Kristianstad University Sweden in May 2022, and the third international workshop was held at the University of Tartu in Estonia from 4th to 9th September 2022. This is the first initiative to develop postgraduate nursing education in Sri Lanka in neurocare.

nEUROcare capacity building Project provides the insight to develop new and innovative courses and methodologies in healthcare, to develop the human capacities in Neurodegenerative disorders within the four selected Higher Education Institutions in Sri Lanka. As a partner university, the University of Colombo would develop the course structure for the Master Degree, Diploma, and Certificate program on Neurodegenerative disorders based on Sri Lankan Qualification Framework. The development of these courses will be facilitated by the Neurosurgeons, Neurologists, Psychologists and General physicians from EU partner universities.



nEUROcare team - University of Colombo



Project ManagerProf. SSP WarankulasuriyaDeanFaculty of Nursing



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Project Member

Mrs. HMCM Herath

Head/Lecturer

Department of Clinical Nursing

Faculty of Nursing

Introduction to the Keynote Speaker



Dr. Barana MillawithanaConsultant Physician in General Internal Medicine
Base Hospital Wathupitiwala
Sri Lanka

Dr. Barana Millawithana, MBBS (Col), MD (Col), MRCP (UK), DGM (Lon), MRCP-SCE Geriatrics (UK), FRCP(Lon), FCCP is a Consultant Physician in General Internal Medicine works at Base Hospital Wathupitiwala, Sri Lanka. He has a special interest in Geriatric Medicine and is currently the chairman of the specialty board in Geriatric Medicine of Postgraduate Institute of Medicine, University of Colombo and the immediate president of Sri Lankan Association of Geriatric Medicine. He has contributed to the curriculum development, undergraduate and postgraduate training and research in Geriatric Medicine in Sri Lanka. He is an examiner in both undergraduate and postgraduate clinical exams and an international examiner for MRCP(UK) PACES.

Abstract of Keynote Speech

Expanding the Horizon for Neurodegenerative Diseases Care in Sri Lanka

Dr. Barana Millawithana

MBBS, MD, MRCP(UK), FRCP(Lon), FCCP,DGM(Lon), MRCP(UK-Geriatrics)

Consultant Physician in General Internal Medicine

Base Hospital Wathupitiwala

Sri Lanka

Neurodegenerative diseases are characterized by the progressive degeneration of the structure and function of the nervous system. Alzheimer, Parkinson, Huntington diseases and motor neuron disease are some common disorders. These diseases are insidious in onset and gradual progression which lead to the loss of cognitive, motor, and emotional abilities of an individual.

Over the last few decades, progress being made in understanding these diseases at a molecular, genetic, and therapeutic level with genetic insights, the discovery of biomarkers, immunotherapy neuroprotective strategies, and the use of artificial intelligence. Despite these advances, there are enormous challenges in treating and caring for these patients. n

Expanding neurocare in Sri Lanka is a priority as Sri Lanka has a rapidly ageing population and these conditions are more prevalent. However, it requires a multipronged approach that includes infrastructure development, education, research, and advocacy. With local and international collaboration, Sri Lanka can create a sustainable neurocare system that addresses the needs of these patients and elevates healthcare standards across the country.

Training and education of healthcare professionals, public awareness and empowerment of neurorehabilitation and neuropsychiatric services are some key strategies in enhancing the neuro care. Inauguration of modular based masters in neurodegenerative disorders is a timely initiative that can elevate the care standards among nursing professionals and the second international conference on neurodegenerative diseases is a landmark event in Sri Lankan health care.

Introduction to the Keynote Speaker



Prof. Steve Smith
Triskelion
Norway

Prof. Steve Smith, SFHEA, MPhil, MSc, BSc, RN managed a sales team for ten years before qualifying as a nurse. Within that profession, he specialised in the management of care facilities for people with neurological disorders and also undertook the role of Clinical Nurse Educator in this field over another decade before teaching health professionals at The University of East Anglia (UEA) School of Health Sciences for the past 22 years, first as a lecturer then Associate Professor, member of the School Executive and Director of Employability.

As well as teaching pre-registration nurses and students of all professions allied to medicine, Steve collaborated with colleagues to develop and run many courses for senior health professions focused on leadership and management.

Steve authored two books on his nursing field and, over three decades, has frequently presented at International conferences and symposia, often invited to speak to staff teams at international centres of excellence for neurological care. Steve has done extensive international presentations on Neurological Care / Huntington's Disease and Co-led a collaborative project (UEA, UK and Ekwendeni Nursing School, Malawi) in 2012, developing a Nurse Mentorship programme.

On retiring from UEA, Steve was awarded the Chief Nursing Officer for England Gold Award for outstanding services to Nursing. Steve continues as a Registered Nurse working on National and International projects relating to his field of expertise.

Abstract of Keynote Speech

Compassion in Care for People with Neurodegenerative Disorders

Prof. Steve Smith

MPhil, MSc, BSc, PGCE, SFHEA, RN,
Retired Associate Professor,
Senior Clinical manager, NHS England, and Representing Triskelion,
Norway.

Compassion is frequently referred to in nursing and allied health professional literature as a key aspect of care. Much of what is written on the topic involves directives, for example, emphasising that nurses must be compassionate; that compassion needs to be a cornerstone in care; that compassion is fundamental to optimum patient experience and health outcomes. The literature also offers many examples of types of behaviour associated with compassion such as kindness, patience, listening, and showing empathy. But there is comparatively limited material aimed at helping to understand what compassion is, or how it can be taught and measured. This may seem surprising given the apparently unchallenged widely upheld assertion that it is an essential component of care.

In recent years there has been growing reference to 'compassion fatigue', a phenomenon reportedly resulting from care professionals experiencing so much suffering and trauma and / or becoming so pressurised by excessive workload that they are no longer capable of having compassion for others. This is apparently closely linked to staff attrition, inadequate staffing levels, longer and more costly patient stays in hospital and poorer patient outcomes. While much is written about causes of compassion fatigue and how it can be mitigated, it must surely be helpful to develop a greater appreciation for what compassion actually is.

This presentation aims to explore the essence of compassion in care for people with neurodegenerative conditions and their impacted families, through reference to theory and examples of lived experience. Defining a characteristic such as compassion is certainly difficult. The presentation aims to draw out the meaning of compassion from demonstrations of it's presence or absence rather than attempt to define such a nebulous yet crucial concept.

Synopses of the Module Presentations

From Patient to Person: Transforming Healthcare Through Person-Centered Care



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The presentation "Person-Centered Care (PCC)" explores a holistic approach to healthcare that prioritizes the individual's unique needs, values, and preferences over their medical conditions or diagnoses. It begins by defining the concept of a person through four ethical principles: autonomy, dignity, integrity, and vulnerability. These principles emphasize the importance of respecting everyone's right to make choices, maintaining their self-esteem, protecting their wholeness, and acknowledging their vulnerability as a fundamental human condition.

The presentation also broadens the understanding of health beyond the absence of disease, incorporating physical, mental, social, and spiritual well-being. This comprehensive view aligns with the PCC approach, which aims to address the entire spectrum of an individual's life and health needs. Originally developed by Professor Tom Kitwood for dementia care in the 1990s, the person-centered approach has expanded to all healthcare contexts. It underscores the importance of seeing patients as whole persons rather than focusing solely on their illnesses, thus fostering a partnership between healthcare providers and patients.

The VIPS framework—Value, Individualized approach, Perspective, and Social environment—serves as a guide for implementing PCC. This framework advocates for recognizing the absolute value of human life, providing care tailored to the individual, understanding the individual's perspective, and creating supportive social environments.

Adopting PCC can significantly improve the quality of care, enhance patient satisfaction, and lead to better health outcomes. It calls for a shift in healthcare systems and practices, encouraging continuous professional development and a reflective, compassionate approach to care that supports the well-being of both the individual's we care for and the healthcare providers.

Quality Assurance of Clinical Outcome Assessment instruments



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Clinical outcome is defined as the study of the end results of health services that take patients' experiences, preferences, and values into account. Quality assurance provides efficiency and effectiveness and standardized measure language for each outcome as researchers, clinicians, and patients can make more informed decisions on diagnosis, benefits, risks, and improvement of therapies. Hence, this study focuses on identifying different types of data, and how to evaluate the quality of different instruments that are used in clinical practices.

Data that are collected as clinical outcomes can be categorized as nominal, ordinal, interval, or ratio data which provides quantitative or qualitative information. Interval or ratio data can be gathered through physical or chemical measurements while nominal or ordinal data can be gathered through observations via rating scales. Quality assurance of these physical or chemical measures should be ensured using proper calibration methods. Industry, academia, and hospitals should develop reference standards at the national level followed by the international level to identify these measures as true value. Data that are collected via rating scales can be kept as nominal or ordinal data or can be converted into scale data. Using a Likert scale in the rating scale is one of the best options to convert these qualitative measures into quantitative measures. Psychometrics such as the validity and reliability of these rating scales should be measured to maximize the quality of the clinical instrument and outcome data. Testretest reliability, intra-rater reliability, and internal consistency of the rating scale should be measured as the reliability. Content validity, criterion-related validity, and construct validity should be measured as the validity. In addition, the Rasch Measurement Theory can be used for the assessment of how well items form a scale for measurement.

In conclusion, the quality of data, study results, and conclusions are dependent on the quality of the instruments used to produce data. Therefore, must be serious about our assessment and measurement instruments and must be aware of the calibration and psychometrics of those measures and tools to ensure quality patient management and outcomes.

Oral Health and Neurodegenerative Diseases



Dr. Riina Runnel

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Oral health plays a crucial role in overall systemic well-being, particularly in its relationship with neurodegenerative diseases such as Alzheimer's disease, Parkinson's disease, and other forms of dementia. Recent research has identified a bidirectional link between oral health and neurodegeneration, where conditions such as chronic periodontitis, tooth loss, and infections — most notably those caused by Porphyromonas gingivalis — contribute to neuroinflammation and may accelerate cognitive decline. Simultaneously, neurodegenerative diseases impair the ability to maintain proper oral hygiene due to cognitive and motor deficits, increasing the risk of oral diseases among these individuals.

Understanding this relationship is critical to improving care for patients with neurodegenerative disorders. Awareness of the impact of oral pathogens on brain health can inform preventive measures, while recognition of the oral hygiene challenges faced by cognitively impaired individuals underscores the need for tailored dental care strategies. Moreover, integrating dental care into the broader management of neurodegenerative diseases is essential for preventing oral health issues from exacerbating systemic and cognitive decline.

Thus, interdisciplinary approaches that involve both dental and medical professionals are vital for improving patient outcomes. By addressing the unique oral health challenges in neurodegenerative populations, such collaborative efforts can lead to better overall health and enhanced quality of life for affected individuals.

Comprehensive Care Approach for Patients with Neurodegenerative Disorders for Improved Quality of Life in the Sri Lankan Context



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Neurodegenerative disorders (NDDs) such as Alzheimer's disease and Parkinson's disease are increasingly prevalent in Sri Lanka's aging population. These conditions significantly impair physical, cognitive, and emotional well-being, placing a heavy burden on patients, families, and the healthcare system. In the Sri Lankan context, comprehensive care approaches that address these multidimensional needs are essential to improve the quality of life (QoL) for affected individuals, especially in resource-constrained settings. Exploring a holistic care model personalized to Sri Lanka's healthcare environment, focusing on integrating medical management with community-based support, rehabilitation, and caregiver education is a real necessity. Medical care, including pharmacological treatment, nutritional management, and symptom control, must be personalized based on each patient's condition and progression.

Moreover, considering the limited availability of specialized neurodegenerative care, training primary care physicians, nurses, and community healthcare workers to recognize and manage these conditions is critical. Rehabilitation services, including physical, occupational, and speech therapy, help maintain functionality and independence in these patients. However, access to such services is often limited, particularly in rural areas. Therefore, it is imperative to develop community rehabilitation programs and mobile care units to bridge this gap. In addition to physical care, the psychological and emotional aspects of NDDs must be addressed. Mental health support, including counseling and therapy, is vital for managing depression, anxiety, and cognitive decline.

Community-based psychosocial interventions and traditional coping mechanisms can be integrated into care plans to address cultural sensitivities. Caregiver education and support are also crucial in Sri Lanka, where family members are often primary caregivers. Training programs that focus on practical caregiving techniques, stress management, and respite care can alleviate caregiver burden. Hence, a culturally sensitive, holistic approach to managing NDDs in Sri Lanka can improve the QoL for patients and their families, fostering dignity and compassion in care delivery.

Aging and Guardians of Youth



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The power of regeneration of the body is a remarkable ability of all humans. Every day we are losing and replacing billions of cells, which is completely normal. key players in this regenerating process are the Stem Cells. Stem cells get signals from other tissues or organs According to those signals stem cells produce many types of cells for many tissues or organs. The regeneration ability of the body declines with age. Not only the aging, but various stresses affect the regenerative action of stem cells

Stem cell structure collapses with age. The vascular system also declines with age. Vascular aging is the key mechanism of aging. According to research findings, although you are older, if your circulatory system can remain active, young, and fit, the stem cells also get the signals from your vascular system and regenerate again as usual as they were young. To keep your vascular system active, be active and reduce your stressors. Celebrate your success, celebrate your achievements You will be young for a long time.

Why and how singing affects the speech, swallowing and cognitive mental wellbeing of people with Parkinson's disease



Dr. Andres Köster

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Idiopathic Parkinson's disease (PD) is a chronic, progressive multisystem neurodegenerative disorder characterised by bradykinesia, rigidity, resting tremor, postural instability, and a range of motor and non-motor symptoms. Beyond movement impairments, PD frequently results in voice disorders, communication challenges, and swallowing difficulties, primarily due to impaired speech breathing, reduced speech motility, and dysfunction of the oropharyngeal muscles. Research has demonstrated that physical therapy, regular physical activity, and exercise can decelerate disease progression. In addition to physiotherapy, activities such as dancing have been shown to support the maintenance of coordination and balance, while playing musical instruments enhances fine motor skills and rhythm. Singing, in particular, has been found to improve voice strength, speech breathing, and reduce the vocal tremors characteristic of PD. The human voice depends on the integrated functioning of several neuromuscular systems, including the respiratory system and vocal organs, which involve both the peripheral and central nervous systems. Singing combines verbal expression with pitch modulation within a single breath, facilitating enhanced control over the oropharyngeal muscles, which are crucial for speech and swallowing. Furthermore, group singing therapy has been shown to alleviate social isolation, significantly improving PD patients' quality of life.

Prevention of Neurodegenerative Disorders - is it possible?



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Preventing neurodegenerative diseases is a complex challenge due to their multifactorial reduce the risk delay but certain strategies can the nature, or onset. While complete prevention may not always be achievable, research suggests several potential avenues for risk reduction with lifestyle interventions. Diet rich in antioxidants, healthy fats, and whole foods, has been associated with brain health; exercises with regular physical activities improve blood flow to the brain, reduces inflammation, and supports neurogenesis; cognitive engagement with mental stimulation through learning new things, and social interaction help maintain cognitive reserves. Also is important to control risk factors of cardiovascular health and avoid smoking and alcohol consumption. Adequate sleep supports brain health, but chronic negatively affects time. stress the brain over

While prevention of neurodegenerative diseases remains elusive, adopting a brain-healthy lifestyle, managing medical conditions, and staying informed about emerging research can improve the quality of life of patients and caregivers.

Palliative Care in Neurodegenerative Disorders



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Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are meeting with challenges associated with life-threatening illnesses. Providing palliative care for people with neurodegenerative disorders (NDDs) focuses on enhancing the quality of life for those who are suffering from progressive, incurable neurodegenerative disorders such as Alzheimer's disease, Parkinson's disease, Amyotrophic Lateral Sclerosis (ALS), and Multiple Sclerosis. This holistic approach covers all aspects of physical, psychological, emotional and spiritual needs in both the person and the family.

The primary benefits of palliative care for people with NDDs include; symptom management, enhancing communication, ensuring emotional and psychological support, providing respite, counseling, and practical advice to reduce caregiver burnout, etc. Symptom management, including pain, fatigue, and cognitive decline, is a primary concern, along with facilitating communication about disease progression and end-of-life care. Early integration of palliative care improves patient comfort, supports decision-making, and enhances overall well-being through personalized care plans even as the condition deteriorates.

In Sri Lanka, despite the positive attitudes, the approaches of palliative care towards NDD were found to be comparatively low, due to lack of awareness. Moreover, the increasing incidences of NDD in Sri Lanka, have created a growing need in the health sector to establish effective palliative care facilities in the country. Thus, raising awareness among health workers is essential, especially since this warrants the need for palliative care education in the curricular and continuous professional development (CPD) among healthcare professionals.

Comprehensive Care for People with Neurodegenerative Disorders



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Comprehensive care approach enables health professionals engaged in providing care for people with neurodegenerative disorders (NDDs) to confidently assess, plan implement and evaluate a person-centred care. It uses a structured conceptual care framework, based on the Roper, Logan and Tierney (RLT) model of nursing. Comprehensive care is personalised, respects patient autonomy and extends to family and society, Patients and health professionals collaborate to arrive at a plan that considers patient preferences and accommodates informed choices, while meeting professional responsibilities regarding the duty of care.

It is important to equip health professionals to understand and adopt this approach because greater independence in patients to make their own decisions and choices enhances social participation and is conducive to a sense of living a meaningful, good quality life. The RLT model facilitates goal-setting aimed at maximising patient's independence in carrying out 12 activities of living: maintaining a safe environment, communicating, breathing, eating and drinking, eliminating, personal cleansing and dressing, controlling body temperature, mobilising, working and playing, expressing sexuality, sleeping, and dying. Five factors that influence a person's independence to carry out these activities must be considered: biological, psychological, sociocultural, environmental and politico-economic. The conceptual framework supports professionals in moving from a formerly widely accepted tendency to focus exclusively on rectifying physical aspects of problems, to a more holistic approach. For example, a person with Parkinson's disease presenting with a swallowing problem might be referred to a speech and language therapist to assess and treat the swallow issue. But perhaps low mood and lack of motivation, cultural unacceptability of foods offered or poverty also need to be addressed before the person will be able to eat and drink adequately. Hence, the comprehensive care approach facilitates exploration of multifactorial causes of problems, and potential remedial initiatives to support people with NDDs.

Integrating Local Environmental and Dietary Risk Factors with Neurodegenerative Disease Development: Insights from Regional Clusters



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Alzheimer's disease (AD), Parkinson's disease (PD), and Amyotrophic Lateral Sclerosis (ALS)exhibit significant regional variability in incidence, often linked to specific local environmental and dietary factors. Evidence from regions such as Guam and Japan's Kii Peninsula suggests that localized disease clusters may emerge due to interactions between genetic susceptibility, exposure to environmental neurotoxins, and shifts in dietary habits driven by socioeconomic and environmental changes.

Regional clusters of neurodegenerative diseases, including the endemic ALS-Parkinsonism—Dementia complex (ALS-PDC) observed in the Western Pacific and the Guam-specific Lytico-bodig disease, may be linked to traditional diets and exposure to potential neurotoxins. Notably, dietary changes that promote the bioaccumulation of beta-methylamino-L-alanine (BMAA) from certain plants and animals could contribute to disease development.

Researches indicate that ALS-PDC clusters often emerge from a combination of genetic predisposition and exposure to neurotoxins like BMAA, produced by cyanobacteria. These clusters are exacerbated by the introduction of Western dietary and lifestyle habits. In Guam, high ALS-PDC incidence has been linked to consumption of BMAA-contaminated cycads and flying foxes, a practice compounded by dietary shifts to high-calorie, nutrient-poor foods after American occupation. Similar mechanisms appear globally, with increased ALS and PD incidence associated with cyanobacterial contamination of fish—a staple food source—or heavy metal exposure from mining.

Additionally, ALS clusters in cyanobacteria-rich environments underscore the global relevance of cyanotoxin exposure combined with lifestyle and nutritional changes.

In areas with a sudden spike in neurodegenerative disease prevalence, examining local dietary patterns, cultural shifts, and socioeconomic factors could be key to understanding disease etiology. These observations suggest that prevention strategies should be customized for atrisk populations, especially those exposed to specific environmental and dietary risk factors. A focus on the relationship between environmental changes, dietary habits, and neurodegenerative disease prevalence may also be crucial in monsoon-affected regions.

Risk Factors for Neurodegenerative Disorders



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Neurodegenerative disorders (NDDs) such as Alzheimer's disease (AD), Parkinson's disease (PD), Huntington's disease (HD), and Amyotrophic Lateral Sclerosis (ALS) are progressive and debilitating conditions. The risk factors for NDDs can be divided into modifiable and non-modifiable categories, each playing a crucial role in disease onset and progression.

Modifiable risk factors are those influenced by lifestyle or environmental changes. Key modifiable factors include cardiovascular health issues like hypertension, hypercholesterolemia, obesity, and diabetes, all of which are linked to higher risks of AD and vascular dementia. Additionally, physical inactivity, poor diet, smoking, and excessive alcohol consumption increase the likelihood of developing NDDs. Regular exercise, adherence to a Mediterranean diet, and avoiding tobacco and excessive alcohol have been shown to reduce the risk of cognitive decline and neurodegeneration. Social and cognitive engagement, through activities like reading or solving puzzles, as well as managing chronic stress, depression, and sleep disorders, can also reduce the risk or delay the onset of these disorders. Environmental factors, such as exposure to toxic metals, industrial pollutants, and infections, are linked to neurodegeneration as well.

Non-modifiable risk factors are inherent characteristics such as age, genetic predispositions, sex, ethnicity, and history of head injury. Aging is the most significant risk factor, particularly for AD and PD, with the risk of AD doubling every five years after age 65. Genetic mutations, like the Apolipoprotein E &4 allele in AD or mutations in the Huntington's disease gene in HD, increase susceptibility to NDDs. Men are more likely to develop PD, while women have a higher risk of AD. Ethnic and racial differences also play a role, with certain populations, such

as African Americans and Hispanics, having higher rates of AD. Traumatic brain injuries, particularly repeated concussions, heighten the risk of conditions like Alzheimer's and chronic traumatic encephalopathy (CTE).

In conclusion, while non-modifiable factors set the baseline risk for neurodegenerative diseases, modifiable factors offer opportunities for prevention and risk reduction. Addressing lifestyle changes like cardiovascular health, cognitive stimulation, and environmental exposure management can mitigate these risks, offering vital interventions for patients with genetic predispositions or advancing age.

Enhancing Person-Centered Care for Elderly Patients with Neurodegenerative Disorders through Continuous Professional Development



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Person-centered care (PCC) is a personalized approach that focuses on respecting the dignity, independence, and the emotional needs of individuals. PCC significantly improves the quality of life among the elderly population affected by neurodegenerative diseases such as Alzheimer's, Parkinson's, and dementia by addressing their unique challenges. These disorders present progressive challenges, including cognitive decline, behavioral disturbances, and physical impairments, which severely affect the quality of life of patients. PCC transcends routine symptom management by integrating personal histories, individual preferences, and emotional well-being into care strategies. It promotes collaboration between patients, caregivers, and healthcare teams to preserve identity, alleviate distress, and improve outcomes.

Continuous professional development (CPD) plays a pivotal role in equipping nurses with the advanced skills necessary to provide effective PCC for this vulnerable population. Through CPD, nurses gain expertise in managing complex symptoms, enhancing communication, and applying non-pharmacological interventions to address behavioral challenges. It also strengthens cultural competence, emotional intelligence, and caregiver support strategies, which are essential for adapting to the evolving needs of patients with neurodegenerative disorders. Fostering a culture of lifelong learning through CPD is critical to ensuring the delivery of high-quality, person-centered care. Regular education, clinical simulations, and reflective practices empower nurses to stay updated with emerging evidence-based practices, enhancing their ability to address ethical dilemmas and recognize patients' evolving needs. In conclusion, continuous professional development enhances nursing practice, ensuring sustainable, compassionate care that upholds dignity and well-being for elderly patients with neurodegenerative disorders.

Understanding Emotion and Emotion Regulation in Neurodegenerative Disorders: Insights from Emotion Theory and Counselling Psychology



Dr. Elly AnastasiadesNeapolis University Pafos

This presentation explores the essential role of emotions in human experience and the specific challenges neurodegenerative disorders (NDDs) create for emotion processing and regulation. Drawing from emotion theory and counselling psychology, it delves into the purpose and nature of emotions, emotional intelligence, and the connections between emotions, the body, and conscious thought. The presentation explores how NDDs can disrupt the expression and regulation of emotion, often leading to emotion dysregulation and instability. By integrating this theory with practical tools, it also offers strategies for supporting emotion regulation in individuals with NDDs, with the goal of improving patient care. Overall, this presentation provides an in-depth understanding of emotions and provides practical approaches for managing emotion-related challenges in the context of neurodegenerative care.

Learning Outcomes:

- 1. Understand the purpose and function of emotions and their critical role in survival and every-day functioning.
- 2. Recognise the impact of neurodegenerative disorders on emotion processing, including emotion dysregulation.
- 3. Apply practical tools to support emotion regulation in individuals with neurodegenerative disorders.



Rehabilitation of Communication Abilities in Patients with Neurodegenerative Disorders: Enhancing Connectivity and quality of life in the Sri Lankan Context



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Neurodegenerative disorders (NDDs) such as Parkinson's disease, Alzheimer's disease, and amyotrophic lateral sclerosis (ALS) are characterized by progressive declines in motor, cognitive, and communication functions. One of the most insidious challenges faced by individuals with NDDs is the gradual onset of communication impairments. Although initial symptoms may not significantly affect speech and language functions, many patients eventually lose the ability to communicate effectively as their condition progresses. Communication is essential for personal expression and maintaining social connections, which directly impacts the quality of life (QoL). Therefore, Prompt rehabilitation interventions tailored to meet the requirements of the patients will be important to improve their QoL. In Sri Lanka, the healthcare system lacks the resources to adequately address the communication needs of individuals with NDDs.

Despite the growing prevalence of these disorders, rehabilitation services tailored for speech and language impairments remain underdeveloped. The speech and language impairments often remain undiagnosed or missed. This gap in care results in a significant proportion of individuals with NDDs not receiving timely or effective interventions, further contributing to social isolation and reduced QoL. A multidisciplinary approach, involving neurologists, speech-language pathologists, nurses, social workers, and occupational therapists, is essential for the accurate diagnosis, timely rehabilitation, and long-term management of communication impairments in NDDs.

It is necessary to develop standardized diagnostic protocols, increase the availability of specialized rehabilitation services, and implement Augmentative and Alternative Communication (AAC) technologies to improve the QoL of these patients. Furthermore, public awareness campaigns and caregiver training programs could improve early recognition and management of communication impairments in NDDs. Bridging these gaps in care will be essential to improve the QoL of individuals with NDDs in Sri Lanka.



Healthy Ageing in an Ageing Society: Addressing Challenges with Support Systems Family and societal perspectives on neurodegenerative disorders (NDDs)



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General Sir John Kotelawala Defence University

The concept of ageing is a natural process marked by normal biological processes associated with structural and functional changes in many parts of the human body. Since the countries' populations aged worldwide, societies face several challenges related to the well-being and caring of older people. Sri Lanka is also recognized as one of the fastest-ageing countries due to its accelerated demographic transition, which has potential implications for various social, economic, and healthcare-related issues. Therefore, it is essential to address the consequences of this demographic transition and promote healthy ageing of older people and manage the impact of ageing on families with older people with neurodegenerative diseases (NDDs).

The World Health Organization (WHO) defines healthy ageing as "the method of developing and maintaining the functional ability that enables well-being in older age." This involves physical health and the ability of older people to meet their basic needs, make decisions, maintain relationships, and contribute to society. The increased incidence of chronic illnesses and neurodegenerative diseases (NDDs) among older people further complicates healthy ageing and successful ageing of this population.

The rapidly ageing population faces many challenges in society, such as a substantial paucity of family support. Various issues related to population ageing in the social, economic, cultural and political dimensions will contribute to a gradual decline in the quantum and quality of caregiving for older people in our society. Caring for an elderly family member with an NDD presents significant challenges for family caregivers. The physical, emotional, and social impact on caregivers is considerable, often leading to caregiver burnout. The limited available

systems for the early detection of NDDs in Sri Lanka worsen this issue, as families may not receive timely support or interventions.

Government and non-governmental organizations are involved in providing various aspects of support for the care and well-being of the elderly population in Sri Lanka. There is an urgent need to increase the number of long-term care services and strengthen the family-based informal care and self-care needs with the participation of the government, the private sector, and NGOs. Since most family caregivers cannot safely and sufficiently provide caregiving for the elderly with complicated care needs, there is a strong need for strengthening family or home-based care services. Furthermore, there is a need to provide training and financial support to identified family caregivers since the families themselves do not have any training and are unable to bear the cost of providing suitable care services for older family members with NDDs.

Therefore, it is reasonable to conclude that investing in healthy and successful ageing is essential for reducing the burden of population ageing in Sri Lanka. The suggested recommendations include complementing informal care arrangements, introducing/expanding social welfare and care services that target older people with NDDs, by providing community and home-based support services for the sick and frail older people and by improving income support programs and health services for the older people. Therefore, addressing these gaps would be most timely and beneficial for the future, with great potential for improving the well-being of the older people living in Sri Lanka.

Counseling Essentials in Neurodegenerative Care



Dr. Marilena Mousoulidou Neapolis University Pafos

This presentation focuses on the essential principles of counseling within neurodegenerative care, specifically emphasizing effective strategies for carers. Neurodegenerative disorders present unique challenges that require a multifaceted approach to caregiving, where both emotional and practical support are key components. The presentation will explore the importance of building a therapeutic alliance between the counselor, caregiver, and patient, a critical factor in improving both psychological well-being and the quality of care provided.

By recognizing the complexity of these conditions, the presentation will highlight effective communication techniques, emotional resilience strategies for carers, and best practices for navigating the physical, emotional, and psychological demands that caregiving for neurodegenerative patients entails. Participants will also learn how to implement adaptable interventions that respect each patient's unique experiences, creating a flexible framework for care.

By the end of this presentation, attendees will gain a deeper understanding of the practical tools and emotional frameworks necessary for fostering more effective caregiving in neurodegenerative care.

Learning Outcomes:

- 1. Understand the core principles of therapeutic alliances in neurodegenerative care and how they improve care outcomes.
- 2. Apply counseling strategies that address the individual needs of patients and their carers.
- 3. Develop effective communication techniques and emotional resilience strategies to support both carers and patients throughout the caregiving process.

Neurology and Comprehensive Care of Patients with Neurodegenerative Disorders



Prof. Zvezdan Pirtošek
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Neurodegenerative disorders, such as Alzheimer's Disease (AD), Parkinson's Disease (PD), Huntington's Disease (HD), and Amyotrophic Lateral Sclerosis (ALS), present complex challenges requiring holistic, patient-centered care. This presentation explores advanced strategies for the comprehensive medical and functional management of patients with neurodegenerative disorders, emphasizing the integration of multidisciplinary approaches to enhance quality of life. Central to care is a focus on maintaining patient autonomy and managing diverse symptoms, including cognitive decline, motor impairments, dysphagia, and neuropsychiatric conditions. Functional therapies, such as physical, occupational, and speech therapies, are highlighted for their roles in mitigating functional decline and addressing communication and swallowing difficulties. Nutritional interventions and respiratory care, especially in advanced ALS and HD, are examined, alongside ethical considerations for advanced directives and end-of-life care.

The presentation underscores the importance of caregiver education and support, addressing their psychological and physical burdens through counseling, respite care, and access to community resources. Innovations in assistive technologies, telemedicine, and digital tools for care coordination are discussed as transformative solutions to accessibility and resource limitations. Case studies provide practical illustrations of coordinated care, emphasizing the importance of early diagnosis, ongoing assessment, and interdisciplinary collaboration. The challenges of delivering equitable care, particularly in underserved areas, and the opportunities for community-based and mobile care models are explored. This presentation serves as a comprehensive resource for healthcare professionals, offering insights into optimizing care strategies and improving outcomes for patients and families navigating neurodegenerative diseases.

Implementation and Evaluation



Prof. Martin Persson
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This presentation emphasises the critical role of evaluation in healthcare. It outlines the necessity of systematic evaluation to ensure quality of care, facilitate continuous improvement, and maintain accountability and transparency in medical practices. Evaluation optimises resource utilisation and supports evidence-based decision-making.

The implementation of Acceptance and Commitment Therapy (ACT) as a case study highlights its potential to enhance psychological flexibility and resilience in caregivers, backed by systematic reviews and meta-analyses. Using a Logic Framework Model, the presentation proposes a structured approach to integrating ACT, with clear goals, implementation strategies, and measurable outcomes. Emphasis is placed on monitoring, mitigating risks, and achieving impactful results through robust evaluation processes.

This underscores that meaningful healthcare improvements rely on diligent evaluation at every stage of implementation.

Scenario-Based Discussion on Neurodegenerative Disorders in Sri Lanka"



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Panel Discussion on "How to Develop Neurocare in Sri Lanka - Experts from Europe and Sri Lanka



Prof. Zvezdan Pirtošek University of Ljubljana, Slovenia



Prof. Steve SmithTriskelion
Norway



Dr. Neil Fernando
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Technical Session - nEUROcare Abstract Presentations

OP1: Carers' Perceived Effectiveness of Exercises and Advanced Technologies in Dementia Care

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Background: Given the known benefits of sport and exercise for people with dementia and their caregivers, physical activity should be prioritized over pharmacological treatment. Research indicates that physical activity not only enhances the overall well-being of individuals with dementia (PWD) but also improves the relationships and well-being of their caregivers.

Objective: The study examines the importance of physical activity for PWD and explores whether certain types of exercise as well as modern tools such as information and communication technology (ICT) and artificial intelligence (AI) are particularly well-suited to this population, considering different living environments, such as at home or in institutional settings.

Methods: The study included three focus groups in Slovenia: caregivers in home care (N = 8), persons with dementia (4), and physiotherapists in care homes (N = 8). Key questions included the types of exercises typically undertaken, challenges encountered, perceived effects of exercise, and how ICT and AI could enhance the implementation of sports activities for PWD. Additionally, interviews with PWD were conducted to understand their preferences regarding physical activity. With qualitative analyses, the study gives insight into physical activity and its importance for the well-being of persons with dementia and their caregivers.

Results: Findings suggest that regular physical activity tailored to an individual's previous lifestyle and abilities is essential for improving the well-being of PWD. ICT and AI play an important role in promoting and monitoring regular exercise and a sense of security - yet the use of ICT and AI tools is the exception rather than the rule. Significant barriers include cognitive decline, physical limitations, safety concerns, and limited access to suitable programs. The study highlights the potential of ICT and AI in overcoming these barriers, offering solutions such as personalized exercise tracking, adaptive programs, and AI-driven virtual assistants that promote safety and encourage regular physical activity.

Conclusion: This study emphasizes the critical importance of personalized and adapted physical activity for improving the well-being of PWD and their caregivers. Innovatively, it explores the use of ICT and AI technologies to overcome existing barriers, proposing personalized solutions and AI that could revolutionize the implementation and monitoring of physical activity. These findings offer new tools to enhance autonomy and health outcomes for PWD, setting this research apart from existing literature.

Keywords: Dementia, Physical activity, ICT

OP2: Improving Positive Ageing of Older Adults through Health Promotion Actions in a Rural Village in Puttalam District

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Background: Sri Lanka has the fastest-growing elderly population in South Asia. There are noticeable gaps in community-based care services for older adults in this context. Older people and their families, therefore experience challenges when managing their health, caregiving, and maintaining quality of life. It is important to create an encouraging environment for older adults to grow old positively, and to live better, healthier, and happier in addition to having longer lives.

Objective: The study aimed to assess the improvement of quality of life (QOL) of a group of older adults in Galmuruwa, a rural village in Puttalam District.

Methods: A participatory action research was conducted in the village among older adults and their families over four months. Phase 1 was a survey with a convenient sample of older adults. Phase 2 was the health promotion action with a purposively selected sample of participants. Data was collected through a pre and post questionnaire-based survey (n=100 older adults), group interviews (12) and home visits. Data analysis utilized both quantitative (simple descriptive statistics) and qualitative methods (thematic analysis).

Results: There were 69 female and 61% were aged 60-69 years. Ninety-one had one or more non-communicable diseases but demonstrated a low level of awareness regarding its management. Before health promotion intervention, only 17% rated good QOL for the WHO QOL Assessment (WHOQOL-BREF), and 60% of them reported moderate to severe pain. In the post-intervention, 54% rated good QOL and pain levels reduced to 29%. Pre-intervention findings (based on interviews) indicated a sedentary lifestyle, unhappiness, loneliness, a sense of dependency, poor interpersonal interactions, and hopelessness among older adults, all of which improved following the intervention. A significant improvement was noted in their physical activity levels, community interactions, perceived happiness, and awareness and practices to manage non-communicable diseases (based on interviews and observations).

Conclusion: Findings imply that the health promotion intervention was able to improve quality of life of participants across physical, psychological, spiritual, and environmental health domains. Utilizing participatory approaches in conjunction with health promotion strategies effectively fosters healthy lifestyle practices among lay communities.

Keywords: Older Adults, Family, Active Ageing, Health Promotion, Community engagement

OP3: Cultural Adaptation and Validation of Dementia Knowledge Assessment Tool version 2 (DKAT 2) for Sinhala-Speaking Nursing Undergraduates in Sri Lanka

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Introduction: Dementia is a syndrome of cognitive impairment that affects memory, cognitive abilities, and behavior and significantly interferes with a person's ability to perform daily activities beyond the usual consequences of biological aging. Dementia education empowers nursing students to understand the reality of dementia, appreciate, provide care, and support the needs of people with dementia

Objective: The study aimed to translate, culturally adapt, and validate the Sinhala version of Dementia Knowledge Assessment Tool version 2 (DKAT2).

Methods: This was a methodological study. The translation and cultural adaptation of the instrument followed a systematic process consisting of forward translation, synthesis of forward translation, backward translation, expert committee consolidation, and pre-testing with a group of 30 fourth-year nursing undergraduates. The modified Delphi technique was used to evaluate content validity. Inter-rater reliability was measured using modified Kappa statistics and reliability was checked using Test-retest reliability.

Results: The wording of twelve out of twenty-one items of the commonly translated version was altered by an expert committee to achieve the exact meaning compatible with the original DKAT2. No modifications were indicated during the pre-test. During content validation, the panel of experts suggested alterations in the statements of eight items of the translated Sinhala version of DKAT2. After modification, all experts agreed and rated each item of the final instrument considering its relevance on a Likert-type scale. The item-level Content Validity Index (I-CVI) for the twenty-one items of the instrument ranged between 0.83 – 1.00. The Scale-Level Content Validity Index (S-CVI) based on the average method (S-CVI/Ave) was 0.96, and the S-CVI based on the universal agreement method (S-CVI/UA) was 0.76. The modified Kappa coefficient for twenty-one items ranged between 0.81 – 1.00 and the Intraclass correlation coefficient was 0.92.

Conclusions: The Sinhala version of DKAT2 is an informative tool with adequate cross-cultural, content validity, and test-retest reliability. It addressed both literal translation and verification of semantic and cultural adequacy of the words for use in the Sri Lankan context.

Keywords: Cultural adaptation, Dementia knowledge assessment tool, version 2, Nursing Undergraduates

OP4: Quality of Life and Perceived Stress Level among Informal Caregivers of People Living with Dementia in National Hospital Galle

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Background: Dementia is a global health concern. Since there is no known treatment for dementia, elderly patients with dementia need help from a variety of sources to live well until they die. A family caregiver or an informal caregiver is a person who assists patients in active daily living in the Sri Lankan environment. It is essential to improve the quality of life (QoL) for both patients and caregivers.

Objective: The study aimed to evaluate the quality of life (QoL) and perceived stress level (PSL) among informal caregivers (IC) of the people living with dementia in National Hospital Galle.

Methods: A hospital-based descriptive cross-sectional study was conducted with ICs of people living with dementia (n=102) who attended monthly clinics in the National Hospital, Galle. Caregivers' QoL and PSL of caregivers were assessed by the World Health Organization Quality of life BREF questionnaire and validated perceived stress scale respectively. Data were analyzed by WHOQOL-BREF scoring protocol, and descriptive statistics were used to describe perceived stress levels. A p-value <0.05 was considered statistically significant.

Results: The majority of participants (76.4%) were between the 40-59 years age group and married (85.3%). Nearly 71% of them were female and 87.3% had been educated up to GCE Ordinary level. The duration of caregiving was less than one year for 55.9%. The mean scores of QoL were 56.49 (\pm 17.19), 60.07 (\pm 13.47), 55.84 (\pm 19.34), and 57.85 (\pm 13.41) for physical health, psychological, social, and environment domains respectively. The low, moderate, and severe levels of stress were 8.8%, 74.5%, and 16.7% of ICs respectively. Physical health (p=0.000), psychology (p=0.000), and environment (p=0.001) domains showed a significant difference between education level and the QoL. The duration of caregiving was significantly associated with the psychological (p=0.047) and social relationship domain (p=0.013) of the QoL. The PSL was significantly associated with gender and duration of the caregiving.

Conclusion: The majority of informal caregivers had moderate perceived stress levels. The duration of caregiving affects both the quality of life and the perceived stress level (PSL) of caregivers. These findings emphasize the importance of specific interventions to support IC of dementia patients.

Keywords: Dementia, Informal caregivers, Perceived stress level, Quality of Life

OP5: Prevalence and associated factors of cognitive impairment among institutionalized older adults in Colombo district, Sri Lanka- Preliminary findings from a cross-sectional study

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Background: Population aging is a global trend where the proportion of older adults is steadily increasing which has become a socio-economic burden that leads to institutionalization. Psychological problems are common among institutionalized older adults including cognitive impairment that tends to go unnoticed and unaddressed.

Objective: The study aimed to determine the prevalence and associated factors of cognitive impairment among institutionalized older adults in Colombo district, Sri Lanka.

Methods: A descriptive cross-sectional study was carried out with the participation of 300 older adults (Age ≥60 years) who were not diagnosed with any psychiatric condition and given informed consent in randomly selected residential care facility homes for elders in Colombo district, Sri Lanka. The Montreal Cognitive Assessment tool (MoCA) was used to screen cognitive impairment along with a pre-tested questionnaire for socio-demographic information. Descriptive and inferential statistics (Pearson correlation, Pearson Chi square test) were performed by using SPSS version 26. Statistical significance was set as <0.05.

Results: The mean age of the study participants was 74.21 ± 6.47 years. A majority (62.3%, 187) were females. Of the participants, 41.7% (125) have been institutionalized for more than 3 years. Only 9.6% (29) of participants had education up to advanced level or higher. Most of the participants (69.0%, 207) have been diagnosed with at least one chronic medical condition. Prevalence of cognitive impairment (MoCA score <26) was 85.7% (257). There was a significantly negative correlation of MoCA score with age (r = -0.184, p = 0.001). Cognitive impairment was significantly associated with duration of institutionalization (p = 0.028). Gender, marital status, level of education, and diagnosis of chronic medical conditions were not significantly associated with cognitive impairment.

Conclusion: The prevalence of cognitive impairment was high in this sample. Advancing age and institutionalization were significantly related factors with cognitive impairment. It emphasizes the importance of screening for cognitive functions of institutionalized older adults to facilitate early detection of cognitive decline and implementation of comprehensive strategies.

Keywords: Cognitive function, Institutionalized, Older adults

OP6: Conceptual and Empirical item Hierarchies of Person-Centered Outpatient Care

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Background: The Person-Centred Care instrument for outpatient care (PCCoc) is a patient-reported experience measure consisting of 36-items with 4 ordered response categories, aiming to capture the degree of perceived person-centred care (PCC) from a patient perspective among persons with long-term conditions. The PCCoc is based on a framework that conceptualizes outpatient PCC from lower to higher levels of perceived PCC, from personalization via shared decision-making to empowerment, where 35 of the PCCoc items are a part of the hierarchy.

Objective: The study aimed to evaluate the degree of alignment between empirical item responses and the hierarchical PCCoc conceptual framework among individuals with long-term conditions receiving outpatient care.

Methods: PCCoc data (323 responses) from persons with long-term neurological, rheumatological, cardiological or psychiatric conditions was analyzed. The Rasch measurement model (RMM) was used to evaluate model fit and the empirical item ordering. Correspondence between the empirical and conceptually expected item hierarchies was assessed graphically and using the polyserial correlation between RMM-derived item locations and their a-priority expected rank order.

Results: Two items indicated a misfit to the RMM. The correlation between empirical item locations and the expected rank order using all 35 PCCoc items was 0.64; after removing the 2 misfitting items it was 0.71. In addition, subtests (i.e., testlets consisting of a combination of all items belonging to the respective domain in the hierarchy) were created to account for any local dependency. Subtest locations on the hierarchical continuum indicated good correspondence between empirical data and the conceptual hierarchy when based on 35 as well as 33 items. Both subtests had a correlation of 0.99 between testlet locations and the expected rank order.

Conclusion: There was a reasonable correlation between empirical data and the conceptual framework, indicating that the PCCoc reflects the underlying framework, and therefore can be a valuable instrument to support targeted PCC-promoting interventions.

Keywords: Person-centered care, PCCoc conceptual framework, outpatient Care

PP1: Role of Type 2 Diabetes Mellitus in the Pathophysiology of Alzheimer's Disease and Vascular Dementia in the Asian Population: A Literature Review

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Background: The global rise in Type 2 Diabetes Mellitus (T2DM) and dementia underscores a strong link between T2DM and neurodegenerative conditions, with T2DM increasingly implicated in the development and progression of Alzheimer's Disease (AD) and Vascular Dementia (VD).

Objective: This review aimed to explore the link between T2DM and cognitive decline, focusing on how insulin resistance and hyperglycemia contribute to AD and VD within the Asian population. It also seeks to evaluate dementia key risk factors contributing to AD and VD in individuals with T2DM.

Methods: A comprehensive search was conducted from 2015 to 2024 using Google Scholar, PubMed, Scopus and ScienceDirect to find peer-reviewed human studies on T2DM, AD, and VD, focusing on shared risk factors and pathophysiology. Eight studies met the inclusion criteria, with key search terms including "T2DM," "Dementia," "Alzheimer's Disease," "Vascular Dementia," "pathophysiological mechanisms," "risk factors," "Asian population," "insulin resistance," "amyloid plaques," and "cognitive impairment."

Results: The results indicate a strong link between T2DM and cognitive decline, particularly AD and VD. Insulin resistance in T2DM contributes to amyloid plaque formation and tau hyperphosphorylation, leading to neurodegeneration and cognitive impairment in AD. According to an Indian study, T2DM also exacerbates AD through chronic inflammation and oxidative stress. High blood sugar levels cause endothelial dysfunction and vascular damage, contributing to cognitive decline in VD. Studies show that T2DM patients diagnosed before age 50 face the highest dementia risk of 4.08 (95% CI: 3.18–5.24) for AD and 5.82 (95% CI: 3.84–8.81) for VD, with women at greater risk than men. Mild cognitive impairment (MCI) is prevalent in T2DM patients, especially women, and increases with age. Dementia prevalence varies across regions, with higher AD rates in late-onset dementia AD (p<0.001), and higher VD (p=0.029). rates in young-onset dementia.

Conclusions: This review emphasizes the strong association between T2DM and increased risks of AD and VD, particularly in those diagnosed before age 50, especially women. While age and gender are key risk factors, the observational nature of the studies limits causal conclusions, highlighting the need for further research on modifiable risks to improve dementia prevention and care, including potential antidiabetic therapies in Asian populations.

Keywords: Diabetes Mellitus, Alzheimer's Disease, Vascular Dementia Insulin Resistance, Endothelial Dysfunction

PP2: Engaging in Artistic Activities: Therapeutic Approach for People with Dementia

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Background: Dementia is a progressive disease that impairs memory, language and problem-solving skills and significantly reduces the quality of life of individuals, families and communities. The World Health Organisation estimates that more than 55 million people worldwide will be living with dementia in 2022, and this number is expected to rise to 78 million by 2030. Arts and crafts have been an integral part of occupational therapy since its inception, benefiting people with physical and mental impairments.

Objective: The study aimed to evaluate the therapeutic value of artistic activities for people with dementia and how these activities can be effectively integrated into their care.

Methods: Using an inductive, theory-based approach, the research focused on identifying the needs of people with dementia, developing tailored arts activities and evaluating the effectiveness of these interventions using a spiral modeling method.

Results: The results show that art-based interventions can reduce depression, anxiety and fear while increasing well-being, self-esteem and cognitive performance. The study found that artistic activities have a positive effect on mood, promote communication and strengthen the social relationships of people with dementia. In addition, occupational therapists can use the creative process to engage people at different stages of dementia and promote physical, mental and emotional improvements.

Conclusion: The findings emphasise the importance of integrating arts-based activities into therapeutic interventions for dementia care. These activities are highly adaptable and offer individuals the opportunity to express themselves creatively and improve their overall quality of life. The study suggests that incorporating arts-based activities into care plans can be of great benefit to both patients and carers.

Keywords: occupational therapy, dementia, quality of life, activities

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