Public Perception on Palliative Care

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Palliative care is specialized medical care for patients, by a multi-professional team when the patient’s disease is no longer curative, with the aim of improving quality of life of the patient and the family. When cure is not possible, as often it is not, the relief of suffering is the cardinal goal in Medicine and the heart of philosophy behind the science and practice of Palliative care. Palliative care was founded on a holistic philosophy encompassing the physical, psychosocial and spiritual needs of patients with life limiting illnesses and those of their families. Palliative care is a developing field in Sri Lanka, thus it is necessary to increase public awareness on palliative care and to create acceptance.

Delivery of health care is complex due to the diverse health needs of health service users. Involving patients and public in health care service provision is important in identifying the diverse health needs, in improving policy and quality of healthcare based on rights of the service users that are important in providing patient centred health services.

A public awareness programme on health care was jointly organized by Ceylon College of Physicians and the National Chamber of Commerce to commemorate the Golden Jubilee of the Ceylon College of Physicians of Sri Lanka. Palliative care task force of SLMA organized a programme comprising of an exhibition stall on palliative care and a symposium for the public to increase awareness and knowledge on palliative care, and end of life issues which is a relatively new concept in Sri Lanka. The Healthcare exhibition “Mahajana Suwa-Dhana”, which was the first public exhibition held by specialist medical professionals was held successfully from the 14th to the 16th of July at the BMICH Colombo.

The objective of the programme was to link the public with the experts to increase public awareness on palliative care and end of life issues. Some of the activities organised during the exhibition were, directly interacting with the public to clarify their doubts, demonstration of palliative care services through videos, providing opportunity to discuss their problems with a consultant and a nurse, a tree of life was available for the public to express their perceptions on palliative care on sticky notes and a symposium on palliative
care. The symposium on palliative care was successfully conducted by, Dr Jayantha Balawardena (Senior Consultant Oncologist / currently Senior Lecturer at the Kotelawala Defence University), Dr Panduka Karunanayake, President Elect CCP and Senior Lecturer, Faculty of Medicine, Colombo, Dr Dilhar Samaraweera (President / Sri Lanka Association of Geriatric Medicine Chairperson/Palliative care task force and Dr Udayangani Ramadasa (Convener/Palliative care task force) and Dr Hemantha Kumarihamy (Consultant Anaesthetist).
The perception of the public on palliative care and end of life issues was obtained following this programme, and analysed manually. Majority had stated that palliative care is very important to patients and their families, “very useful information for individuals facing problems, they can be helped to solve their problems”. "මෙයින් ජාතික ප්‍රාදේශීය මෙහෙයින්". It was also emphasised that palliative care will be useful for Sri Lanka and that the service should be accessible to the public, “This service should be taken to the public and it should be spread around the country to access services”. "නමුත් එකක් පවතී මෙහෙයි මා එකක් පවතී මෙහෙයි ගැනීම් රාශියේ පැවතී ගැනීම් මාදියේක්".

“A very useful service for Sri Lanka, as we are facing the problem of ageing”. "මෙයින් එකක් මා පවතී මා ගැනීම් තොරතුරු ගැනීම් ඒරියකම් අභයා ඇත".

“Since it is a useful service for Sri Lanka, this should be developed to improve quality of care of patients with incurable diseases”. "මෙයින් එකක් මා මා ගැනීම් ඒරියකම් අභයා ඇත".

“This is very useful, have looked at an aspect of care that is neglected in the society”. "මෙයින් එකක් මා මා ගැනීම් ඒරියකම් අභයා ඇත".

Some had stated that the service will be able to improve quality of life of patients.
“A very good service, can improve the quality of life, and can gain merits for people doing the service”. "ඇයක් ලකුණු බොහෝ ප්‍රාදේශය ගැන පළමුවන්ට පාලනය කළ බවට පත්වින් පියැවේ. පෙළමුතු කරන්නේ සිටිමින් පිළිතුරු පෙන්වමෙන්ම අමිතයක් කළ නොමැත”.

“Everybody will have to face this someday, but some of us will face this without getting prepared. Someone who has to face this needs lot of skills”

The other benefits stated were, ability to care for the patients in their home setting, ability to provide good care till the death of the patient.

“It is a very useful service, including home care, and social service”. "ප්‍රාදේශය තුළ මහනුවර යිරීමට සහ ගොඩනැගුරු පොළොක්දොරට මහනුවර වීමට පෙන්වමෙන්ම අමිතයක් කළ නොමැත”.

“This service can be useful to improve care of individuals till death”

“Very worthy work for helping the people to die in dignity”

It was also stated that it is important to develop the service through assistance from the government as well as the private sector, and that media could be involved in educating the public regarding the service.

“Should obtain government assistance as well as assistance from the private sector”

“Very useful to have such informative and educational programmes to educate us on services like this”. "පිළිබඳ තුළ මහනුවර යිරීමට පොළොක්දොරට මහනුවර වීමට පෙන්වමෙන්ම අමිතයක් කළ නොමැත”.

"It will be useful to obtain the services of the media to educate people about this service”. "පිළිබඳ තුළ මහනුවර යිරීමට පොළොක්දොරට මහනුවර වීමට පෙන්වමෙන්ම අමිතයක් කළ නොමැත”.

“Today we learnt that there is a way for a pain free peaceful death at the end stage of life. I wish further success for the palliative care service”. “මෙමදද අතුර්මයි නිදහස් බවට අතුරන්තව අක්ලකුණු මැදිනවා කළ බවට අතුරයි කාරනුමූලයෙන්. මනුවු string අතුරු කෝන්ට් තිරගත් විශ්වාසයක් කළ නොමැත”. 
“Palliative care is a very important caring service for our patients” “இளையூருக்கும் திறனான கல்லையைச் சேர்த்து கட்டுப்பகுதிகளையிட்டு அமைப்பேல் தாம் அதன் திறனை அதை”.

“Palliative care is very important when there is no cure” “இன்பத்திற்கும் பாதிக்கப்பட்டு கையாளப்படும் பாதிக்கும் கையாளப்பட்டிருப்பது இல்லை அதனால் கிளகு பகிர்கின்றானால்”.

**Implications for policy, practice, and teaching and training**

Palliative care needs to be strengthened in Sri Lanka to provide holistic care for patients with incurable diseases. When considering developing Palliative care it is essential to focus on education and training of existing staff, and to incorporate this in to under graduate and postgraduate curricula of heath care providers, create advocacy among health care providers and the general public. A National steering committee for palliative care has been established.

Medical education in palliative care needs to be introduced to undergraduate and post graduate curricula of medical practitioners as well as nursing and other allied health care workers. A training of trainers programme was carried out with the assistance of Lien Foundation Singapore, Asia pacific Palliative care network through National cancer control programme to train the existing staff. A Diploma curriculum for medical officers has been approved by the UGC and the PGIM has taken the initiative in commencing the programme.

We need to consider policy development and legal aspects, and improve drug and service availability and to incorporate this service in to the health care system through establishing palliative care services in hospitals and the community. Research and audit is an essential component in developing care plans that are acceptable to our culture, lifestyle and believes.
References

