

Replicating a Collaborative Partnership Model in providing a Sustainable Palliative Care Program to the Community

Fahisham Taib¹, Rosmawati Mat Ali²

¹ School of Medical Sciences, Universiti Sains Malaysia, Kubang Kerian, Kelantan, Malaysia

² Faculty of Medicine and Health Science, Universiti Sultan Zainal Abidin, Kuala Terengganu, Terengganu

Abstract

Paediatric Palliative Care (PPC) is a relatively new sub-specialty in Malaysia. Universiti Sains Malaysia (USM) under the Division of Community & Industry Network (DICN) has initiated a community engagement and collaborative project with the Foundation for Disabled People in Kelantan (YOKUK) from 2012 through knowledge transfer training programme. The service focuses on an outreach and holistic PPC approach for pediatric oncology and life-limiting illnesses patients. The aim was to provide multidimensional care including needs assessment; nursing and personal care; support programme; psychosocial and bereavement support in the community. The knowledge transfer programme starts by disseminating palliative care knowledge to targeted health care professional; training of staffs for community work; preparing parents of children with life limiting illnesses with adequate information; facilitating access to medical care and educating the public on care at end of life issues with compassion. This is a novel university-led programme in an untapped and under resourced area by collaboration with the non-governmental party thus creating a viable and expanded outreach services to the community. Other sustainable success was the involvement of students as volunteers, formation of parental support group and availability of modular workshop for references. The next step is to provide a joint venture replication of the model in the planned state such as Terengganu to ensure sustainable outcome of PPC service outside Kelantan.

Keywords: *community engagement, palliative, pediatrics, knowledge transfer programme*

Introduction

Palliative care service for children in Malaysia is relatively non-existence for majority of the cases of life limiting illnesses. The Ministry of Health (MOH) has created hospice care in the government vicinity (Leong, 2004), however, the service only focuses for certain discipline of medicine only. It remained as an unexplored and neglected area due of absence of trained personnel, unavailability of community support, inadequate specialised equipment and lack of investment and funding to children's end of life care programme. Effort has been made to

* **Corresponding author.** Email: fahisham@usm.my

change the perception among the healthcare professional through continuous education and advocacy on palliative care subject. Lack of exposure to PPC has become a stumbling block to skeptical healthcare professionals on the importance of the service throughout the country.

Children comprise about 37.3% of the Malaysian population. It is crudely estimated that approximately 9590 children will be diagnosed with life-limiting illnesses (LLI) annually in Malaysia (Knapp et al, 2012). Most of childhood death in Malaysia is related LLI such as congenital malformations, chromosomal abnormalities and chronic illnesses. Children with cancer accounted for a small in number compared to LLI. These patients suffer from a complex medical, social and spiritual difficulty. Delayed seeking treatment is commonly seen and is related to various psychosocial influences—family preference to alternative therapy, referral system failure, diagnostic uncertainties, family objections to treatment and rigid cultural beliefs.

Importance of palliative care

Palliative care is an approach that aims to improve the quality of life of the patients with LLI by identifying the needs of the patients and their families. This is achieved through the prevention and relief of suffering by means of the early identification, assessment and treatment of physical, psychosocial and spiritual problems (Hemelstein et al, 2004). Many children with LLI in the community have a shorter life span due to inadequate care and poor palliative care provision. These children are left without adequate community based healthcare support. Psychosocial, emotional and spiritual dimension are often ignored and regarded as sensitive area to be addressed. Palliative care service should be geared in a holistic manner with community support to the patients and family members even into their bereavement period.

Objectives

The project was commenced under DICN, USM as pilot community engagement programme in Kelantan. The main objectives are:

- (1) Educating healthcare providers in the hospital and community with various skills of physical, emotional, spiritual and psychosocial assessment and management. This is done by sessional workshops with certification by the Department of Paediatrics, USM.
- (2) Collaboration with YOKUK to provide a sustainable outreach programme in the community. Funding and staffs have been provided for YOKUK. Training was organised locally at Hospital USM, Hospital Raja Perempuan Zainab II, Hospis Malaysia, Klang Hospice and Perak Hospice Association. This helps in networking, training and partnership in education.
- (3) Developing module for palliative care programme – Pain management, Needs assessment, Social care, Play therapy, Advanced care planning and therapeutic communication.
- (4) Continuation of Parental Support Group to provide moral support and sharing of experience and information. The new way is to include parents into WhatsApp application to allow continuous communication with healthcare personnel.

Methodology

The hospital serves as referral centre for managing many acute and chronic diseases. There are few hospitals which have in-built palliative care ward for terminally ill patients. This only applied for adult with chronic diseases following MOH effort to expand the palliative care services in Malaysia. Family structure is still considered strong in Kelantan and usually relatives live close by to support and help each other. The programme in Kelantan uses a two prongs model. The first prong is to create functioning palliative care team that based in the hospital vicinity. Pediatric palliative care has yet to receive a recognition and the service on voluntary basis. This has allowed advocacy of palliative care to the USM community, sustainable running of the service, utilisation of hospital resources and continuous medical education to the targeted hospital community. These advocacy programmes run in parallel with education of the grass root, especially the medical students, in relation to palliative care approach.

The second prong approach is via providing community outreach service by community network such as YOKUK (Yayasan Orang Kurang Upaya Kelantan). YOKUK is a non-governmental organisation which serves disabled people in term of community rehabilitation, education dissemination capacity and training for handicapped clients. The initial part was to train staffs using module under the specialist guidance. The training is based on adult self-learning followed by group discussion and problem solving learning. Staffs were given opportunity to polish their clinical skills by attaching to the appointed hospitals prior to working independently in the community. The goal of training was to be able to perform a thorough needs assessment, nursing care and giving a moral and spiritual support. Trained staffs are monitored and supervised by an experienced nurse coordinator. The pilot project initially covered a small number of pediatrics patients especially those who live in Kota Bharu district.

These nurses also functioned to become advocate for palliative care, disseminating information, training caregivers and addressed difficult issues such as advanced care planning and end of life care. During this time, psychosocial, emotional, spiritual interventions and bereavement support were offered even to the family members (Benini et al, 2008). The healthcare workers must strive to improve their skills by regular getting into regular education and training programme. They also had the chance to visit other hospices for networking and collaboration. Modular teaching are produced based on the completed educational workshop. Education skills are directed towards preparing trained community nurses and volunteers with broad theoretical competency. The regular educational activities were conducted in YOKUK on weekly basis. There were 9 nurses completed the training module, and largely involved to support and empower patients and family members. For parents, support group was formed to ensure parent to parent indirect education and sharing of experience through cyberspace.

The team members consist of multidisciplinary teams require to work together in a common goal and objective. The hospital provides specialist consultation, medications and equipment for patients' supply. YOKUK plays an active role for outreach visit in the community with the support from specialist guidance. There is also opportunity to educate parents and caregivers for specific palliative care skills such as therapeutic communication. Interventions, either in the hospital or community level, are designed to get patients well and functioning normally by putting '*life rather than days*' into patients' and family's experience. It is hoped a comprehensive and holistic approach can be achieved despite limited funding.

Replicating the project is done by partnership with other university to further transfer of knowledge and skills outside the locality. The initial workshop was planned with Universiti Sultan Zainal Abidin (UnisZA) in Terengganu as the potential collaborator. Similar exercise was done to empower personnel with the concept of palliative care. Budget and distance remained an issue to continue outside USM. The team from UnisZA was invited to join local workshop at YOKUK for practical experience and skill improvement. Future plan was to embark on

dissemination of knowledge to other locality such as at the Advanced Medical and Dental Institute (AMDI) in Bertam, Penang.

Results

The PPC is a novel venture of service with the aim at improving quality of life and alleviating suffering on the pediatric patients with chronic illnesses. The project was initiated using DICN service grant to target on '*bottom billion*' or those who required care in the population. Niche area of community engagement programme includes producing a sustainable service to the respective patients, training educational programme for the healthcare workers, parents and volunteers on Pediatrics Palliative Care skills. The course content (Table 1) is converted into module for future references and replication of the programme. Sustainability comes from collaborative manpower provided by YOKUK, external grant for the service to move, parental support group, informative website, parental chat group for communication.

	Knowledge Transfer Programmes
1	Introduction to Pediatric Palliative Care
2	Needs assessment
3	Play therapy I – Introduction for Play Therapy
4	Play therapy II – Bereavement
5	Therapeutic communication
6	Social care
7	Pain assessment
8	Spiritual care
9	Advanced Care Planning
10	Parental Support Group & volunteerism

Table 1: Workshop held in the community engagement pediatric palliative care in Kelantan

The number of required workshops for the project was derived and modified from Specialist Certificate of Palliative Care (SpecCertPallCare) course at the University of Melbourne. The degree was individually obtained by the author prior to commencement of the project. Collaboration with internationally recognised centres such as Taiwan Medical University and Universitas Jogjakarta was made for training, networking and exchanging experience (Table 2). This was successfully achieved due to previous agreement and partnership between School of Medical Science and respective universities. YOKUK was identified as the collaborator from a long term history of service to the community. The initial consensus was to establish a pilot programme using a freshly trained nurse to engage in the PPC service. Significant external fund was obtained to sustain YOKUK outreach community service for 3 years.

	Level	Collaborator	Purpose
1	Local	Yayasan Orang Kurang Upaya (YOKUK)	Service in the community
2	National	Hospis Malaysia Klang Hospis Perak Association of Palliative Care	Training and collaborative partnership
3	International	Taiwan Medical University University Gadjah Mada	Exchange of experience and partnership

Table 2: Collaborators during the ongoing project for training and service

Involvement of the government and non-government sectors are important part of service delivery and community engagement plan. The team has invited Majlis Agama Islam Kelantan (MAIK) to produce local spiritual approach for end of life. This can be an important steps to demystify taboo, refine information and make it more relevant to the local community. Collaboration with undergraduate medical students was formed to participate in Community and Family Case Study programme (Taib et al, 2014). The step has allowed students to explore and research in the palliative care subject using dispersed learning. Elective programme involving Year 3 medical students also is valuable insight whereby these students went for home visit with palliative care nurse, and performed qualitative exploration of psychosocial and spiritual aspects of the patients. The elective attachment has successfully garnered humanistic, compassionate and empathic values in the students when learning medicine outside the scope of hospital care. Training sites for the nurses have been identified locally using Hospital Raja Perempuan Zainab II and Hospital USM. The trained nurses was also sent for a short attachment with Hospis Malaysia, Klang Hospice and Perak Association of Palliative Care. The collaboration for different hospices were done through networking and joint venture programme. Collaborated training programme has been seen as potential extension of experience to YOKUK and staffs. Palliative care programme also actively involved in the other community engagement such as SOS-OKU II (Sustainable Optimal Service for Orang Kurang Upaya), USM-RICD (Rajanagarindra Institute of Child Development Chiangmai) wheelchair project, management of bedridden patients and creation of one stop Centre for Family Support Group. Author has been actively involved as trainer in the PPC programme set up locally, nationally and internationally to advocate palliative care programme in Malaysia.

Module development phase involves capturing information on various aspect of care. The focus is to devise guideline for general approach, communication techniques, spiritual care, play therapy, volunteerism and assessment of needs of the patients and family members. Completed knowledge from the organised workshop is then used through replicating palliative care model to the other area. Communication channel has been diversified using cyberspace, thus this has improved care and consultation between healthcare professionals.

There were a total of 38 pediatrics patients enrolled in the pilot programme. The patients were selected based on disease status either relapsed malignancy, late stage disease, defaulted treatment and patients who were on palliative chemotherapy. Patients who have poor prognosis of LLI were also selectively considered. Most of these patients live in Kota Bharu district and only a small percentage live outside the mapped area. Since the project inception 10 patients have passed away during 2 year service period. The service was performed initially by a single nurse and earlier this year further 8 personnel were recruited. Type of service includes nursing care, psychosocial support and needs assessment. Medical problems will be communicated between the team members and the specialist from the hospital. A nurse supervisor has been employed in the team to ensure monitoring of staffs competency, health navigations for the family and day to day management of the team. Detail of the outreach activities by the nurses are captured and revised regularly. The team progress is monitored through weekly team discussion and academic update.

Discussion

Palliative care models worldwide were built with different approach depending on availability of resources, funding, manpower and expertise. Our community engagement model in Kelantan is built to tailor the local needs and suit partnership between USM and community group. This is perhaps the first model in palliative care setting, by using university to transfer knowledge and skills to the local community through NGO. USM through DICN, has allocated a service grant for the university researchers to deliver a high impact community engagement project (Abdul

Razak, 2009). This is seen as win-win strategy for both university and the community. Smart partnership and community empowerment is achieved by education of volunteers and medical grass root, development of sustainable service and creation of support system to parents. Pediatric Palliative Care programme focuses on care of children with LLI, whom majority of them are deprived from getting optimal medical care. The scope of work for end of life patients' can be challenging. Statement like '*nothing else can be done*' reflects overgeneralisation and oversimplification of medical fraternity to palliative medicine leading to inappropriate action to these patients.

There are not many emphasis on palliative care education even in medical schools in Malaysia. Galvanisation of the interest requires paradigm changes to accommodate with the scholarship progress. Malaysia is known with its diverse population with multiracial, multicultural and multi religion background. Individualised approach to palliative care in Malaysia is required due to individual preference and family choice (Taib, 2013). Many of the patients' needs are complex with multiple psychosocial issues. The effective decision making is negotiated throughout consulting process to find suitable goals rather than favouritism. Educational activities cover the development of the team skills, advocacy to local community and creating awareness for voluntary work. Life-long palliative care programme help to influence the community into common attitude and interest. In patients' education, information regarding their right and available support in the community should be disseminated. Discussion with stakeholders is essential to move PPC service forward.

Documentation and data capturing are important for research purpose and improvement. Palliative care should not be static, but has the ability to cover the demand of the society. Research has to focus on improving the quality of life, quality of care, quality of death by relieving the suffering. The project has community engagement element from angles – training of healthcare professionals from workshops allocated, recruitment of volunteers and grass root on the work, collaboration with non-governmental organization (YOKUK) for outreach service and creation of parental network like Parental Support Group (Table 3) to ensure knowledge transfer and community empowerment on long term basis.

	Method	Outcome
1	Workshops	Trainee from YOKUK Certification and recognition of PPC training Memorandum of Understanding (MoU) with YOKUK
2	Manuscript retreat	Module PPC in Bahasa Melayu
3	Workshops & YOKUK's involvement	Volunteers & Students attachment to YOKUK for outreach service
4	Whatsapps application	Parent Support Group
5	Outreach education	Collaboration to replicate project in UnisZA

Table 3: Sustainable impact and outcome of PPC project

Replicating the Model: Future Planning

Successful training model by collaborative partnership has triggered further evolution of training elsewhere as part of community engagement model. This chain reaction perhaps better modelled when collaboration by university to university transfer of knowledge and hence the second university identified to partner further with the identified community locally. Future partnership between USM and Universiti Sultan Zainal Abidin (UnisZA) in Terengganu has opened up bilateral training opportunity and cooperation. The set up in Terengganu may be

different and the model should be tailored according to local set up. To ensure successful and fruitful programme, the Ministry of Health should be brought together to complement the gap of service. Domiciliary homecare team is an established service to help debilitating patients in the community but the approach to pediatric patients is still minimal. Perhaps UnisZA – MOH collaboration will spark out new initiative of patients' care. The presence of 'Dasar Baru' of MOH perhaps will be vital steps in pushing PPC up for service engagement. Pediatric Palliative Care should also be utilised medical students from UnisZA for practical and community experience as grass root experience may eventually help to better understanding of PPC approach.

Conclusion

Pediatric palliative care has been seen as an untapped area due to many social and medical reasons. It has moved towards more non-governmental and community engagement responsibility. Sustainable PPC program using carefully designed educational activities, community empowerment and support group in the community could drive the service forward. 'Home-based' pediatric palliative care with outreach service perhaps should be a way forward in a diverse society such as Malaysia.

Acknowledgements

The author would like to thank DICN for providing a grant for the community engagement project (pediatric palliative care patients) in Kelantan. Secondly, all the Sayangku Homecare team members who have worked hard to contribute to the success of this project.

References

- Leong, R.B. (2004). Palliative Care in Malaysia: A Decade of Progress and Going Strong. *Journal of Pain & Palliative Care Pharmacotherapy*, 17(3–4), 77–85.
- Himelstein, B.P., Hilden, J.M., Boldt, A.M., Weissman, D. (2004) Pediatric Palliative Care. *N Engl J Med*, 350,1752–1762.
- Benini, F., Spizzichino, M., Trapanotto, M., Ferrante, A. (2008) Pediatric palliative care. *Italian Journal of Pediatrics*, 34(4), 1–9.
- Knapp, C., Madden, V., Fowler-Kerry, S. (2012). *Pediatric Palliative Care: Global Perspectives*. p.109–126. Springer: London, New York.
- Taib, F., Mohd Fakri, N.M.R., (2014). Revitalizing Community and Family Case study. *Education in Medicine Journal*, 6(3),e46–e50.
- Abdul Razak D. (2009) USM Apex University Status: Transforming Higher Education For A Sustainable Tomorrow. *Malays J Med Sci*, 16(1), 1–6.
- Taib, F. (2013). Family involvement in palliative care – Malaysia's View' in inter professional work in enhancing family roles in palliative care: Lesson learned from several countries. *Proceeding of the International Palliative Care Seminar*, School of Nursing, Faculty of Medicine, Universitas Gadjah Mada, Yogyakarta.
- Farish, J. (2014). University-Community Engagement: Empowering the Community. *International e-Journal of Community & Industry Engagement*, 1, 49–56.