Original article

Pediatric Palliative Care in Kelantan: A Community Engagement Model

Taib F[1], Rostenberghe HV[2], Muhammad NA[3]

Abstract:

Holistic package of palliative care service for children is not available in most places in the South East Asia. This has resulted in unwanted suffering and loss of hope in the unfortunate families. Pediatric palliative care (PPC) is a new subspecialty in Malaysia. In our region, it was started in 2012 as a University's '*community engagement project'* following completion of self-initiated palliative care distance learning in Australia by a pediatrician. The grant was labeled as a flagship project and secured under the Division of Community & Industry Network of USM (BJIM) to provide service in the hospital and outreach home based PPC services, which include nursing care, needs assessment and psychosocial support for the patients and caregivers. '*Knowledge transfer program'* was initiated, in collaboration with Yayasan Orang Kurang Upaya (YOKUK) or Kelantan Foundation for the Disabled, to equip the outreach team with skills dealing with children with life limiting illnesses (LLI) in Kelantan. The move has propagated regular training setup with transformational program from hospital to community settings. This setup has led to mutual cooperation across the disciplines and provided linkages for stronger networking and training either locally or internationally. Better understanding on the importance of palliative care in the community can be achieved by having active community participation and volunteerism.

Keywords: pediatric palliative care; knowledge transfer; life limiting illnesses.

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Introduction:

Palliative care worldwide is slowly becoming more accepted as a vital and necessary part of medicine. The aim of medicine is to find cure but in certain circumstances cure is not possible. To stop continuity of care is no longer acceptable at that stage. Our care should be continued and perhaps intensified to achieve a holistic and integrated approach, not only on the physical, but also on the social, emotional, psychological, financial and spiritual plane.

In most developed nations, palliative for both adults and children is well established. In contrast to developing nations, this is often not the case. The World Health Organization (WHO) and large international organizations have reported multiple success stories of establishing local palliative care service for adults and children alike in some of the poorest African countries, including Zimbabwe, Nigeria and several other countries. In the middle income countries, acute care is often preferred and this has significantly reduced the mortality in these countries. However, extended care for the chronically ill patients in the community is poorly developed especially for palliative care. There are handfuls of international organizations which offer help in the palliative services. Local initiatives by individuals, and adequate support from local government and non-governmental organizations, are seen as a stepping stone towards successful and sustainable project in the long run.

We describe a novel approach where an individual doctor ensured his own training, obtained a substantial grant from a national university that had a campus in the region, and worked closely together with an established foundation for people with disabilities to establish palliative care service

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1. Fahisham Taib, MB BCh, MRCPCH, MMedSci, DCH Spec, Cert Pall Care, Pediatrician, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan.
2. Hans Van Rostenberghe, MD. Professor of Pediatrics, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan.
3. Nurul Adilah Muhammad, Diploma in Nursing, Staff Nurse, Yayasan Orang Kurang Upaya (YOKUK).

Corresponds to: Fahisham Taib, Pediatrician, Hospital Universiti Sains Malaysia, 16010, Kubang Kerian, Kelantan. **E-mail:** fahisham@gmail.com

for children. This care is among the first one in Malaysia with its own unique model of integration at different levels of care.

Status of Pediatric Palliative care in Malaysia:

Palliative care service is largely scarce in South East Asia (SEA) and in particular to the East Coast of Peninsular of Malaysia. Pediatric palliative care in Malaysia is coordinated by with the adult-palliative care services and the non-governmental organizations typically concentrated in urban area[3]. Different model of care have been applied to cover specific needs of the patients in the community. The outreach services range from nursing care, social support, multidisciplinary team involvement and spiritual care. Holistic care for children is a challenging task due to majority of the chronic debilitating patients is inadequately assessed of their personal and clinical needs as a result of misunderstanding of palliative care concept.

The Malaysian government has established a palliative care (PC) initiative for adult patients since 1991[2]. However, the service has benefited only certain group of patients especially cancer patients. The adult PC services have progressed with the establishment of national training program and centers, and the appointment of adult palliative care specialists in Malaysia. In contrast, pediatric patients with life-limiting illnesses (LLI) either from the hospital or community setting have received minimal PC support. Malaysia's population was estimated to be around 28 millions in 2010 and further increased in the future. Children account for 37.3% of the Malaysian population. There is no existing database to estimate the prevalence of LLI among children in Malaysia. It is crudely estimated, by referring to the prevalence study in the western countries (10 per 10000), that the annual estimation of children with LLI in Malaysia is around 9590[3]. The number may be under representative of its true scale. The common causes of death for children in Malaysia are due to congenital malformations, chromosomal abnormalities, infections and poisoning. Most of these children died in the hospital despite knowing their incurable disease status. They could have been managed effectively with familiar surroundings, holistic care and supported by the palliative team in the community.

HUSM is a tertiary university hospital located in Kubang Kerian, Kelantan, a North East state of West Malaysia. The hospital is tertiary referral centre for childhood cancer service covering 3 states – Kelantan, Terengganu and Pahang. It has 730 bedded capacities providing all type of services including pediatric oncology and palliative care[6]. There are estimated 50 new oncology cases that are referred for treatment annually. Palliative care service has been relatively a new discipline to HUSM. Currently, it has no infrastructural and monetary allocation. In the hospital setting, the service works by accommodating interdisciplinary teams on consultative basis. Referral made will be seen by specific team following suggestion by the palliative care team. The community service network is extensive but it focuses more on preventive medicine and maternity-child care. Many children with LLI are poorly supported. This gap of service has lead to the formation of home based palliative care with the help of USM partnership. Malaysian's social structure is quite stable depended on the close kinship and family who live together in close proximity. Addressing cultural and psychosocial beliefs between different sections of the community is also an essential element.

Late presentation with metastasis is a common scenario especially in pediatric patients with solid tumor. The behavior was influenced by socio cultural context such as seeking treatment with traditional healers, poor or failure of the referral system, diagnostic uncertainties, family objections to treatment and rigid cultural barriers. As a result, these children are managed sub-optimally with the input from faith-healers or unqualified personnel.

The World Health Organization (WHO) has suggested that people with LLI should have palliative care assessment throughout their illness trajectory. 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[7]. The practice of palliative care includes providing relief from pain and other distressing symptoms; affirming life and regards dying as a normal process; intending neither to hasten nor postpone death; integrating the psychosocial, emotional and spiritual aspects of patient care; offering a support system to help patients live as actively and normally as long as possible until death; offering a support system to help the family cope during the patients illness and in their own bereavement; using a team with multidisciplinary approach to address the needs of patients and their families and early care in the course of illness, in conjunction with other therapies that are intended to prolong life[8].

Methodology:

The development of service is unique depending to geopolitics, population needs, resources availability, education, training and the presence of the other supportive services. Various models have evolved internationally to cater the needs of malignant and non-malignant conditions LLI in children. This group of children utilizes many ranges of services and supports from the service within pediatric specialties, palliative care and disability sectors; as well as community-based support agencies.

Kelantan Foundation for the Disabled (YOKUK) has been selected as the collaborative partner in this first service for PC children. YOKUK is a charitable organization establishes to alleviate plight of people with disability. It has 3300 registered clients with different form of disabilities and also provides physical therapies, welfare services and vocational training. Community-based rehabilitation is the fundamental training for the locals to help disabled person in the community.

The first phase of the PC model development involved the initiation of PC distance learning by a pediatrician in Australia. Upon completion, certification of PPC was obtained and BJIM grant has been applied to develop the pilot service in Kelantan. The grant was secured in 2012 and it was intended to be used in palliative care knowledge transfer to the healthcare providers, family members and the community in parallel to service development. The training programs include knowledge transfer from academic personnel through workshops in stages. The trainers also actively participated with outreach training within local, national or international by providing information, advocacy's role and participation to education. This is part of the knowledge transfer and sharing information outside Kelantan. In term of service, we were able to empower one nurse to cater mainly 30 pediatric oncology patients at a time. The area coverage at that stage is only a single district in Kelantan. The focus of PPC is by performing needs assessment, giving psychosocial support and nursing care. Medical issues will be dealt by hospital team in view of minimal community support at this stage. The second phase involves YOKUK contribution in obtaining sponsorship in order to hire further PC personnel. We were fortunate to have significant corporate community contribution by recruiting further 10 personnel – 5 Palliative Care Nurses and 5 Palliative Care Therapists. This will allow 5 units of team to work simultaneously across state of Kelantan for free. The training of new personnel was modified from the topics in distance learning (Australia) and used as self learning module during the meeting. The meeting has allowed debriefing, discussion on difficult cases and presentation of modular self learning. The outreach and home based care will be monitored by experience nurse supervisor for training competency, and she also act as nursing navigation for the patients and the family. The medical personnel will be involved in the steering committee by monitoring progress and performance. Feedback of patients and caregivers are valuable tools to indicate knowledge and practical competency. At times the palliative care nurses and therapists attended attachment at the hospital setting to improve confidence and skills guided by the trainers from various backgrounds. This includes communication skills, spiritual assessment, counseling session, play therapy and providing information technology (IT) literacy. Ethical approval was taken locally prior the study

Results:

The initial phase was to employ single experienced nurse to be involved in the knowledge transfer program. With the seed grant of 100k, allocation was made to develop structure training workshop for healthcare providers and trainee. Medical students were also involved as part of Community and Family Case Study and active participation. Further to that, the nurse was sent to Hospice Malaysia to sample experience and practical competency. Further university collaboration was achieved with Taiwan and Indonesia counterpart hence the trainers were able to visit respective countries to develop networking and collaboration in palliative care. In 2014, YOKUK has received handful amount of grant to expand the program. Later recruitment has shown better application and we have created 5 further units with the supervision from an experienced nurse supervisor.

We recruited total of 38 patients to date. The patients were selected based on disease status either relapsed malignancy, late stage disease, defaulted treatment and patients who are on palliative chemotherapy. Patients who have poor prognosis of LLI were also selectively considered. Most of these patients lives around the Kota Bharu district and occasionally we visited patients in the outskirt. There were 10 patients who have passed away and 5 of them had relatively stable disease. We have set a ratio 1 nurse to 30 patients in order for the care to be given effectively in the community.

Type of services includes nursing care, psychosocial support and needs assessment. Medical needs will be communicated between the team members and covered whilst the patients are in the hospital. The nurse supervisor has a major role to play. She acts to monitor competency, health navigations for the family and day to day management of the team. All detail outreach activities by the nurses are captured and revised accordingly. There are 5 new PC nurses together with 5 PC therapists appointed. The importance of PC therapists is to assist in the care of the patients and providing other technical and physical assessment whilst visiting patients in the community. The academics within the steering committee will function to monitor team progress as a whole and specific medical problems will be dealt by respected pediatrician or physician.

Knowledge transfer activities include formation of regular workshop to cover important practical and clinical skills in palliative care. This was achieved through the BJIM grant. The initial part involved author's completion of PPC modules in Australia. The second part involved designing local modules to impart knowledge and understanding to the team, healthcare professional and caregivers. Active involvement in media discussion and also invitation to represent the local PC team is an essential recognition and participation to disseminate information and interest in palliative care. The author has been involved in series of PC sharing information discussions in Indonesia (Universitas Gadjah Mada), Taiwan (Taiwan Medical University) and India (Tata Memorial Hospital).

The grant is designed to implement the service and formation of the PPC service. Using external grant, graduate interns are employed to explore and study on organizational activities of the service, spiritual care in children, quality of life in certain LLI, according to cultural context and needs. Other approach would include designing on spiritual model and approach to terminally ill children.

Discussion:

Universiti Sains Malaysia is known as the APEX University – a university which is striving for continuous excellence by having transfer the knowledge programs to empower the 'bottom billions' or community in parallel with the university aspiration. APEX or Accelerated Program for Excellence is a program which is implemented by USM in 2008 to achieve integration of sustainable educational systems to the community in order to produce a sustainable world, humanity and future[8].

The new PPC model consisted of two prongs approach. The first prong deals with the formation of service in the hospital vicinity. It is designed to support consultation of cases, and synchronizing contribution of other disciplines such as psychologist, medical educationists, allied health professionals, social workers and religious officers for the service. Regular palliative care discussion is important to get mutual agreement on effective palliation for children with LLI.

The second prong is through the community engagement and patients' outreach project. This was done by collaboration with the Foundation of the Disabled People in Kelantan (YOKUK) for outreach services and manpower in the community.

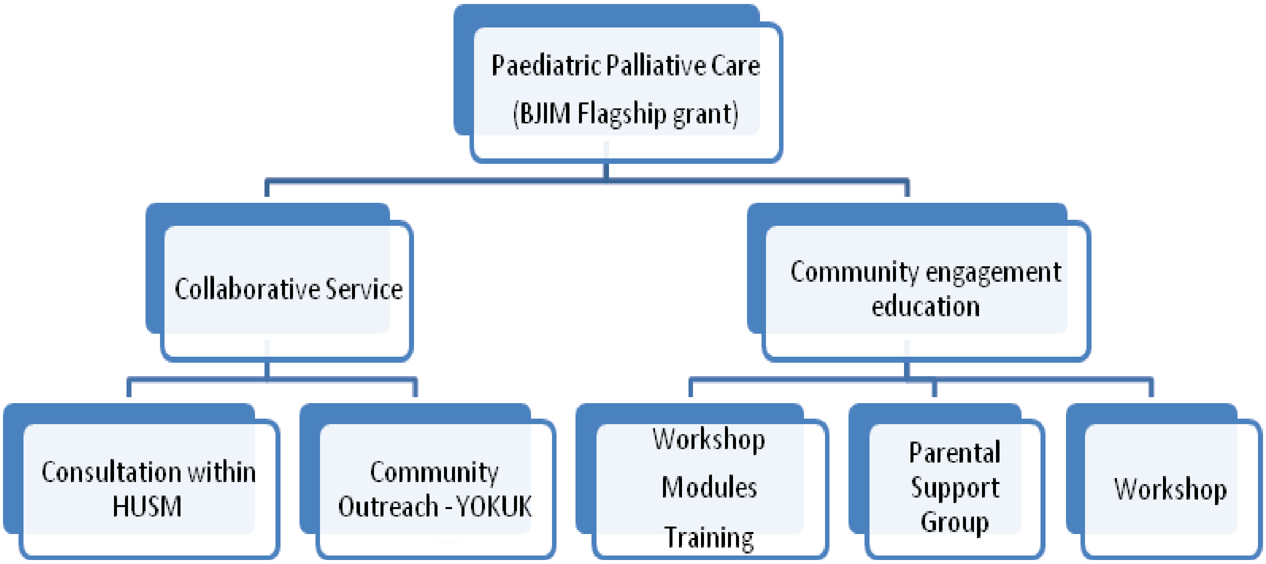

Figure 1: Model of PPC through low cost community engagement programme

An experienced nurse has been employed under YOKUK-HUSM-BJIM cooperation. She received her initial training is through attachment to at HUSM and Hospice Malaysia with interval attendance to training workshops organized under the BJIM program. The pilot project is considered as part of social responsibility to the specific group of children in need. Activities are focused at knowledge transfer program (KTP) by creating continuous educational training to the families, caregivers and community. Service and training are delivered by experts from the HUSM multidisciplinary team.

Table 1: No of patients involved covered in pilot outreach PPC project since 2013 by a single YOKUK nurse

Current	Number (n)
Total patients for palliative care	30
Total no of patients who passed away	8

The lack of PPC service in Kelantan has been perceived important by the university to cater increasing demand palliative care service to the targeted groups. Many physicians would opt for curative therapy rather than early palliation. In our setting, home based palliative care perhaps is the way forward in view of good family support when the patients are back in the community. The need for palliative care intervention should be assessed according to the complexity of the child's needs and trajectory of their illnesses. The integrated 'whole person' approach is required to provide ongoing support to the patients and their family members. Many children with oncology and LLI have uncertain prognoses characterized by recurrent relapses and morbidities. These children will continue to pursue treatment until very late in their illnesses.

There were many challenges during the development of the PPC service. First, death of a child is considered taboo discussion in the community. Death is not an easy subject to be discussed due to its sensitivity topic. Majority of local population has a strong belief and adherence to Islamic principles. Concealment of information occurs to avoid emotional misunderstanding between the parents and their children. Secondly, the majority of the physicians are traditionally trained to cure rather than opting for early palliation in many of chronic diseases. Palliation has proven to provide better quality of life, quality of care and improved survival for terminal ill patients[4]. Efforts have been made to change the perception among the health-care professionals by continuous education and advocacy role. Disseminating the knowledge to skeptical healthcare professionals seems to a monumental task. Changes and increased understanding have occurred, albeit in a slower pace. Thirdly, alternative or traditional medicine is commonly used along with conventional medicine. Alternative therapy is preferred due to minimal investigations, easy approach and easy access to the respective practitioners[5]. This issue has traversed the boundary of cultural, custom, ethnics, religious and spiritual context. Such complex issues must be dealt in a sensitive and appropriate manner. Most parents embarked for a cure by parallel use of traditional and modern medicine. People are still hoping for a cure despite knowing that patients are at the terminal stage.

We consider this PPC knowledge transfer program is the first in Asia whereby university has enabled the community participation in a niche area. This was done by establishing educational workshops from introduction to PPC, identifying needs, therapeutics communication, social care, strategy of pain relief in children, spiritual care module and creation of parental support group. These educational activities were designed to cover various difficult discussions especially in advanced care planning, bereavement care, ethical issues and provision of health care in the community. Practical support is achieved by the hospital for training, the presence of nurse supervisor and navigator, and involvement with multidisciplinary team discussion. Coordination of the multidisciplinary teams requires all agencies to come together to a common goal and objective. The programs are made with the aim to get patients to function as normal as possible at home by instilling '*life'* rather than *'days*' into patients' and family's experience.

Community support such as parental support group or having someone at the end of the line is an essential element. The socio-structure of Asian population is pretty rigid, with many extended family lives close to the area especially in the rural setting. Malaysia is a multi faith, multi religion and multi racial nation. Therefore understanding of patients personal needs according to cultural, religious and local custom is as important as holistic approach for patients' care. Information should also be available locally by having website access or consultation means. This could help to effectively provide information and support especially for those who live outside coverage area. The team has to take a leadership in palliative care service and championing the service in Kelantan. Family support is essential to reduce anxiety and uncertainty; this is because many parents will have an unprecedented experience when they have to make decision and taking greater medical role for their beloved children. Patients and family should have regular discussions to achieve personalized and achievable goals in life.

Conclusion:

Pediatric palliative care has been seen as an unexplored area due to many social and medical reasons. It has moved towards more non-governmental and community engagement responsibility. With a low cost funding, sustainable PPC program could be kick-started using carefully designed educational package, expert contribution, community empowerment and parental support group in the community. The model of 'home-based' pediatric palliative care with outreach service perhaps should be a way forward in a multiethnic and multicultural society such as Malaysia.

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