**POP UP: A New model of paediatric palliative care**

**New Model of Paediatric Palliative Care**

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**Pop Up: A new model of paediatric palliative care (PPC)**

Children and young people who require palliative care have a heterogeneous range of life limiting conditions such as a malignant disease, chromosomal, neurodegenerative and genetic metabolic disorders. The benefits of paediatric palliative care (PPC) continue to be recognised across the world. This increased awareness has led to the development of new services and the expansion of local programs globally. The delivery of paediatric palliative care differs in various parts of the world depending on available resources, finances, availability of health professionals trained in the care of children requiring palliative care and local health policies¹. Health professionals with formal training in the provision of specialist paediatric palliative care (SPPC) are an integral part of PPC service delivery. Despite the fact that this area of medicine is a growing field, children in many parts of the world still have no access to any form palliative care².

Even in developed countries, most SPPC services are located in cities and are found within clinical services provided at tertiary children’s hospitals, provided by a team trained to care for the physical, psychosocial, emotional, spiritual and practical needs of the child and family. This team provides the complex care and support that children and young people with a life limiting illness need as a consequence of high medical need and complications related to their primary disorderᵌ˒⁴˒⁵˒⁶. The SPPC team works in partnership with families and other carers to improve the quality of life of the child or young person. The SPPC team can facilitate a multimodal approach to difficult symptom management and help link families with appropriate home care, hospital and community services⁷.

**Models of care in Paediatric Palliative Care**

New models of care are needed that utilise all available resources to provide holistic palliative care to the child and their family and care-givers to support the location of palliative care provision for children at home or as close to home as possible.

There are several models of SPPC which are dependent on location, resources available and/or historical factors that have influenced service funding and development. Specialist PPC services in Australia currently provide consultative services in hospitals, in-patient hospices (if available), and also home care. These services enhance the coordination of care to deliver individualised, person-centred care that meets the needs of each child. An integrated model of care has been identified as the preferred model in the provision of palliative care for children. In this model, elements of palliative care are offered at diagnosis and continue and/or increase throughout the course of illness, whether the outcome is cure or death⁸.

Integral to planning palliative care for children is the development of a comprehensive care plan. These plans are formulated to provide medical care, ongoing support, manage difficult symptoms, including end of life planning. Many families prefer to remain at home as the home environment provides security and familiarity and meets the needs of the siblings who are often neglected ⁹˒¹⁰.

How to deliver on the challenging needs of children cared for at home when they represent a small and potentially geographically dispersed population, is the focus of this report. Some of the challenges delivering care at home include the lack of access to clinicians trained in PPC, coupled with limited resources for the provision of education and training. Meeting the individual and diverse needs of children, their families and carers is best managed when specific SPPC clinical expertise for complex cases is integrated with the expertise of the primary care team and networks of services in their community.

The Paediatric Palliative Care Service at the Children’s Hospital at Westmead (CHW) is a multidisciplinary specialist team represented by medical, nursing, allied health and psychology. Approximately 55 children a year are referred for specialist palliative care. The CHW Specialist palliative care services’ catchment extends across metropolitan, rural and remote locations. Each year there is a small number of children who are approaching the end of their life in any particular community. The specialist palliative care team aims to provide a responsive, individualised and dynamic service to meet the needs of each child and their family and care-givers. This requires a high level of engagement with local community care providers and adult focused specialist palliative care services.

The challenges identified in providing SPPC support to CHW patients and families include:

1. Ensuring access to specialist support for each patient is available and equitable throughout an illness trajectory, irrespective of geographical location.
2. Engaging with local health services with limited community resources available.
3. Developing confidence and knowledge in local health services providing PPC (through the delivery of education when required that is individualised to each child and family’s needs).
4. Providing a responsive specialist service that is available for community providers when needed during a child’s illness.
5. Providing after hours support to clinicians caring for children with life limiting conditions and children requiring end of life care.

This paper describes a model of PPC called “Pop Up”, developed in the Australian context, to improve access to specialist PPC for children at home. A case study is described to illustrate this new model of care.

**The Pop Up Model of Care**

A Pop Up intervention occurs when a SPPC service responds to the needs of an individual child and builds capacity within a child and family’s local community to establish a ‘bespoke’ paediatric network incorporating the following triad:

1. Family/carer

2. Local health services (GPs, community nursing, community adult palliative care, local hospital services)

3. Specialist PPC Service.

A Pop Up is a specific intervention over and above the care that is provided to a child and family with identified goals, objectives and interventions leading towards improving confidence of local care providers to deliver PPC. The model was developed to ensure that SPPC services could provide responsive support to local health providers using just-in-time learning with the objective of building capability and capacity required to deliver high quality palliative care irrespective of geographical location .The intervention may require that the specialist service travel from a city location to a rural or remote location, or alternatively, use novel communication technologies such as teleconference and videoconference, to deliver just-in-time training. Using telemedicine for consultations in palliative care has been reported to be as effective as face to face consultations ¹¹.

A Pop Up intervention may require multiple occasions of service by the SPPC service over a specific period of time to develop capability within the local care services. Pop Up interventions are always linked with just-in-time training provided to local health staff. Just-In-time training is a major component of the Pop Up model of care. Just-in-time training is defined as specific, high level training that is delivered when the need for that knowledge arises. It may cover:

1. Symptom management
2. End of life care
3. Physical aspects of patient care according to individualized need and diagnosis
4. Psychosocial aspects of paediatric palliative care
5. Bereavement support.

Just-in-time training may need to be re-delivered to local health services when a child’s care needs change throughout their illness trajectory.

Specialist paediatric palliative care services are few in Australia and this model can potentially be implemented in any geographical location. The end goal of a Pop Up intervention is to establish enhanced capacity, enabling local health services to confidently manage the care of a child with a life limiting illness. Pop Up interventions provide the local health services with the knowledge and skills necessary to deliver safe and effective care. Further Pop Up interventions may occur as the needs of the child or family change, or the local health services required additional support. The SPPC care team would “Pop Up” to re-coordinate a comprehensive care plan and provide necessary education (and just-in-time training) to enable local teams to continue to provide effective care for the child and their family.

Effective pop-up interventions can be achieved by:

1. **Case Conferencing**

This can occur in person or via Tele-health i.e. telephone video conference. The latter technology is an effective resource that can be initiated to provide a Pop Up intervention. Families do not need to travel to a tertiary centre to receive specialist support because local resources can be enhanced through just-in-time training to provide the needed care. During a case conference a comprehensive care plan is created which identifies:

a. Names of local services involved

b. Role description that each local health service will have in the care of child and family

c. Access and support that will be available from the SPPC services for local health providers

d. Agreed outcomes for operating as a paediatric based network.

b) **Education**

Just-time training provided to local care teams in the Pop Up intervention is usually specific to the care needs of the child and around the issues that may be pertinent at the time. Education facilitates improved care planning and continuity of care.

c) **Re-developing the comprehensive care plan**

Each child or young person referred to the SPPC service has a comprehensive care plan formulated to support the community or tertiary based health clinicians involved in a child’s care, clearly outlining the care required. Families are often involved with the creation of a care plan. The plan identifies:

1. The health care providers involved in the child’s care. For example the general medical practitioner or family doctor, community nursing, paediatrician, adult palliative care service providers. Collaboration with other adult specialist palliative care services enables the enhancement of confidence to care for a child and family.
2. An outline of how the PPC team will support the local service
3. Clear strategies for symptom management
4. Drug dosing
5. Emergency Management Plans.
6. End of life management strategies for possible complications related to the disease such as escalation of symptoms which maybe distressing. This may include documentation of family goals of care that may have changed as the child’s illness progresses.

The plans can be redesigned as the needs of the child/young person and family change. Health care providers that participate in a Pop Up intervention are sent a survey to complete which helps the service evaluate the care provided.



**Figure 1**

**Case study**

*Andy was a 5 yr. boy with a neurodegenerative disorder living 120km from Sydney known to the palliative care service at CHW. He had several medical complications including profound global developmental delay, seizures, severe gastroesophageal reflux, recurrent urinary tract infection, and obstructive sleep apnoea. The family received a comprehensive care plan prior to discharge. For continuity of care a face to face Pop Up intervention was organised with the local care providers after discharge from hospital. The multidisciplinary team from the service met with the local team and Andy’s parents. The local services were offered occupational therapy support for accessing equipment needs for use at home. After-hours SPPC contact details were provided to the team. This service is a telephone support service available to all clinicians caring for a child with a life limiting illness in New South Wales. The Pop Up intervention was a timely one linking Andy’s care with the local health services.*

*When Andy’s illness progressed with worsening symptoms another Pop Up intervention was organised which was a teleconference. Education and just-in-time training about Andy’s symptoms and management was discussed.*

The benefits of the Pop Up were:

1. Enabling discussions about current and anticipated issues in a considerate and sensitive manner for a child with complex needs and his family.
2. An equipment assessment was completed which identified his physical needs and including equipment to assist in his cares of daily living.
3. Re-establishing a comprehensive care plan that is individualised to Andy’s need’s to support and guide the local services
4. Networking collaboratively with the local hospital and community providers.
5. Providing family centred care.
6. Supporting family goals including choices for location of care
7. Providing SPPC support to manage escalating symptoms in a timely manner including after-hours telephone support.

Previously reported reviews have identified the absence of SPPC information as a barrier to delivery of services². The use of telehealth is necessary to facilitate models of care such as Pop Up, especially for families living in rural and remote locations. The Pop Up interventions have enabled the SPPC service at CHW to facilitate not only the provision of PPC but improve in the delivery of education. Further research and evaluation is required to inform how the Pop Up model of care can continue to be improved.

**Conclusion**

New models of care are required for the improvement of PPC in community settings. The PPC Pop Up Model is one way of delivering SPPC to a relatively small, but geographical dispersed population. It can be adapted in any setting as it uses local available resources to enhance the care of children requiring palliative care.

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