Occupational Therapy in Paediatric Palliative Care

The New Direction...

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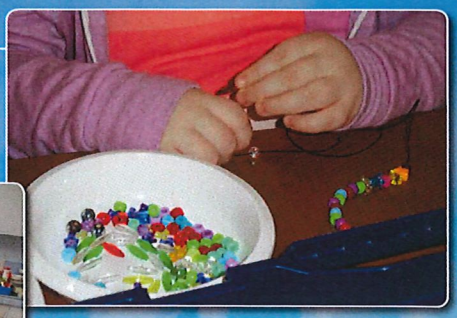


In January 2012 the Paediatric Palliative Care Service (PPCS) at the Royal Children's Hospital, Brisbane introduced a 0.5 full time equivalent Occupational Therapy (OT) role to service children and their siblings across psychosocial and physical domains. A large number of patients supported by OT within the palliative care team are children who have relapsed and have incurable oncology diagnoses.

The OT role in paediatric palliative care is an area that is developing not only across Australia but internationally. Part of the remit of the role was to conduct an evidence based practice review, including critical appraisal of the literature and benchmarking with other tertiary paediatric services across Australia. The purpose of this was to ensure best practice and to establish clear service parameters and guidelines to fit within the existing PPCS structure.

The Evidence Reviewed

Detailed critical review of the literature was conducted to provide evidentiary support for the OT role in PPC.

Underlying themes consistently reflected in the literature (both paediatric and adult):

- Promoting and maintaining a child's occupational function is vital to a child's quality of life (QOL). This includes maintaining participation in daily occupations that are meaningful for the individual child/family (e.g. student, friend, family member, sports person and self-care routines).
- Equipment prescription and environment modification helps to maintain participation.
- Promoting choice and control for the child and family. Engaging child and family in determining what is meaningful and important for them.
- Importance of developmentally appropriate education for the child regarding their functional decline in skills and impact on participating in meaningful occupations.
- Be guided by parents on appropriate education about death and dying to the child and their siblings.
- Education and skill building of non-pharmacological strategies to manage fatigue, pain, anxiety and sleep difficulties.

Benchmarking Summary

- Ongoing process, currently have feedback from 3 tertiary hospitals.
- Staffing: 2 have allocated OT funding and 1 provides consultative services in an ad-hoc manner.
- Caseloads: predominately oncology; some non-oncology.
- Model of Care: varies depending on team, funding and service structure (e.g. use of other linked community services and funding for patient resources/equipment).

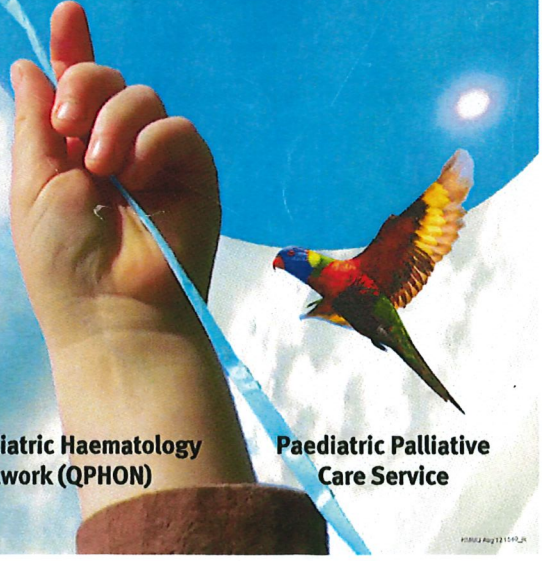
Common Intervention:

- Person: self-esteem, self concept, developmentally appropriate education, sibling support, adjustment and coping.
- Environment: home assessment, equipment prescription, pressure care.
- Occupation: promoting meaningful engagement in activities (e.g. school, role of friend/sibling, leisure, self care), fatigue management and cognitive strategies.

The future of the OT role at PPCS, RCH, Brisbane

- Embedding evidence and benchmarking into clinical practice.
- Keeping occupation, QOL and meaningful activities at the centre of our interactions with child, family and MDT.
- Developing innovative multidisciplinary services in clinical areas such as bereavement support for siblings.
- Extending benchmarking to international services.
- Expanding the role to provide state-wide clinician support and consultation for Therapist's supporting palliative children in their local area.
- Development of resources to support best practice in provision of OT in paediatric palliative care.
- Actively participate in a range of networks to explore emerging practice and research opportunities. e.g. QOL measures in PPC.

Participation in Meaningful Occupations = Quality of Life



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Queensland Paediatric Haematology Oncology Network (QPHON)

Paediatric Palliative Care Service