

Videotelephony: An Innovative Mode of Palliative Care Service Delivery in Regional and Remote Areas

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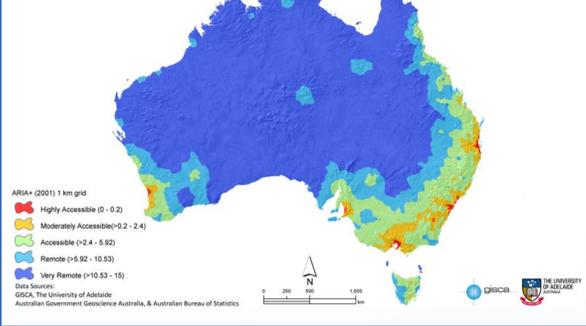
Background

The Queensland Children's Cancer Centre (QCCC) at the Royal Children's Hospital Brisbane (RCHB) is one of the largest tertiary centres in Oceania, receiving referrals from Queensland, Northern New South Wales, Northern Territory, Papua New Guinea and the Pacific Rim.

Queensland (QLD) is Australia's second largest state geographically with a population approaching four million. Around 2.5 million people live in the South East corner, one million live in towns along the coast and the remainder dispersed across the state in smaller rural towns [1].

Accessibility Remoteness Index Australia - 2001

ARIA+ and ARIA- are indices of remoteness derived from measures of road distance between populated localities and service centres. These road distance measures are then used to generate a remoteness score for any location in Australia.



In the late 1990s our group undertook a series of studies which highlighted very limited paediatric palliative care resources across QLD.

Service Review 1999

Health professional survey	Bereaved families interviews
17% - little or no resources available	Co-ordination of care
There were no specific paediatric palliative care resources	Optimal symptom control
Liaison with adult based specialist palliative care services	Information
There was a need for specific paediatric information and 24 hour access to resource person	Access to a 24 hr "on call" familiar resource person

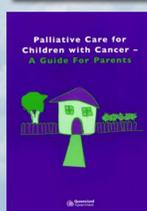
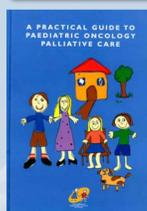
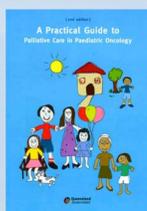
Results and service development

The need for education and training of health professionals and access to a 24 hour 'resource person' were considered vital by health professionals and families caring for children dying from cancer. The 'Blue' and 'Purple' books were written and published in 1999 and 2001. The second edition of the 'Blue' book, "A Practical Guide to Palliative Care in Paediatric Oncology" was written with an Australia wide collaboration and launched in 2010, and is in regular use by health care professionals and education facilities.

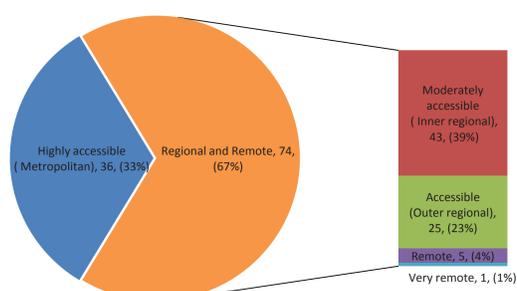
A 24 hr on call service, known as the "1800 number", was established for health professionals and families across the State. The phone is manned by Clinical Liaison Nurses who are known to the families. Over 1900 calls have been made since the introduction of the "1800 number".

Call summary from 2002-2009:

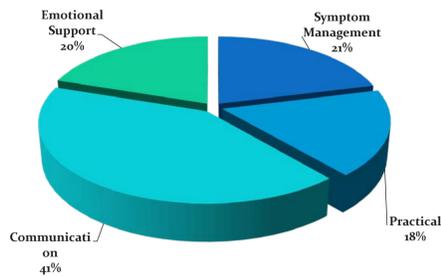
- 110 patients offered service
- ~70% regional or remote locations
- 103 (94%) used service at least once
- Average number of calls per patient = 18
- Average duration 10.39min
- Emotional support, symptom management and practical advice were the main reasons for calls
- Total number of calls - 1954



Approximately 70% of patients are from regional or remote locations



Reason for telephone connection with the "1800 number"



Review and development of tele-health

As an extension of the outreach programme and the geographical isolation of many patients, it was thought telepaediatrics could play an important role in service delivery [2,3,4]. In 2003, the University of Queensland's, Centre for Online Health (COH) in collaboration with the QCCC began investigating the use of home telemedicine as an adjunct to the supportive care offered.

A pilot study was conducted to determine the feasibility of home telemedicine support.

Results

Eleven families participated in a feasibility and acceptability study of in-home videoconferencing (VC) in 2008. Links were made between the RCHB oncology team and families, coordinated by the COH. VC summary:

- 25 calls made with 11 families
- 11/25 calls included the Paediatric Oncologist
- 22 /25 resulted in a change to symptom management
- Consensus that home based video conferencing was an acceptable method for delivering support and management [5]
- Updated hardware and software, and videotelephony now integrated into care with a secure network



Convenience of videotelephony in the home



Mobile set-up for in hospital/clinic use for home video telephone connection

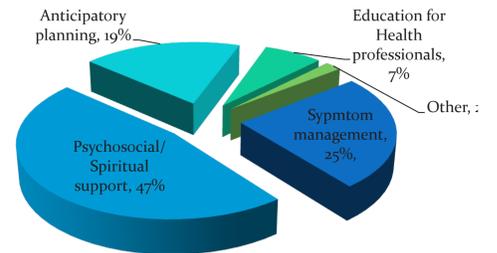
Developments

In 2009 the oncology palliative care service extended to form the Paediatric Palliative Care Service (PPCS) to also meet the needs of children with non-oncological life-limiting conditions. The PPCS provides both inpatient and outpatient care across South East Queensland's tertiary paediatric hospitals. The COH has been working collaboratively with the PPCS to provide services to families irrespective of geographical location. Services are delivered direct to the family home, ensuring that the support, advice and care of specialist health professionals are available with real time audio-visual communication from the hospital into the patient's home.

With expansion of the PPCS there have been:

- 95 tele-paediatric palliative care links
- 35 different Families
- from 1870 km to 8km from RCHB

Reason for video link



Conclusion

The use of telepaediatrics as a mode of service delivery to support this vulnerable group is developing within Queensland and presents a viable method of reaching both health professionals and families who require support. Most patients wish to be cared for in their home environs which can be burdensome for families and local health carers. The QCCC, at the RCHB has developed multiple strategies to facilitate care, including; an on-call service for health care professionals and families, published guides, teleconferencing and recently in-home video telephony. These strategies are acceptable to families and health professionals and have broader application across all care parameters and geographical locations.

Case Study

14 year old indigenous girl with metastatic Wilms tumour from far North Queensland

- Initially treated SIOP WT Study Stage II
- Relapse with metastatic disease off Rx, transferred back for multi-modal treatment in Brisbane.
- Initial response to treatment, but progressive disease after XRT
- Family elected not to pursue further treatment and return home
- Videoconference to regional team, specifically to communicate family and oncology discussions and decisions
- Symptom management plan and course of disease progression discussed
- Contacts established for after hours support, education for regional staff
- Home video links using family laptop computer and a mobile broadband internet connection
- "Happy Birthday video" link requested with favourite doctors and nurses singing to a beaming 15 year old
- 5 video links over several weeks during palliation
- Video link also used to provide peer support, reassurance and advice with respect to symptom management to community nurse who was home visiting



"The doctor and the child being able to see one another is very beneficial when your child can't travel. She especially loves the clown doctors and looks forwards to seeing them"

Acknowledgments: The families we care for and the opportunities provided to assist in learning how to meet needs. The Sporting Chance Cancer Foundation for their generous support of the home video program. The QCCC, QPHON, QHealth and University of Queensland COH.

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