



---


**Effectiveness of Home tele-consultations  
in paediatric palliative care**



Natalie Bradford  
PhD candidate  
Centre for Online Health

---







---

**Overview**

- Palliative care and Telehealth
- The study
- Findings
- Implications

---







---


**Palliative care**

- Palliative stems from Latin verb 'Palliare' - to cloak
- Not only concerned with end of life care
- Any form of medical care that aims to provide relief from symptoms and suffering of disease and illness



---







---

**Paediatric Palliative care**

- Important differences compared to adult palliative care
  - Provided alongside curative or treatment orientated care
  - 500 compared to 50'000
  - Rare diseases
  - Care of extended family and community
  - Physiological differences of child vs adult
  - Emotional factor and societal expectations
- Recognising need for specialist care- developing speciality
  - Tertiary based speciality, one service for QLD



---



### Palliative care and Telehealth



- Significant body of research over last decade
  - "Telehospice"
  - Mostly small studies
  - Measure effects on Quality of life, Anxiety, Costs
- Despite research & advances in technology- not widely used in palliative care
  - Lack of evidence to support effectiveness
  - Difficulties integrating telehealth into routine care



### The home telehealth program



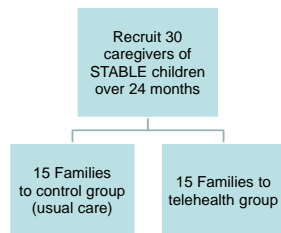
- Developed from pilot studies
- Established as a routine service in 2009
- Medical, nursing and allied health consultations into patients homes
  - Symptom management
  - Anticipate changes and subsequent management
  - Psychosocial support
  - Peer support
  - Case conferencing



### The study



- Evaluation of the home telehealth program
  - Feasibility
  - Satisfaction
  - Acceptability
  - Effectiveness
    - Caregiver quality of life
    - Symptom burden

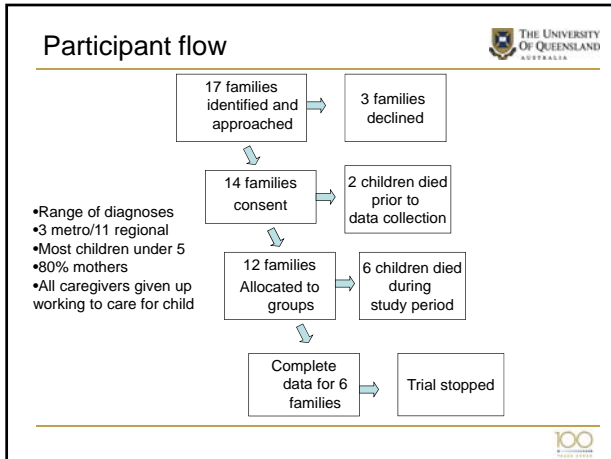


### Outcome measures

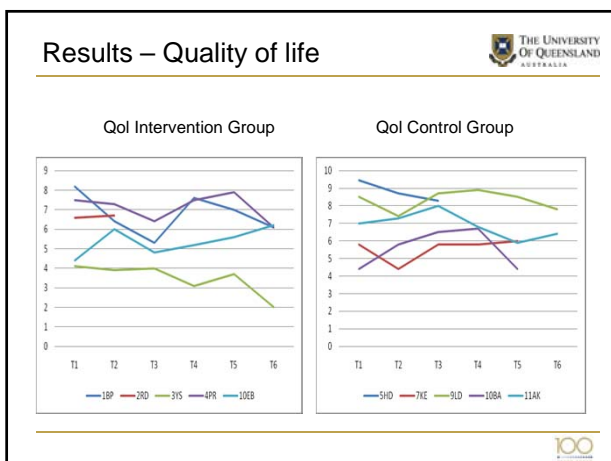


- Collected over 10 week period
  - Utilisation of telehealth
  - Surveys with clinicians
  - Symptom Burden (SAS)
  - Satisfaction (Famcare)
  - Quality of life (QOLLI-F)





- ### Results
- No differences in demographics between groups
  - Surveys with clinicians
    - Supportive of telehealth
    - Equally satisfied with co-ordination of care in control group
  - Utilisation
    - 6 families in intervention group
    - 17 tele consultations (range 1-4 over 10 weeks)
  - Symptom Burden
    - No differences between groups
  - Satisfaction
    - Highly satisfied with care in both groups



- ### Tele-consultation and Quality of life
- QOL domains:
- Finances ~
  - Relationships with others x
  - Quality of care ✓
  - Environment of care ✓
  - Own physical and mental state x
  - Caregivers outlook x
  - Patient state x

## Lessons Learnt



- Recruiting families during palliative care
  - 85% recruitment
  - Flexibility, choice, observant of non verbal cues
  - Very difficult to predict stability of patients
  - Families valued the opportunity to participate
- Outcome measures
  - Need to ensure they are capable of measuring a change attributable to the intervention



## Comments



"I was worried I would feel isolated (going home), but all of the phone calls and the 'TV' connections were wonderful"

"This is our first experience with this system. It was very good and provided everything we needed. I would like to see this used in all such situations. It was good to see everyone from the RCH"

From Regional Nurse- Tweed heads



## Conclusion



Tele consultations in paediatric palliative care are feasible and acceptable

Families and clinicians are equally satisfied with provision of palliative care via usual care or tele-consultation

Effectiveness of tele-consultation remains difficult to quantify

*Suffering is not a question that demands an answer,  
It is not a problem that demands a solution;  
It is a mystery that demands a presence*  
Author Unknown

