

Data linkage studies in paediatric palliative care



Planning for paediatric palliative care services: Characteristics and demographics of children and young people with life-limiting conditions in Queensland

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PhD Research

- PhD – Planning for paediatric palliative care services: Characteristics, demographics and health needs of children and young people with life-limiting conditions in Queensland – Under examination
- Two phase study
 1. Administrative health data analysis
 2. Semi-structured interviews with parents and health professionals

Objective

- Clinical and demographic characteristics
- Health service usage characteristics
- Children and young people aged 0 to 21 years
- Living in Queensland
- Life-limiting condition eligible for palliative care
- 2011 and 2016 calendar years

Method

- Queensland Hospital Admitted Patient Data Collection
- Queensland Perinatal Data Collection
- Registrar General Deaths
- ICD-10/ICD-10-AM codes¹

¹Hain, R., & Devins, M. (2011)

Analysis

- IBM SPSS v25

 - Descriptive statistics

 - ICD-10/ICD-10-AM chapter title

- Online epidemiology calculator²

 - Prevalence proportions

 - 95% CI

²Dean, A.G., Sullivan, K.M., & Soe, M.M. (2013)

Data Set

Data set	Variables	Rows
Main admission	23	56,649
Morbidity	5	195,031
Sub and non-acute (SNAP)	8	771
Activity of daily living	8	7,276
Main perinatal	4	3,389
Perinatal morbidity	2	10,469
Perinatal congenital abnormalities	2	2,037
Death	9	480





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Results

Demographics	2016 n (%)	2011 n (%)
Admitted	5,739 (100.0)	4,500 (100.0)
Male	3,099 (54.0)	2,495 (55.4)
Female	2,640 (46.0)	2,004 (44.5)
Aboriginal and/or Torres Strait Islander	542 (9.4)	336 (7.5)

Results

Age (years)	2016 n (%)	2011 n (%)
<1	1,576 (27.5)	1,350 (30.0)
1 to 3	675 (11.8)	665 (14.8)
4 to 6	748 (13.0)	502 (11.2)
7 to 9	502 (8.7)	361 (8.0)
10 to 12	749 (8.3)	347 (7.7)
13 to 15	490 (8.5)	348 (7.7)
16 to 18	616 (10.7)	455 (10.1)
19 to 21	653 (11.4)	472 (10.5)

Results

Accessibility/Remoteness Index of Australia (ARIA)	2016 n (%)	2011 n (%)
Major Cities of Australia	3,538 (61.6)	2,647 (58.8)
Inner Regional Australia	1,216 (21.2)	1,054 (23.4)
Outer Regional Australia	837 (14.6)	655 (14.6)
Remote Australia	86 (1.5)	77 (1.7)
Very Remote Australia	62 (1.1)	67 (1.5)

Results

ICD-10-AM chapter	2016 n (%)	2011 n (%)
Congenital malformations, deformations and chromosomal abnormalities	1,515 (26.4)	1,012 (22.5)
Diseases of the nervous system	1,035 (18.0)	892 (19.8)
Certain conditions originating in the perinatal period	778 (13.6)	615 (13.7)
Neoplasms	645 (11.2)	570 (12.7)

Results

Prevalence per 10,000 population	2016	95% CI	2011	95% CI
Overall	43.2	42.1 to 44.4	35.2	34.2 to 36.3
<1 year	291.0	277.2 to 305.5	237.2	225.1 to 250.0
Aboriginal and/or Torres Strait Islander	4.1	3.7 to 4.4	2.6	2.4 to 2.9
Queensland Aboriginal and/or Torres Strait Islander population	58.7	54.0 to 63.8	41.8	37.6 to 46.5
Congenital malformations, deformations and chromosomal abnormalities	11.4	10.9 to 12.0	7.9	7.4 to 8.4
Diseases of the nervous system	7.8	7.3 to 8.3	7.0	6.5 to 7.4
Conditions originating in the perinatal period	5.9	5.5 to 6.2	4.8	4.5 to 5.2
Neoplasms	4.9	4.5 to 5.2	4.4	4.1 to 4.8

Results

Age at time of death (years)	2016 n (%)	2011 n (%)
< 1	120 (57.4)	128 (59.0)
1 to 3	22 (10.5)	21 (9.7)
4 to 6	9 (4.3)	13 (6.0)
7 to 9	6 (2.9)	10 (4.6)
10 to 12	11 (5.3)	4 (1.8)
13 to 15	10 (4.8)	8 (3.7)
16 to 18	20 (9.6)	11 (5.1)
19 to 21	11 (5.3)	22 (10.1)

Limitations and strengths

- Admitted data only
- 2016 death data identified by text and coded by researcher
- Quality of data varied
- Linkage error rate $\leq 5/1000$ records³
- Unable to estimate incidence
- Unable to accurately determine palliative care services
- Only children and young people with a diagnosis
- Linked data
- Conservative approach

Conclusion

- Health administrative data can be helpful to inform health service planning
- Data were limited in quality and quantity to determine health service usage

References

1. Hain R, Devins M. Directory of Life-Limiting Conditions Cardiff 2011. Available from: http://www.togetherforshortlives.org.uk/assets/0000/7089/Directory_of_LLC_v1.3.pdf.
2. Dean AG, Sullivan KM, Soe MM. Open source statistics for public health 2013. Available from: <https://www.openepi.com/Proportion/Proportion.htm>.
3. Queensland Statistical Services Branch. Comprehensive quality assessment 2015/16. 2016.

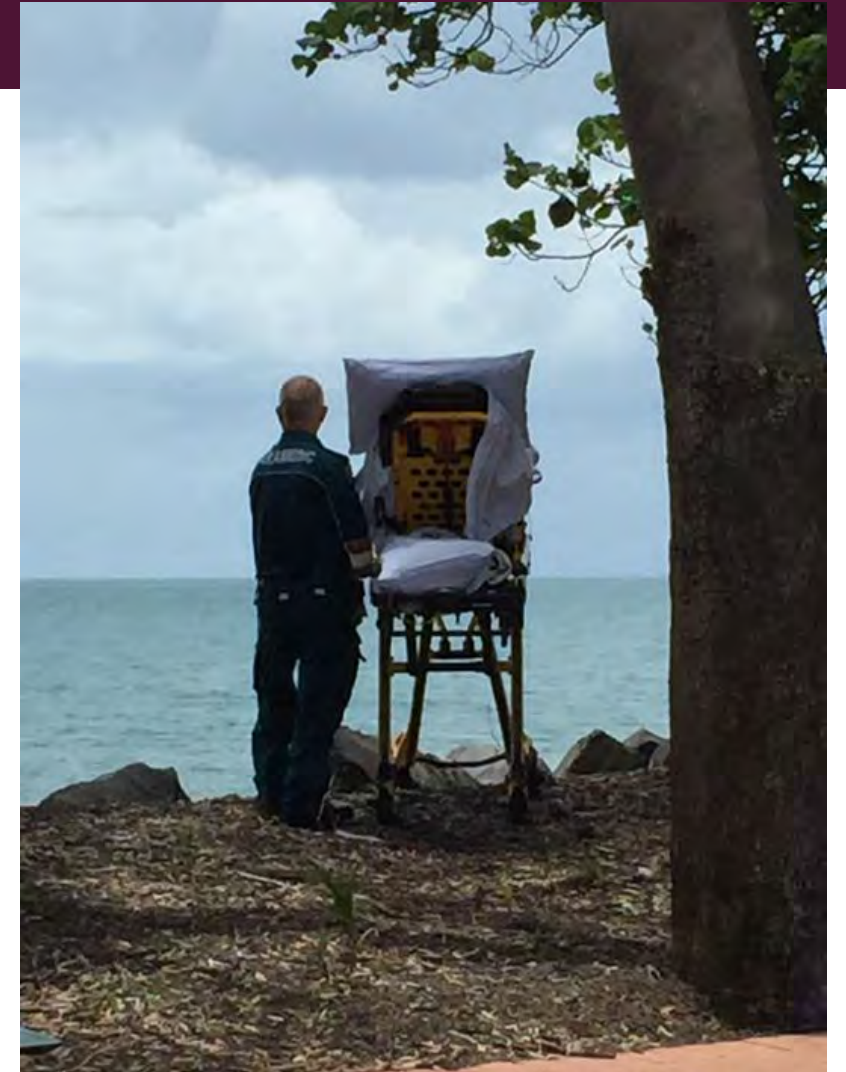
EMERGENCIES IN PAEDIATRIC PALLIATIVE CARE: UNDERSTANDING THE INTERFACE BETWEEN PARENTS AND AMBULANCE SERVICES

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INTRODUCTION

- **OUR ROLE:** To support patients and their families to remain at home, even in the terminal phase of their illness, if this is their preference
- **INTERMINAL PHASES:** Acute symptoms or rapidly evolving critical situations which may require rapid intervention are more likely to arise than earlier in disease progression
- **AND SO:** Emergency medical services may be acutely called, or patients may need inter-hospital transfer facilitated by ambulance officers
- **RECENT:** Increased interest in ambulance and emergency services facilitating final wishes of dying patients e.g. Ambulance Wish Queensland (<https://ambulancewishqld.org.au/>) which utilizes volunteers

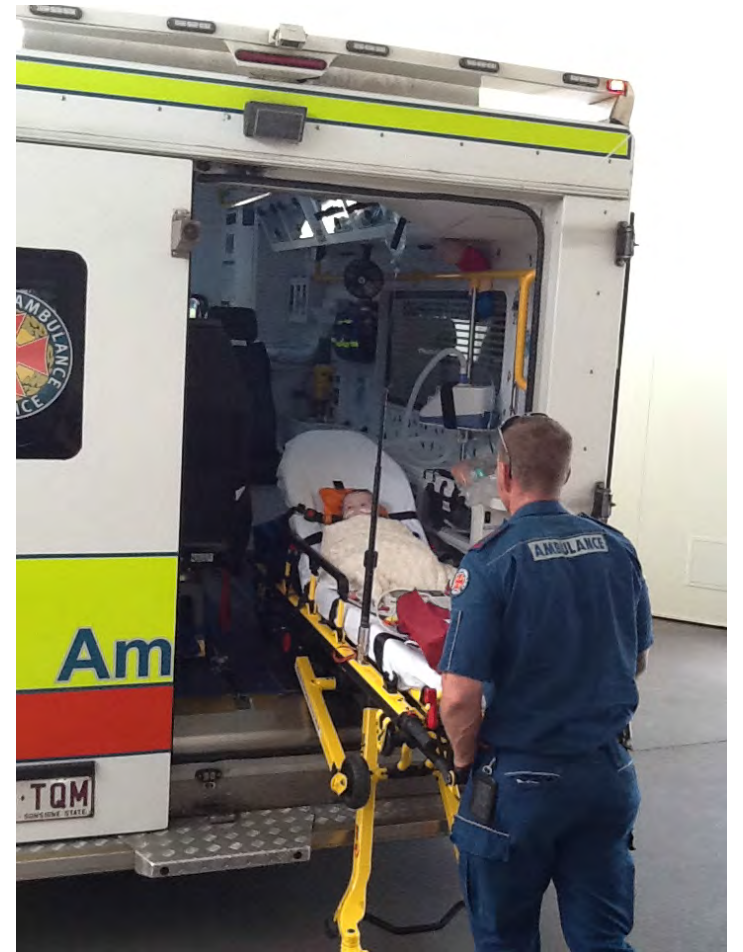


PREVIOUS RESEARCH

- **Paucity** of literature around this interaction
- The interaction between these groups is **rare**
 - 0.3% of calls to emergency services (Wiese, Nauck, Graf, & Hanekop, 2010)
 - 5 cases where emergency services were called for paediatric palliative care patients with an oncology diagnosis from 133 patients over a 10-year period (Kuhlen et al., 2015)
- Emergency calls are more likely to come from patients **outside the service local area** (Kuhlen et al., 2015)
- End-of-life decisions in paediatric patients specifically causes “**mental strain**” to emergency medical teams such that formal psychological support is thought to be “reasonable” (Wiese et al., 2010)
- Paramedics have expressed a **knowledge gap** in palliative care (Morhaim & Pollack, 2013), suggesting an even larger gap regarding specifically paediatric palliative care.

STUDY AIM

- HYPOTHESIS:
 - Given the **rarity** of these interactions, we were wanting to assess the experience and confidence of ambulance officers
- AIM OF THE PROJECT:
 - Identify the **positive and negative aspects** of the interaction between Queensland ambulance services (QAS) and our patients from the perspective of ambulance officers
 - Identify the **frequency** of these interactions
 - Identify QAS **educational needs** and expectations from the paediatric palliative care service
 - Make recommendations to **enhance** this interaction for QAS officers



METHODS – DATA LINKAGE

- 50 most recent referrals to the Queensland paediatric palliative care service were determined (50 Children's Health Queensland Unit record numbers)
 - Covered a period of just over 13 months (March 2016 to April 2017)
- These unit record numbers could then be linked to patient record numbers for QAS for the same patient group
- Instances where QAS were called for any of the 50 patients, since their time of referral to palliative care services
- An email with a link to an online survey was sent to these targeted QAS officers

BENEFITS OF LINK BETWEEN Q HEALTH AND QAS INFORMATION SYSTEMS

- Concerns about survey fatigue by QAS and understandably wanting to have a strategy and focus to service wide surveys
- This approach also allowed a more focused group of ambulance officers who had an experience of caring for a child requiring palliative care
 - Smaller number to survey
 - Ambulance officers more likely to respond due to having recent professional (and personal) experience
 - For above reasons, likely to have an improved response rate
 - Data provided by ambulance officers more likely to be relevant and based on experience rather than perception

METHODS

- The questionnaire was primarily quantitative, with yes/no, option selections and Likert scale questions
- One question around resuscitation planning also allowed for free text input (question 12).

1. Were you aware you recently been involved with a patient who is linked with the paediatric palliative care service in the last 6 weeks?

2. If yes, how many encounters have you had with paediatric palliative care patients?

3. Was the child easily identified as a palliative care patient?

4. Did you contact either of the state-wide paediatric palliative care phone contacts (1800 249 648 or 1800 501 670)?

5. Were you aware that the palliative care 1800 numbers existed?

6. What was the nature of the call to emergency services?

7. How confident were you with your ability to manage this case?

8. Was a Paediatric Acute Resuscitation Plan (PARP) available for the patient either from the QAS Operations Centre or the parent?

9. Were there any caution notes (flags) on the Computer Aided Dispatch (CAD) for this patient?

10. Did this plan request that interventions be limited?

11. Do you think all paediatric palliative care patients should have a “not for resuscitation” order?

12. What would most guide your plan for resuscitation?

13. How supported did you feel in managing this case?

14. Were you offered or did you utilise any counselling or formal debriefing after the interaction (e.g. Priority One)?

15. Would counselling or formal debriefing be helpful in managing such cases?

16. In what ways do you think you could have been better supported?

RESULTS

- A total of **122 QAS attendances** were identified for the cohort of 50 paediatric palliative care patients, representing roughly **0.02%** of call outs based on QAS-provided statistics
 - The attendances were provided by **56 ambulance officers**, of an estimated 4400 total ambulance officers (1.3%)
 - Thirty-four of the fifty patients were found in the QAS database (**68%**)
 - There were 22 responses received in total from the two email links sent (**39% responded**)
- The majority (16, **73%**) recalled being involved with a paediatric palliative care patient
 - The majority who recalled an interaction reported being involved in **multiple interactions** with a paediatric palliative care patient (63%), with two respondents reporting **more than five interactions recalled**
 - 10/16 (who recalled the interaction) felt the patient was **easily identified** as known to paediatric palliative care in **all** cases

RESULTS

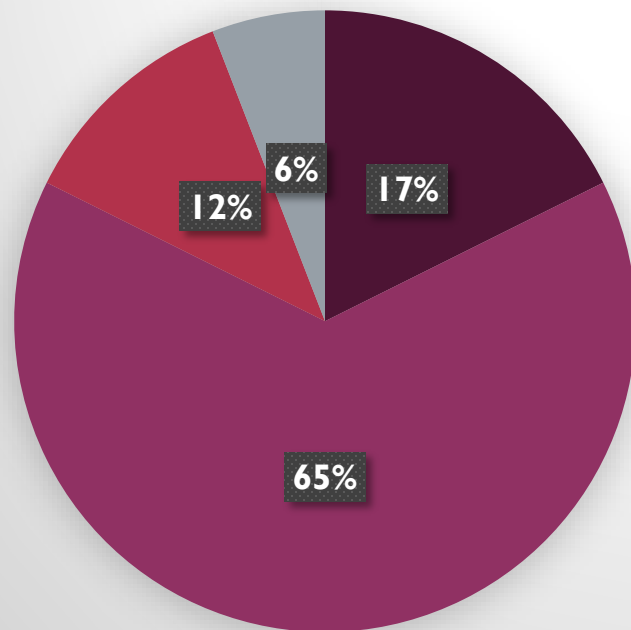
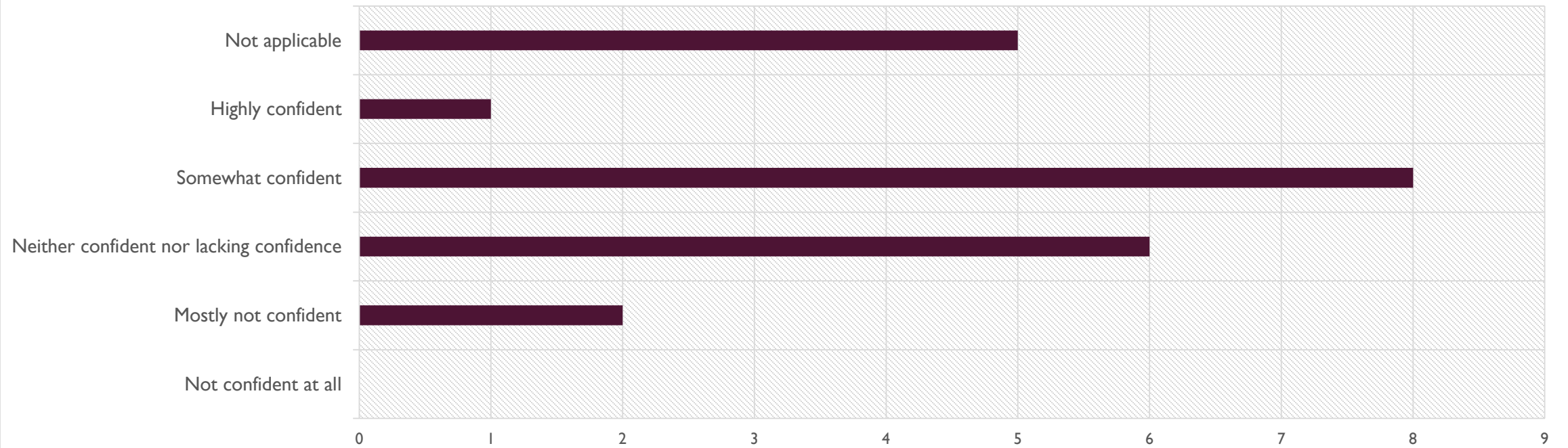


Figure 1: Reasons for QAS attendance

- For planned transport
- For management of escalating previous symptoms
- For management of critical new issue
- For post death care and management of a child who has died

RESULTS

Figure 2: Level of confidence in managing paediatric palliative care patients



LIMITATIONS

- A significant issue with this study is reliance **on recall**
 - Covered a longer period to increase response numbers – 13 months
 - It is possible the QAS officers were involved in more or less interactions than stated, and that the details varied
 - The rarity of the situation and emotive nature of the patients at times, may mean that these patients are more memorable than recalled situations in other studies
 - It is also possible that those people who were sent the survey did not respond if they did not recall having been involved with a patient linked to paediatric palliative care services, and identification of these patients may be **poorer than presented** here



FUTURE DIRECTIONS

- Audit of our service's provision of communication and documentation to QAS
 - Implementation of this provision as a standard of care
 - Importance of letting QAS know when one of our patient's dies?
- Further QAS survey refined from this study
- Survey of parents and families on their perspective of these interactions
 - Particularly given high proportion of included patients who had this interaction over the 13 month period (68%)

SUMMARY AND RECOMMENDATIONS

- Important reminder for paediatric palliative care services to actively engage ambulance services
- Practical tools to support QAS
 - Increased documentation given to QAS dispatch as it is what they **are most likely to look for in an acute situation** and **PARP presence may increase confidence**
 - Ideally patient summary, PARP and clear documentation of 1800 number to contact
 - Ensuring all documentation is up to date
 - Increase awareness of available supports such as the after hours telephone support number
 - Many more ambulance officers felt **counselling or debriefing would be helpful** than the number who recalled being offered it
 - Both QAS and PPCS could consider how to increase both formal and informal support in this area
- Other measures should include development of clinical guidelines and collaborative education
- Empowering patients and their families with documentation and awareness of supports may also lead to better supported ambulance officers



WHAT CAN BE ACHIEVED

*Collaborative
Integrated
Supported
Efficient*

AND

*Consistent with the wishes of the
patient and their family*