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Original article

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What is already known on this topic
In the developed world, most paediatric inpatient deaths occur following WWMT and in children with chronic diseases. Rates of WWMT vary between countries, but have been increasing over time. Virtually all previous studies provide data on the intensive care setting only, where the majority of these deaths occur.

What this paper adds
This study provides data on hospital deaths not only in intensive care but also outside it. Deaths outside intensive care are strongly associated with both early discussions with families about WWMT and involvement of palliative services, and are more likely to have limitations of treatment in place at the time of death.

Acknowledgements
The authors wish to thank the RCH Hospital Information Services for their help in locating the records relevant to this audit, as well as the Clinical Epidemiology and Biostatistics Unit and in particular A/Prof Susan Donath for her statistical support. We would also like to thank PPC Services for the provision of useful background information and guidelines.

Conflicts of interests
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Abstract

Background: In the developed world, most paediatric deaths follow withdrawal or withholding of medical treatment (WWMT), and have largely been studied from an intensive care setting perspective.

Method: A retrospective review of medical records was conducted for all paediatric inpatient deaths at the Royal Children's Hospital, Melbourne from April 2015 to April 2016, and results were compared to 2007 data from our centre. Chi squared tests were used for comparisons.

Results: 101 deaths occurred in the inpatient setting in 2015-2016. Most deaths followed WWMT (88/101, 87%) and occurred in children with pre-existing chronic conditions (85/101, 85%). There was a shift to earlier discussions with parents around WWMT compared to 10 years prior. Cases where discussions began prior to the last admission increased from 4% to 19% ($p=0.004$). There was increased paediatric palliative care (PPC) involvement (10% vs. 37%, $p<0.001$), and a slightly greater proportion of children died outside of intensive care (16% vs. 22%, $p=0.25$). In 2015-2016, subgroup analysis revealed that children who died as inpatients but outside of intensive care were 76% more likely to have PPC involved than those who died in intensive care ($p<0.001$). Their families were 51% more likely to have discussed WWMT with medical staff before the last admission ($p<0.001$).

Conclusions: The last decade has seen an increase in PPC involvement and advance discussions around WWMT at our centre. These are both associated with death outside of intensive care.

Keywords

Treatment limitation, paediatrics, end-of-life care, documentation, palliative care, advanced care planning.

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Introduction

Most paediatric deaths in the developed world now occur following withdrawal or withholding of medical treatment (WWMT) (1-12). The proportion of hospital deaths that follow WWMT differs greatly between countries, with Australia reporting some of the highest rates (1-4). In many countries there has been an increase in WWMT over the last two decades (4, 6, 7). Decision-making and legal context are culture- and system-dependent (2, 6, 9, 11).

In paediatrics, WWMT generally occurs in intensive care units (ICUs). However, the importance of initiating end-of-life discussions earlier, potentially avoiding the ICU altogether, has been highlighted (13). Two Australian studies include deaths outside ICU in audits of all-cause hospital deaths; an audit of 50 consecutive deaths at the Royal Children's Hospital, Melbourne (RCH) in 2007 (3) and an audit of 62 records in 2011 at the Royal Children's Hospital in Brisbane (5). While the latter study reported a correlation between paediatric palliative care (PPC) involvement and death in hospital but outside ICU, demographics and characteristics of these children as a subgroup were not described in either study, and this remains a poorly understood population.

Most children who die after WWMT have pre-existing chronic conditions, with proportions reported between 63-88% internationally (1, 2, 5, 8, 10, 14). Children who die following WWMT have significantly longer ICU and hospital stays than children who die with full treatment (1, 6-8, 11). There are few data on previous admissions and overall hospital contact. At RCH (in 2007 study), 42% of patients had a previous hospital admission for the same condition (3).

The association between longer hospital stay, chronic disease and WWMT is one of the reasons for the recent focus on advanced care planning – that is, early initiation of discussions with families about resuscitation, treatment limitation, but also values and broader end of life care issues and wishes. Most end-of-life guidelines discuss the

importance of family-centred care, with the parents as an integral part of WWMT decision-making (5, 13, 15). While involvement of parents varies greatly internationally (1, 9, 14), it is generally high in Australia (1, 3, 5). In Oncology, national efforts towards better advance care planning led to earlier conversations with families (16), but this timing has been poorly studied in a whole-hospital population.

The aim of this study was to audit WWMT practice at RCH identifying any changes in practice that may have occurred in the past 10 years. We focused on gaining a more detailed understanding of the entire medical journey of the child and identifying potential variables associated with WWMT occurring outside of ICU.

Patients and Methods

We conducted a retrospective observational single-centre audit of medical records with identical methodology to the 2007 study at our centre (3). The sample population included all children aged 0 days to 18 years who died as a hospital inpatient at RCH between April 30th 2015 and April 29th 2016. The RCH electronic medical record was introduced on April 30th 2016, so this represents the last year of paper records, 5 years after the introduction of documentation for end-of-life decisions, the Treatment Plan for Children with a Life-Limiting Condition (TPCLLC) form (supplementary information S1).

A list of patients meeting the inclusion criteria was obtained from Hospital Information Services, and the scanned medical record of each patient was reviewed by a study investigator (MA). De-identified data were recorded securely in an electronic database. Ethics approval was provided by the RCH Human Research and Ethics Committee (DA001-2017-97).

All previous RCH admissions were quantified, excluding Outpatient, Hospital In The Home and Emergency Department presentations. Brain death was regarded as a separate category to WWMT and full treatment, consistent with previous studies.

Data on WWMT discussions were obtained from scanned inpatient progress notes, outpatient records or letters. A "WWMT discussion" was defined as a discussion between the family and medical team(s) in which the issue of ceasing or not initiating treatment was documented, including language such as "not in their best interests", "letting them go", "palliative approach" or similar. Discussions about details of palliative management were not included. Progress notes and discharge summaries were used to determine whether treatment was withheld or withdrawn. The "last admission" refers to the admission during which the child died.

Data were analysed alone and comparing to 2007 data, using Microsoft Excel and Oracle® analysis software. All statistical tests were conducted using STATA software. Pearson's Chi-squared tests were used for categorical data, as well as a difference of the mean and 95% confidence interval. Medians were used for time intervals and quantities due to the highly skewed nature of the data. The first and third quartiles are given rather than the range to better represent the spread of data. No statistical tests on the medians were undertaken, as these were secondary outcomes.

Results

We identified 101 cases in our studied time period. Of these, 55 (55%) were male, with little change in proportions in various analysed subgroups. The median age at death was 281 days (9 months), range: 0 days to 16 years. In the following analyses, the WDT group refers to all children that died following withdrawal of treatment, regardless of whether other forms of treatment were also withheld. The WHT group refers to children who died with withholding of treatment. Mechanical ventilation was the most commonly withdrawn intervention (54 cases), and cardio-pulmonary resuscitation the most commonly withheld (47 cases).

Comparison to 2007 data

The 101 deaths from April 2015 to April 2016 were compared to the 50 between January and June 2007 (3) (see Table 1). The proportion of deaths following WWMT, full treatment, and brain death did not change significantly. There was a small shift towards more WHT and less WDT but this was not significant.

In both populations, the majority of children had underlying chronic conditions, with similar proportions (82% vs. 86%, p=0.85). Similarly, death was expected in both the short- and long-term for the majority of patients in both time periods.

The timing and number of discussions changed significantly with a shift towards more discussions, beginning earlier in the child's disease course (see Table 1). PPC involvement increased from 10% of cases in 2007, to 37% in 2015-2016 ($p<0.001$). The TPCLLC form was used in 28 cases in 2015-2016, with an average of 1.5 forms per case where they were used.

ICU vs. non-ICU deaths

Seventy-seven children (76%) died in ICU and 84 (83%) were ICU inpatients during their last admission, including 5 who were transferred out of ICU before death. All 22 deaths outside ICU had WWMT compared to 64% in ICU. These children were significantly more likely to have WHT than the ICU group, while ICU deaths more commonly followed WDT. Non-ICU deaths had paediatric palliative care (PPC) involvement in 95% compared to 19% in ICU ($p<0.001$). A TPCLLC form was used in 86% of non-ICU deaths but only 12% of ICU deaths ($p<0.001$).

Discussions about WWMT were initiated significantly earlier for children who died outside ICU (see Table 2). There was a discussion about WWMT before the last admission in 59% of non-ICU deaths against 8% of ICU deaths ($p<0.001$).

Children dying outside ICU were older, with more overall hospital contact and commonly with a cancer diagnosis (see Table 2). Death was more often expected long-term (91% vs. 70%, p=0.048), and they were more likely to never have been admitted to ICU (41% vs. 0%, p<0.001). ICU deaths commonly involved children with neonatal and congenital conditions. Nine children were never admitted to ICU.

The significant age difference between the ICU and non-ICU groups seemed largely related to a large proportion of neonates in the ICU group compared to none in the non-ICU group. Further comparison was made with exclusion of neonates (see Table 3). Here there was no significant difference in the median age of the ICU and non-ICU groups, and no significant difference in overall hospital contact and underlying diagnoses. The associations described above regarding TPCLLC forms, WDT vs. WHT, PPC involvement and timing of discussions, however, remained significant.

Discussion

The aim of this study was to identify changes in WWMT practice at our centre over the last 10 years. We observed a change towards earlier discussions about WWMT in the clinical trajectory, and identified a growing subgroup of hospital deaths – children dying outside ICU, with treatment withheld, early WWMT discussions, and PPC involved.

The overall proportion of WWMT of 87% at RCH is similar to those previously published in the Australian literature (74-88% (1-4)), and remains one of the highest in the world (31-88% (1-4, 6-11)). In our cohort, withdrawal was more common than withholding (63% vs 25%), with ventilatory support the most frequently withdrawn intervention. This is similar to published literature from the USA (51% vs 17%) (10), but different to practice in Japan, where ventilation is never withdrawn (11). We saw a small shift from WDT to WHT over the past 10 years at our centre, which, although non-significant, may represent a move to planned non-escalation rather than trial of treatment, fitting with the growing trend towards advance care planning (5).

We found 86% of deaths occurring in children with pre-existing chronic illness. Published literature has reported proportions from 63% to 88% (1, 2, 5, 8, 10, 14). While children with acute illnesses are more likely to die with full treatment, insidious pre-existing diagnoses can often be supported by life-sustaining treatment, and a deliberate decision must be made about death (8). RCH is a quaternary referral centre, where children with rare conditions are treated more frequently than in smaller centres, likely explaining the relatively high proportion of children with chronic conditions, and high rates of WWMT.

One of the biggest changes observed since 2007 is in the timing of discussions around WWMT, with a clear shift to earlier discussions. This is indicative of efforts towards advanced end-of life planning, and is in keeping with the direction of end-of life care worldwide (5, 16-18). A 2014 review of healthcare records in the United Kingdom found that the first discussion in children with life-limiting conditions was usually between 1 and 6 months prior to death (19). In contrast, the median time of first discussion in our study was later, in the last month of life. Their sample population was different however, with a focus on children with known life-limiting conditions rather than all deaths. We also found a greater average number of conversations compared to 2007, reinforcing advance care planning as a gradual process.

The UK authors also found most of the initial discussions were documented in an outpatient letter. In contrast, our audit revealed only four discussions documented in the outpatient setting, with the large majority in inpatient progress notes. It may be that these outpatient discussions are occurring at RCH but not documented. Alternatively, paediatricians at RCH may tend not to discuss WWMT in the outpatient setting. With growing emphasis in guidelines on WWMT discussions while a child is relatively well (13, 20), this is a potential area for development.

The recent audit in Brisbane RCH (5) focussed on the documentation of resuscitation plans. They reported 31% of cases where these were documented before the last admission. In contrast, a discussion about WWMT could be found before the last admission in 19% of cases in our study. This may be accounted for by the inclusion of children who died at home in the Brisbane study – a population that would be more likely to have early discussions about WWMT.

As advanced care planning develops, and the importance of end-of life discussions before the need for intensive care arises has become increasingly recognized (13, 20), information on deaths outside ICU will become particularly important in identifying and managing the subgroup of patients most likely to benefit from this approach. We found that 22% of children died outside of ICU, which is higher than previously reported at our centre in 2007 (3). The audit of Brisbane RCH reports a similar proportion of ward deaths (15/62, 24%) but fewer deaths in ICU (16/62, 26%) (5). Their largest group was of deaths at home (23/62, 27%), which were not included in our study, but represent an important population for study to further understand this field. We found significantly earlier WWMT discussions for children dying outside intensive care, similar to Brisbane RCH (5). The time range from first WWMT discussion to death was 1-7 days for children dying in ICU (8% of these prior to the last admission) but 9-229 days in those dying outside of ICU (59% prior to last admission). This demonstrates early advance care planning in a large number of cases in the non-ICU group, and the opportunity to bypass the ICU completely in 9 cases. With neonates excluded, there did not appear to be significant demographics difference between the ICU and non-ICU groups that would explain difference in timing of WWMT discussions (specifically, age, prior hospital contact, or underlying conditions). This suggests a causative relationship between early WWMT discussions and death outside of ICU but warrants further, prospective study. The outcome of each WWMT discussion also warrants further consideration in prospective research, as there is suggestion that decision for WHT in the form of Do-Not-Resuscitate orders (DNR) (which was the most common form of WHT in our study) is in itself

associated with death at home (21). While we did not specifically look at the involvement of the child in WWMT discussions, this study has a very young median age at death making involvement less likely.

Involvement of PPC at our centre has increased significantly from 10% of deaths in 2007 to the current 36%. There is general consensus that PPC involvement is beneficial at the end-of life for children (5, 15, 17, 20, 22). A review of over 24,000 deaths found that those with PPC involvement received fewer invasive interventions at the end of life and were less likely to die in ICU (23). Similarly, introduction of PCC services is liked to hospital-wide increase in Do-Not-Resuscitate orders (DNR) (22), while direct involvement of PPC is linked to a nearly eight-fold increase in the likelihood of a Do-Not-Resuscitate order being in place at the time of death (24), and 70% reduced odds of dying during a code (12). We found a significant correlation between death outside of ICU and PPC involvement, similar to other studies. The recent study at Brisbane RCH found that 81% of children dying on the wards were referred to PPC, against 27% of those dying in ICU (5). In Canada, PPC services were involved in all paediatric deaths outside of the ICU (25). It is possible that some units do not refer to PPC as there is insufficient time for such a referral. However there is evidence that PPC involvement in acute illness leads to earlier documentation of an end-of-life plan (26), so there is likely scope for more widespread PCC referral.

One important limitation of this study was its retrospective nature and relatively small size. Another possible issue was lack of detail in documentation, which may have led to incorrect conclusions about the events in the child's disease course and discussions about WWMT. This highlights the need for good documentation for clinical implementation of evolving discussions. Documentation of the WWMT process has previously been described as poor (3, 5, 19). The TPCLLC form was created following the 2007 audit – a tick-box form with details of treatments to be withheld or given, and which emphasises a discussion with the family about these – and was used in 28% of cases in this audit. Children who died following WHT were

significantly more likely to have the form completed, and at an earlier date. A study of advance care planning in the UK found the implementation of a documentation tool improved the quality of advance care planning (18). In France, a detailed form was created for documentation of WWMT discussions and palliative care provision (Supplemental information S2). An evaluation of its use concluded that it allowed for a more formal approach to WWMT discussions and decisions, as well as ease of handover of the information (27). As we move towards fully integrated electronic medical records, it will be important to incorporate advance care documentation and decision support tools, and to study the impact of these on clinical practice.

Conclusion

Most deaths at RCH occur in children with chronic conditions, and following WWMT. The last decade has seen discussions initiated earlier in the child's clinical trajectory, accompanied by increased referrals to PPC, and an increase in deaths outside of intensive care. Non-ICU deaths represent a previously under-described group which highlights of the benefits of advanced care planning and PPC involvement. This group warrants further study.

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Table 1: Characteristics of children who died in 2007 compared to 2015-2016
Data is presented as percentage (number of cases)

	Number in 2007 n=50	Number in 2015-2016 n=101	%Difference [95%CI]	Chi squared
PPC involvement	10 (5)	37 (37)	27 [14–39]	p<0.001
TPCLLC forms	NA*	28 (28)		
WWMT				
WDT	66 (33)	62 (63)	4 [-13–19]	p=0.66
WHT	18 (9)	25 (25)	7 [-7–20]	p=0.35
Full treatment	12 (6)	6 (6)	6 [-4–16]	p=0.20
Brain death	4 (2)	7 (7)	3 [-4–10]	p=0.47
Location of death				
ICU	84 (42)	76 (77)	8 [-5–21]	p=0.27
Non-ICU	14 (7)	22 (22)	8 [-5–20]	p=0.25
Other	2 (1)	2 (2)	0 [-5–5]	p=0.99
Underlying diagnosis				
Congenital including congenital malformations, neurological, genetic, and metabolic conditions	28 (14)	40 (40)	12 [-4–27]	p=0.16
Cardiac including congenital malformations	26 (13)	14 (14)	12 [-2–26]	p=0.07
Neonatal	14 (7)	11 (11)	3 [-8–14]	p=0.58
Neoplastic	12 (6)	12 (12)	0 [-11–11]	p=0.98
Acute illness only	16 (8)	15 (15)	1 [-11–13]	p=0.85
Other	4 (2)	12 (12)	8 [0–16]	p=0.12
Death expected?				
Long term	70 (35)	75 (76)	5 [-9–20]	p=0.32
Short term	92 (46)	95 (96)	3 [-6–12]	p=0.46
Both long and short term	62 (31)	75 (76)	13 [-3–29]	p=0.09
Discussions about WWMT				
Cases with discussions about WWMT	92 (46)	91 (92)	1 [-8–10]	p=0.85
Cases with a discussion before last admission	4 (2)	19 (19)	15 [5–24]	p=0.004
First discussion on the day of death	30 (15)	18 (18)	12 [-5–27]	p=0.09
First discussion in the week before death	40 (20)	51 (51)	10 [-6–27]	p=0.18
Total number of discussions	n=64	n=254		
Average number of discussions per child	1.3	2.5		
Total number of discussions on the day of death	50 (32)	22 (55)	28 [15–42]	p<0.001
Total number of discussions in the week before death	38 (24)	47 (120)	10 [-4–23]	p=0.16

*The TPCLLC form did not exist in 2007

	Non-ICU n=22	ICU n=77	%Difference [95% CI]	Chi squared

Table 2: Characteristics of children who died outside ICU vs. ICU

Data is presented as percentage (number of cases), time values as a median [IQR]

Age at death	2.2y [1y-12y]	104d [14d-4y]		
PPC involvement	95 (21)	19 (15)	76 [64–88]	p<0.001
TPCLLC forms	86 (19)	12 (9)	75 [59–91]	p<0.001
Underlying diagnosis (can overlap)				
Genetic	36 (8)	17 (13)	19 [-2–41]	p=0.049
Congenital	0 (0)	19 (15)	19 [10–28]	p=0.03
Oncology	32 (7)	6 (5)	25 [5–46]	p=0.001
Perinatal and neonatal	0 (0)	13 (10)	13 [5–20]	p=0.08
Metabolic	14 (3)	6 (5)	1 [-20–22]	p=0.91
Cardiac	9 (2)	14 (11)	5 [-9–20]	p=0.53
Other	9 (2)	19 (15)	10 [-5–25]	p=0.26
Previously well – no chronic disease	5 (1)	18 (14)	14 [1–26]	p=0.12
Death expected?				
Long term	91 (20)	70 (54)	21 [5–37]	p=0.048
Short term	100 (22)	94 (72)	6 [1–12]	p=0.22
WWMT				
WDT	32 (7)	71 (55)	40 [18–62]	p=0.001
WHT	68 (15)	12 (9)	56 [36–77]	p<0.001
All WWMT	100 (22)	83 (64)	17 [9–25]	p=0.04
Full treatment	0 (0)	8 (6)	8 [2–14]	p=0.18
Brain death	0 (0)	9 (7)	9 [3–16]	p=0.14
Discussions about location				
Plan for home	18 (4)	1 (1)	17 [1–33]	p=0.001
Plan for non-ICUs	46 (10)	0 (0)	45 [25–66]	p<0.001
Plan for ICU	0 (0)	4 (3)	4 [0–8]	p=0.35
No discussion	36 (8)	95 (73)	58 [38–79]	p<0.001
Discussions about WWMT				
No of discussions per case	2 [1-3]	3 [2-5]		
Time from first discussion to death (days)	50 [9-229]	1 [1-7]		
Time from last discussion to death (days)	2 [0-7]	0 [0-1]		
Cases with a discussion before last admission	13 (59)	6 (8)	51 [30–73]	p<0.001
First discussion was on the day of death	0 (0)	16 (21)	21 [12–30]	p=0.02
Previous hospital contact				
Number of admissions	4 [3-10]	1 [1-3]		
Number of days	44 [20-82]	18 [5-73]		
Number of ICU admissions	1 [0-2]	1 [1-2]		
Number of ICU days	2 [0-11]	13 [5-31]		

Table 3: Characteristics of children who died outside ICU vs. ICU with neonates excluded

Data is presented as percentage (number of cases), time values as a median [IQR]

	Non-ICU n=22	ICU n=54	%Difference [95% CI]	Chi squared
Age at death	2.2y [1y-12y]	1.7y [94d-7y]		
PPC involvement	95 (21)	26 (14)	70 [55–84]	p<0.001
TPCLLC forms	86 (19)	13 (7)	73 [56–90]	p<0.001
Underlying diagnosis (can overlap)				
Genetic	36 (8)	19 (10)	18 [-5–40]	p=0.10
Congenital	0 (0)	15 (8)	15 [5–24]	p=0.06
Oncology	32 (7)	9 (5)	23 [2–44]	p=0.01
Perinatal and neonatal	0 (0)	9 (5)	9 [2–17]	p=0.14
Metabolic	14 (3)	7 (4)	6 [-10–22]	p=0.39
Cardiac	9 (2)	4 (2)	5 [-8–18]	p=0.34
Other	9 (2)	24 (13)	15 [-2–32]	p=0.14
Previously well – no chronic disease	5 (1)	17 (9)	12 [-1–25]	p=0.16
Death expected?				
Long term	91 (20)	67 (36)	24 [7–42]	p=0.03
Short term	100 (22)	91 (49)	9 [2–17]	p=0.14
WWMT				
WDT	32 (7)	67 (36)	35 [12–58]	p=0.005
WHT	68 (15)	17 (9)	52 [30–73]	p<0.001
All WWMT	100 (22)	83 (45)	17 [7–27]	p=0.04
Full treatment	0 (0)	6 (3)	6 [-1–12]	p=0.23
Brain death	0 (0)	11 (6)	11 [3–19]	p=0.10
Discussions about location				
Plan for home	18 (4)	2 (1)	16 [0–33]	p=0.01
Plan for non-ICUs	46 (10)	0 (0)	45 [25–66]	p<0.001
Plan for ICU	0 (0)	4 (2)	4 [-1–9]	p=0.36
No discussion	36 (8)	94 (51)	58 [37–79]	p<0.001
Discussions about WWMT				
No of discussions per case	2 [1-3]	2 [1-3]		
Time from first discussion to death (days)	50 [9-229]	2 [1-20]		
Time from last discussion to death (days)	2 [0-7]	0 [0-1]		
Cases with a discussion before last admission	59 (13)	11 (6)	48 [26–70]	p<0.001
First discussion was on the day of death	0 (0)	20 (11)	20 [10–31]	p=0.02
Previous hospital contact				
Number of admissions	4 [3-10]	2 [1-10]		
Number of days	44 [20-82]	46 [11-110]		
Number of ICU admissions	1 [0-2]	1 [1-2]		

Number of ICU days	2 [0-11]	24 [7-43]