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Ethical dilemmas in providing acute medical care at home for children

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ABSTRACT

Objective: Acute care at home is increasing. We aimed to determine the views of healthcare professionals on the ethics of providing home care.

Design: An analysis of opinions of home healthcare professionals.

Setting: The Australasian Hospital-in-the-Home Annual Conference, November 2017.

Participants: Physicians, nurses and allied health staff who providing acute care for children and adults at home.

Methods: Clinical scenarios were presented about a 14-year-old receiving intravenous antibiotics at home, and participants were asked to vote manually on whether providing home care was ethical.

Main Outcomes: The proportion of healthcare professionals who believed that provision of home care was ethical in different situations.

Results: For each question the response rate ranged from 71-100%. While the provision of acute home care was deemed ethical by the majority (77/80, 96%), this decreased when other factors were involved such as domestic violence (37/63 (59%) OR 0.06 95%CI 0.02-0.20, $p < 0.001$) and, parental reluctance (28/67 (42%) OR 0.02 95%CI 0.008-0.09, $p < 0.001$). The age of consent against parental wishes affected the proportion who considered home care ethics: 16 years versus 14 years: OR 4.4 95% CI 1.9-10.1, $p < 0.001$. The lowest proportion to consider home care ethical (16%) was when home care was deemed less than hospital care.

Conclusions: This is the first study to assess opinions of healthcare providers in applying the tenets of medical ethics (autonomy, non-maleficence, beneficence and justice) to acute home care to children. It provides a benchmark against which to assess other stakeholders' opinions and to allow reflection of this increasing practice.

INTRODUCTION

Care at home for acute medical conditions is increasingly viewed and used as a viable alternative to hospital admission^{1 2}. The rationale is for both patients and organisations. The majority of patients prefer to receive their care at home if possible, and have improved psychological outcomes and reduced risks associated with admission such as hospital-acquired infections^{3 4}. For organisations, improved flow of patients and reduced costs make home care attractive^{5 6}. There is evidence in adults that safety and efficacy are comparable between home and hospital care in selected patients and conditions⁷. While the evidence for safety and efficacy in acute conditions is scarcer in children, this too is accumulating⁸⁻¹¹. However, while there is some literature around the ethics of treating children with chronic conditions at home^{12 13}, the ethical aspects of treating children at home for acute conditions have not previously been explored.

Ethical behaviour has been considered in medicine since Hippocrates, and the International Code of Medical Ethics¹⁴, or variants, have been adopted by many national medical associations¹⁵⁻¹⁸. These are based on the four principles of medical ethics described by Beauchamp and Childress: autonomy, non-maleficence, beneficence and justice¹⁹.

We aimed to understand the views of clinical professionals who provide home care on various ethical aspects of managing children with acute medical conditions at home that would otherwise necessitate hospital admission. Acute home programs have names including hospital-in-the-home and medical home, whereby nursing, medical and allied health staff provide at least daily medical interventions in the

1
2
3 home including intravenous antibiotics, acute wound dressings, chemotherapy, and
4
5 physiotherapy. We aimed to determine the ethical parameters within which home
6
7 healthcare professionals believe they should be providing care to children at home.
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10 11 12 **METHODS**

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15 **Setting:** The Australasian Hospital-in-the-Home (HITH) Annual Conference
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17 November 2017.

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20 **Participants:** Medical, nursing and allied health staff attendees to the conference, all
21
22 of whom provide clinical services to patients at home.

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24
25 **Design:** All attendees were invited to a session titled 'Ethical dilemmas in HITH
26
27 practice'. The intention to survey opinions on ethical matters was explained and
28
29 attendees were invited to participate or not. Nobody left the session but four
30
31 attendees declined. Background was given on how ethical constructs can be used to
32
33 explore practical dilemmas. A non-clinical scenario was given to show there is often
34
35 no right answer, how ethical reasoning can be applied to either side of an argument,
36
37 and that increasing or changing available information can change how a situation is
38
39 viewed ethically. It was explained that several questions would be asked for which
40
41 there was no right answer and that the information they needed to make a fully
42
43 informed decision may not be there. For each question, participants could choose to
44
45 vote or not, and they were requested to hold up a blue sign if they thought the
46
47 situation was ethical and a red one if they thought not. Two people counted votes and
48
49 in case of discrepancy, a photograph was taken and attendees were assured these
50
51 would be destroyed after verification. The session used a fictitious situation based on
52
53 real dilemmas that arise in acute home care.
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3 **Main Outcomes:** The proportion of healthcare professionals who believed that
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5
6 provision of home care was ethical in different situations.

7
8 **Statistical analysis:** Statistics are descriptive, with Chi-square test used for
9
10 comparisons to assess odds ratios (OR) with 95% confidence intervals (CI).

11
12 **Patient and public involvement:** There were no patients or members of the public
13
14
15 involved in any aspect of the study as it is an examination of opinions of clinical staff.

16
17 **Ethics approval:** This was not required.
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21

22 **RESULTS**

23
24 Two test questions ascertained the maximum number of voting participants and
25
26 ensured an understanding of the process – the first aiming to elicit an ‘ethical’
27
28 response and the second a ‘not ethical’ response. 80/84 (95%) attendees
29
30 participated, all of whom voted ‘ethical’ for the first question and ‘not ethical’ for the
31
32 second question. For the clinical scenario, after each piece of additional information,
33
34 participants were asked to vote on ‘Is it ethical to provide a home service for this
35
36 patient in this situation?’ Response rates for each question ranged from 71-100%.
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43 *Question 1. A 14-year-old girl with cystic fibrosis (CF) needs a planned episode of care*
44
45 *for an infective exacerbation. Your institution has a well-established home care*
46
47 *pathway for ‘CF tune-ups’ with intravenous antibiotics and physiotherapy. You offer her*
48
49 *home or hospital care and she chooses home.*
50
51

52 Home care was voted as ethical by a very high proportion of participants (77 votes,
53
54 96%), all of whom work in home care and are therefore familiar with it (table 1).
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3 *Question 2. You discover that there is a history of domestic violence between adults in*
4 *the household.*

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7
8 Compared to the previous response, the proportion (37/63, 59%) who thought
9
10 providing a home service was ethical when domestic violence was involved was
11
12 significantly decreased (OR 0.06 95%CI 0.02-0.20, $p < 0.001$).

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14
15
16
17 *Question 3a. You determine there is no current risk to nursing staff. However, the girl's*
18 *mother tells you she is exhausted from chronic care of her child and was counting on*
19 *hospital admission for respite.*

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22
23
24 *3b. Her mother tells you if she doesn't get this respite, she will have to take unpaid leave*
25 *and won't be able to afford to take everyone on a family holiday.*

26
27
28
29 *3c. Her mother tells you if she doesn't get this respite, she will have to take unpaid leave*
30 *and won't be able to afford to buy a wheelchair for her other child who has a disability.*

31
32 Compared to the first response, the proportion (28/67, 42%) who thought providing
33
34 home care was ethical when the mother declared her reluctance due to exhaustion
35
36 was significantly decreased (OR 0.02 95%CI 0.008-0.09, $p < 0.001$). Although there
37
38 was an increase when the admission request was to pay for a family holiday and a
39
40 decrease again when it was to pay for a wheelchair, these differences were not
41
42 significant.
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51 *Question 4a. You are about to acquiesce to parental wishes, but the 14-year-old girl now*
52 *insists that she wants to go home via HITH.*

53
54
55 *4b. What if the girl was 16 years old?*

56
57 There was a significant difference with patient age (without any further information)
58
59 about whether it was deemed ethical to provide home care per the patient's wishes
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3 against parental wishes: 48/58 (83%) at 16 years versus 33/63 (52%) at 14 years
4
5 (OR 4.4 95% CI 1.9-10.1, $p < 0.001$).
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10 *Question 5. Everyone now agrees to proceed with treatment at home. However, the*
11 *home care physiotherapist will be away during the treatment period, so the girl and her*
12 *parents will need to do her physiotherapy.*
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16

17 Compared to the first response, the unavailability of physiotherapy led to the lowest
18 proportion (10/61, 16%) of all questions of those who felt providing home care in
19 this scenario was ethical (OR 0.008 95%CI 0.002-0.03, $p < 0.001$).
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26 *Question 6. Your first visit to the home reveals a small apartment where the young girl's*
27 *bedroom is her only sanctuary. This is currently full of medical equipment to facilitate*
28 *her being at home.*
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33 A high proportion of participants (63/64, 98%) voted that providing home care in
34 this situation was ethical, with no difference from the original scenario (OR 2.5
35 95%CI 0.2-24.1, $p = 0.4$).
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43 *Question 7a. Towards the end of her HITH stay her peripherally-inserted central*
44 *catheter (PICC) blocks and you are unable to insert a cannula despite repeated*
45 *attempts. The options are intramuscular injection or reinsertion of the PICC, for which*
46 *she would need admission for a general anaesthetic. You decide to give an*
47 *intramuscular injection so she can continue at home as she only needs one more day of*
48 *parenteral antibiotics.*
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57 *7b. Two days of intramuscular injections.*
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59 *7c. Three days of intramuscular injections.*
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3 As the number of days of intramuscular injections at home in preference to admission
4 for PICC replacement increased, the proportion of participants that felt this was
5 ethical fell significantly (figure 1): 61/62 (98%) versus 31/60 (52%), OR 57 95%CI 7-
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10 439, $p < 0.001$).

11 12 13 14 15 **DISCUSSION**

16
17 This is the first examination of the application of ethical values to acute care for
18 patients at home. The questions were designed to test various aspects of the four
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22 tenets of medical ethics.

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27 Patient autonomy refers to respectful treatment of patients by ensuring disclosure of
28 information and not constraining their right to make their own informed decision.

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31 This is exemplified in the first question where information is given to the patient and
32 she decides between home care and hospital admission. The strong vote that this was
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ethical indicates that participants feel there is sufficient evidence that home care is
effective and safe. Insufficient information is given to assess whether there was
patient coercion, which is prohibited by the concept of autonomy, but on the face of it,
the process appears ethical. The decision becomes less clear, as highlighted by the
drop in 'ethical' votes, when the patient's mother's autonomy is included. This
question also raised whether different reasons underpinning her autonomy
(exhaustion, lack of funds) affect the ethical construct, but these were not viewed by
participants as having as much impact as the mere fact of her opposing decision. In
adult medicine, the patient's autonomy is paramount with the wishes of spouses and
children being secondary^{20 21}. In paediatrics, autonomy regarding medical care lies
with those (usually the parent/s) holding parental rights, but the age at which the

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3 child's best interests are served by the child being autonomous is debated. More
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5 participants felt it was ethical for a 16-year-old to provide consent than a 14-year-old.
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7 The age at which a child can legally provide consent is different in different countries.
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10 In the UK, the test of 'Gillick competence' allows a minor under the legal age of
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12 consent (16 years) to be assessed as sufficiently mature to understand and make
13
14 their own decisions and provide consent. This is in line with the ethical tenet of
15
16 autonomy, which relies on competence. This medical case law has essentially been
17
18 adopted in Australia and Canada, although only sporadically in the USA. However,
19
20 even if consent is given by the adolescent, each home care service may have its own
21
22 rules about whether an adult also needs to be present, which may supersede the
23
24 ethical aspects of who ultimately provides consent.
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31 Non-maleficence refers to the duty to avoid causing harm including pain, suffering
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33 and disablement. Beneficence refers to the duty to actively promote good for patients,
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35 to defend their rights and to remove conditions that will cause harm. Although, they
36
37 are sometimes seen as two sides of the same coin, one can obey the dictates of non-
38
39 maleficence simply by refraining from acting, but beneficence requires positive
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41 action. Several questions highlighted these dual tenets, essentially creating an ethical
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43 dilemma, including provision of potentially invasive services in her place of
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45 sanctuary: beneficence of active care provision for her health, but non-maleficence
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47 requires not to the detriment to her psyche. However, as long as the patient is fully
48
49 informed and has consented, autonomy dictates that we should not be paternalistic.
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52 Any detrimental effects may also differ between short episodes of acute care and
53
54 ongoing chronic care where medical equipment might be a permanent fixture. The
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56 benefits and harms are also raised in the question on intramuscular injections, with
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3 increasing number (and therefore pain) correlating with decreasing acceptance. This
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5 adds a level of complexity when deciding on the ethical imperatives between the
6
7 three options of home care, intramuscular injections and the small but serious
8
9 potential harm of a general anaesthetic.
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15 The issue of household domestic violence raises to whom the beneficence and non-
16
17 maleficence need to be applied. In this situation there is an obligation of specific
18
19 beneficence to the patient, and it potentially even increases the imperative for a
20
21 professional to visit the home. However, the ethical balance shifted for non-
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23 responders when non-maleficence needed to be considered for a staff member
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25 entering a potentially unsafe situation. Since there is a moral obligation to both, other
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27 aspects should be considered to guide decision-making such as the vulnerability of
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29 the individual and the risk of potential harm to either party, and for that more
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31 information is required. It is, however, worth stating that it is rare for domestic
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33 violence to be perpetrated against outsiders, and that the balance of most home
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35 healthcare providers is to provide the care and, if necessary, have two staff members
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37 visit together.
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45 Finally, justice refers to how benefits and burdens should be distributed. It mandates
46
47 the fair medical treatment of patients, with equal situations being treated equally, and
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49 unequal situations being treated in proportion to their inequalities. A large majority
50
51 of participants felt it was not just to provide inferior treatment at home compared to
52
53 what would be offered in hospital, reflecting the importance of physiotherapy in CF
54
55 care. This is important because the concern around home care being inferior is a
56
57 barrier to acute home care for many institutions and clinical staff^{22 23}. Robust
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3 evidence that home care is as efficacious and safe as hospital care for children is
4
5 increasing, but more is needed²⁴. Of note, most home programs only provide daily
6
7 physiotherapy at home compared to twice daily in hospital, which is therefore
8
9 already less, yet this is considered acceptable by respiratory physicians. The concept
10
11 of 'good enough' has been discussed regarding parenting where perfection is not
12
13 deemed necessary. It may be appropriate to apply the same concept to home services
14
15 where the intensity of services is lower, but the quality must be as high. We did not
16
17 explore how good would be considered 'good enough' (eg physiotherapy via
18
19 telehealth, a physiotherapist visiting alternate days) or compare this with the risks of
20
21 inpatient admission. The other aspect is the balance of unequal situations. In a recent
22
23 study of home intravenous antibiotic treatment for cellulitis, it was shown that parent
24
25 and child quality of life was significantly higher at home and it cost three times less
26
27 for the family than in hospital^{24 25}. The efficacy level (the primary outcome) for non-
28
29 inferiority was set lower for home than in hospital at the start of the trial²⁶ because of
30
31 the recognition of the benefits of home and acceptance of a proportionally lower level
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33 of efficacy, although efficacy was actually found to be higher at home.
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43 Study limitations are that it only evaluated opinions of those providing home
44
45 services. Additionally, because it was not anonymous (the technology was unavailable
46
47 for electronic voting) people may have felt peer pressure to vote similarly, although
48
49 the differences in proportions for different questions suggest otherwise. The
50
51 questions were limited to clinical dilemmas, and did not include other ethical
52
53 dimensions to acute home care such as organisational issues (eg rationing or
54
55 payment of services²⁷) and research.
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3 The tenets of medical ethics do not aim to provide answers, or even guidelines, for
4
5 managing moral issues; rather they provide a framework to identify and reflect upon
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7 them. As the first survey of its kind, these results provide a benchmark against which
8
9 surveys of other groups regarding acute home care in children can be compared. The
10
11 next important step will be to obtain the opinions of patients, families and other
12
13 healthcare providers. The results show the importance of considering ethical aspects
14
15 of the provision of home care, both in building a service and in providing and
16
17 constantly improving the quality of delivering acute medical care to children at home.
18
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27
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29
30 had no role in any aspect of the study.
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36 **Conflicts of interest:** This study was not funded and there are no conflicts of interest
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38 to declare.
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What is already known on this topic

- Children are increasingly managed at home for treatment of acute conditions that would traditionally require hospital admission
- There is emerging evidence for the efficacy and safety of this approach, but a lack of discussion on the ethical aspects.

What this study adds

- Healthcare providers who are familiar with acute home care believe this care follows the ethical tenets of autonomy, beneficence, non-maleficence and justice.
- Ethical dilemmas arise when other people such as staff members and parents need to be considered.
- Provision of home care was felt to be least ethical when it was deemed inferior clinically to hospital care.

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Tables

Table 1. Responses to ethical questions (see text for full questions)

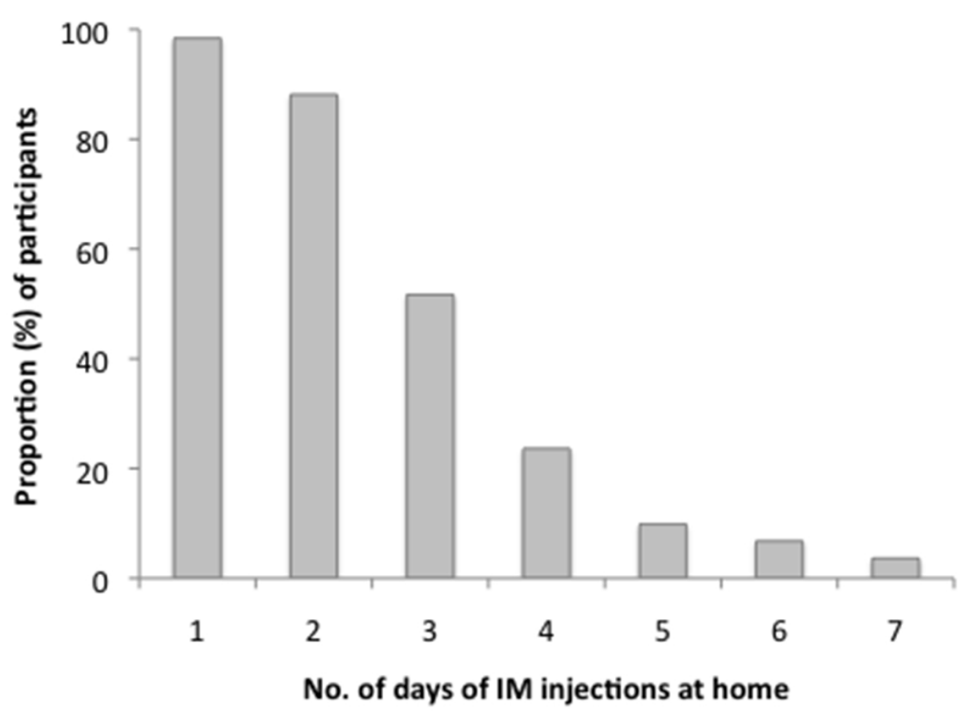
Question	Responses No. (%)	Vote results	
		Ethical No. (%)	Not ethical No. (%)
1. Home treatment	80 (100)	77 (96)	3 (4)
2. Domestic violence	63 (79)	37 (59)	26 (41)
3. Parental respite			
a. Maternal exhaustion	67 (84)	28 (42)	39 (58)
b. Afford a family holiday	57 (71)	28 (49)	29 (51)
c. Afford a wheelchair	64 (80)	28 (44)	36 (56)
4. Consent			
a. 14 years old	63 (79)	33 (52)	30 (48)
b. 16 years old	58 (73)	48 (83)	10 (17)
5. Physiotherapy unavailable	61 (76)	10 (16)	51 (84)
6. Bedroom sanctuary	64 (80)	63 (98)	1 (2)
7. Intramuscular injections			
a. 1 day	62 (78)	61 (98)	1 (2)
b. 2 days	59 (74)	52 (88)	7 (12)
c. 3 days	60 (75)	31 (52)	29 (48)

Figure legends

Figure 1. Proportion of participants who believe it is ethical to administer intramuscular (IM) injections at home by number of days

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Ethical dilemmas in providing acute medical care at home for children: a survey of health professionals

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3 **Ethical dilemmas in providing acute medical care at home for children: a survey**
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5 **of health professionals**
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ABSTRACT

Objective: Acute care at home is increasing. We aimed to determine the views of healthcare professionals on the ethics of providing home care and compare the impact of situational changes on their opinions.

Design: An analysis of opinions of home healthcare professionals.

Setting: The Australasian Hospital-in-the-Home Annual Conference, November 2017.

Participants: Eighty physicians, nurses and allied health staff who provide acute care for children and adults at home.

Methods: Clinical scenarios were presented about a 14-year-old receiving intravenous antibiotics at home via an established home care pathway, and participants were asked to vote manually on whether providing home care was ethical.

Main Outcomes: The proportions of healthcare professionals who believed that provision of home care was ethical in different situations.

Results: For each question the response rate ranged from 71-100%. While the provision of acute home care was deemed ethical by the majority (77/80, 96%), this decreased when other factors were involved such as domestic violence (37/63 (59%) OR 0.06 95%CI 0.02-0.20, $p < 0.001$) and, parental reluctance (28/67 (42%) OR 0.02 95%CI 0.008-0.09, $p < 0.001$). The age of consent affected the proportion who considered home care ethical against parental wishes: 16 years versus 14 years: OR 4.4 95% CI 1.9-10.1, $p < 0.001$. The lowest proportion to consider home care ethical (16%) was when home care was deemed less than hospital care.

Conclusions: Home healthcare providers are supportive of the ethics of providing acute care at home for children, although differ amongst themselves with situational complexities. Applying the tenets of medical ethics (autonomy, non-maleficence,

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3 beneficence and justice) can provide insights into the factors that may influence
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6 opinions.
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INTRODUCTION

Care at home for acute medical conditions is increasingly viewed and used as a viable alternative to hospital admission^{1 2}. The rationale applies to both patients and organisations. The majority of patients prefer to receive their care at home if possible, and have improved psychological outcomes and reduced risks associated with admission such as hospital-acquired infections^{3 4}. For organisations, improved flow of patients and reduced costs make home care attractive^{5 6}. There is evidence in adults that safety and efficacy are comparable between home and hospital care in selected patients and conditions⁷. While the evidence for safety and efficacy in acute conditions is scarcer in children, this too is accumulating⁸⁻¹¹. However, while there is some literature around the ethics of treating children with chronic conditions at home^{12 13}, the ethical aspects of treating children at home for acute conditions have not previously been explored.

Ethical behaviour has been considered in medicine since Hippocrates, and the International Code of Medical Ethics¹⁴, or variants, have been adopted by many national medical associations¹⁵⁻¹⁸. These are based on the four principles of medical ethics described by Beauchamp and Childress: autonomy, non-maleficence, beneficence and justice¹⁹.

We aimed to understand the views of clinical professionals who provide home care on various ethical aspects of managing children with acute medical conditions at home that would otherwise necessitate hospital admission. Acute home programs have names including hospital-in-the-home and medical home, whereby nursing, medical and allied health staff provide at least daily medical interventions in the

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3 home including intravenous antibiotics, acute wound dressings, chemotherapy, and
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5 physiotherapy. We aimed to determine the ethical parameters within which home
6
7 healthcare professionals believe they should be providing care to children at home.
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10 11 12 **METHODS**

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15 **Setting:** The Australasian Hospital-in-the-Home (HITH) Annual Conference
16
17 November 2017.

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19
20 **Participants:** Medical, nursing and allied health staff attendees to the conference, all
21
22 of whom provide clinical services to patients at home.

23
24
25 **Design:** All attendees were invited to a session titled 'Ethical dilemmas in HITH
26
27 practice'. The intention to survey opinions on ethical matters was explained and
28
29 attendees were invited to leave the session if they wished, or stay and participate or
30
31 not as they wished. Nobody left but four attendees declined to participate.

32
33 Background was given on how ethical constructs can be used to explore practical
34
35 dilemmas. A non-clinical scenario was given to show there is often no right answer,
36
37 how ethical reasoning can be applied to either side of an argument, and that
38
39 increasing or changing available information can change how a situation is viewed
40
41 ethically. It was explained that several questions would be asked for which there was
42
43 no right answer and that the information they needed to make a fully informed
44
45 decision may not be there. For each question, participants could choose to vote or not,
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47 and they were requested to hold up a blue sign if they thought the situation was
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49 ethical and a red one if they thought not. To try to mitigate any feeling of peer
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51 pressure to vote in a certain way, the signs were white on the back so the choice of
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53 response was only visible from the front with all participants facing forward. Two
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55 people counted votes and in case of discrepancy, a photograph was taken and
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3 attendees were assured these would be destroyed after verification. The session used a
4
5 fictitious situation based on real dilemmas that arise in acute home care.
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7

8 **Main Outcomes:** The proportion of healthcare professionals who believed that
9
10 provision of home care was ethical in different situations.
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12 **Statistical analysis:** Chi-square test was used to compare the proportion of
13
14 responses to different situational questions, with odds ratios (OR), 95% confidence
15
16 intervals (CI), and $p < 0.05$ considered significant.
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18

19 **Patient and public involvement:** There were no patients or members of the public
20
21 involved in any aspect of the study as it is an examination of opinions of clinical staff.
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24 **Ethics approval:** This was not required due to the opinions belonging to the
25
26 healthcare staff and not associated with healthcare institutions and not involving
27
28 clinical care. The purpose of the session was clearly set out prior to starting and
29
30 participants were offered the opportunity to leave, or stay but not participate without
31
32 having to declare their non-participation. All data were anonymised and collated and
33
34 presented in aggregate.
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40 **RESULTS**

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42 The participants at the Australasian Hospital-in-the-Home Society Annual Conference
43
44 were predominantly from Australia and New Zealand and between the ages of 25 and
45
46 65 years. Their professional background was all in healthcare and all in home care,
47
48 with 70% nursing, 20% allied health (predominantly physiotherapists) and 10%
49
50 medical. A minority (5-10%) were directly involved in paediatric home care. Two
51
52 test questions ascertained the maximum number of voting participants and ensured
53
54 an understanding of the process – the first aiming to elicit an ‘ethical’ response and
55
56 the second a ‘not ethical’ response. 80/84 (95%) attendees participated, all of whom
57
58
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3 voted 'ethical' for the first question and 'not ethical' for the second question. For the
4
5 clinical scenario, after each piece of additional information, participants were asked
6
7 to vote on 'Is it ethical to provide a home service for this patient in this situation?'

8
9
10 Response rates for each question ranged from 71-100%.

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15 *Question 1. A 14-year-old girl with cystic fibrosis (CF) needs a planned episode of care*
16
17 *for an infective exacerbation. Your institution has a well-established home care*
18
19 *pathway for 'CF tune-ups' for adolescents with intravenous antibiotics and*
20
21 *physiotherapy. You offer her this home care pathway or hospital care and she chooses*
22
23 *home.*

24
25
26 Home care was voted as ethical by a very high proportion of participants (77 votes,
27
28 96%), all of whom work in home care and are therefore familiar with it (table 1).

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33 *Question 2. You discover that there is a history of domestic violence between adults in*
34
35 *the household.*

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38 Compared to the previous response, the proportion (37/63, 59%) who thought
39
40 providing a home service was ethical when domestic violence was involved was
41
42 significantly decreased (OR 0.06 95%CI 0.02-0.20, $p < 0.001$).

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47 *Question 3a. You determine there is no current risk to nursing staff. However, the girl's*
48
49 *mother tells you she is exhausted from chronic care of her child and was counting on*
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51 *hospital admission for respite.*

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55 *3b. Her mother tells you if she doesn't get this respite, she will have to take unpaid leave*
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57 *and won't be able to afford to take everyone on a family holiday.*

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3 *3c. Her mother tells you if she doesn't get this respite, she will have to take unpaid leave*
4 *and won't be able to afford to buy a wheelchair for her other child who has a disability.*

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8 Compared to the first response, the proportion (28/67, 42%) who thought providing
9
10 home care was ethical when the mother declared her reluctance due to exhaustion
11
12 was significantly decreased (OR 0.02 95%CI 0.008-0.09, $p < 0.001$). Different reasons
13
14 for the respite request did not significantly affect the opinion on whether the care
15
16 was ethical compared to maternal exhaustion: to afford a family holiday: 49% versus
17
18 42%, OR 1.3 95%CI 0.7-2.7, $p = 0.3$), or to buy a wheelchair: 44% versus 42%, OR 1.1
19
20 95%CI 0.5-2.1, $p = 0.5$). Whether it was ethical to care for a child at home when the
21
22 request for respite hospitalisation was to pay for a family holiday had the lowest
23
24 response rate for all questions (71%).
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31 *Question 4a. You are about to acquiesce to parental wishes, but the 14-year-old girl now*
32 *insists that she wants to go home via HITH.*

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36 *4b. What if the girl was 16 years old?*

37
38 There was a significant difference with patient age (without any further information)
39
40 about whether it was deemed ethical to provide home care per the patient's wishes
41
42 against parental wishes: 48/58 (83%) at 16 years versus 33/63 (52%) at 14 years
43
44 (OR 4.4 95% CI 1.9-10.1, $p < 0.001$).
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50 *Question 5. Everyone now agrees to proceed with treatment at home. However, the*
51 *home care physiotherapist will be away during the treatment period, so the girl and her*
52 *parents will need to do her physiotherapy.*
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3 Compared to the first response, the unavailability of physiotherapy led to the lowest
4 proportion (10/61, 16%) of all questions of those who felt providing home care in
5 this scenario was ethical (OR 0.008 95%CI 0.002-0.03, $p<0.001$).
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12 *Question 6. Your first visit to the home reveals a small apartment where the young girl's*
13 *bedroom is her only sanctuary. This is currently full of medical equipment to facilitate*
14 *her being at home.*
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19 A high proportion of participants (63/64, 98%) voted that providing home care in
20 this situation was ethical, with no difference from the original scenario (OR 2.5
21 95%CI 0.2-24.1, $p=0.4$).
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29 *Question 7a. Towards the end of her HITH stay her peripherally-inserted central*
30 *catheter (PICC) blocks and you are unable to insert a cannula despite repeated*
31 *attempts. The options are intramuscular injection or reinsertion of the PICC, for which*
32 *she would need admission for a general anaesthetic. You decide to give an*
33 *intramuscular injection so she can continue at home as she only needs one more day of*
34 *parenteral antibiotics.*
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43 *7b. Two days of intramuscular injections.*

44 *7c. Three days of intramuscular injections.*

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47 As the number of days of intramuscular injections at home in preference to admission
48 for PICC replacement increased, the proportion of participants that felt this was
49 ethical fell significantly (figure 1): 61/62 (98%) versus 31/60 (52%), OR 57 95%CI 7-
50 439, $p<0.001$).
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59 **DISCUSSION**

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3 This is the first examination of the application of ethical values to acute care for
4 patients at home. The responses are those of health professionals who are all engaged
5 in home healthcare, predominantly in adults. The questions were designed to test
6 various aspects of the four tenets of medical ethics.
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14 Patient autonomy refers to respectful treatment of patients by ensuring disclosure of
15 information and not constraining their right to make their own informed decision.
16 This is exemplified in the first question where information is given to the patient and
17 she decides between home care and hospital admission. The strong vote that this was
18 ethical indicates that participants feel there is sufficient evidence that home care is
19 effective and safe. Insufficient information is given to assess whether there was
20 patient coercion, which is prohibited by the concept of autonomy, but on the face of it,
21 the process appears ethical. The decision becomes less clear, as highlighted by the
22 drop in 'ethical' votes, when the patient's mother's autonomy is included. This
23 question also raised whether different reasons underpinning her autonomy
24 (exhaustion, lack of funds) affect the ethical construct, but these were not viewed by
25 participants as having as much impact as the mere fact of her opposing decision. In
26 adult medicine, the patient's autonomy is paramount with the wishes of spouses and
27 children being secondary^{20 21}. In paediatrics, autonomy regarding medical care lies
28 with those (usually the parent/s) holding parental rights, but the age at which the
29 child's best interests are served by the child being autonomous is debated. More
30 participants felt it was ethical for a 16-year-old to provide consent than a 14-year-old
31 and this may reflect some lack of familiarity with the care of younger mature
32 adolescents. The age at which a child can legally provide consent is different in
33 different countries. In the UK, the test of 'Gillick competence' allows a minor under
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3 the legal age of consent (16 years) to be assessed as sufficiently mature to understand
4 and make their own decisions and provide consent. This is in line with the ethical
5
6 tenet of autonomy, which relies on competence. This medical case law has essentially
7
8 been adopted in Australia and Canada, although only sporadically in the USA.
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11 However, even if consent is given by the adolescent, each home care service may have
12
13 its own rules about whether an adult also needs to be present, which may supersede
14
15 the ethical aspects of who ultimately provides consent.
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22 Non-maleficence refers to the duty to avoid causing harm including pain, suffering
23
24 and disablement. Beneficence refers to the duty to actively promote good for patients,
25
26 to defend their rights and to remove conditions that will cause harm. Although, they
27
28 are sometimes seen as two sides of the same coin, one can obey the dictates of non-
29
30 maleficence simply by refraining from acting, but beneficence requires positive
31
32 action. Several questions highlighted these dual tenets, essentially creating an ethical
33
34 dilemma, including provision of potentially invasive services in her place of
35
36 sanctuary: beneficence of active care provision for her health, but non-maleficence
37
38 requires not to the detriment to her psyche. However, as long as the patient is fully
39
40 informed and has consented, autonomy dictates that we should not be paternalistic.
41
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43 Any detrimental effects may also differ between short episodes of acute care and
44
45 ongoing chronic care where medical equipment might be a permanent fixture. The
46
47 benefits and harms are also raised in the question on intramuscular injections, with
48
49 increasing number (and therefore pain) correlating with decreasing acceptance. This
50
51 adds a level of complexity when deciding on the ethical imperatives between the
52
53 three options of home care, intramuscular injections and the small but serious
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55 potential harm of a general anaesthetic.
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6 The issue of household domestic violence raises to whom the beneficence and non-
7
8 maleficence need to be applied. In this situation there is an obligation of specific
9
10 beneficence to the patient, and it potentially even increases the imperative for a
11
12 professional to visit the home. However, the ethical balance shifted for non-
13
14 responders when non-maleficence needed to be considered for a staff member
15
16 entering a potentially unsafe situation. Since there is a moral obligation to both, other
17
18 aspects should be considered to guide decision-making such as the vulnerability of
19
20 the individual and the risk of potential harm to either party, and for that more
21
22 information is required. It is, however, worth stating that it is rare for domestic
23
24 violence to be perpetrated against outsiders, and that the balance of most home
25
26 healthcare providers is to provide the care and, if necessary, have two staff members
27
28 visit together.
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36 Finally, justice refers to how benefits and burdens should be distributed. It mandates
37
38 the fair medical treatment of patients, with equal situations being treated equally, and
39
40 unequal situations being treated in proportion to their inequalities. A large majority
41
42 of participants felt it was not just to provide inferior treatment at home compared to
43
44 what would be offered in hospital, reflecting the importance of physiotherapy in CF
45
46 care. This is important because the concern around home care being inferior is a
47
48 barrier to acute home care for many institutions and clinical staff^{22 23}. Robust
49
50 evidence that home care is as efficacious and safe as hospital care for children is
51
52 increasing, but more is needed²⁴. Of note, most home programs only provide daily
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54 physiotherapy at home compared to twice daily in hospital, which is therefore
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56 already less, yet this is considered acceptable by respiratory physicians. The concept
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3 of 'good enough' has been discussed regarding parenting where perfection is not
4 deemed necessary. It may be appropriate to apply the same concept to home services
5 where the intensity of services is lower, but the quality must be as high. We did not
6 explore how good would be considered 'good enough' (eg physiotherapy via
7 telehealth, a physiotherapist visiting alternate days) or compare this with the risks of
8 inpatient admission. The other aspect is the balance of unequal situations. In a recent
9 study of home intravenous antibiotic treatment for cellulitis, it was shown that parent
10 and child quality of life was significantly higher at home and it cost three times less
11 for the family than in hospital^{24 25}. The efficacy level (the primary outcome) for non-
12 inferiority was set lower for home than in hospital at the start of the trial²⁶ because of
13 the recognition of the benefits of home and acceptance of a proportionally lower level
14 of efficacy, although efficacy was actually found to be higher at home. Unequal
15 situations were tested in the question around maternal reasons for wanting her
16 daughter to have a hospital admission. That the lowest response rate was recorded
17 for whether saving for a family holiday was an ethical reason for not wanting
18 homecare may reflect the lack of paediatric healthcare professionals in the audience,
19 as in paediatrics the child is considered within the holistic sphere of the family, and
20 family well-being is considered an important component .

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48 Study limitations are that it only evaluated opinions of those providing home
49 services. The majority predominantly provide care to adult patients, so would be less
50 familiar with considering ethical aspects of paediatric care at home. The patient was
51 chosen as an adolescent for this reason, but the answers around age of consent and
52 parental respite may have been answered differently by hospital paediatricians and
53 other healthcare providers. Additionally, because it was not completely anonymous
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3 (the technology was unavailable for electronic voting) people may have felt peer
4 pressure to vote similarly. The mitigation for this was that the which way people
5 voted (red or blue colour of vote) were only visible from the front and the
6 participants were all facing forward. Additionally, the differences in proportions of
7 votes for different questions suggest that this factor was not strong. One other
8 limitation is that questions were limited to clinical dilemmas, and did not include
9 other ethical dimensions to acute home care such as organisational issues (eg
10 rationing or payment of services²⁷) and research.
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24 The tenets of medical ethics do not aim to provide answers, or even guidelines, for
25 managing moral issues; rather they provide a framework to identify and reflect upon
26 them. These results can provide a benchmark against which surveys of other groups
27 regarding acute home care in children can be compared. The next important step will
28 be to obtain the opinions of patients, families and other healthcare providers. The
29 results show the relevance of considering ethical aspects of the provision of home
30 care, both in building a service and in providing and constantly improving the quality
31 of delivering acute medical care to children at home.
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47 Clinician Scientist Fellowship from the Murdoch Children's Research Institute, which
48 had no role in any aspect of the study.
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57 **Conflicts of interest:** This study was not funded and there are no conflicts of interest
58 to declare.
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What is already known on this topic

- Children are increasingly managed at home for treatment of acute conditions that would traditionally require hospital admission
- There is emerging evidence for the efficacy and safety of this approach, but a lack of discussion on the ethical aspects.

What this study adds

- Healthcare providers who are familiar with acute home care believe this care follows the ethical tenets of autonomy, beneficence, non-maleficence and justice.
- Ethical dilemmas arise when other people such as staff members and parents need to be considered.
- Provision of home care was felt to be least ethical when it was deemed inferior clinically to hospital care.

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Tables

Table 1. Responses to ethical questions (see text for full questions)

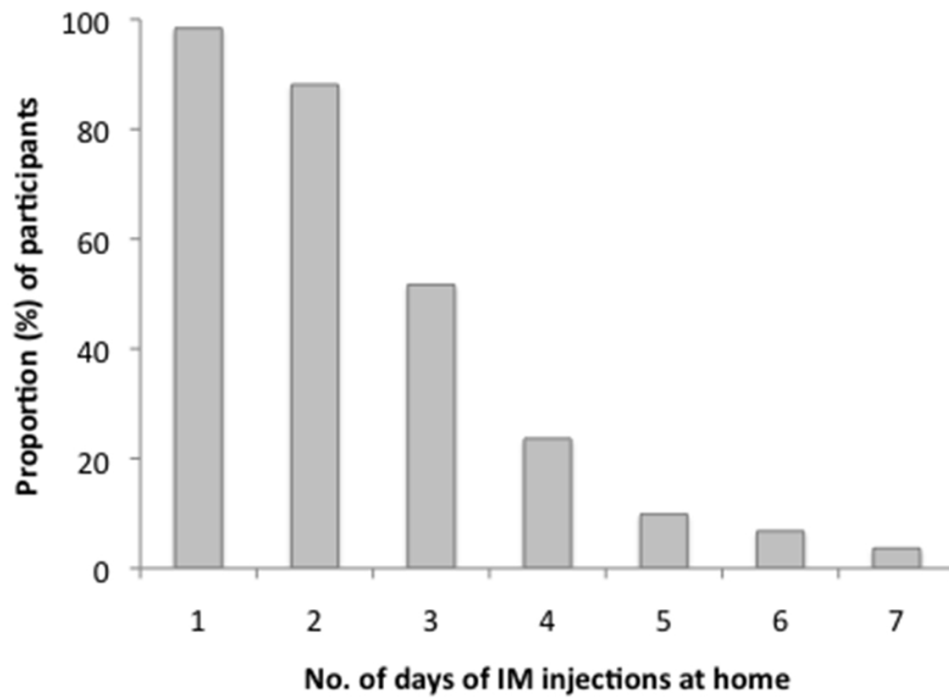
Question	Responses No. (%)	Vote results	
		Ethical No. (%)	Not ethical No. (%)
1. Home treatment	80 (100)	77 (96)	3 (4)
2. Domestic violence	63 (79)	37 (59)	26 (41)
3. Parental respite			
a. Maternal exhaustion	67 (84)	28 (42)	39 (58)
b. Afford a family holiday	57 (71)	28 (49)	29 (51)
c. Afford a wheelchair	64 (80)	28 (44)	36 (56)
4. Consent			
a. 14 years old	63 (79)	33 (52)	30 (48)
b. 16 years old	58 (73)	48 (83)	10 (17)
5. Physiotherapy unavailable	61 (76)	10 (16)	51 (84)
6. Bedroom sanctuary	64 (80)	63 (98)	1 (2)
7. Intramuscular injections			
a. 1 day	62 (78)	61 (98)	1 (2)
b. 2 days	59 (74)	52 (88)	7 (12)
c. 3 days	60 (75)	31 (52)	29 (48)

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3 **Figure legends**
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5 Figure 1. Proportion of participants who believe it is ethical to administer
6 intramuscular (IM) injections at home by number of days
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Ethical dilemmas in providing acute medical care at home for children: a survey of health professionals

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3 **Ethical dilemmas in providing acute medical care at home for children: a survey**
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5 **of health professionals**
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ABSTRACT

Objective: Acute care at home is increasing. We aimed to determine the views of healthcare professionals on the ethics of providing home care and compare the impact of situational changes on their opinions.

Design: An analysis of opinions of home healthcare professionals.

Setting: The Australasian Hospital-in-the-Home Annual Conference, November 2017.

Participants: Eighty physicians, nurses and allied health staff who provide acute care for children and adults at home.

Methods: Clinical scenarios were presented about a 14-year-old receiving intravenous antibiotics at home via an established home care pathway, and participants were asked to vote manually on whether providing home care was ethical.

Main Outcomes: The proportions of healthcare professionals who believed that provision of home care was ethical in different situations.

Results: For each question the response rate ranged from 71-100%. While the provision of acute home care was deemed ethical by the majority (77/80, 96%), this decreased when other factors were involved such as domestic violence (37/63 (59%) OR 0.06 95%CI 0.02-0.20, $p<0.001$) and, parental reluctance (28/67 (42%) OR 0.02 95%CI 0.008-0.09, $p<0.001$). The age of consent affected the proportion who considered home care ethical against parental wishes: 16 years versus 14 years: OR 4.4 95% CI 1.9-10.1, $p<0.001$. The lowest proportion to consider home care ethical (16%) was when home care was deemed less than hospital care.

Conclusions: Home healthcare providers are supportive of the ethics of providing acute care at home for children, although differ amongst themselves with situational complexities. Applying the tenets of medical ethics (autonomy, non-maleficence,

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3 beneficence and justice) can provide insights into the factors that may influence
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6 opinions.
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INTRODUCTION

Care at home for acute medical conditions is increasingly viewed and used as a viable alternative to hospital admission^{1 2}. The rationale applies to both patients and organisations. The majority of patients prefer to receive their care at home if possible, and have improved psychological outcomes and reduced risks associated with admission such as hospital-acquired infections^{3 4}. For organisations, improved flow of patients and reduced costs make home care attractive^{5 6}. There is evidence in adults that safety and efficacy are comparable between home and hospital care in selected patients and conditions⁷. While the evidence for safety and efficacy in acute conditions is scarcer in children, this too is accumulating⁸⁻¹¹. However, while there is some literature around the ethics of treating children with chronic conditions at home^{12 13}, the ethical aspects of treating children at home for acute conditions have not previously been explored.

Ethical behaviour has been considered in medicine since Hippocrates, and the International Code of Medical Ethics¹⁴, or variants, have been adopted by many national medical associations¹⁵⁻¹⁸. These are based on the four principles of medical ethics described by Beauchamp and Childress: autonomy, non-maleficence, beneficence and justice¹⁹.

We aimed to understand the views of clinical professionals who provide home care on various ethical aspects of managing children with acute medical conditions at home that would otherwise necessitate hospital admission. Acute home programs have names including hospital-in-the-home and medical home, whereby nursing, medical and allied health staff provide at least daily medical interventions in the

1
2
3 home including intravenous antibiotics, acute wound dressings, chemotherapy, and
4
5 physiotherapy. We aimed to determine the ethical parameters within which home
6
7 healthcare professionals believe they should be providing care to children at home.
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10 11 12 **METHODS**

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14
15 **Setting:** The Australasian Hospital-in-the-Home (HITH) Annual Conference
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17 November 2017.

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20 **Participants:** Medical, nursing and allied health staff attendees to the conference, all
21
22 of whom provide clinical services to patients at home.

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24
25 **Design:** All attendees were invited to a session titled 'Ethical dilemmas in HITH
26
27 practice'. The intention to survey opinions on ethical matters was explained and
28
29 attendees were invited to leave the session if they wished, or stay and participate or
30
31 not as they wished. Nobody left but four attendees declined to participate.

32
33
34 Background was given on how ethical constructs can be used to explore practical
35
36 dilemmas. A non-clinical scenario was given to show there is often no right answer,
37
38 how ethical reasoning can be applied to either side of an argument, and that
39
40 increasing or changing available information can change how a situation is viewed
41
42 ethically. It was explained that several questions would be asked for which there was
43
44 no right answer and that the information they needed to make a fully informed
45
46 decision may not be there. For each question, participants could choose to vote or not,
47
48 and they were requested to hold up a blue sign if they thought the situation was
49
50 ethical and a red one if they thought not. To try to mitigate any feeling of peer
51
52 pressure to vote in a certain way, the signs were white on the back so the choice of
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54 response was only visible from the front with all participants facing forward. Two
55
56 people counted votes and in case of discrepancy, a photograph was taken and
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3 attendees were assured these would be destroyed after verification. The session used a
4
5 fictitious situation based on real dilemmas that arise in acute home care.
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8 **Main Outcomes:** The proportion of healthcare professionals who believed that
9
10 provision of home care was ethical in different situations.
11

12 **Statistical analysis:** Chi-square test was used to compare the proportion of
13
14 responses to different situational questions, with odds ratios (OR), 95% confidence
15
16 intervals (CI), and $p < 0.05$ considered significant.
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18

19 **Patient and public involvement:** There were no patients or members of the public
20
21 involved in any aspect of the study as it is an examination of opinions of clinical staff.
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24 **Ethics approval:** This was not required due to the opinions belonging to the
25
26 healthcare staff and not associated with healthcare institutions and not involving
27
28 clinical care. The purpose of the session was clearly set out prior to starting and
29
30 participants were offered the opportunity to leave, or stay but not participate without
31
32 having to declare their non-participation. All data were anonymised and collated and
33
34 presented in aggregate.
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40 **RESULTS**

41
42 The participants at the Australasian Hospital-in-the-Home Society Annual Conference
43
44 were predominantly from Australia and New Zealand and between the ages of 25 and
45
46 65 years. Their professional background was all in healthcare and all in home care,
47
48 with 70% nursing, 20% allied health (predominantly physiotherapists) and 10%
49
50 medical. A minority (5-10%) were directly involved in paediatric home care. Two
51
52 test questions ascertained the maximum number of voting participants and ensured
53
54 an understanding of the process – the first aiming to elicit an ‘ethical’ response and
55
56 the second a ‘not ethical’ response. 80/84 (95%) attendees participated, all of whom
57
58
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1
2
3 voted 'ethical' for the first question and 'not ethical' for the second question. For the
4
5 clinical scenario, after each piece of additional information, participants were asked
6
7 to vote on 'Is it ethical to provide a home service for this patient in this situation?'

8
9
10 Response rates for each question ranged from 71-100%.

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14
15 *Question 1. A 14-year-old girl with cystic fibrosis (CF) needs a planned episode of care*
16
17 *for an infective exacerbation. Your institution has a well-established home care*
18
19 *pathway for 'CF tune-ups' for adolescents with intravenous antibiotics and*
20
21 *physiotherapy. You offer her this home care pathway or hospital care and she chooses*
22
23 *home.*

24
25
26 Home care was voted as ethical by a very high proportion of participants (77 votes,
27
28 96%), all of whom work in home care and are therefore familiar with it (table 1).

29
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31
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33 *Question 2. You discover that there is a history of domestic violence between adults in*
34
35 *the household.*

36
37
38 Compared to the previous response, the proportion (37/63, 59%) who thought
39
40 providing a home service was ethical when domestic violence was involved was
41
42 significantly decreased (OR 0.06 95%CI 0.02-0.20, $p < 0.001$).

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47 *Question 3a. You determine there is no current risk to nursing staff. However, the girl's*
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49 *mother tells you she is exhausted from chronic care of her child and was counting on*
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51 *hospital admission for respite.*

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55 *3b. Her mother tells you if she doesn't get this respite, she will have to take unpaid leave*
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57 *and won't be able to afford to take everyone on a family holiday.*

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3 *3c. Her mother tells you if she doesn't get this respite, she will have to take unpaid leave*
4 *and won't be able to afford to buy a wheelchair for her other child who has a disability.*

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8 Compared to the first response, the proportion (28/67, 42%) who thought providing
9
10 home care was ethical when the mother declared her reluctance due to exhaustion
11
12 was significantly decreased (OR 0.02 95%CI 0.008-0.09, $p < 0.001$). Different reasons
13
14 for the respite request did not significantly affect the opinion on whether the care
15
16 was ethical compared to maternal exhaustion: to afford a family holiday: 49% versus
17
18 42%, OR 1.3 95%CI 0.7-2.7, $p = 0.3$), or to buy a wheelchair: 44% versus 42%, OR 1.1
19
20 95%CI 0.5-2.1, $p = 0.5$). Whether it was ethical to care for a child at home when the
21
22 request for respite hospitalisation was to pay for a family holiday had the lowest
23
24 response rate for all questions (71%).
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31 *Question 4a. You are about to acquiesce to parental wishes, but the 14-year-old girl now*
32 *insists that she wants to go home via HITH.*

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36 *4b. What if the girl was 16 years old?*

37
38 There was a significant difference with patient age (without any further information)
39
40 about whether it was deemed ethical to provide home care per the patient's wishes
41
42 against parental wishes: 48/58 (83%) at 16 years versus 33/63 (52%) at 14 years
43
44 (OR 4.4 95% CI 1.9-10.1, $p < 0.001$).
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50 *Question 5. Everyone now agrees to proceed with treatment at home. However, the*
51 *home care physiotherapist will be away during the treatment period, so the girl and her*
52 *parents will need to do her physiotherapy.*
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3 Compared to the first response, the unavailability of physiotherapy led to the lowest
4 proportion (10/61, 16%) of all questions of those who felt providing home care in
5
6 this scenario was ethical (OR 0.008 95%CI 0.002-0.03, $p<0.001$).
7
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12 *Question 6. Your first visit to the home reveals a small apartment where the young girl's*
13 *bedroom is her only sanctuary. This is currently full of medical equipment to facilitate*
14 *her being at home.*
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19 A high proportion of participants (63/64, 98%) voted that providing home care in
20 this situation was ethical, with no difference from the original scenario (OR 2.5
21
22 95%CI 0.2-24.1, $p=0.4$).
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29 *Question 7a. Towards the end of her HITH stay her peripherally-inserted central*
30 *catheter (PICC) blocks and you are unable to insert a cannula despite repeated*
31 *attempts. The options are intramuscular injection or reinsertion of the PICC, for which*
32 *she would need admission for a general anaesthetic. You decide to give an*
33 *intramuscular injection so she can continue at home as she only needs one more day of*
34 *parenteral antibiotics.*
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43 *7b. Two days of intramuscular injections.*

44 *7c. Three days of intramuscular injections.*

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47 As the number of days of intramuscular injections at home in preference to admission
48 for PICC replacement increased, the proportion of participants that felt this was
49
50 ethical fell significantly (figure 1): 61/62 (98%) versus 31/60 (52%), OR 57 95%CI 7-
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52 439, $p<0.001$).
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58

59 **DISCUSSION**

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1
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3 The application of ethical values to acute care for patients at home is a new area as
4 home-based acute healthcare is in its relative infancy. The responses are those of
5 health professionals who are all engaged in home healthcare, although predominantly
6 in adults. The current model of care throughout Australia for paediatric acute non-
7 inpatient services is for nurses to visit the child's home to deliver care: hospital-in-
8 the-home rather than, for example, outpatient infusion services. The questions were
9 designed to test various aspects of the four tenets of medical ethics in this clinical
10 environment.
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24 Patient autonomy refers to respectful treatment of patients by ensuring disclosure of
25 information and not constraining their right to make their own informed decision.
26 This is exemplified in the first question where information is given to the patient and
27 she decides between home care and hospital admission. The strong vote that this was
28 ethical indicates that participants feel there is sufficient evidence that home care is
29 effective and safe. Insufficient information is given to assess whether there was
30 patient coercion, which is prohibited by the concept of autonomy, but on the face of it,
31 the process appears ethical. The decision becomes less clear, as highlighted by the
32 drop in 'ethical' votes, when the patient's mother's autonomy is included. This
33 question also raised whether different reasons underpinning her autonomy
34 (exhaustion, lack of funds) affect the ethical construct, but these were not viewed by
35 participants as having as much impact as the mere fact of her opposing decision. In
36 adult medicine, the patient's autonomy is paramount with the wishes of spouses and
37 children being secondary^{20 21}. In paediatrics, autonomy regarding medical care lies
38 with those (usually the parent/s) holding parental rights, but the age at which the
39 child's best interests are served by the child being autonomous is debated. More
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3 participants felt it was ethical for a 16-year-old to provide consent than a 14-year-old
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5 and this may reflect some lack of familiarity with the care of younger mature
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7 adolescents. The age at which a child can legally provide consent is different in
8
9 different countries. In the UK, the test of 'Gillick competence' allows a minor under
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11 the legal age of consent (16 years) to be assessed as sufficiently mature to understand
12
13 and make their own decisions and provide consent. This is in line with the ethical
14
15 tenet of autonomy, which relies on competence. This medical case law has essentially
16
17 been adopted in Australia and Canada, although only sporadically in the USA.
18
19 Although adolescents in Australian and New Zealand hospitals are usually treated by
20
21 paediatric/adolescent teams, the current limited reach of paediatric homecare means
22
23 that many adolescents at home are looked after by adult homecare teams. The
24
25 responses to this question raise the important issue of the need for adult homecare
26
27 providers to be upskilled in the specific ethical aspects of care needs for adolescents.
28
29 However, even if consent is given by the adolescent, each home care service may have
30
31 its own rules about whether an adult also needs to be present, which may supersede
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33 the ethical aspects of who ultimately provides consent.
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43 Non-maleficence refers to the duty to avoid causing harm including pain, suffering
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45 and disablement. Beneficence refers to the duty to actively promote good for patients,
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47 to defend their rights and to remove conditions that will cause harm. Although, they
48
49 are sometimes seen as two sides of the same coin, one can obey the dictates of non-
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51 maleficence simply by refraining from acting, but beneficence requires positive
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53 action. Several questions highlighted these dual tenets, essentially creating an ethical
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55 dilemma, including provision of potentially invasive services in her place of
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57 sanctuary: beneficence of active care provision for her health, but non-maleficence
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3 requires not to the detriment to her psyche. However, as long as the patient is fully
4 informed and has consented, autonomy dictates that we should not be paternalistic.
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6 Any detrimental effects may also differ between short episodes of acute care and
7
8 ongoing chronic care where medical equipment might be a permanent fixture. The
9
10 benefits and harms are also raised in the question on intramuscular injections, with
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12 increasing number (and therefore pain) correlating with decreasing acceptance. This
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14 adds a level of complexity when deciding on the ethical imperatives between the
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16 three options of home care, intramuscular injections and the small but serious
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18 potential harm of a general anaesthetic.
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27 The issue of household domestic violence raises to whom the beneficence and non-
28
29 maleficence need to be applied. In this situation there is an obligation of specific
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31 beneficence to the patient, and it potentially even increases the imperative for a
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33 professional to visit the home. However, the ethical balance shifted for non-
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35 responders when non-maleficence needed to be considered for a staff member
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37 entering a potentially unsafe situation. Since there is a moral obligation to both, other
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39 aspects should be considered to guide decision-making such as the vulnerability of
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41 the individual and the risk of potential harm to either party, and for that more
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43 information is required. It is, however, worth stating that it is rare for domestic
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45 violence to be perpetrated against outsiders, and that the balance of most home
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47 healthcare providers is to provide the care and, if necessary, have two staff members
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49 visit together.
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57 Finally, justice refers to how benefits and burdens should be distributed. It mandates
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59 the fair medical treatment of patients, with equal situations being treated equally, and
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3 unequal situations being treated in proportion to their inequalities. A large majority
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5 of participants felt it was not just to provide inferior treatment at home compared to
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7 what would be offered in hospital, reflecting the importance of physiotherapy in CF
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9 care. This is important because the concern around home care being inferior is a
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11 barrier to acute home care for many institutions and clinical staff^{22 23}. Robust
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13 evidence that home care is as efficacious and safe as hospital care for children is
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15 increasing, but more is needed²⁴. Of note, most home programs only provide daily
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17 physiotherapy at home compared to twice daily in hospital, which is therefore
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19 already less, yet this is considered acceptable by respiratory physicians. The concept
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21 of 'good enough' has been discussed regarding parenting where perfection is not
22
23 deemed necessary. It may be appropriate to apply the same concept to home services
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25 where the intensity of services is lower, but the quality must be as high. We did not
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27 explore how good would be considered 'good enough' (eg physiotherapy via
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29 telehealth, a physiotherapist visiting alternate days) or compare this with the risks of
30
31 inpatient admission. The other aspect is the balance of unequal situations. In a recent
32
33 study of home intravenous antibiotic treatment for cellulitis, it was shown that parent
34
35 and child quality of life was significantly higher at home and it cost three times less
36
37 for the family than in hospital^{24 25}. The efficacy level (the primary outcome) for non-
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39 inferiority was set lower for home than in hospital at the start of the trial²⁶ because of
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41 the recognition of the benefits of home and acceptance of a proportionally lower level
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43 of efficacy, although efficacy was actually found to be higher at home. Unequal
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45 situations were tested in the question around maternal reasons for wanting her
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47 daughter to have a hospital admission. That the lowest response rate was recorded
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49 for whether saving for a family holiday was an ethical reason for not wanting
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51 homecare may reflect the lack of paediatric healthcare professionals in the audience,
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3 as in paediatrics the child is considered within the holistic sphere of the family, and
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5 family well-being is considered an important component .
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10 Study limitations are that it only evaluated opinions of those providing home
11 services, and while a high proportion of participants engaged, it was a small survey.
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13 The majority predominantly provide care to adult patients, so would be less familiar
14 with considering ethical aspects of paediatric care at home. The patient was chosen as
15 an adolescent for this reason, but the answers around age of consent and parental
16 respite may have been answered differently by hospital paediatricians and other
17 healthcare providers. Additionally, because it was not completely anonymous (the
18 technology was unavailable for electronic voting) people may have felt peer pressure
19 to vote similarly. The mitigation for this was that the which way people voted (red or
20 blue colour of vote) were only visible from the front and the participants were all
21 facing forward. Additionally, the differences in proportions of votes for different
22 questions suggest that this factor was not strong. One other limitation is that
23 questions were limited to clinical dilemmas, and did not include other ethical
24 dimensions to acute home care such as organisational issues (eg rationing or
25 payment of services²⁷) and research.
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48 The tenets of medical ethics do not aim to provide answers, or even guidelines, for
49 managing moral issues; rather they provide a framework to identify and reflect upon
50 them. These results can provide a benchmark against which surveys of other groups
51 regarding acute home care in children can be compared. The next important step will
52 be to obtain the opinions of patients, families and other healthcare providers. The
53 results show the relevance of considering ethical aspects of the provision of home
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3 care, both in building a service and in providing and constantly improving the quality
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5 of delivering acute medical care to children at home.
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24 to declare.
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What is already known on this topic

- Children are increasingly managed at home for treatment of acute conditions that would traditionally require hospital admission
- There is emerging evidence for the efficacy and safety of this approach, but a lack of discussion on the ethical aspects.

What this study adds

- Healthcare providers who are familiar with acute home care believe this care follows the ethical tenets of autonomy, beneficence, non-maleficence and justice.
- Ethical dilemmas arise when other people such as staff members and parents need to be considered.
- Provision of home care was felt to be least ethical when it was deemed inferior clinically to hospital care.

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Tables

Table 1. Responses to ethical questions (see text for full questions)

Question	Responses No. (%)	Vote results	
		Ethical No. (%)	Not ethical No. (%)
1. Home treatment	80 (100)	77 (96)	3 (4)
2. Domestic violence	63 (79)	37 (59)	26 (41)
3. Parental respite			
a. Maternal exhaustion	67 (84)	28 (42)	39 (58)
b. Afford a family holiday	57 (71)	28 (49)	29 (51)
c. Afford a wheelchair	64 (80)	28 (44)	36 (56)
4. Consent			
a. 14 years old	63 (79)	33 (52)	30 (48)
b. 16 years old	58 (73)	48 (83)	10 (17)
5. Physiotherapy unavailable	61 (76)	10 (16)	51 (84)
6. Bedroom sanctuary	64 (80)	63 (98)	1 (2)
7. Intramuscular injections			
a. 1 day	62 (78)	61 (98)	1 (2)
b. 2 days	59 (74)	52 (88)	7 (12)
c. 3 days	60 (75)	31 (52)	29 (48)

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3 **Figure legends**
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5 Figure 1. Proportion of participants who believe it is ethical to administer
6 intramuscular (IM) injections at home by number of days
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