Clinical Law. What do paediatricians want to know?

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Clinical Ethics Committees set out the lawful and ethical treatment options available to clinicians, dealing with a steady trickle of cases concerning the care of children in hospital. It became apparent some years ago that many less contentious (elementary, but nonetheless relevant) enquiries were not being aired in our CEC, perhaps because the enquirers perceived the questions to be of insufficient gravity. But such enquiries were oft repeated, such as: 'Who can give consent for this child's treatment'?

Whilst in the absence of an answer (or an opinion) children were safely treated, the feeling nevertheless endured that their clinical management would be enhanced by the support of a clinical legal service, which was set up in 2009¹. The service was initially focussed on children's hospital care, but within 3 months encompassed adult practice within the hospital and local community. Here we report the enquiries concerning the legal aspects of clinical care of children, for the attention of their doctors. During this 13-year period, 434 enquiries were made, amongst the total of 1349 enquiries derived from all age groups². The prospective collection of data began immediately, our department of clinical law taking enquiries from any member of a regulated clinical profession. It is likely that a similar number of referrals, in proportion to the total patient population, would be encountered in any UK centre providing an equivalent service. Most enquiries originated locally, some from other UK centres, a few from abroad; the responses are based solely on English law. The local referrals included those from our Clinical Ethics Committee. In addition, there have been a few referrals from community, social and primary care. A series of around 100 short summaries of clinical legal dilemmas are available in the website library³. The 12,500 or so annual visits may have prompted referrals from within the hospital and further afield.

In the paediatric group, we have identified 90 separate 'phenotypes', within 7 broad categories, set out in Table 1. Fifty-nine further phenotypes inapplicable to children were identified in the adult population. Since first publishing the data, we have encountered 16 more phenotypes, 3 that are applicable to children, including 'interfering with inpatients mail'. The continuing accrual of phenotypes hints that our list of important issues is incomplete.

Comparison with the enquiries made relating to adult services was instructive. Of 42 enquiries relating to the duty of candour, only 5 came from paediatric clinicians. Either children's doctors have little to be candid about...or perhaps we are simply better versed in our regulated duties. On the other hand, *paediatric* clinicians brought 7 of the 9 clinically 'extraordinary' enquiries to the service (Table 1b. 6), giving an opportunity to illustrate the breadth and depth of clinical law in children's practice; we provide a brief summary of the cases in this phenotype.

One related to an adolescent swimming at Paralympian level who had lost a foot but was seeking more proximal amputation. This would make her more competitive, re-classification of the disability acting in her favour. Another; the request for general anaesthesia for a haircut in a child with severe behavioural difficulties, and untreatable head lice. There was an enquiry as to whether a cardiac pacemaker could be turned off during withdrawal of care; profoundly disturbing from the perspective of the clinicians. Separately, a family requesting that their 14-year-old schizophrenic daughter should be restrained for exorcism, to rid her of the responsible demon. A mother to be, 34/40 weeks gestation, sought a near-immediate induction of premature labour to provide her dying 7-year-old with the consolation of meeting his new sibling. A PICU admission and sedation or general anaesthesia was proposed to facilitate feeding a competent 14-year-old with anorexia, who was steadfastly opposing treatment. Finally, an overseas enquirer sought advice as to whether separation of conjoined twins that would likely cause the death of at least one of the children was lawful in England. If nothing else, this collection of cases hints at the potential interaction of family, criminal, tort, mental health, regulatory and capacity law flowing from a clinical enquiry.

The other 89 phenotypes so far described may deceive in their simplicity...the parent who wished to administer intramuscular injections of unknown composition to her child herself posed, on reflection, a rather complex legal problem. But despite our encountering but a single case of this phenotype in 13 years, it is likely that several similar cases arise nationally each year...and cause similar consternation. We only dealt with one child whose criminal record led to unusual arrangements for her inpatient stay; one case where a family friend (regrettably) provided interpretation services diametrically counter to the child's welfare; or one case of a clinician being defamed by her patient. Each of these cases lead to a clinical legal solution; but it would have been easier to refer to a previously drafted formula, that would at least have provided us with a starting point. The benefit of promulgating skeleton guidance for each of the 'rare' phenotypes seems self-evident. This task, taken on by paediatric groups in association with lawyers and ethicists (and others) across the nation would not be onerous.

Our data reveals that matters relating to parental responsibility/opposition of treatment, the welfare checklist, contested blood transfusion, competence/capacity/consent, records' disclosure, and standard of care comprise more than one third of the children's enquiries received. We fully expect this to be true in any acute hospital, within and beyond the United Kingdom. The fact that clinicians are making these enquiries hints of an awareness that their clinical dilemma is of legal significance; but needs to be better articulated as a legal question. Since these fields of law are readily accessible, it would be straightforward to set out guidance for paediatricians.

Clinical law and ethics are no less fundamental academic disciplines than the other 'basic sciences' on which children's medicine is founded. Radiology and therapeutics are indivisible from physics and chemistry...as surgery is inextricable from anatomy. Arguably, of equal value from the child's perspective is to be treated ethically, according to law. Yet *this* basic science has received less attention, if the paediatricians' enquiries to our clinical legal service are considered as a measure of their uncertainty in this discipline.

Clinical education is flourishing, with greater understanding of adult learning theory and more recently the need to adopt new strategies; we are at a point in medical education where the world is our oyster. Stories⁴ offer an insight into new vistas and for millennia have been used to spread wisdom from human experience. Whilst many of these modern techniques could be adopted to train doctors in clinical law and ethics, perhaps simply telling the stories of these phenotypes would be the best start to embedding an awareness of how they are relevant to all of us as children's doctors; probably much more so than we realise.

We propose these data as a starting point for those who seek to provide paediatricians with a working knowledge of clinical law as it applies to children. We'd welcome collaboration in creating a 'library' of guidance or promulgating 'stories'.

Although familiar with curricula that include medical law, we are not aware of any other published evidence of what children's clinicians want to know.

¹ Wheeler R, Marsh M. Making legal advice a clinical department. *Health Service Journal* 2016 Apr 13; 20-21. http://www.hsj.co.uk/hsj-knowledge/making-legal-advice-a-clinical-department/7003514.article

² R Wheeler, N Hall. Clinical law: what do clinicians want to know? The demography of clinical law. *J Med Ethics*. 2022: http://dx.doi.org/10.1136/medethics-2022-108131

³ https://www.uhs.nhs.uk/whats-new/clinical-law-updates

⁴ K Calman. A study of story-telling, humour and learning in medicine. *Clinical Medicine*. 2001 1(3) 227-229

Table 1a. Demography of clinical law in paediatric practice: Enquiries relating to <u>clinical care</u> of the child (n = number within phenotype)

1. Parents & Children

Refusing to withdraw on any grounds (4)

Surrogacy decisions (6)

Gender dysphoria (3)

Compelling children (non-transfusion) (13)

Conflicts/Questions over Parental Responsibility (36)

Distinguishing child/young person/adult (7)

Incompetent children (8)

Using welfare checklist (19)

Parents opposing treatment (26)

Local Authority role in Parental Responsibility (12)

Withdrawal at any age of childhood (17)

Child excluding parents (5)

Restraining children (17)

Jehovah's Witness blood product transfusion [any age] (24)

Paternity (2)

Unlawful separation child from parents (3)

Competence v capacity (5)

Teenage pregnancy and aftermath (7)

Children for simulation (1)

Circumcision [Male & Female] (2)

Parents performing clinical activity (1)

Beneficent children (3)

Parents seeking ostensibly bizarre treatment (1)

Emergency protection (1)

2. Mental Disorder

Search under Mental Health Act 1983 (1)

Physical treatment under (5)

Mental Health Act 1983 Absconders (1)

Awaiting Tier 4 beds (3)

Capacity in Mental Health Act 1983 (1)

Mental Health Act 1983 logistics (3)

Self-harm and swallowing foreign bodies(1)

Religious reasons against withdrawal (1)

Vulnerable Young Person (1)

Mental Capacity Act 2005 v Mental Health Act 1983 for physical treatment (1)

Compelling non- Mental Health Act 1983 treatment (5)

Incapacity & capacity Young Person (3)

3. Consent for treatment

Recording consent (5)

Substance of disclosure (1)

Delegation of consent (2)

Consent for untried technology (2)

Consent by children (15)

Consent logistics (2)

'Rolling' consent for future treatment (3)

4. Disclosure of private information

Consent for disclosure (2)

Access to health records (5)

Disclose to police/authorities/Courts (4)

Disclosing children's records (21)

Health record confidentiality (10)

Competent Young Person refusing disclosure (4)

Virtual consultations (1)

Parent refusing disclosure own data (2)

Table 1b. Demography of clinical law in paediatric practice: Enquiries relating to the <u>conduct of clinical</u> <u>care</u> of the child (n = number within phenotype)

5. Regulatory

Candour (5)

Part payment for National Health Service treatment (1)

Trialling innovative equipment (5)

Funding exceptional treatment (2)

Commercial enterprises for hospital (1)

Pregnancy testing prior to surgery (1)

Suspected offender (1)

Interfering with child patient's mail (1)

Disclosing/recording aberrant behaviour (4)

Legal privilege (1)

Altering hospital records (4)

Charging overseas patients (3)

Policy & Guidelines (1)

Doctors treating their relatives (1)

6. Professional

Response to scarce resources (2)

Dispute resolution (2)

Interpretation +/- in bad faith (1)

Coronavirus exigencies (4)

Developing Clinical Ethics Services (1)

Extraordinary requests (e.g. General anaesthesia for haircut) (7)

Standard of care (14)

Standards for image & sound recordings (1)

Patient/parent making unsafe demands (1)

Capacitous absconders (1)

Doctrine of double effect (1)

'Professionalism' (7)

Duty of care (1)

Defamation of clinician by patient/parent (1)

7. 'Other Statutory'

Discrimination (2)

Freedom of information (1)

Gender recognition (2)

Banned cannabis treatment (1)

Relationship to legal authorities (14)

European Convention Human Rights considerations (specific) (2)

Prohibition female genital mutilation (1)

Sexual offences (2)

Children's Medical Treatment Bill (1)

Nationality & Borders Bill (1)

Human Tissue Act 2004 (4)