

ORIGINAL ARTICLE

Evaluation of a paediatric clinical ethics service

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Aim: To evaluate a paediatric clinical ethics service incorporating both normative and empirical analysis.

Methods: Section 1: Review of consensus guidelines to identify emerging standards for clinical ethics services (CES) and evaluation of the service in relation to these. Section 2: Description of service activity data. Section 3: Feedback from clinical staff involved in clinical ethics consultations was collected using a web-based survey.

Results: Four guideline documents were reviewed, and clear emerging consensus standards were identified. Our service fulfils identified knowledge and skill core competencies and at least partially fulfils all of the identified service-level standards. Clinicians report that clinical ethics consultation decreases their moral distress.

Conclusions: There is emerging consensus for staff competencies and service-level standards for CES. The role of CES in staff well-being needs to be explored. Collaborative, multi-modal research to develop standards and evaluate CES is needed.

Key words: burnout; clinical ethics committee; clinical ethics service; ethics; evaluation; moral distress.

What is already known on this topic

- 1 Clinical ethics services (CES) are increasingly common but are variable in form and function.
- 2 There are limited recommendations defining minimal standards for CES.
- 3 There is a need to critically evaluate existing services.

What this paper adds

- 1 There is emerging consensus for staff competencies and procedural standards for CES.
- 2 Evaluation with reference to these standards is an important quality improvement activity.
- 3 CES may decrease staff moral distress.

The past decades have witnessed a dramatic change in paediatric medicine in high-income countries. Improved survival for once-fatal conditions has increased the population of children with complex, chronic illnesses¹ such as hypoplastic left heart syndrome and rare metabolic disorders. Technological advances, such as extracorporeal life support or gene therapy, raise new ethical questions. In concert with this, ethical complexity intensifies. High-stakes ethical decision-making is associated with health-care staff stress,² and moral distress has been identified as a key factor in staff burnout.^{3–6} Clinical ethics services (CES) have emerged as a resource to provide assistance for difficult ethical decisions. The importance of CES is recognised by health-care accreditation and other bodies both within Australia^{7,8} and internationally.^{9,10} However, there is a lack of standards defined for these services and limited literature evaluating them. The EQuIP National Guidelines of the Australian Council on Healthcare Standards state that health services should have a 'formal,

nominated consultative entity where ethical decision making can be referred...⁷; however, they do not specify the design and function such an entity should take or any standards it must adhere to. The situation is similar in other nations, and the variability in services is well described.^{11–13}

There are increasing calls to evaluate CES, credential the people that work within them and develop standards for practice.^{14–17} Several centres have published papers describing CES,^{11,13,18–23} and one explored clinicians' experience of ethics in practice,²⁴ but there is a lack of reports on the evaluation of existing services using normative standards. The aim of this paper is to evaluate a newly established paediatric CES, incorporating both normative and empirical analysis. We performed a literature review to identify emerging CES standards and then evaluated our service in reference to these. In addition, service activity data and results of feedback surveys from referring clinical staff are used for evaluation.

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Conflict of interest: None declared.

Accepted for publication 19 March 2018.

Methods

Setting and participants

The Centre for Children's Health Ethics and Law (CCHEL) is situated within a 359-bed, tertiary-quaternary paediatric hospital in

Brisbane, Australia. All cases referred to the Clinical Ethics Consultation Service (CECS) between February 2015 and January 2017 and all referring teams are included in this study. The Human Research Ethics Committee of Children's Health Queensland Hospital and Health Service approved this study (HREC/17/QRCH/120).

Study description

Section 1: Review of consensus guidelines and a practical evaluation

A literature review was performed to identify consensus guidelines on the evaluation of, and standards for, CES. EBSCO Host (including CINAHL and Medline) and PubMed searches were performed up to 2017 using the search terms 'clinical ethics service', 'clinical ethics case consultation', 'clinical ethics committee', combined with 'evaluation', 'regulation' and 'competency'. Emerging consensus standards for CES were identified, against which the CCHEL was evaluated.

Section 2: Service activity data

Data were collected on: Number of referrals, moral tensions in each case, referral specialty and education activity. The nature of moral tensions in each case is explicitly recorded in the case notes at the time of the case deliberation. The description of moral tension in each case was collected directly from the notes and aggregated with all cases. Education activity data are also reported.

Section 3: Feedback survey results

A quantitative feedback survey is routinely sent to all participants involved in a deliberation. The survey questions aim to assess clinicians' perceptions of the service using multi-chotomous responses (Table 5). Three questions were added after CCHEL's first two consultations and are marked*.

Statistical analysis

Section 1 is an informal qualitative analysis of the literature. Descriptive statistics describe the quantitative data collected in section 2. The nature of moral tensions in each case is explicitly recorded within the deliberation notes and do not require complex qualitative analysis. Descriptive statistics are generated by the survey software (SurveyMonkey Inc., San Matteo, CA, USA) used for section 3.

Results

Section 1: Review of consensus guidelines and a practical evaluation

Literature review identified four documents that directly address core competencies for clinical ethics consultation: National Health and Medical Research Council's *Clinical Ethics Capacity Building Resource Manual (CECBRM)*²⁵; United Kingdom Clinical Ethics Network's *Core Competencies for Clinical Ethics*²⁶; the American Society for Bioethics and Humanities *Core competencies for health care ethics consultation*²⁷; and *Charting the Future: Credentialing, Privileging, Quality, and Evaluation in Clinical Ethics Consultation*.¹⁶

All four documents acknowledged that there are multiple effective ways for CES to function and emphasised that, rather than aiming for uniformity in service delivery, it is important each service has explicit terms of reference and standard

Table 1 Emerging Service-level Standards and the extent to which they are met by the Centre for Children's Health Ethics and Law (CCHEL)

Service-level standards	CCHEL
Multidisciplinary approach to consultation	Partial
Deliberative approach to consultation	Yes
Has published Terms of Reference and/or Standard Operating Procedures	Partial
Has review and quality improvement processes in place	Yes
Is accessible and well integrated with clinical practice	Yes
Is adequately resourced	Partial
Carries out education, policy work and case consultation	Yes

operating procedures to ensure transparency of process. Service-level standards are summarised in Table 1, and core competencies for staff participating within a CES are summarised in Table 2. There was consensus between the documents that not every member of a CES need have all competencies but that the group collectively has these. In service models with an individual clinical ethicist, this individual should hold all competencies. There is a key emerging consensus for a multidisciplinary, deliberative

Table 2 Core competencies for clinical ethics consultation (Adapted from National Health and Medical Research Council.²⁵)

Knowledge core competencies	
Knowledge of basic concepts and analytical strategies relevant to clinical ethics (including a requirement for advanced knowledge of ethical theory and moral reasoning by at least one committee or consultation group member)	
Knowledge of relevant professional codes, standards, guidelines and policies (local, national and international)	
Knowledge of relevant legal and regulatory matters	
Knowledge of relevant clinical practice and processes related to clinical decision-making	
Knowledge of the role of clinical ethics services in the management of clinical situations	
Knowledge of the local community, including patients, families and organisational staff	
Knowledge of health-care services and systems as they relate to the work of the clinical ethics service	
Skill core competencies	
Ability to apply the relevant knowledge (per above) to clinical and organisational issues	
Ability to identify and analyse the ethical dimensions of issues considered by the clinical ethics service	
Ability to facilitate effective deliberation (including eliciting the views and values of those involved)	
Ability to practice and promote active listening and respectful communication	
Ability to synthesise relevant considerations and formulate a range of potential responses	
Ability to appropriately document and communicate the deliberations and decisions of the clinical ethics service	
Ability to locate and critically use relevant academic literature	

approach to consultation. Recommendations as to how this should be operationalised differ markedly.

We assessed the CCHEL CES with reference to service-level standards (Table 1) and to staff competencies recommended in the National Health and Medical Research Council's CECBRM²⁵ (Table 2) because: (i) the CECBRM is the closest to a national guideline that the clinical ethics community in Australia currently has; and (ii) it is the most contemporary document and explicitly synthesises the recommendations in the American Society for Bioethics and Humanities and United Kingdom Clinical Ethics Network documents.

Description of the CCHEL CES

CCHEL has three branches of activity: (i) CECS that undertakes individual case consultation as well as policy work; (ii) education for clinical staff; and (iii) pursuit of a research agenda. The service has Terms of Reference that detail its purpose, function, activities, governance, membership and model of service and review processes.

Staff

During the study period, CCHEL was staffed by a medical specialist clinical lead at 0.2 full time equivalent (FTE), a paediatric fellow (0.5 FTE) and an administrative officer (0.2 FTE). Funding is currently non-recurrent and non-core. The clinical lead role description requires postgraduate training in ethics and fulfilment of all of the knowledge and skill core competencies in Table 2. The fellow role is a yearly contract for advanced trainees in paediatrics. Selection criteria include postgraduate study in ethics. The fellow is mentored by the clinical lead and is expected to develop the above knowledge and skill core competencies to a high level.

CECS response pool members contribute their time in addition to their clinical or academic roles. Membership is sought by expression of interest. At the end of the study period, the pool contained 44 members. Of these, there were 5 academics, 10 nurses, 1 chaplain, 2 aboriginal liaison officers, 20 doctors and 6 allied health-care professionals. Each member is not required to have all competencies outlined in Table 2, but collectively, the group enriches the skill mix of the core CECS staff. Through participation in CECS activities, members develop competencies over time.

Consultative model

The CECS uses a facilitative model that assists the clinical team's decision-making. The decision remains with the clinical team – the CECS itself does not make specific recommendations.

Referrals are accepted by the consultant or fellow who decides on an appropriate response. A level one response is attendance, by the fellow or consultant, at a multidisciplinary team meeting where they participate in discussion to identify and clarify ethical concerns of the clinical team. For more complex cases, a level two response (CECS deliberation) is convened where the multidisciplinary clinical team and a CECS response team meet and deliberate using the CCHEL framework. The meeting is chaired by the fellow or clinical lead. The CECS terms of reference commits to being able to convene a deliberation within 48 h of referral. In practice, we have been able to respond much more quickly than this when required. The CECS response team is made up of at least three people from the CECS pool not clinically involved with the case. Where practicable, these members are from different clinical/academic backgrounds. The clinical ethics consultant or fellow is available to meet with the patient and/or family before the

deliberation. This occurs at the discretion of the referring team and the preference of the patient/family. See Figure 1 for a graphical depiction of the CCHEL case consultation model.

Involvement in policy development is an activity of the CECS; however, there is not a documented process for this.

Education and research

CCHEL provides education to all clinical staff as part of regular teaching programmes as well as on request by specific departments or for conferences and workshops. CCHEL also hosts student electives. One research project has been completed.²²

Evaluation

CCHEL fulfils the knowledge and skill core competencies in Table 2 and at least partially fulfils all of the identified service-level standards, with three areas noted for improvement (Table 1). First, while the CECS response team is multidisciplinary, its membership is skewed towards doctors (45%). In addition, CCHEL's core staff members are doctors. The second area for improvement is the need for secure, recurrent funding to ensure sustainability and development of the service. Third, CCHEL should have a more clearly documented process for involvement in policy development.

Section 2: Service activity

During the study period of 24 months, referrals for 10 level 1 and 14 level 2 responses were accepted by the CECS. Two level 1 responses escalated to level 2, and of the level 2 responses, 12 were resolved after one CECS deliberation. One case required two and another required three meetings.

Seventeen specialities were involved across the 24 responses. General paediatrics was the most frequently involved clinical team (10 cases, 41.6%) with three responses involving general paediatric teams from peripheral centres (Table 3). The total number of cases (56) in Table 3 is larger than the number of responses because the majority of referrals were jointly referred by two or more specialty teams.

There were five key themes of moral tension identified across all level two cases (Table 4). Two cases are excluded from reporting here as the nature of moral tension identified could risk patient confidentiality.

CCHEL delivered 35 education sessions in 2 years. These were delivered to 17 different clinical departments and several multidisciplinary conferences and workshops.

Section 3: Feedback data

A total of 35 responses were received out of 11 cases surveyed. The overall response rate was 35 out of 97 participants (36%). Of the 35 respondents, there were 16 consultant medical officers, 10 nurses, 4 allied health-care professionals, 3 advanced trainee medical officers and 2 social workers. The majority of respondents found the CECS deliberation helpful. Of the 35 respondents, 34 would definitely recommend the service to colleagues. Most respondents reported that involving the clinical ethics service in the case at least somewhat reduced their own moral distress, with only 7 of 35 respondents reporting no decrease in moral distress. Six of these seven respondents were consultant medical officers, and one

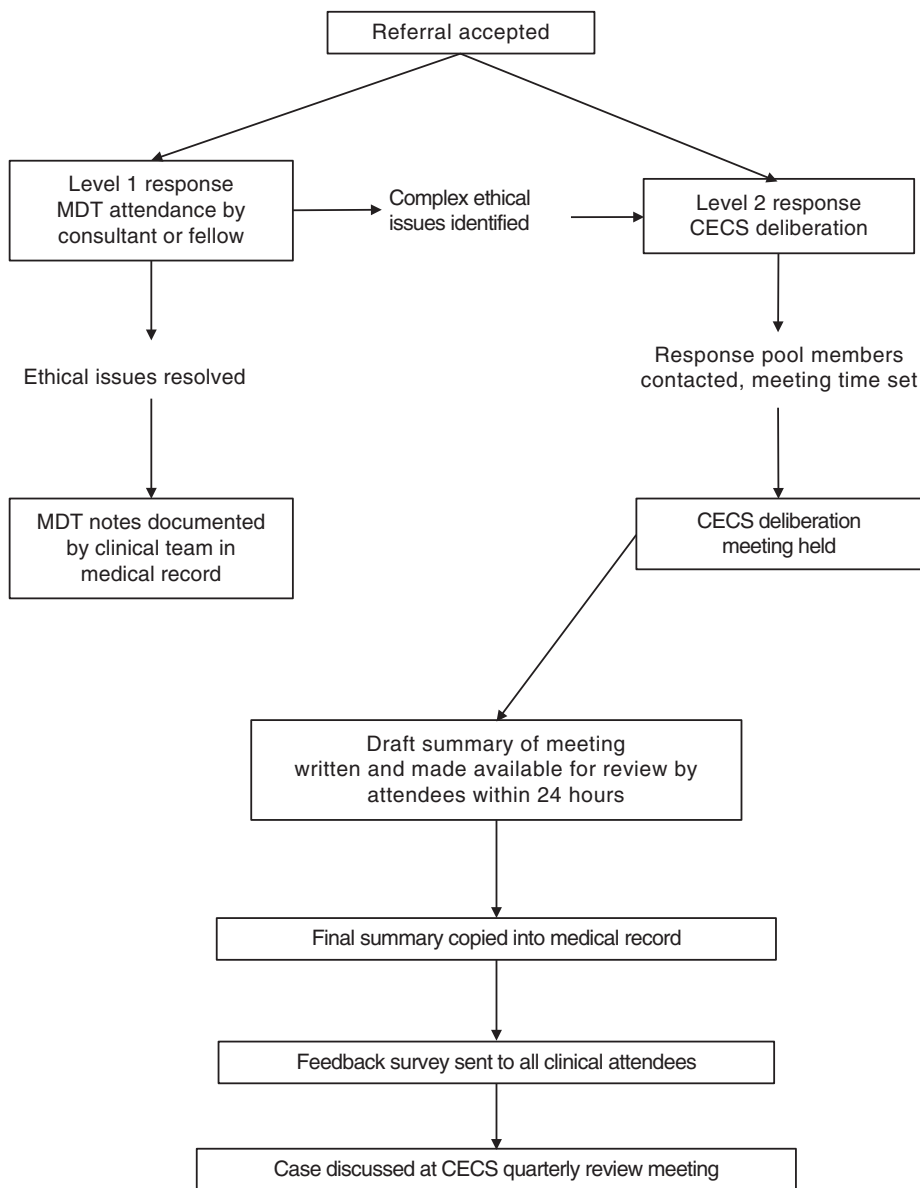


Fig. 1 Clinical ethics referral process. CECS, Clinical Ethics Consultation Service; MDT, multidisciplinary team meeting.

was a social worker. The conglomerate results of the surveys are summarised in Table 5.

Discussion

The marked overlap in the identified guidelines confirms emerging consensus standards for CES. The CCHEL CES fulfils most of these standards, has similar activity to other described paediatric CES,^{18,19} and clinicians are generally satisfied with the service. Importantly, we have found that the CES can decrease moral distress in staff. To our knowledge, this is the first evaluation of a paediatric CES with reference to consensus standards and the first to specifically assess the effect of clinical ethics consultation on self-reported staff moral distress.

The identified guideline documents stress the importance of transparency, which is a reasonable response to the concerns of many authors about the *ad hoc* nature of CES. It may be tempting

for the clinical ethics community to aim for uniformity and work toward a prescriptive model for consultation; however, there are dangers in this. First, CES need to be integrated with the health service they serve, and different consultation models will suit different health services. Second, there is no empirical evidence for what model of service is most effective. Similar to our study, empirical work has thus far mainly been descriptions of service processes and activity^{18–20} and feedback surveys of users of services.^{11–13} A small number of studies have surveyed multiple centres.^{11,13,21,22} This kind of data is valuable as it provides a contemporaneous picture of CES, encourages transparency and allows comparison; however, it must be interpreted carefully. For example, high referral rates are often presented as indicative of quality; however, they may reflect poor capacity building programmes or a defensive culture. Likewise, low referral rates may reflect high-quality education by CES but may also reflect a lack of trust in CES or a perception that it is not useful.^{21,28} Feedback

Table 3 Specialties involved in clinical ethics consultations (level 1 and level 2)

Specialty team	Number of cases
General paediatrics	10 (3 from peripheral centres)
Palliative care	7
Intensive care	5
Endocrinology	5
Respiratory	5
Neurology	5
Metabolic	3
Rheumatology	3
Surgery	3
Gastroenterology	2
Infectious diseases	1
Cardiology	1
Immunology	1
Rehabilitation medicine	1
Anaesthesia	1
Otorhinolaryngology	1
Neonatology	1
Child protection	1

data are also a limited measure of quality. Clinician satisfaction may simply reflect the CES process tending to deliver outcomes that appeal to clinicians. Gathering similar data from patients and families who have contact with the service would build a fuller picture. Interventional studies are the gold standard for testing efficacy but must be designed and interpreted carefully in this context. There are two randomised controlled trials and one prospective cohort study testing efficacy of CES in the intensive care setting.^{29–31} All found that CES decreased length of stay and the duration of life-sustaining measures in patients who did not survive to discharge. While appealing to administrators, measures like this are not necessarily indicative of the overall quality of an ethics service.

Our finding of decreased staff moral distress in association with CES input is important from an organisational perspective. Moral distress is a recognised risk factor for burnout in health-care workers,^{5,6} and there are increasing calls to develop strategies for

sustainable workforces in health.^{4,32} Research into the links between ethics consultation processes and clinician well-being are important from this point of view, along with exploring and defining the well-being function of CES and considering incorporating it into an evaluative framework. Our results indicate that specific inquiry into the possible differences between professions and the effect of CES on moral distress may be worthwhile. Within our survey instrument, we did not define the term ‘moral distress’, and this may mean that respondents are not reporting precisely the same phenomenon. Moral distress is variously defined in the literature;³³ however, in our institution, the term moral distress is generally used to describe an unpleasant emotional experience arising from a perceived moral tension. In education and information sessions, the CCHEL staff encourage clinicians to use moral distress as a trigger to consider clinical ethics consultation.

Clinical ethics practice is a philosophical activity that occurs in a science-driven environment, and so, its evaluation requires both normative and scientific work. Health-care professionals are less familiar with normative research than they are with the scientific method, and so, it must be stressed that without robust normative work to build on, it is difficult to design meaningful scientific research. For example, while the competencies listed in Table 2 represent an emerging consensus for skills required for clinical ethics consultation, there is no normative consensus on what constitutes ethics ‘expertise’. There is important normative work defining clinical ethics expertise emerging,^{34,35} which clinical ethics professional bodies need to engage with in order to develop professional standards that truly reflect the required expertise. A recent special edition of *Bioethics*³⁶ identified the need for research that integrates both empirical and normative elements, and there is exciting research of this nature emerging – for example, Jellema, Mackor and Molewijk’s study developing a coding scheme for assessing quality in deliberation³⁷ and Schildmann *et al.*’s work on reconstructing quality norms in CES.³⁸ However, until we have a more comprehensive body of evidence to draw from, it is appropriate that consensus standards emphasise transparency and critical reflection rather than being prescriptive. As in our case, critical reflection prompted by external standards can be useful, helping to identify areas for improvement that may not have been recognised internally.

Limitations

Our findings have several limitations. First, self-assessment of fulfilment of standards needs to be interpreted with caution. Second, our activity data is retrospective and therefore descriptive in nature rather than testing CES as an intervention. Third, three of the CECS deliberations in 2016 did not have the feedback survey sent due to administrative failure. In addition, the response rate to feedback surveys was 36%, and so, there is a significant non-response bias. Multiple factors contribute to this, not least the ‘survey fatigue’ many clinical staff experience due to the high volume of quality improvement activities requesting their feedback. We believe these numbers are also impacted by the attendance of multiple members of one clinical team and, anecdotally, that a senior person fills out a feedback survey on the team’s behalf.

Table 4 Key moral tensions identified in cases handled by the Clinical Ethics Consultation Service

Identified moral tension/s	Case numbers
Appropriateness of experimental therapy	3
Difference in perception of child’s best interests between parents and treating team	5
Difference in perception of child’s best interests between treating teams	2
What degree to respect an adolescent’s autonomy	1
Conflict between respecting parental autonomy and protecting child from potentially unethical research group.	1

Table 5 Feedback survey data

Question	Answer options			
*Did the CECS members give you confidence that they had a full grasp of the clinical ethical problems that you wished to discuss?	Yes definitely 23 (71%)	Mostly 9 (28%)	Somewhat 0 (0%)	Not at all 0 (0%)
Do you think involving the clinical ethics service clarified the ethical questions and issues in the case?	Yes 29 (83%)	Maybe 6 (17%)	No 0 (0%)	
*Did the CECS process identify ethical issues that you had not previously thought of?	Yes 14 (44%)	Maybe 6 (19%)	No 12 (38%)	
*Did the CECS discussion help to 'formalise' your thinking about the ethical issues?	Yes 22 (67%)	Somewhat 8 (25%)	No 2 (6%)	
Do you think having the clinical ethics service involved changed the way the case was handled, regardless of the ultimate decision/outcome?	Yes 18 (51%)	Maybe 13 (37%)	No 4 (11%)	
Did involving the clinical ethics service decrease your own moral distress in relation to the case?	Not at all 7 (20%)	Somewhat 24 (69%)	Significantly 4 (11%)	
Were the processes (referral/meeting/co-ordination/etc) associated with clinical ethics service efficient?	Not at all efficient 0 (0%)	Somewhat efficient 1 (3%)	Adequately efficient 13 (37%)	Very efficient 21 (60%)
Overall, did you find involving the clinical ethics service helpful?	Not at all helpful 1 (3%)	Neither helpful nor unhelpful 0 (0%)	Somewhat helpful 12 (34%)	Very helpful 22 (63%)
Would you recommend the clinical ethics service to colleagues who are in ethically difficult situations?	Yes 34 (97%)	Maybe 1 (3%)	No 0 (0%)	

Conclusions

There is emerging consensus for staff competency and service-level standards for CES. The CCHL CES generally fulfils these standards and has comparable activity to other paediatric CES. Clinical staff feedback indicated a decrease in self-reported moral distress. We acknowledge that this is not a complete evaluative picture, and we look forward to further collaborative, multi-modal research to develop normative standards and empirically evaluate consultative processes.

Acknowledgements

The authors acknowledge all clinical staff who took part in the feedback surveys and the work that Clinical Ethics Response Pool members undertake to support CCHL. This study was undertaken as a quality improvement project.

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