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Report by Dr Melanie Jansen, 2016 Churchill Fellow

Investigating ways to enrich and inform the development of Paediatric Clinical Ethics Services in Australia

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Keywords

Clinical Ethics Consultation Services; Medical Humanities; Deliberation; Clinical Ethics Education; Communication.
A note on narratives

Every clinical ethics service I visited had a unique narrative. How it looked and functioned at the time I visited, was a product of its history, its relationships, the political landscape it is a part of. Perhaps most profoundly, it is a product of what matters, and has mattered, to the people it serves.

Of course, what mattered overwhelmingly to all I spoke to, was the wellbeing of children. The complex web of relationships and community that we all inhabit, but that children are dependent on in special ways, is inescapable to healthcare workers. The fact of cultural and moral pluralism in all of the places I visited has resulted in services paying great attention to ensuring broad representation of views, and developing processes designed to overcome existing inequality. Respect for pluralism matters. There were some interesting nuances at different centres that spoke to their unique story. A central part of the identity of Great Ormond Street Hospital is that of being a rare disease centre. A place where very sick and very complex children go with hope for the newest, most innovative treatment that may change their lives for the better. Reflective of this, consideration of the ethical issues relating to innovative and compassionate therapy for rare diseases is a core purpose and part of the identity of the clinical ethics service. Most other services I visited grew up organically in response to the familiar ‘difficult’ ethical issues in paediatrics such as those around end of life care and child protection. Increased resourcing, and the resultant professionalisation, of clinical ethics services appears (unsurprisingly) temporally linked to whenever they become a requirement for hospital accreditation. In the Veneto region of Italy this is particularly apparent. While the paediatric clinical ethics committee has been established since 1994, in 2004 the Veneto regional government passed legislation that there must be region-wide clinical ethics committees, and as a consequence, the Veneto has one of the most comprehensive and coherent clinical ethics networks that I am aware of. It is also part of the legislation that these committees must be independent of hospital administration. There are several checks and balances in the Venetian system to ensure as much as possible that the ethics committee is independent, speaking to an idea of anti-corruption that matters to the local people.
One of the inspirations for my Churchill Project was Dr Rita Charon, a world leader in narrative method.¹ She says that each telling of a story is a singular event, created by both the giver and the receiver. That both the telling and the listening, or reading, of a story is an ethical act that has as its basis an openness to altering the Self by entering another’s world. This report is the story of my Churchill Fellowship. It has a more reflective tone than I initially intended. It speaks to the character of my Churchill experience, and to my Self. Thank you for reading it.
Executive Summary

Project description
Ethical decision making in health care is increasingly complex, with added layers of complexity in children’s healthcare. Reflecting this, clinical ethics services are becoming more common in Australia but there are few well-established services. The UK, Europe and North America all have longer histories than Australia in provision of clinical ethics services.

I visited these well-established clinical ethics services to gain insight into general operational issues, with particular focus on case consultation models and education programmes. I also visited centres of excellence in medical humanities teaching, to gain an understanding of how the humanities can enrich clinical ethics processes.

Highlights
- Visiting the Columbia University Narrative Medicine group and meeting medical humanities scholars who were truly engaged in medical education and able to explain and demonstrate the value that their discipline adds. This institution was inspiring for its truly interdisciplinary nature, and it was wonderful to meet healthcare professionals who were also fully engaged with the arts.
- Attending the George W. Gay Lecture at the Center for Bioethics at Harvard and being reminded what depth and rigour philosophers can bring to clinical ethics.
- Attending the European Association of Centres of Medical Ethics (EACME) conference and meeting and talking with experts in Moral Case Deliberation.
- Presenting at the Ethox Centre speaker series in Oxford, and the robust discussion that followed my presentation about the role and utility of clinical ethics services.
- Being exposed to the highly developed clinical ethics services in Boston, Toronto, Padova, and London and gaining insight into operational issues as well as advice on long term service development.
- Attending a Program to Enhance Relational and Communication Skills (PERCS) round at Boston Children’s Hospital and meeting with and learning from the founders of the PERCS.
Major Lessons
- Relational skills are at the core of meaningful clinical ethics case consultation.
- Critical Reasoning skills are imperative for robust ethics deliberation, however are often neglected in clinical ethics training and education.
- The humanities are a key pedagogical instrument in developing both relational skills and critical reasoning capacity.
- Deliberative models need to be normatively developed, and qualitatively and quantitatively assessed, in order to build a quality framework for clinical ethics deliberation.
- Clinical ethics services may be serving a wellbeing function for clinical healthcare staff and this needs to be explored further.

Proposed implementation and dissemination
- Collaborate with international and local partners to develop education programmes that specifically address the skills required for clinical ethics case consultation work.
- Develop links with local humanities scholars and explore ways to integrate humanities teaching into continuing medical education.
- Seek research funding for normative and empirical work on deliberative methods and evaluative tools for clinical ethics practice.
- Collaborate with specialists in healthcare staff wellbeing to develop research into the possible wellbeing function of clinical ethics services.
- Develop tools for clinical healthcare staff to further develop critical reasoning skills.
Program Description

European Association of Centres of Medical Ethics (EACME) Conference
A/Prof Bert Molewijk
Associate Professor of Clinical Ethics at the Department of Medical Humanities of the VU Medical Centre in Amsterdam.
Associate Professor of Clinical Ethics at the Centre for Medical Ethics (SME) at the University of Oslo (UIO) in Norway.

Dr Rouven Porz
Head, Clinical Ethics Unit at the University Hospital in Bern, Switzerland.
President, European Association of Centres of Medical Ethics.

Dr Allessandra Gasparetto
Researcher, Center for Clinical Ethics, Insubria University, Varese Italy.

Veneto Region, Italy
Fondazione Lanza
- Dr Lucia Mariani
- Dr Luciana Caenazzo
- Professor Renzo Pegoraro

Paediatric Ethics Committee
- Dr Enrico Furlan, President

Great Ormond St Hospital, London, United Kingdom
- Dr Joe Brierley, Chair, Clinical Ethics Committee, Paediatric Intensive Care Consultant.
- Rev Jim Linthicum, Head of Spiritual Care.
- Mr Luke Murphy, Patient Advice and Liaison Service (PALS) Manager.
- Dr Vic Larcher, Clinical Ethics Committee.
Oxford University, Oxford, United Kingdom
- Professor Dominic Wilkinson, Neonatologist; Director, Medical Ethics, Uehiro Centre for Practical Ethics.
- Dr Michael Dunn, Director of Undergraduate Medical Ethics and Law Education and Director of the Ethox Centre Graduate Training Programme.
- Dr Mark Sheehan, Research Fellow, Uehiro Centre for Practical Ethics, Faculty of Philosophy, Senior Research Fellow in Philosophy, St Benet's Hall.
- Professor Joshua Horder, A/Professor in Christian Ethics, Faculty of Theology & Religion.

SickKids, The Hospital for Sick Children, Toronto, Canada
- Dr Randi Zlotnik Shaul, Director, Department of Bioethics; A/Professor, Department of Paediatrics, University of Toronto.
- Dr James Anderson, Clinical Ethics Consultant, Department of Bioethics.
- Dr Roxanne Kirsch, Staff Physician, Cardiac Intensive Care Medicine; Associate Physician, Department of Bioethics; A/Professor, Department of Paediatrics, University of Toronto.

Faculty of Narrative Medicine, Columbia University, New York City, USA
- Dr Helen Towers, A/Professor Clinical Pediatrics, Co-Chair Pediatric Ethics Committee, New York Presbyterian Hospital.
- Ms Mary Tresgallo, A/Prof Nursing, Co-Chair Pediatric Ethics Committee, New York Presbyterian Hospital.
- Mr Ephraim Rubenstein, Artist; Lecturer in Narrative Medicine. Class: The Literature of Art.
- Professor Craig Irvine, Academic Director, Master of Science in Narrative Medicine. Class: Self and Other in Clinical Encounter.
- Dr Owen Lewis, Clinical Professor of Psychiatry, Columbia University; Poet.
- Dr Kenneth Prager, Director of Medical Ethics and Chairman of the Medical Ethics Committee at Columbia University Medical Center.
- Dr Danielle Ofri, Writer; Staff Physician, Internal Medicine, Bellevue Hospital, New York City; Associate Professor of Internal Medicine, New York University Medical School.

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a Dr Danielle Ofri is not a faculty member at Columbia University Narrative Medicine program but I arranged to meet with her during my stay in New York City.
Boston Children's Hospital and Harvard Medical School Center for Bioethics
- Professor Robert Truog, Director, Harvard Center for Bioethics; Frances Glessner Lee Professor of Legal Medicine; Professor of Anaesthesia.
- Dr Charlotte Harrison, Director, Office of Ethics, Boston Children's Hospital; Ethics Advisory Committee Co-Chair.
- Ms Christine Mitchell, Executive Director, Harvard Center for Bioethics.
- Ms Kerri Kennedy, Registered Nurse and Clinical Ethicist, Boston Children's Hospital.
- Dr Stephen Brown, Radiologist, Associate in Ethics, Clinical Ethicist, Boston Children's Hospital.
- Dr David Urion, Associate Neurologist, Clinical Ethicist, Boston Children's Hospital; Ethics Advisory Committee Co-Chair; Charles F. Barlow Chair in Neurology; Director, Behavioural Neurology Program, Harvard Medical School.
- Dr Jonathan Marron, Paediatric Oncologist, Associate in Ethics, Clinical Ethicist, Boston Children's Hospital.
Introduction and Goals

Clinical Ethics is in its infancy in Australia, although less so in the paediatric world, with recent evidence that the vast majority of children’s hospitals in Australia and New Zealand have a clinical ethics service. While there is a commitment to clinical ethics service provision generally, many services are inadequately resourced and rely heavily on clinical and academic staff volunteering their time in addition to their usual roles. In Australia and internationally, there are few regulatory standards for clinical ethics services, including for training for clinical ethicists, and calls to evaluate and apply standards to the field are increasing.

The clinical ethics consultation service (CECS) for Children’s Health Queensland is one of the activities of the Centre for Children’s Health Ethics and Law (CCHEL). CCHEL was established in 2015 and across the first two years of operation the CECS has handled 29 clinical case referrals. CCHEL also provides education to clinical staff, is available for policy consultation, and pursues a research agenda. It has 3 core staff members – a consultant clinical lead (0.2 FTE), a clinical ethics fellow (0.8 FTE), and an administrative officer (0.5 FTE) – and a response pool group of approximately 45 people which is composed of interested clinical staff across all disciplines and partner academics from the Australian Centre for Health Law Research at the Queensland University of Technology, and the University of Queensland Faculty of Medicine.

Some of the goals for my fellowship were very specific to the nuts and bolts of clinical ethics service provision: how are other services staffed? How are they funded? How do they manage referrals and document outcomes? What quality improvement activities do they do? Of particular interest to me was to know exactly how the services deliberate about clinical cases. I think it is important that clinical ethics services deliberate in robust ways – it must be clear that there is something about how this is done that promotes integrity, to ensure that the service is not just a rubber stamp, or a process of group-think, or no different to any bunch of people sitting in a room discussing a case and reaching consensus.

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b Data taken from Quality Improvement data at CCHEL.
As Dr Enrico Furlan, from the paediatric ethics committee in Padova said: “It must be an ethics committee, not a cosmetics committee.” In light of this, I was very interested in the education that is provided to the people who work in these services – how do we foster capacity for rigorous ethical thinking in already time-starved clinicians and academics? And so, I chose to visit places with well-established clinical ethics services, operating in social and political contexts similar to that in Australia. Finally, I wished to explore the role of the arts and humanities in ethical decision making – and by extension to the practice of medicine more generally. I have a persistent unease that as healthcare practitioners we are increasingly disconnected from our patients. The hyperspecialisation of medicine, the incredible volume of scientific knowledge that must be mastered, and the ever increasing and unwieldy administrative tasks that invade our clinical time seem all to be impacting negatively on our ability to maintain human connections with our patients. I had an inkling that perhaps the arts and humanities could help us – and so visited places where these disciplines are embraced, explored and applied.

My report is divided into three sections, 1) Case consultation, 2) Education, and 3) The Arts and Humanities in Medicine. I include a short note on the role of clinical ethics services in staff wellbeing before reaching the summary and recommendations.
Case Consultation

What is the purpose of ethics case consultation? Does ethics expertise exist?

All centres I visited acknowledged the importance of explicitly defining the purpose of clinical ethics case consultation (CECC). For example, some clinical ethics committees are convened to look at a specific clinical situation often in the context of possible legal action, such as in late termination of pregnancy. In instances like this, the purpose of the CECC is to make a specific decision about whether the hospital should proceed with this care. More recently, CECC is used for a wider variety of cases, and in services that are well integrated into clinical care, rather than being convened ad hoc for a specific decision, the purpose of CECC is often broader. Common themes in the stated purposes of services I visited were, creating a space for discussion; educating clinical staff through case support; exploring narrative; resolving conflict and facilitating consensus; exploring ethical arguments for different positions; helping teams and families arrive at a well-considered, reasoned, and compassionate decision. The ultimate purpose seemed most commonly to be assistance in decision making, rather than the ethics team itself making the decision. Even if the service provided a written recommendation to the team and family, it was emphasised that this was not binding, and that the ultimate decision making authority remained with the clinical team and family.

This leads many people to wonder whether CECC does anything in addition to facilitating discussion and resolving conflict. A common question raised is – does ethics expertise exist? If yes, what is its nature, and do CES have this expertise? If no, what exactly is it that CES do?

This question has been given significant thought by the team in Oxford, who are in the process of setting up a clinical ethics service, and also by the research group at VU Medical Centre in Amsterdam. In addition, at the EACME conference there was a presentation and discussion around this issue. In this session, the idea was presented that there are two kinds of ethics service – normative services that give a recommendation and facilitative services
that facilitate decision making by clinical teams. The normative model implies that there is ethical expertise involved in giving a recommendation, the facilitative model is more about skills in communication and education. I am not convinced that the dichotomy is as sharp as this, though I do think there are a variety of types of expertise involved in CES, and it is important to define what these are. Dr Mark Sheehan from the Ethox Centre has co-authored a paper titled, *Expertise, Ethics Expertise, and Clinical Ethics Consultation: Achieving Terminological Clarity,*\(^{10}\) in which he and Dr Ana Itis argue that an expert is a person with expertise in a certain domain, that ethics is about deciding what ought to be done, and therefore ethics expertise consists of being better at deciding what ought to be done than non-experts. Many clinical ethics consultants would be uncomfortable with this idea, given that, in general, they do not like to claim that they are necessarily more moral than the next person. However, they nonetheless believe they have expertise of a kind. So, what is this expertise? To try to come to an answer to this question, I will discuss each theme mentioned above of purposes that CECC may serve, and through this try and define what expertise is actually at play.

*C/Create a space*

Common to all the services I visited was the idea of creating a particular kind of ‘space’ that ethical concerns can be discussed in. There is broad acknowledgement that the usual clinical environment is not always conducive to the raising and discussion of difficult ethical issues. A variety of reasons were noted for this: time starved clinical staff with urgent clinical responsibilities; entrenched power hierarchies that can make it difficult for some team members and patients/families to speak out; lack of quiet, private physical space in which to discuss sensitive matters.

*Strategies identified to create appropriate space*

- To have as a defined key role of the facilitator to promote an equitable discussion eg ensuring all have a chance to speak; encouraging questioning of the reasoning behind all claims, even if the person who made them is senior/powerful; fostering a culture of openness to discussing difficult intuitions and emotions.
- Co-ordination with clinical staff to set aside adequate time for the consultation in an appropriate room.

The physical space and carving out of sufficient time are practical concerns that are necessary but don’t reflect a particular type of expertise. Some may argue that a degree of expertise is required to recognise the need for this and be assertive enough to make it happen in practice but these traits are not unique to clinical ethics expertise.

There is considerable skill in facilitating an equitable discussion as defined above. In the clinical ethics setting, given the gravity of what is at stake for patients, families, and clinicians; and given the complex, hierarchical, and emotionally charged space it occurs in, a skilled facilitator is essential. However, there are many other contexts where similarly skilled facilitation is essential and it is hard to claim that this kind of expertise is unique to clinical ethics consultation.

*Education through case consultation*

Some clinical ethics consultants see their role as purely educative. That with each case referral, through assisting clinicians to make decisions - for example by identifying ethical questions, clarifying what is at stake, identifying principles that are in conflict, and coaching them to reason in a robust manner – that they aid with the case in question as well as build capacity in the clinicians themselves.

Other consultants I spoke with agreed that there is a large educational component to case consultation, but that there are additional functions. Services that function in a collaborative and deliberative way, particularly those that expressly avoid giving recommendations, may be more comfortable with the idea that their role is solely educational. Consulting on real-time cases is a particularly responsive type of education but education nonetheless. Services that provide recommendations, particularly those that deliberate without the clinical team and/or family present, are less likely to fit comfortably with this model. Either way, education through coaching clinicians to think critically and
comprehensively about an ethical dilemma is something that could reasonably be described as expertise in ethics.

Conflict resolution and mediation

All of the services I visited agreed that conflict resolution and mediation are often at least part of the function of clinical ethics services. Some hold that clinical ethics is solely a form of mediation. There are multiple approaches to mediation, a discussion of which is outside of the scope of this report. However, it is worth noting that mediation as a profession seems as beset by problems of regulation, evaluation and legitimacy as clinical ethics consultation practice is.\textsuperscript{11} Given the variation in practice in both clinical ethics and mediation, it is difficult to draw sharp lines around what the difference between them may be. A personal observation I have (which many of the people I met with during the Churchill Fellowship shared) was that if I compare the way the CES at Children’s Health Queensland functions with the mediation training I completed with the Resolution Institute,\textsuperscript{12} a key difference is that the goal of mediation is for the two parties to reach an agreement, whereas the goal of an ethics consultation is to make an ethically sound decision enabling clinical teams to proceed with care in an ethically appropriate way. Ethics consultations often involve two or more parties in conflict, and while it is necessary to come to an agreement, an agreement on its own is not sufficient for a good quality ethics consultation. Likewise, there are ethics consultations that do not involve conflict between two parties, yet there is still work for the ethics service to do.

Deliberation

While many clinical ethics services use deliberation as at least part of their consultation method, few specify a particular model for this or have an approach to evaluating the quality of this part of their service. The group at VU Medical Centre in Amsterdam pay a lot of attention deliberation, and practice a method of clinical ethics support called Moral Case Deliberation (MCD). MCD is described as “the methodical reflection on an actual moral dilemma by a group of healthcare practitioners that is facilitated by a trained practitioner (a philosopher, an ethicist), in order to improve the quality of care and to share expertise and
responsibility." Facilitators of MCD use particular conversation techniques to explore values, norms, and knowledge about a particular case to build understanding in those involved in the case, enabling them to more easily see a way forward. The approach is firmly facilitative and final decision making remains with the clinical team. While facilitating discussion is not unique to clinical ethics consultation, these facilitative skills are directed toward encouraging thinking of a distinctly philosophical nature, and, as much as ethics expertise encompasses particular ways of thinking about ethical problems, then this kind of facilitation could be seen as ethics expertise. On the other hand, some may argue it is consistent with the educational role described above.

*Narrative Exploration*

A key issue in clinical ethics is identifying *what matters* to those involved. Narrative ethics methods involve respecting narratives as they stand, recognising the intersubjective experience of listening to a person’s narrative, and using methods borrowed from literary scholars to interpret the stories of the people involved. It seems to share the idea of understanding through dialogue that underpins MCD, but it places emphasis on narrative interpretation rather than particular conversation methods. Narrative methods are used in other fields – including narrative medicine more generally and narrative psychology. So, while these methods add much richness to the exploration and resolution of ethical problems they are not unique to clinical ethics.

*And now to answer the question...in my own words...*

Clinical ethics consultation services vary greatly in their specific activity depending on the institution in which they work and how they interface with other services. In my view, the activity that is specifically the domain of ethics is that which involves the critical appraisal of ethical claims and arguments. Lest this sound too cold and analytical, I wish to stress that nothing can be critically appraised, or argued for or against, in a robust manner without considering the human complexity and rich narratives that inform people’s values and life views. Skills in conflict resolution, mediation, facilitation of discussion, and narrative exploration are necessary skills for an ethics team, as they enable them to engage
meaningfully with all the stakeholders in a situation, gather all the information (including narrative information) required to comprehensively think about an ethical dilemma, and arrive at a workable plan. These skills are not unique to clinical ethics, but they are necessary for the practice of clinical ethics consultation using a collaborative model. Finally, the fact that many of the skills utilised in clinical ethics consultation are not unique to clinical ethics need not threaten the legitimacy of clinical ethics itself. What is most important is that these skills are identified so that those working in clinical ethics consultation can be adequately trained, and so that we can begin to think about how to evaluate these skills.

**Staffing for Clinical Ethics Case Consultation**

**Funding**

Each service I visited was staffed by people who carry out the clinical ethics consultations and by administrative staff. There was broad variability in funded core staff for each service. The most sparsely staffed service had 0.7 full time equivalent (FTE) staff in total whereas the most generously staffed service had 3.8 FTE. Even in those services with less than 1 FTE, ethics support was usually available during business hours, as the people holding the partial FTE also had full-time jobs in the hospital. Only one service provided support out of hours. The level of funded ethics support is truly variable given that the hospitals of the services I visited each have a similar number of beds. The ethics committee in Padua is unique in that it pays a small fee to external members (such as experts in law, experts in moral philosophy and bioethics, representatives of the parents and of the community) to compensate them for their expertise and for their time in attending meetings and being involved in clinical consultations.

All services depended significantly on volunteer time from partner clinicians and academics. Unsurprisingly the dependence on volunteer staff was lowest at the most highly staffed service.

Most services have the broad structure of having a core group of funded staff who lead clinical ethics consultations with support from volunteer members. This support takes a
number of forms. Most commonly, volunteer members made up a committee that met regularly and discussed non-urgent cases, worked on policy, undertook educational activities for committee members, and planned education for general clinical staff or the community. Depending on the consultation model (discussed in greater detail below), members of the committee may also be called upon to be part of a rapid response team for real-time clinical ethics cases.

There were a variety of creative ways that services built relationships with other clinical departments to enrich their ethics services. For example, at SickKids, Toronto, the ethics service has clinical associates in addition to their core group of clinical ethicists. These associates are medical doctors from key specialties who have master level qualifications in ethics. They support many facets of the service activity by providing education to clinical staff, engaging in Bioethics research and scholarship, contributing to policy development and attending regular Bioethics Department meetings in which past cases are reviewed and active cases may be discussed, but they do not lead clinical ethics consultations. At GOSH, the ethics service has a strong relationship with the Patient Advisory and Liaison Service (PALS) and the spiritual care team. These services actively support patients and families going through the clinical ethics process.

Staff qualifications/competencies

Core clinical ethics staff at all the services I visited were required to have at least Master level qualifications in ethics, one service required clinical ethicists to be PhD trained. In addition, many core staff had done other short courses, internships, or other programs in clinical ethics. With regard to the committee membership, all services were committed to multidisciplinary membership but there was variability in how broad this was. For example, some services required laypeople (though the definition of a lay person was interpreted very differently in different institutions); some required representation of certain backgrounds such as philosophers or lawyers; other groups required some members to be external to the hospital from which the case was referred. Most committee members are chosen on the basis of interest in ethics and to represent certain clinical or academic
groups, although some committees, for example at GOSH, have a high proportion of members with formal ethics qualifications.

Models of Service for Clinical Ethics Case Consultation

Most of the services I visited carry out consultations as a small group with a core ethics staff member leading the process. The small group is usually drawn from the membership of the clinical ethics committee. An exception to this is at SickKids, where the PhD trained clinical ethicists usually conduct the ethics consult individually, however there is scope for them to discuss active consults with the broader group of clinical ethicists and associates at frequent departmental meetings.

With regard to how the ethics consultations are specifically handled, there is a reasonable amount of variability. The broad goals of consultation are similar, and the variability in how things are operationalised is generally a product of service resourcing and the culture of the institution the service sits within. As discussed earlier in this section, the specific role of clinical ethics services is still being defined. It is important for each service to define their role and scope and then design their consultation process with reference to this, being mindful of the culture and needs of their own institution. Most of the services I visited had done this well. For example, SickKids state their objective as follows:

*The objective in the usual clinical consultation is to define the values underlying choices, to ensure that the relevant voices are involved in the process, to ensure that a fair process is undertaken, and to elucidate the ethical defensibility and vulnerability of each option.*

The service at Boston Children’s Hospital (BCH) explicitly addresses the multiple functions that clinical ethics consultation services may serve. BCH has defined three types of consult services they provide – communication, facilitation, and full consultation. Communication is a one-on-one discussion with a patient, family or staff member, who has requested to speak with the ethicist. Facilitation is a clinical team requesting to talk through a problem with the ethics service. In this case, the ethics team facilitate a team meeting and coach them through reasoning but do not provide a recommendation. A full “ethics consult”, is a
patient-specific ethical analysis with deliberation and a resulting, non-binding recommendation.

Involvement of patients and families was generally explicitly done, but again was operationalised in different ways. Some services left the decision of whether patients and families were explicitly included in the ethics consultation process up to the discretion of the treating team, others refused to carry out a consultation without it. This involvement took different forms, partly depending on how the overall ethics process was carried out. How clinical team members were involved also depended on the overall model. For example, at GOSH, a deliberation meeting is held with the clinical team and the ethics Rapid Response Team (RRT), and the patient/family attends at the beginning to present their point of view. The clinical team and RRT then deliberate. The service in Padua is similar. The ethics committee convenes and, in the first part of the meeting, the clinical team involved in the case and the family have an opportunity to present their points of view. Then, the ethics committee continues the deliberation and develops a recommendation without the clinical team or the patient/family present.

Documentation of consults differs significantly as well. Some services document at length the rationale for the recommendation that is given, and a copy is provided to the medical record, clinical team and patient/family. Others simply document that a consult has occurred and what the outcome was, keeping more detailed minutes in a separate file. This is an area of clinical ethics practice that is known to differ widely internationally. There is much work to be done in this area, clarifying the legal principles behind clinical ethics consultation and discussing how best to make decision making more transparent.
Education

Education is a key part of all services I visited and there is a rich variety of programs. I have listed common educational activities under the headings of those intended to educate people who are actively contributing to the clinical ethics service, those intended for general clinical staff, and those intended as community engagement activities. Following this list, I will describe in more detail the programs of particular interest to me – intensive courses for training in clinical ethics, and communication skills training.

Education for clinical ethics service members
- Short intensive courses, for example the Harvard Clinical Bioethics Course,\(^\text{17}\) and the VU University Medical Centre course for Facilitators in Moral Case Deliberation\(^\text{16}\)
- Longer formal course programs, for example Corso di perfezionamento in Bioetica (Advanced Course in Bioethics) at the University of Padua\(^\text{17}\)
- Regular ongoing education, often incorporated as part of ethics service review meetings
- Encouragement of attendance at sessions available for clinical staff and community
- Regular ethics consortia. For example, Harvard University have regular clinical, research, and organisational ethics consortia
- Contemporary authors in Bioethics series at Harvard University\(^\text{18}\)

Education for clinical staff
- Regular presentations in forums such as grand rounds.
- Regular contributions to ongoing programs such as junior doctor teaching.
- Department specific sessions on request by clinical departments.
- Ethics rounds – open sessions where a paper or a case will be discussed.
- More elaborate annual events such as Bioethics Week at SickKids where they hold 17-18 events related to bioethics over that week.\(^\text{19}\) Another example is the Great Ormond Street Hospital’s Paediatric bioethics and law masterclass.\(^\text{20}\)
- Small group, ward based education done in response to requests from clinical departments.
Community engagement and education  
- School visits, for example, representatives from the clinical ethics committee in Padua regularly visit schools to raise awareness of bioethics issues. 
- Conference organisation, for example the Annual Bioethics Conference at the Harvard Centre for Bioethics.  
- Public events.

Intensive Courses

*Harvard Clinical Bioethics Course*


Centre for Bioethics, Harvard Medical School

This is a 3 day intensive course that aims to provide a foundational understanding of ethical theories and methods related to issues in clinical care. It is intended for anyone interested in bioethics but particularly for those serving, or preparing to serve, on ethics committees. It utilises a combination of lectures, case discussions and seminars. There are some concurrent sessions to allow for attendees to pursue areas of interest.

Faculty are sourced from Harvard Medical School and affiliated hospitals and institutions. The course is a requirement for Boston Children’s Hospital Ethics Advisory Committee members and is also marketed nationally and internationally.

*International Intensive Course for Facilitators in Moral Case Deliberation*


Department of Medical Humanities, VU University Medical Centre, Amsterdam

This is a 5 day course with 3 days of initial instruction followed by 6 months of practicing MCD in one’s home institution, followed by 2 days of follow up and consolidation. The course objective is to train the knowledge and skills required for MCD facilitation, and is aimed at a broad audience, including members of ethics committees and clinical ethicists.
Communication and Relational Skills

Program to Enhance Relational and Communication Skills (PERCS)

This is a comprehensive collection of programs run by the Boston Children’s Hospital Institute for Professionalism and Ethical Practice (IPEP). IPEP’s mission is to, “...promote relational learning for healthcare professionals that integrates patient and family perspectives, professionalism, and the everyday ethics of clinical practice.”

The programs are based on relational and experiential learning strategies, using simulation, debriefing, reflection, and engaged discussion to develop skills for difficult conversations in healthcare. PERCS situates good communication as an ethical imperative, and refreshingly puts everyday interactions with patients at the centre of ethics education for practitioners. I think this is of particular value to those working at the coal-face of healthcare. Bioethics programs are often focused on hot-button issues like abortion and euthanasia. While these are interesting topics to learn about and be aware of, they do not make up the bulk of the ethical work in clinical practice. Every interaction we have with patients and other staff, every small medical decision we make involves value judgements. The PERCS program brings this everyday practice into the spotlight, honing the foundational skills of healthcare practitioners. The founders of the PERCS program have written further on this issue of the ethics in everyday practice, in their paper titled, "Micro-ethics: The Ethics of Everyday Clinical Practice."
Humanities and the Arts in Clinical Ethics

Since high school, the only time that I have studied the arts or humanities (apart from philosophy of course) was a poetry writing subject I took as part of my Master of Arts (Phil). I thought of it as a somewhat indulgent elective. I had always loved to write, but had chosen a life path that left little space for it. The poetry writing subject was as I expected – balm to a starved creative soul. What was unexpected was how it influenced my practice of medicine. The intense focus on language – word choice, rhythm, space – made me more aware of how I use language at work. The exposure to peer review of my own poems, and participating in that of others, was an exercise in humility and a reminder of the mystery of the inner worlds of others. Humility not because I was humiliated in the process, but because so often what I wanted to convey in my poems was not what was perceived by others, motivating me to reflect on language, on my own experiences and assumptions, and on the nature of meaning itself. Yet even after a hundred re-workings, still a reader may see something I had not intended. A reminder that reality is as each person sees it, and that to enter the worlds of others, as healthcare workers must, requires a genuine curiosity about those worlds, and an openness that is all too easily trained out of people who are taught to categorise, slice with Occam’s razor, and treat accordingly.

I am articulating this experience with more sophistication than I would have at the time, having now had the benefit of talking with so many medical humanities scholars, and observing how they teach. I had a strong sense that there was something deeply important about engaging with creative arts in this way, but I could not quite describe exactly what, and even less could I envision how an education program of this kind might work in practice. So, I had a simple question for all of the medical humanities scholars I met with, “what do the arts and humanities really add to medical practice?” I received many eloquent and enlightening answers, which appealed to me as a person inherently open to the arts, but not many that I thought would necessarily convince any of my clinical colleagues that this was important. Until I asked Dr Renzo Pegoraro, a neurologist and bioethicist at Fondazione Lanza, who crystallised my intuitions when he answered, “Melanie, to learn to be a doctor you must learn about disease – pathology, pathophysiology, anatomy, etc – and this
requires science. But it is humans that get sick, and it is the humanities that teach us about humans.”

This need to learn about humans rings urgently. A recurring theme when I spoke with non-medical staff members such as spiritual care/chaplains, social workers, lay members of committees, patient liaison workers, was that they saw their key role in the proceedings as to remind the clinical team that they were working with a person. This disturbs me greatly. As clinicians, are we losing our grip on the humanistic dimensions of medical practice? I asked many of the people I met what they thought the reason for this was – most cited the increasingly crowded medical curriculum, squeezing out anything that was not “core” knowledge or skills. But this speaks to a deeper problem – that knowledge of human beings is not seen as a core medical skill. This persists despite evidence that good relational skills, improve patient outcomes and decrease litigation.24 Anne Hudson Jones has written eloquently and incisively about the history of medical humanities and literature in medicine.25 She speaks of two justifications for the teaching of literature in medicine – the aesthetic and the ethical. The aesthetic focuses on the cognitive skills that studying literature develops, and that are directly transferable to medical practice. She quotes Trautman,25

In short, to teach a student to read, in the fullest sense, is to help train him or her medically. To ask the medical student what is being said here—not at all an easy question when one must look at words in their personal and social contexts and when several things are being said at once—is to prepare him or her for the doctor-patient encounter.

The ethical approach emphasises the value that lies in the close reading of texts that explore the moral dimensions of life, encouraging existential reflection on the good life and what it means to live as a physician. These two approaches are not mutually exclusive and can, and should, be taught in concert.

Dr Danielle Ofri,26 a general physician and writer, introduced me to the poem Gaudeamus Igitur, written by a cardiologist-poet and given as a commencement address to medical students. It is a lengthy epistle, below is an excerpt that affected me greatly:
For there will be the arts
   and some will call them
soft data
   whereas in fact they are the hard data
   by which our lives are lived
For everyone comes to the arts too late
For you can be trained to listen only for the oboe
   out of the whole orchestra
For you may need to strain to hear the voice
of the patient
   in the thin reed of his crying
For you will learn to see most acutely out of
   the corner of your eye
   to hear best with your inner ear

My time at Columbia University with the Narrative Medicine Faculty gave me insight into how a program of the arts and humanities for clinical practice may be taught. Students in the Masters of Narrative Medicine program study a broad range of fine arts subjects. I sat in on a class in the Literature of Art – where students study artworks to gain access to the artist’s world and reflect on their own reactions to it. They study life drawing to learn to see the body in a more comprehensive way, the lecturer reports that there is evidence that art education improves the observational skills that are key to competent physical examination. A class on Self and the Other in Clinical Encounter had students studying literature that explored the lives of disadvantaged people, leading them to reflect on the experience of the Other. The Masters in Narrative Medicine is a program to aspire to in the long term, but there were many smaller courses and electives that I had the opportunity to learn about, that could be incorporated into our clinical ethics education programs. For example, Dr Owen Lewis runs a 6 week elective on poetry for medical students, where students closely read poems and work on their own anthology. His learning objectives for the students are as follows:
1. To build the capacity to react to language in a deeper way.
2. To give students the ability to learn from their own writing.
3. To give students the confidence to trust that they can discover something through their own writing.
4. To identify potential writers and give them support for going on with their work.

Dr Lewis explained that there is a writing voice, and that this voice calls on experience that is not otherwise accessible to a person. Through close reading and writing, students learn that they don’t know everything there is to know about themselves, or others, and that this experience fosters the openness that is key to good medical practice.

To quote Dr Ofri again, when speaking of her residents and students, “I remind them...that medicine is fully integrated into the world at large, and that being a physician means engaging all aspects of life to the fullest because, in the end, we doctors are in the same lifeboat as our patients.” Bringing us to another verse from Gaudeamus Igitur:

For this is the end of examinations
For this is the beginning of testing
For Death will give the final examination
    and everyone will pass.

A full and rich understanding of humans, the personal openness, and cognitive flexibility that the medical humanities teach, are foundations of skilled medical practice. There is a great need to lift the profile of medical humanities to that of an integral component of medical education, rather than being seen as an indulgent elective, a bit of cake icing, or an eccentric waste of time.
A note on wellbeing

Ever since I have been lecturing in ethics, and giving teaching sessions to clinical staff at the hospital, I have noticed that the sessions often evolve to take on the quality of a debrief. Clinicians use the teaching case as a springboard to share other similarly distressing or complex cases. I also notice this effect in clinical ethics consultation, and receive a lot of corridor feedback that staff find the clinical ethics process beneficial for their own wellbeing. We have managed to capture this effect in our quality improvement data, which shows that the majority of clinical staff who have been involved in an ethics consult report that their own moral distress was decreased as a result of having the clinical ethics service involved.\(^2\)

I have spoken about this with clinical ethics colleagues in Australia over the years, who notice the same phenomenon in their own institutions, so it was not a surprise to find that all of the services I visited during the Churchill Fellowship reported similar experiences. Most have an intuition that it is because there is a startling lack of forums in which healthcare workers can discuss their moral distress about a case, and that ethics provides a space for this. We know from the literature that moral distress is a recognised factor in clinician burnout.\(^{27,28}\) There is little to no research on why or how clinical ethics services are alleviating some of this distress. Everyone I spoke with agreed that we should look more closely at this positive, but thus far unintended, effect of clinical ethics services. If CES have a therapeutic function it is important that this is meaningfully executed, and that it becomes recognised as a competency for CES.
Conclusions & Recommendations

The key theme emerging from my Churchill Fellowship experience is that relational skills are at the core of meaningful clinical ethics consultation. In fact, they are at the core of good medical practice, and, to go even further, at the core of living the good life. By relational skills, I refer not just to the mechanical aspects of communication that are so commonly taught to healthcare professionals - such as paying attention to body language and speaking without jargon – but to the skills required to authentically connect with other human beings. The many and varied pressures on clinical staff have led to an erosion of these skills, as more urgent, but not necessarily more important, tasks press out these less tangible aspects of medical practice. Perhaps clinical ethics services can be one of the instruments that helps claw back these rich resources. Clinical ethics needs to distinguish itself from bioethics by making the ethics of everyday practice its central task. The other key theme is that critical reasoning and argumentation are central parts of a deliberative approach to clinical ethics consultation and that these skills need to be explicitly taught. Collaboration within and between clinical ethics services, with humanities departments, and with all clinical departments and healthcare professions will be the key to developing a rich pedagogy and practice of clinical ethics. This pedagogy needs to be informed by robust research, both normative and empirical, to define efficacy in clinical ethics and develop meaningful ways to evaluate our services. Evaluation needs also to look at other, perhaps not originally intended functions of clinical ethics, such as staff wellbeing.

Recommendations

1. Clinical Ethics Education programmes addressing the varied skills that are required for consultation need to be developed. Specific areas that need to be addressed are critical reasoning and argumentation skills teaching, and high level communication skills training.

2. Clinical Ethics Services should engage with the medical humanities, advocating for their teaching in medical education as an ethical imperative.
3. Deliberative models need to be normatively developed, and qualitatively and quantitatively assessed, in order to build a quality framework for clinical ethics deliberation.

4. The impact of clinical ethics services on clinician wellbeing should be explored.
References


