Clinical Ethics Support in Contemporary Health Care: Origins, Practices, and Evaluation

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Introduction

This chapter concerns current initiatives to create and maintain specialized services to help respond to ethical issues that arise in the practice of health care. These initiatives, the obstacles they face, and the controversies they engender should be of considerable interest to those concerned with the management of health care organizations. This is because ethics is and should be intrinsic to routine health care practice. Also, no less, it is because ethical disputes and controversies, even if they seldom occur, can severely disrupt the complex organizations that deliver health care in modern societies.

Clinical ethics support services (CES services) are comprised of an individual or group, usually in an organization, who can provide a suite of services to support all stakeholders in identifying and managing the ethical issues that inevitably arise in the design and delivery of health care. While there is a degree of consensus about the potential value of such services, they are also the focus of ongoing theoretical, methodological and political debates. This chapter does not aim to resolve these debates. Rather, our aim is to provide health care managers with an account of how and why CES services are becoming a part of the contemporary organizational landscape of health care, and describe the concerns that bioethicists and observers and critics of bioethics have raised regarding their role, function, and dissemination.
We first describe the origins of CES services, to provide a context for the following discussion about the goals, functions and models of support that exist across this discipline—drawing on some relevant examples. We then describe how CES services can be evaluated. Third, we discuss initiatives that aim to optimise quality of CES services and some of the criticisms and suspicions that these initiatives have engendered. Finally, we offer some reflections on the direction that CES services may take in the future.

The Origins of CES Services

Clinical ethics support is derived from the discipline of bioethics, which, at least as it applies to the health care sector, can be defined as the study and critical appraisal of ethical, legal, social and political issues arising in the delivery and management of health care and research. Bioethics operates in three distinct spheres: academic, policy and clinical. The incorporation of bioethics into clinical practice to improve patient care (clinical ethics) may be seen as a continuation of the tradition of medical ethics—the means by which the medical profession itself has attended to ethical problems that arise in practice (Dzur, 2002; Pellegrino, 1988; Moreno, 2009). However it can also be seen as a significant departure from that tradition. Bioethics is an interdisciplinary enterprise in which philosophers, lawyers, social scientists and the public engage with biomedical researchers and clinicians. Bioethics has thus opened up the ethics of medical encounters and biomedical research to external ethical scrutiny and critique and so represents a break in the tradition of medical ethics (Dzur, 2002).

Histories of bioethics offer a variety of explanations for its emergence during the twentieth century. In some accounts (e.g., Callahan, 1999), bioethics emerged from biomedical researchers and clinicians reaching out to non-medical disciplines such as philosophy and law for support with the perplexing moral choices imposed by new medical technologies. In other accounts (e.g., Rothman, 1992; Bosk, 1999) bioethics emerged as a response to medical scandals such as the infamous Tuskegee Syphilis Experiment, with critics both within and outside medicine concerned to more closely monitor biomedical research and practice. Bioethics is also seen to emerge (e.g., Jonsen, 1993) from increased secularism and greater awareness of moral pluralism. Intellectual histories of bioethics have also associated it with the rise of new social movements of the 1960s, such as the civil rights movement, feminism and environmentalism, which questioned all forms of authority and called for the public to have a greater say in institutional decision-making (Dzur, 2002).

Similarly, accounts of the emergence of CES services point to the technological and social changes that have increased the ethical complexities of patient care (Aulisio, Arnold, and Youngner, 2000; Agich, 2005; Larcher, Slowther, and Watson, 2010). Advances in specialties such as critical care, reproductive medicine, fetal medicine and genetic testing, have led to new treatments that blur important boundaries (e.g., between life and death) and create unprecedented ethical and legal dilemmas around issues such as withdrawing/withholding care. Diversity of values in society is reflected in the clinical setting; also compounded by differences between the health professions, and institutional and systemic imperatives (Aulisio, Arnold, and Youngner, 2000). As a number of authors (e.g., Zussman, 1997; Royal College of Physicians,
2005) have noted, clinical relationships have changed: medicine has lost some of its authority; paternalism is yielding to “partnership” and shared decision-making with better educated patients and more assertive “consumers”; nursing is more professionalized. The medical encounter is increasingly crowded with competing interests and influences. Clinical transactions usually involve third party payers such as governments or private insurers, making clinical work increasingly subject to scrutiny from these and related institutions. The ethical issues that arise as a result are not confined to the clinic, but often attract intense scrutiny from the media, from religious authorities and from the law. As a result, clinical decisions (such as a withholding treatment) can become the focus of far-ranging public debates.

CES services first emerged in a few hospitals in the USA in the 1960s and 1970s (Moreno, 2009; Tapper, 2013). According to several scholars (e.g., Cranford and Doudera, 1984; Rosner, 1985; Jonsen, 1993; Rubin and Zoloth, 2004), the catalyst for the growth of CES services was the judgement of the New Jersey Supreme Court in the case of Karen Quinlan in 1976. This case was prompted by a disagreement about whether to withdraw ventilation support from a young woman who was in what would now be called a minimally conscious state. Quinlan’s parents asked her doctors to cease ventilation, but her doctors refused to do so, due to concerns about their legal liability. The case was the first legal adjudication on life-support in the US and it generated intense public interest (Jonsen, 1993). In a landmark decision, the Court found in favour of extubation, drawing on a paper by Teel (1975) which argued that doctors frequently face difficult ethical and legal decisions in end-of-life care, which they are ill-equipped to deal with. Teel argued for greater access to mechanisms for support such as the then novel hospital ethics committees (Tapper, 2013; Engelhardt, 1999). The judgement in the Quinlan case included a recommendation that clinical ethics committees be established to offer doctors guidance in such cases.

The Quinlan case is significant as it is frequently cast as emblematic of the factors that precipitated the spread of CES services. The case is often cited to show how physicians reached out for assistance with the perplexing choices created by advances in medical technology. Tapper (2013) uses the case to argue that the advent of extreme life-prolonging measures created a yearning among clinicians to share the responsibility for the tough decisions these technologies imposed. ECs were “[b]orn to serve the dual and reinforcing fears of futile care and medicolegal liability” (Tapper, 2013, 417). In other histories, the Quinlan case represents the moment medical ethics became a more public affair and the “internal morality” of medicine opened up to the norms and values of the wider community (Pellegrino, 1988; Bosk, 1999; Dzur, 2002; Rubin and Zoloth, 2004). For Engelhardt (1999) the Quinlan judgment represents the point at which moral authority within health care could, and should, be transferred from clinicians, patients and their families to CES services “in the name of oversight and the protection of patients” (Engelhardt, 1999, 92). For Jonsen (1993) the Quinlan case heralded a “culture sensitive... to the rights of individuals and their abuse of powerful institutions” and stimulated a movement committed to vigorously asserting the “needs and preferences of patients” (1993, S3).
The Quinlan case and a later series of Baby Doe cases (also involving the withdrawal of life supporting interventions) gave momentum to the idea that clinical ethics committees provided an alternative to resolving medico-ethical disputes in courts of law.

The idea of CES services was taken up by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which recommended that health care institutions explore the use of ethics committees for decisions regarding incapacitated patients (Agich, 2009a; Dzur, 2002). Momentum grew to effective mandate when in 1992 having an institutional means of addressing the ethics of patient care was made a requirement of hospital accreditation by the Joint Commission on Accreditation of Health Care Organisations (Agich, 2009a, 2009b; Pope, 2009). This event, more than any other, induced the rapid spread of CES services in the US, to the extent that they have become an almost ubiquitous feature of health care organizations in this country. The most recent US national data indicated that 81% of general hospitals have an ethics consultation service and a further 14% are in the process of establishing a service (Fox, Myers, and Pearlman, 2007).

Following these early US developments, CES services have now become established in many other nations—with the experience and knowledge gained in the US motivating the creation of services elsewhere (Slowther, Hill, and McMillan, 2002; Pfafflin, Kobert, and Reiter-Theil, 2009). CES support is now a feature of at least some hospitals in Australia, Belgium, Bulgaria, Canada, Croatia, Finland, France, Germany, Israel, Italy, Japan, Lithuania, Netherlands, New Zealand, Switzerland and the United Kingdom, to name just a few (McNeill, 2001; Meulenbergs, Vermylen, and Schotsmans, 2005; Aleksandrova, 2008; Gaudine et al., 2010; Frikovic and Gosic, 2006; Guerrier, 2006; Louhiala et al., 2011; Wenger et al., 2002; Hurst et al., 2007a; Akabayashi et al., 2008; Bankauskaite and Jakusovaite, 2006; Dauwerse et al., 2011; Macdonald and Worthington, 2012; Hurst et al., 2008; Slowther, McClimans, and Price, 2012).

Accounts of the emergence of CES in these nations (e.g., Beyleveld, Brownsword, and Wallace, 2002; Dorries et al., 2011) are similar to US histories in attributing their emergence to factors such as advances in biomedical technologies, moral pluralism (there being more than one view on an issue that could be said to be reasonably held), the rise in patient rights and medical scandals. The developmental trajectory has been quite different, however. With the exception of Norway, Belgium, Greece (where they have legal status) and Spain, most nations have not made CES services mandatory for hospitals (Lebeer, 2005). Rather, CES services have developed in an ad hoc and sporadic way; usually led by motivated clinicians (Beyleveld, Brownsword, and Wallace, 2002). Even here, however, most countries have witnessed the gradual emergence of CES services. In Canada, a survey by Gaudine and colleagues found that in 2008 85% of hospitals had an ethics committee compared to 58% in 1989 and 18% in 1984 (Gaudine et al., 2010). A recent survey of clinical ethics committees in the UK showed the number of identified committees to have risen from 20 in 2001 to 82 in 2010 (Slowther, McClimans, and Price, 2012). Clinical ethics networks have also been established in Europe with the European Clinical Ethics Network (Fournier et al., 2009) and in the UK with the United
Kingdom Clinical Ethics Network (UKCEN) in an attempt to embed clinical ethics as a core element of health care systems (Slowther, 2008).

The spread of CES services internationally shows that the idea of having available some manner of expert ethical support, has clearly taken hold (Aulisio, Arnold, and Youngner, 2000; Gill et al., 2004; Agich, 2005; Royal College of Physicians, 2005; Williamson, McLean, and Connell, 2007; Larcher, Slowther, and Watson, 2010; Dorries et al., 2011). In the next section we will describe some of the major, common features of CES services. We start, however, by noting that there is continuing debate on foundational issue of CES services—what goals can and should a service strive to meet. This issue partly explains the somewhat precarious institutional existence of such services, at least in some jurisdictions.

Goals, Functions, and Models of CES Support

Goals

The commonly stated or implied goals of support services include: minimising the distress and conflict that clinicians and patients experience when faced with ethically difficult clinical decisions (Yen and Schneiderman, 1999); improving the quality of patient care (Slowther, 2008); controlling health care costs; reducing complaints; reducing litigation and the costs associated with it; reducing the fear of litigation; increasing trust in health care professions and institutions; creating better decision-making processes; facilitating decision-making where there is disagreement; creating a greater focus on patient-centred outcomes; reducing the frequency of intractable or unresolved disputes; improving staff morale; developing policies and practices that reduce risks to health care organizations, and promoting greater understanding of ethics (Nelson et al., 2010a).

Whilst there is broad acceptance of the potential value of CES services, the characteristics of existing services reflect a plurality of visions and values. For CES services can be envisaged as a service accessible to clinicians (and perhaps patients as well); or as a watchdog for the ethical quality of patient care; or as a champion of patient rights, or as a means of risk management and legal cover for their institutions. These various visions of CES services can be classified in different ways. Beyleveld, Brownsword, and Wallace (2002), for example, identify two main categories. The first is “bottom-up” and clinician-oriented, while the second is “top-down” and managerial. The first category describes settings where enthusiasts for clinical ethics are likely to have established a CES service; while the second describes those in which CES support has been encouraged or mandated by an entity other than those who form the service itself.

These categories highlight the fact that CES services can serve different purposes: they can help clinicians to deal with ethically complex issues; and/or they can help health care organizations manage risks and crises (Beyleveld, Brownsword, and Wallace, 2002). While these different goals are not mutually exclusive, sometimes they conflict. Thus questions about what CES services can and should do are political as well as theoretical and technical. Clinical ethics support is not politically innocent (Dzur, 2002; Brecher, 2006; Engelhardt, 2009); there are
always partisan ideas, interests and agendas at work and it is possible for CES services to be “captured” in the interests of some at the expense of others.

Functions

There are three main functions typically associated with CES: education, policy development and case consultation (Singer, Pellegrino, and Siegler, 1990; Blake, 1992), although a fourth—providing assistance with organizational ethics—is gaining increasing prominence. Different services emphasise different functions (Mills, Rorty, and Spencer, 2006). Of these three functions, case consultation, the “driving force” of clinical ethical infrastructure (Mills, Tereskerz, and Davis, 2005, 57), has received the most scholarly attention. It is “the most potentially volatile and the most labor-intensive” function (Moreno, 2009, 577).

The CES function of education is considered by some clinical ethicists to be its most important and efficient function (Moreno, 2009). However it is relatively under-represented in the literature and there are few detailed descriptions and recommendations for the educative role of ethics support services (Chidwick et al., 2010). In most discussions, description of a service’s educational activity is limited to enumerating the types of ethics teaching activities that are commonly undertaken such as presenting a case or an issue at a Grand Rounds seminar, or conducting in-service training sessions for clinical staff. An exception to this is the educational method called “moral case deliberation” employed in some Dutch health care institutions (Weidema et al., 2012).

The policy development function of ethics services is also not usually discussed in the literature at length. More typically it is limited to stating that an institution’s ethicist or committee frequently provide input into policies and guidelines. The neglect of the policy function of CES support has recently been noted elsewhere (Frolic et al., 2012), although exceptions to this are the descriptions of policy work by Ells (2006) and McDonald, Simpson, and O’Brien (2008).

Further, there does not appear to have been any systematic evaluation of the process and impact of the educational and policy functions of CES services. Frolic et al. seek to redress the policy development knowledge gap, arguing that the policy review function is a distinctive practice requiring its own metrics, which the authors have developed (Frolic et al., 2012).

In contrast to the education and policy functions, case consultation has been the subject of considerable debate and also significant attempts at reaching consensus on what best practice might look like. In a case consultation, clinicians, patients or their carers who are uncertain or troubled by a particular issue or decision may consult with a CES service much as they might seek the opinion and advice of colleagues with expertise in other specialty areas. The CES service (individual or committee) assists by clarifying the values and conflicts involved, advising on the ethical implications of the available courses of action and facilitating an ethically justified consensus on what should be done (Tarzian and the ABSH Core Competencies Update Task Force, 2013). Case consultation appears to be a central function of many CES services in the US but is less so in the UK (Slowther, McClimans, and Price, 2012) and other European nations.
(Lebeer, 2005; Pfafflin, Kobert, and Reiter-Theil, 2009) where CES services are seen more as a “body for reflection” provided primarily to clinicians (Lebeer, 2005).

There are differing approaches to both the role and method of clinical ethics consultation (Dzur, 2002) but the most commonly accepted approach is ethics facilitation. CES services have previously tended to lean towards one of two approaches: authoritarian or pure consensus, both of which are argued to be inadequate (Aulisio, Arnold, and Youngner, 2000; American Society for Bioethics and Humanities, 2011, 6-7). In the authoritarian approach, the ethicist (or clinical ethics committee) becomes the central figure in the deliberation; the expert making decisions and issuing binding recommendations. The obvious concern here for critics of CES is that the ethicist assumes decision-making authority—usurping the authority of the patient and the clinical team.

In contrast, in the pure consensus approach the ethicist’s role is to broker consensus. While superficially this seems less problematic, even here the focus on consensus can compromise patient autonomy, for example where consensus between clinicians and the patient’s family overrides the wishes of the patient and thereby diminishes patient self-determination (Aulisio, Arnold, and Youngner, 2000; American Society for Bioethics and Humanities, 2011, 7).

A third and now most widely adopted approach to CES services is “ethics facilitation”—where consultation involves clarifying the value uncertainty or conflict involved and facilitating consensus—“agreement by all involved parties, whether that agreement concerns the substantively morally optimal solution or, more typically, who should be allowed to make the decision” (Aulisio, Arnold, and Youngner, 2000, 61). The ethics facilitation approach differs from the pure consensus approach in that it considers whether the consensus decision reached is ethically justified (Tarzian and the ABSH Core Competencies Task Force, 2013).

A fourth function of CES services is to provide assistance with ethics at the level of the organization as opposed to the level of patient care. This usually entails working through the ethical issues involved in areas such as health care management, resource allocation and quality improvement (Dorries et al., 2011; McClimans, Slowther and Parker, 2012). This development reflects the rise in a “systems” approach which seeks to integrate clinical ethics into the institution and wider health care system. But while some of the field’s most influential scholars and practitioners have advocated for this model (Singer, Pellegrino, and Siegler, 2001; MacRae et al., 2005; Fox, 2010) a systems approach to clinical ethics remains to be widely adopted (MacRae et al., 2005). There are, however, a number of well-developed frameworks for implementing systems thinking in ethics support (Fox, 2010; MacRae et al., 2005; Nelson et al., 2010a). All posit the mutual dependence of quality care and ethical principles. With reference to ethics, “quality” means that practices throughout an organization are consistent with the accepted ethical standards, norms, or expectations for the organization and its staff (Fox, 2010). Drawing on theoretical developments in disciplines such as organizational studies and social, cognitive, and cultural psychology, all share a commitment to ethics services having a more proactive role in the continuous quality improvement effort of the organization and system
within which it operates. In a systems approach, ethics support moves “upstream” to address systemic and structural elements that produce value conflict rather than remaining only at the level of the particulars of the issue or case at hand. This encourages a more proactive and preventative (the approach is some time labelled “preventive ethics”) form of ethics support (Fox, 2010; MacRae et al., 2005; Nelson et al., 2010a).

**Service Models**

“The ethics consultation team is ideally composed of individuals who bring a balance of the knowledge and skills requisite for effectively providing ethics consultation services. Although it is an open and empirical question whether such skills and knowledge are best delivered by teams or individual ethics consultants, it is certainly evident that both formats are thriving in a wide variety of health care settings” (Agich, 2009a, 14).

As Agich indicates, there is considerable uncertainty about how best to deliver CES services. Three models are currently prevalent: the “ethicist” model of an individual with specialist training in ethics; the “clinical ethics committee” model—a multi-disciplinary group convened on a regular basis; and a small team model, often convened as a sub-group of the larger ethics committee. The individual ethicist model is more prevalent in the United States and Canada, while the committee model appears to be favoured in the UK, Europe and elsewhere (Larcher, Slowther, and Watson, 2010).

Both models have strengths and weaknesses. The consultant model, for example, may be more flexible and responsive (Aulisio, Arnold, and Youngner, 2000; Slowther, Hope, and Ashcroft, 2001), but also relies on the perspective of a single individual. In contrast, the major strength of the committee model of ethics support, which appears to be the most widely adopted model internationally, is that it brings multiple disciplines, professions and perspectives to bear in consideration of the issues or problem under debate (American Society for Bioethics and Humanities, 2011, 20). But while a larger group may provide better procedural practice, with it comes more constraints, such as meeting times and responsiveness to requests for case consultation. The ethics team model, which has been widely adopted in the US and elsewhere, attempts to address philosophical issues raised by single ethicists operating as expert ethics consultants and practical issues associated with large ethics committees performing contemporaneous case consultation (Fox, Myers, and Pearlman, 2007). In this model, a small number of members of the larger committee undertake consultation work, thereby allowing for a more timely response to a request for advice than is possible for the full committee. While a quicker response comes at the cost of the greater range of views offered by a multi-disciplinary committee, the ethics team can also contact members of the larger committee for advice.

To date, few studies have systematically compared the different models of CES support. Increasingly, those engaged in ethics consultation advocate for a support service to combine all three models in order to maximize the strengths and minimize the weaknesses of each (American Society for Bioethics and Humanities, 2011, 19; Fox, 2010). Fox (2010) recommended that the consultation task itself should determine which model is utilized.
While there is no consensus, there are a number of well-developed approaches. In the following section we briefly describe two with a systems-oriented approach.

**Integrated Ethics**

The *IntegratedEthics* program was developed by the National Center for Ethics in Health Care of the United States Government’s Department of Veterans Affairs (VA) which operates the largest integrated health care system in the United States (Fox, 2010). The IntegratedEthics approach was developed to address some of the perceived shortcomings of traditional approaches to CES services such as the lack of integration of CES into its host organization, lack of defined purpose and lack of standards and accountability for quality. The IntegratedEthics program is a standardized approach designed to help individual health care facilities improve “ethics quality” at three levels: decisions and actions, systems and processes, and environment and culture. The need to recognise levels is illustrated using an iceberg analogy; at the tip of the iceberg are ethically problematic decisions and practices; below these are the organizational systems and process that inform decisions and practices; and below these are the organizations’ ethical environment and culture which through values and norms almost imperceptibly shape ethics practices.

The approach is structured around three core functions associated with each of the levels: *ethics consultation* targets ethics quality at the level of decisions and actions; *preventive ethics* targets the level of systems and processes; and *ethical leadership* targets the level of environment and culture. The IntegratedEthics approach to consultation, which is closely aligned with the ABSH Core Competencies approach, is captured in the acronym CASES: Clarify the consultation request, Assemble the relevant information, Synthesize the information, Explain the synthesis, Support the consultation process. The acronym ISSUES is used for preventive ethics at the systems level: Identify an issue, Study the issue, Select a strategy, Undertake a plan, Evaluate and adjust, Sustain and spread. At the environmental and cultural level, ethical leadership involves demonstrating that ethics is a priority, communicating clear expectations for ethical practice, practicing ethical decision-making and supporting institutional ethics programs.

**The Hub and Spokes Model**

A more recent innovation for providing ethics support is the “hub and spokes” strategy developed by the Joint Centre for Bioethics (JCB) at the University of Toronto, Canada in conjunction with ten affiliated hospitals (MacRae et al., 2005). The core approach of the strategy is to provide decentralized resources, with the “spokes,” coordinated by the centralized “hub.” The hub provides the bioethics expertise and leadership to the spokes. Clinicians and others organized along professional or departmental lines throughout the organization then act as a local ethics resource.

The Hub and Spokes model tries to create an “ethics infrastructure” within health care organizations. The goal is for ethics support services to become fully integrated into the life of the organization it serves over time (MacRae et al., 2005). The model aims to foster an ethical
climate where the responsibility to be ethically engaged and aware is recognized from “those in the boardroom to those at the bedside” (MacRae et al., 2005, 257). The core innovation of the strategy is that builds capacity through ethical expertise “radiating” from the Hub, through the Spokes and to the clinical and general staff (MacRae et al., 2005).

This diffusion of knowledge and skills is intended to overcome some of the limitations of the typical static model of ethics support where expertise remains concentrated in the individual consultant or committee. The Spokes reach out to all parts of the organization generating ethics awareness and competence and thereby minimising the perennial challenges of workload, peer support and isolation facing the lone ethicist (or committee). The strategy establishes an infrastructure of relationships within an organization which serves to both formalize previously implicit responsibilities and generate a commitment (or “buy-in”) to ethics at all levels; this helps address the problem of poor sustainability and limited accountability of traditional models of support.

Evaluation of CES Services

The proliferation of clinical ethics support has seen a rapidly growing literature, but there has been less by way of empirical research and evaluation of the CES process and outcomes. Empirical studies of clinical ethics support services are overwhelmingly descriptive in nature, with only a few attempting systematic evaluation. There is also no consensus in the literature as to how CES services should be evaluated (Schildmann et al., 2013).

Most studies of ethics support services have sought to establish aspects such as: the prevalence of support services, their type, structure, composition, main functions, activities and processes (see for example McGee et al., 2001; Slowther et al., 2001, 2004; Slowther, McClimans, and Price, 2012; Godkin et al., 2005; Milmore, 2006; Fox, Myers, and Pearlman, 2007; Frewer and Fahr, 2007; Swetz et al., 2007; Pedersen, Akre, and Ørde, 2009; Romano et al., 2009; Whitehead et al., 2009; Kesselheim, Johnson, and Joffe, 2010; Gaudine et al., 2010; Nelson et al., 2010b; Tapper et al., 2010; Moeller et al., 2012). What these studies mostly show is the diversity of CES services. Many CES services provide all three of the core functions of education, policy review and development and consultation; but usually focus on one function. Some services are provided by a single ethicist; some by committees; others use both. Regarding consultations, many issue non-binding recommendations, a small number issue binding recommendations and some do not make any recommendations at all. Most ethics committees are multidisciplinary but vary in their membership mix and their mode of recruitment. Some committees have members with formal ethics training, many do not; legal expertise is represented on some committee but not on others. Some committees actively educate their members, while others do not or are unable to. Some services involve patients and families directly in their deliberative process and allow them to refer to the service, in many others support is primarily if not exclusively for clinicians (Fournier et al., 2009). Some committees have adopted systematic means of documenting their activities, others do not. Some services undertake to evaluate their activities, many do not.
A small number of studies have focussed on the interaction between a service and clinicians. Studies have looked at the types of ethical issues (variously referred to as *inter alia*—problems, dilemmas, difficulties) that clinicians face; what issues prompt clinicians to seek ethical support; what enables or impedes access to support; clinician’s perceptions of the adequacy of ethics support available to them and their preferences for types of ethics support. Studies such as that by Du Val et al. (2001, 2004) and the Royal College of Physicians (2005) show ethics consultations are mostly requested for end-of-life issues, decisions about withdrawing “futile” treatments, and late-term abortions. Other frequently occurring issues include disagreement among clinicians, professional misconduct, and concerns related to truth-telling and confidentiality. Dilemmas about justice, such as lack of insurance or limited resources, were rarely referred (Du Val, 2004).

Many of these studies have investigated why clinicians do or do not seek ethics support. Findings suggest that clinicians tend to seek support for conflict resolution, reassurance about a decision, clarification of issues, new insights on a case and emotional support (Du Val et al., 2001). Clinicians with ethics training appear to be more likely to request ethics support, although it is unclear whether this represents greater awareness of CES services, greater support for CES services or greater willingness to seek external review of clinical decisions or difficulties (Du Val et al., 2004; Hurst et al., 2007b). Clinicians often do not seek support because consultations are difficult to access, the process is time consuming or intimidating, the outcomes may be unhelpful, they may fear being scrutinized, fear loss of autonomy, or they may fear retaliation (Du Val et al., 2004; Førde, Pedersen, and Akre, 2008; Gaudine et al., 2011). Other possible reasons for underutilization include clinicians not being aware that a clinical support service exists, fear that a committee will worsen the situation (Gaudine et al., 2011) and placing a low value on shared decision making (Orlowski, et al., 2006).

Two prospective studies by La Puma et al. (1988, 1992) collected descriptive information on consultations including the reason(s) for consultation, the characteristics of the patients involved, the clinicians’ satisfaction with the service and whether they would use it again. In both studies large majorities of clinicians found consultation helpful and nearly all indicated they would use the service in the future. Similar findings on the perceived helpfulness of consultations have been found in other studies of clinicians (Orr and Moon, 1993; McClung et al., 1996; Yen and Schneiderman, 1999). Interestingly, in those studies that have compared clinician with patient satisfaction, patients have been found to be less satisfied with ethics consultation (McClung et al., 1996; Yen and Schneiderman, 1999).

A few studies have assessed clinical ethics support service using an experimental design. The best-known are a series of studies by Schneiderman and colleagues looking at the impact of ethics consultation in intensive care settings (Schneiderman, Gilmer, and Teetze, 2000; Schneiderman et al., 2003). These trials examined consultations involving parents who had “value laden” treatment conflicts as identified by clinicians. A single-centre trial and a multi-centre trial were conducted, with patients randomized to the intervention (offer of ethics consultation) or control (not offered). Both trials found that ethics consultation was associated
with shorter hospital ICU stays, reduced use of services and less cost among those who did not survive to discharge. There were, however, no statistically significant differences between the intervention and control arms for those who survived to discharge. The results of these studies suggest that the intervention of ethics consultation was beneficial to patients who did not survive to hospital discharge and was not harmful to patients who did survive. The authors’ conclusion was that consultations “seem to be useful in resolving conflicts that may be inappropriately prolonging nonbeneficial or unwanted treatments at the end of life” (Schneiderman et al., 2003, 1172). A later cost analysis of data from the multi-centre trial confirmed the finding that ethics consultation was associated with a reduction hospital days and treatment costs (Gilmer et al., 2005).

To summarise, there has been extensive uptake of CES services, most widely in the US but with increasing numbers in many other nations. Empirical studies (as well as more general reports) indicate that CES services vary considerably in form, function and activity. The limited and contested nature of evaluation of performance means the overall value of CES, its effectiveness, costs and benefits, cannot be precisely determined. And as we discuss below, the heterogeneity of CES and the paucity of evaluation have raised considerable concern about the quality and impact of CES services.

Two particular concerns regarding case consultations arise from studies of CES services—the often low utilization by clinicians and lack of patient involvement in consultations. Empirical evidence suggests that many CES services have low rates of referral. According to the most recent data for the US (Fox, Myers, and Pearlman 2007) the median number of consultations for the year prior to the survey was 3. In the UK, Slowther, Mcclimans, and Price (2012) found half of the committees they survey had between 1–5 consultations in the previous year. Another relatively recent study of clinical ethics services in the United Kingdom led the researchers to conclude “At the moment, the stark reality about CECs in the UK is that clinicians are not using them” (Whitehead et al., 2009, 454). While this is an important observation, these data are limited in that they are not recent and where CES services are flourishing, rates of consultation are likely to be higher.

It is widely acknowledged that there has been mixed success with establishing and maintaining CES support services. Some flourish, others fail to thrive (Conrad, 2006). Failure to thrive can arise from: a lack of clear purpose or lack of institutional support (Mills, Rorty, and Spencer, 2006); clinician reluctance to seek support because of factors such as fear of scrutiny or loss of authority; because they are not found to be helpful; because they are not trusted or simply because clinicians are not aware of them (DeRenzo Mokwunye and Lynch, 2006; UNESCO, 2005; Slowther, Mcclimans, and Price, 2012). No particular model appears to be any more likely to flourish or fail to thrive than any other.

The low rates of consultation experienced by many services might indicate that what is being offered is seen by many clinicians as neither desirable nor warranted. A low rate of referral could mean that clinicians do not perceive a need for ethics support. Neither the “bottom-up” development nor increased prevalence of support services show how widely the
need for ethics support is shared among clinicians. With only a small number of studies attempting to empirically establish need among clinicians (Larcher, Lask and Mcarthy, 1997; Slowther, 1998; Racine and Hayes, 2006), need for formal clinical ethics support appears more assumed than systematically, empirically established (Williamson, 2007; Dauwerse et al., 2011).

Many CES services do not appear to facilitate the direct participation of patients and their families in the consultation process (e.g., Newson, Neitzke, and Reiter-Theil, 2009). There has also been contention in the literature as to whether patients should be involved in ethics case consultations and if so, to what degree. Some have claimed that where consultations have a direct bearing on care, the lodestars of clinical ethics support are potentially undermined, namely, patient autonomy and self-determination (Wolf, 1992), raising important questions about due process (McLean, 2007, 2009). This concern has been expressed most forcefully in the US, with critics of CES fearing that a creeping quasi-legal status may become attached to the deliberations of committees and consultants (Pope, 2009), reflecting the possibility that, as McLean (2008) has observed, it is “all-too-easy move from advice to authority and from commentary to decision-making” (2008, 101). Even if the consultant (or committee) issues non-binding advice, this may still impact on subsequent actions (McLean, 2007). In cases where a consultation involves a dispute between the patient (and family) and the clinical team, there is a need to ensure some degree of procedural fairness; all parties in a dispute have the right to a fair hearing. Attention to formal justice and due process is considered particularly important (McLean, 2007).

Optimizing the Quality of CES Services

The heterogeneity of CES and the paucity of evaluation have given rise to concerns about the quality of CES services. Tulsky and Fox have claimed, for example, that: “Despite all that has been written about this field, two fundamental questions remain unanswered. First, does ethics consultation offer measurable benefits worthy of the current investment of time and money? Second, if it is effective, which models are the most effective and under what conditions are different models more or less effective?” (1996, 111).

According to Magill (2013), quality has become the preeminent discourse on CES services in the US (and elsewhere). The heterogeneity of CES services, given a lack of standards of practice, oversight and accountability, is likely to be matched by variation in service quality (Aulisio, Arnold, and Youngner, 2000; Slowther, 2008; Frolic and PHEEP Steering Committee, 2012; Schiedermayer and La Puma, 2012). Quality, particularly in regards to case consultation, is predominantly concerned with the competence of CES services—that is, whether they command the necessary knowledge and skills in ethics and health law. Given that the evidence indicates many people involved in CES have only rudimentary training in philosophical ethics (e.g., Fox, Myers, and Pearlman, 2007; Slowther, Mcclimans, and Price, 2012), claims to ethics expertise are often questionable. Claims to moral expertise are also subject to critique on more theoretical grounds, such as debate over what moral expertise is. We discuss this further below.

For some, this worryingly indicates that well-meaning but inexpert consultants or committees are having a potentially decisive influence on decisions about patient care (Fletcher
and Hoffmann, 1994; Dubler and Blustein, 2007; Courtwright, et al., 2014). Clinical ethicists have responded by devoting significant intellectual and material effort to develop standards of practice for CES and develop appropriate and rigorous methods to evaluate quality (e.g., Tarzian and ABSH Core Competencies Update Taskforce, 2013; Larcher, Slowther, and Watson, 2010).

The most significant development in practice standards has been the Core Competencies developed by the American Society of Bioethics and Humanities, first issued in 1998 (Society for Health and Human Values–Society for Bioethics Consultation, 1998) and more recently updated (American Society for Bioethics and Humanities, 2011; Tarzian and ASBH Core Competencies Update Taskforce, 2013). The foundational assertion of the Core Competencies is “that HCEC done well by competent HCE consultants benefits stakeholders, and HCEC done poorly by unqualified HCE consultants either fails to benefit or harms stakeholders” (Tarzian and ASBH Core Competencies Update Task Force, 2013, 3). The Core Competencies focus on the knowledge, skills and character traits that any service (consultant or committee) must have to adequately perform as an ethical consultation service. The knowledge required is wide-ranging and calls for targeted recruitment of suitable members or co-opting relevant expertise as it is needed. The values required of a committee are described as “aspirations” to be acquired over time similar to professional development. While there is limited evidence on the extent to which the Core Competencies are applied by individual services, and whilst there is some concern that emphasis on competencies reflects the malign influence of managerialism and may divert CES from the primary goal of moral inquiry towards more institutional or bureaucratic goals (King, 1999; Bishop, Fanning, and Bliton, 2009), there is little doubt that debate about the competencies of CES has had a significant impact on the establishment of standards for CES services (Adams, 2009; Bishop, Fanning, and Bliton, 2009).

A parallel development to developing practice standards to enhance quality has been the push to professionalise clinical ethics expertise (Tarzian, 2009; Childs, 2009; Frolic and PHEEP Steering Committee, 2012; Acres et al., 2012; Reel, 2012). For some, professionalization is not only necessary and desirable but also inevitable given the increasing emphasis on standards, quality and accountability, concerns about medical liability and the emergence of the patient safety movement (Acres et al., 2012). More generally, both advocates and critics of CES agree that in order to fulfil their function and meet the expectations and needs of relevant stakeholders the people doing the work of clinical ethics consultation (CEC) should be able to demonstrate at least minimal levels of competence (Tarzian, 2009).

On our reading, the predominant theme in the literature addressing quality is that CES services are too often underpowered; they lack ethics expertise, standards and evaluable outcomes; they engage consultants who lack professional standing; they are poorly integrated into their organization and consequently are under-used; they are frequently under-resourced, and they have unproven benefits. The main solution offered is further institutionalization, through the standardization of consultation, the professionalization of consultants, a thorough integration into its host organization and having CES more generally incorporated into a particular health care system. The influence of the Core Competencies, the accelerating push to
professionalise consultants (at least in the US) and the prominence of integrated approaches such as the VA’s IntegratedEthics model suggest that institutionalization is well under way.

Institutionalization, however, has its critics. The concern is that standardization and professionalization risks overpowering the very clinicians and patients it is meant to serve. Institutionalization can inflate the authority of CES at the expense of patients, may homogenise practice, diminish moral inquiry and result in CES being co-opted as a tool for risk-management and saving money. Others are concerned that standardization forces ethics consultation towards procedural efficiency and metrics and away from the substantive goods of the case at hand. A focus on standardized, measurable process can limit the capacity of a CES service to reveal, clarify and perhaps challenge the various understandings, of all parties, of what is a medical good, an institutional good and what a patient holds as good (Bishop, Fanning, and Bliton, 2009).

There has also been resistance to the notion of an ethics “expert” from the inception of CES services (Bishop, Fanning, and Bliton, 2009) and this has been a significant obstacle for establishing CES and gaining patronage (Rasmussen, 2011a). The notion of expertise in ethics is a complicated matter that involves both metaphysical and epistemological questions of whether expertise in ethics is actually possible and moral and normative questions of whether such expertise and the authority it brings is desirable (Noble, 1982; Yoder, 1998; Rasmussen, 2011a). Critics of ethics expertise such as Scofield (2008) and Smith (2001) argue that expertise presumes access to facts or consensus among practitioners. In the absence of any moral consensus among ethicists, holding actual “expertise” on moral issues simply isn’t possible (Engelhardt, 2009; Scofield, 2008). As Shalit argues, “[t]he philosopher’s recommendation depends on a set of criteria that is not agreed upon, but varies from culture to culture and, more and more, from individual to individual” (1997, 24). For some critics (e.g., Noble, 1982), even if ethics expertise is possible, it may not be desirable because it shifts moral authority from the patient, and their carer, to the ethics expert, thereby undermining the agency and autonomy of both and challenging the very principles of democracy upon which the idea of CES is based (Scofield, 2008).

Advocates of CES argue that ethics expertise need not involve any metaphysical claim regarding moral truths or the claim that clinical ethicists have epistemic access to such truths (Yoder, 1998; Steinkamp, Gordijn, and ten Have, 2008; Rasmussen, 2011a, 2011b). According to Rasmussen (2011a), metaphysical objections largely stem from the ambiguity of the term “moral expertise”. She claims that expertise here should be conceived as a “facility with moral arguments” (2011a, 649) rather than “possession of moral truth” (2011a, 649). Ethics expertise involves a “superior familiarity with context” (2011a, 651) where the consultant uses her training and knowledge to guide the parties involved through the relevant “facts” (laws, policies, norms, cultural values) to a more informed understanding of the situation (Rasmussen, 2011a). Ethics expertise, as opposed to moral expertise, involves making “non-normatively binding recommendations grounded in a pervasive ethos or practice within a particular context” (Rasmussen, 2011a, 650). Steinkamp, Gordijn, and ten Have (2008) use a similar definition of ethics expertise, that is, the capacity to provide “strong justifications” to argue that the dialogue
between the expert ethicist and clinicians is a cogently democratic means of reaching consensus on the moral norms at hand (Steinkamp, Gordijn, and ten Have, 2008). In this dialogue, the expertise of the ethicist complements and enhances the moral competence of the non-ethicists, clinicians (and patients) by clarifying what is ethically at stake (Steinkamp, Gordijn, and ten Have, 2008). Conceived as such, ethics expertise does not make a metaphysical claim that there are moral truths and that clinical ethicists have epistemic access to such truths, does not usurp the autonomy and agency of the non-expert and offers expertise but does not assume authority (Rasmussen, 2011a).

Evaluating the quality of a clinical ethics services is therefore an area of considerable uncertainty and debate. Major criticism has been voiced at evaluating clinical ethics services using outcome measurements more suitable for standard clinical interventions. It is not clear to some observers that quantitative measures, such as tallying the tasks performed by a service, measuring user satisfaction or calculating cost savings are appropriate for assessing the quality of a clinical ethics service (Mills, Tereskerz, and Davis, 2005; Gordon, 2007; Williamson, 2007; Pfafflin, Kobert, and Reiter-Theil, 2009). The number of consultations a service provides is clearly not a proxy for quality. One ethics committee may conduct a large number of consultations but be a little more than a rubber stamp; another committee may conduct fewer consultations but provide rigorous ethical analysis (Williamson, 2007). While user satisfaction with an ethics service may be helpful in assessing service quality, there are some difficulties with it. Williamson (2007) advises caution in using satisfaction, firstly because its validity as a measure of quality is suspect given its inherent subjectivity, and secondly because often only clinicians and not patients are asked to participate.

A number of authors have voiced concern at the use of cost-savings to evaluate the effectiveness of CES (e.g., Mills, Tereskerz, and Davis, 2005; Rasmussen, 2006, 2011b). Rasmussen (2006) argues that if cost saving is the measure by which an ethics service is evaluated, there could be significant pressure on CES services to achieve savings, such as providing advice that encourages less costly decisions. Mills, Tereskerz, and Davis (2005) similarly argue that savings may come to rival if not dominate the integral goals of consultation resulting not only in consultation emphasising the least costly options but in making consultation mandatory for cases where costs may be saved, for example end of life care decisions. The potential for co-optation of CES services as a cost-saving measure (which Rasmussen (2006) labels as a “sinister innovation”) could result in a profound loss of trust among clinicians (and patients) if they come to perceive this as the primary objective of consultation “If the ‘quality’ or effectiveness of an outcome has any relationship to trust, as it should in healthcare-related activities, then quality will be eroded, as stakeholders understand that cost savings may be one of the reasons for initiating a consultation” (Mills, Tereskerz, and Davis, 2005, 60).

Conclusion

The story of CES services is one of increasing expansion and advocacy for its potential benefits. It is also a cautionary tale about the challenges involved in ensuring competency and viability. A
review of the literature and the international experience with CES services suggests that they have considerable potential to prevent and resolve moral conflicts, minimise moral distress, support patient autonomy and enhance institutional efficiency and cost-effectiveness. But while these benefits are highly plausible, the ad hoc development and heterogeneity of CES services and the lack of consensus over the evaluation of their performance raises some doubts about how often they are achieved. Many questions remain to be answered regarding the structure, function and organizational model for CES support. Where should CES services be located within hospital structures? How independent should they be? Should CES provide contemporaneous case consultation or retrospective case review? Should case consultation be provided by “experts”? Should the deliberations of CES services be advisory or binding (or neither)? Who should be the primary beneficiary of CES support? How should potential conflicts of interest be managed? While it is crucial that institutions seeking to establish CES services and those working in clinical ethics confront these issues, questions about CES should not obscure the fact that CES services have primarily spread because those involved in patient care have recognized the need for support. These questions should also not diminish the significant intellectual effort devoted to thinking through the appropriate purposes and best practices of CES services. There are now decades of collective experience and scholarship, well-established approaches and detailed models and guidelines from which those seeking to establish a CES service can draw.

Experience suggests that to be active and sustainable, a CES service must be visible, accessible, understood and trusted. These in turn require the service to be clear in purpose; fully integrated into the life of the organization; adequately resourced; appropriately constituted and competent; accountable (transparent and assessable), and independent. Ongoing evaluative research should be a core component of the development of CES services. This will have three distinct benefits—it will enable evaluation of clinical ethics services; it will strengthen the culture of ethical inquiry and ethical practice within the health service; and it will provide opportunities to increase understanding of issues of ethical and legal importance in the design and delivery of health care. It is crucial that ongoing research into clinical ethics is conducted in order to establish what is necessary for clinical ethics services to work.

References


