Special Section: Coming of Age in Clinical Ethics Consultation: Time for Assessment and Evaluation

Ethics Case Consultation in Primary Care: Contextual Challenges for Clinical Ethicists

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Introduction

The development of ethics case consultation over the past 30 years, initially in North America and recently in Western Europe, has primarily taken place in the secondary or tertiary healthcare settings. The predominant model for ethics consultation, in some countries overwhelmingly so, is a hospital-based clinical ethics committee.[1] In the United States, accreditation boards suggest the ethics committee model as a way of meeting the ethics component of the accreditation requirement for payment by Health Maintenance Organizations (HMOs),[2] and in some European countries, there are legislatory requirements or government recommendations for hospitals to have clinical ethics committees.[3] There is no corresponding pressure for primary care services to have ethics committees or ethics consultants to advise clinicians, patients, and families on the difficult ethical decisions that arise in clinical practice. I am not aware of any published accounts of ethics support in the primary care setting. In a recent survey of primary care physicians in four European countries, only 17.6% reported that they had access to ethics support in individual cases.[4] As this survey included physicians who had admitting rights to a hospital or whose work included inpatient care, access to support in a primary care outpatient or clinic setting is likely to be much lower.

There are several reasons for this discrepancy in the availability of ethics case consultation in primary and secondary care. Historically, ethics support has developed because of concerns about cases, or types of cases, that occur in an inpatient setting, often in an intensive care setting. In the United States, an important initial impetus came from legal cases and government recommendations.[5] In the United Kingdom, the development of ethics support has been driven by clinicians rather than by the courts or government regulation, but it is clinicians working in secondary and tertiary care who have identified a need for help in resolving difficult ethical issues, again often relating to end-of-life decisions.[6] From a practical perspective, it is easier to provide an ethics consultation service in a hospital setting than in the much more geographically dispersed setting of primary care. There may also be the issue of who pays for the service if it is not located in a specific institution.

A further reason for the discrepancy in ethics support between primary and secondary care is the perceived nature of ethical difficulties that arise in these different contexts. Much of the literature on clinical ethics and case consultation focuses on cases at the extremes of life and/or involve high technology interventions,

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where decisions are often literally a matter of life and death.[7] As already noted, these are the types of cases that have precipitated the development of clinical ethics committees. In contrast, much of primary care involves low-technology interventions with relatively few decisions that could be seen as related to life and death. They do not catch the public or media imagination in the same way, nor do they attract the attention of the courts so readily. They may, therefore, not be seen as problems that require the advice of an ethics committee or ethicist.

There is, however, emerging evidence that primary care clinicians do experience ethical difficulties in their work.[8] In the United Kingdom, some primary care organizations have established clinical ethics committees, and hospital-based committees are approached for advice by local general practitioners.[9] If ethics case consultation is to develop in primary care, then ethics consultants and ethics committees will be working in a very different context from the hospital environment that they are used to. This context will have implications for the kinds of cases they will be asked to advise on and may also provide new challenges for both the process of case consultation and the wider role of the clinical ethicist in facilitating ethical decisionmaking in clinical care. In this paper, using the U.K. primary care model as an example and drawing on the limited literature on ethical decisionmaking in primary care, I explore some of the opportunities and challenges for ethics case consultation in primary care.

What Is Primary Care? The U.K. Model

The structure of primary healthcare is not uniform across all healthcare systems, but there are key similarities that permit some generalization of a discussion of the moral framework of primary care. In the United Kingdom, primary care has the following features:

1) It is the first point of contact with the healthcare system for almost all people, with the exception being those who attend a hospital Accident and Emergency Department.
2) It has a gatekeeping role to secondary care. To see a specialist physician, a person needs to be referred by his or her general practitioner (primary care physician) in most circumstances. This includes access to specialists within the private healthcare sector.
3) Primary care physicians are generalists. A general practitioner may treat a young girl's asthma, provide antenatal care for her during her pregnancies, manage her depression following the break up of her marriage, and treat her hypertension in middle age.
4) The primary care clinician will have a concurrent role in many different multidisciplinary healthcare teams, for example, community paediatrics, mental health, palliative care, diabetes care, and addiction services.
5) It offers continuity of care, both within the narrative of a single illness and across different illnesses over time.
6) It is community based, with patients being seen in the clinic (General Practice surgery) or in their own homes rather than in a hospital setting.
7) It is family sensitive in two important ways. General practitioners are family doctors, often looking after several members of the same family throughout their lives. Also, family members often are the main carers of

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patients with chronic disabling conditions or terminal illness; thus their well-being is a significant concern of the primary care clinician in providing medical care for the patient.

These key features, which will be recognized by many primary care clinicians in countries other than the United Kingdom, illustrate the strong social context that is characteristic of primary care and which is less evident in secondary and tertiary care. The main focus of primary care clinicians remains their relationship with an individual patient. But decisions about management of specific illness episodes or problems are set in the context of an ongoing relationship that extends beyond the current problem and of a complex web of other relationships that include members of the patient's family and other healthcare professionals. This social context of primary care will give rise to ethical difficulties that are less acute than the question of a patient refusing life-saving treatment or withdrawing artificial feeding from a patient in a persistent vegetative state. The ethical difficulties in primary care are likely to be of a more subtle and chronic nature. Nevertheless, they give rise to conflict and concern for health professionals and patients and their families. The brief case examples described serve to illustrate the kind of ethical difficulty that may face a primary care clinician, and on which a clinical ethicist could be asked to advise.

Case 1

Dr. Davis is the family doctor for a retired couple, Mr. and Mrs. Jones, and their adult son Michael, who lives with them. Michael has schizophrenia and is currently refusing to take his regular medication. He has been steadily deteriorating for some time and he is now extremely agitated. The mental health team does not think that he needs admission to the hospital, especially as an admission is likely to be involuntary in view of his resistance to taking medication. They consider that his autonomy and best interests require that he be encouraged to participate in a therapeutic program while living at home with his family's support. Mr. Jones has angina and has had two myocardial infarctions in the past 5 years. His cardiologist has strongly advised him that he should not get unduly stressed and expresses concern in his letter to Dr. Davis that Mr. Jones' angina has increased in the last few months. A daughter, who is married and has two small children, contacts Dr. Davis, asking her to put pressure on the mental health team to admit her brother and thus relieve the pressure on her parents. She is terrified that her father will have another MI and that this time it will be fatal. Mrs. Jones is torn between worry for her husband and her son and feels guilty that she is letting them both down.

Case 2

Alicia is a 15-year-old girl who attends her General Practitioner's (GP) surgery and is worried that she might be pregnant. A pregnancy test is positive and examination confirms a pregnancy of about 10 weeks. Alicia tells her GP (Dr. Lacey) that she cannot continue with the pregnancy and wishes to be referred for a termination of pregnancy. She is also clear that she does not want her parents to know. (In English law a child under 16 years can consent to medical treatment if the clinician assesses that she is competent to make the specific decision.) After a long discussion in

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which Dr. Lacey is unable to persuade Alicia that it may be helpful for her to have her mother's support, she refers her to the local clinic for further counseling and possible termination of pregnancy. This is an urgent appointment, as the termination should ideally take place before 12 weeks. Dr. Lacey considers that Alicia is competent to make such a decision, but also thinks that Alicia is ambivalent about her feelings. She knows that Alicia is unreliable at keeping medical appointments and worries that she may not turn up at the clinic. Alicia's mother is a regular attender at the surgery with her diabetes and has shared her worries over Alicia's behavior with Dr. Lacey in the past. She seems to Dr. Lacey a caring and understanding mother.

Problems such as these are part of the everyday experience of primary care health professionals, but may not be acknowledged specifically as ''ethical dilemmas'' by those struggling to do what is best for all concerned, often in the space of a brief consultation in a busy surgery or clinic. Clearly the opportunity to seek advice and support in resolving these difficult situations would be of benefit to worried clinicians and families, and (we would hope) lead to improved care of the patient (or patients, as in Case 1). The question, then, must be whether a model of clinical ethics consultation developed in secondary and tertiary care can provide support that is relevant to the experience of patients, families, and health professionals in the primary care setting.

An Ethical Framework for Primary Care?

Most conceptual models of primary care describe two specific features that distinguish it from secondary care. It is both first contact care and continuing care. Pellegrino has identified the moral focus of primary care as the fulfillment of a universal human need for first contact and accessible care, as perceived by the patient rather than as defined by the health professional.[10] It is this need for care, reassurance, or treatment in response to the existential distress of illness that generates a right to primary healthcare. Pellegrino sees this as a more fundamental right than the right to other forms of healthcare, such as preventive medicine or radical cure.

The ethical implications of the second key feature of primary care, that of continuing care, have also been explored, highlighting the importance of relationships and narrative in moral decisionmaking in the primary care setting. Doyal uses the example of informed consent to suggest that the long-term nature of relationships in primary care gives a different perspective on the interpretation of ethical principles, such as respect for autonomy, and one that is not captured by the standard model of informed consent that appears in ethical guidelines.[11] He argues that the traditional view of medical ethics is closely linked to the practice of acute medicine in the hospital setting and does not capture the experience of primary care practitioners. Brody makes a similar point, going so far as to suggest a different standard of informed consent in primary care, which takes account of the deeper relationship between physician and patient that takes place in this setting.[12] Others have focused on the importance of social justice in forming an ethical framework of primary care, linking it to other features of primary care such as a focus on prevention of disease and public health interventions.[13]

Drawing on the above, we can describe two contrasting models of medical care emerging in the contexts of primary and secondary care. A primary care model is one of accessible first contact and continuing care, with an emphasis on long-term

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relationships, community, and preventive healthcare. In this model, the health professional is an advocate of the patient in the wider healthcare system. The secondary (or tertiary) care model is one of technology-based individualistic, short-term care, with an emphasis on management of identifiable pathology where the health professional is specialist in a specific disease or system. Of course, in reality there is considerable overlap; many secondary care specialists will have long-term clinical relationships with their patients, and some conditions in primary care are acute and respond to technological intervention. However, there is a core distinction based on the predominant contextual features described above, which holds for a large part of the work carried out in the two healthcare arenas. It would thus seem plausible that the different conceptual frameworks may give rise to different ethical perspectives in at least some aspects of the provision of care. Empirical evidence on ethical decisionmaking in primary care would support this premise. Rogers has shown that contextual factors in primary care, including the clinician–patient relationship and the long-term nature of many conditions, shape the interpretation and implementation of key ethical principles such as respect for autonomy and beneficence.[14] Other studies suggest that relationships, including family relationships, play an important role in decisionmaking for primary care clinicians[15] and that in some situations this role is less significant for secondary care clinicians.[16]

Identification of Ethical Issues in Primary Care

The structure and setting of primary care may also mean that the range of ethical issues or the frequency with which specific issues are encountered are different from that found in secondary and tertiary care. Working with families at the health/social care interface, dealing with diagnostic uncertainty, maintaining interdisciplinary professional relationships, and addressing issues of justice are areas that are more likely to be the source of ethical problems than, say, discontinuing life-prolonging treatment or balancing the risk of harm and benefit in novel treatments. Empirical ethics studies in primary care support this view, identifying issues such as relationships with colleagues,[17] confidentiality,[18] refusal of and compliance with treatment,[19] resource allocation,[20] and access to healthcare.[21]

Studies focusing on single issues suggest that they are interpreted differently in different contexts. For example, patients' views on confidentiality regarding medical records differ depending on whether the context is primary or secondary care.[22] Being at the first point of contact for medical care, primary care clinicians will often be in the position of deciding who and when to refer for further investigation or specialist treatment. These decisions will be influenced by clinical judgment, but will also be influenced by available resources. There is some evidence that primary care physicians in Europe experience ethical difficulties arising from bedside rationing.[23] In the United Kingdom, some primary care clinicians are also involved in commissioning services for their local population and in hearing appeals in individual cases for exceptional access to treatment not normally funded by the primary care organization.

Implications for Ethics Consultation in Primary Care

It seems that the context of primary care, which includes first contact and continuing care set in a wider social context, can shape the nature and frequency

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of ethical dilemmas faced by health professionals and may also shape the interpretation and implementation of ethical concepts in approaching these dilemmas. Is this necessarily problematic for ethics consultants or ethics committees who venture out of the hospital environment and seek to offer their services in the more dispersed and complex arena of primary care? At one level the answer would quite clearly be no. Context is important in ethics case consultation, whatever the setting, in terms of both the facts of the case and the perspectives of those affected[24] as well as the wider institutional context.[25] The *Core Competencies* document[26] issued by the American Society for Bioethics and Humanities (ASBH) lists areas of knowledge required for ethics consultation that include knowledge of clinical context, the healthcare institution in which the consultant works, and the beliefs and perspectives of patient and staff population where the consultation takes place. An ethics consultant working in primary care would thus need to have a working knowledge of the clinical context of primary care and of the organizational rules and codes of practice. Developing this knowledge would be a relatively straightforward but important task. Knowledge of the beliefs and perspectives of the patient and staff population who are involved in the context of consultation is perhaps a more important requirement, or at least one that poses more of a challenge. The ASBH document emphasizes the different perspectives of racial, ethnic, cultural, and religious groups,[27] which are, of course, as important in primary care as they are in secondary care. However, the theoretical models and empirical data discussed in the first part of this paper point to a perspective that arises from the concept and practice of primary care as a social enterprise that is different from the perspective of healthcare that predominates in a hospital setting. This perspective may include a different emphasis on specific values, for example, justice; a different interpretation of some ethical principles, for example, autonomy; and a different approach to ethical decisionmaking that relies on ethical models other than the principle-based approach that forms the basis of much clinical practice in secondary care.

The importance of consensus building as an integral part of ethics consultation is a recurring theme in the literature in this area.[28] Facilitation and communication skills, as well as the ability to build moral consensus, are listed as core skills in the ASBH document.[29] In this respect, ethics consultants may find working in primary care easier than in secondary care. Health professionals in primary care are used to working in multidisciplinary and multispecialist teams, as well as with families. In a recent study of ethical decisionmaking in primary care in the United Kingdom, when clinicians and nonclinicians working in primary care were given a clinical scenario that presented a conflict of values, the responses focused on negotiation, compromise, and exploring alternative courses of action, rather than specific moral rules.[30] Thus, consensus building as a model for achieving resolution of ethical difficulties may be less alien in the primary care context than in some acute hospital settings, such as intensive care. This is not to say that primary care clinicians do not need the support of a clinical ethicist or ethics committee. Achieving consensus is not enough in itself; what is required is a *moral* consensus, an agreement that the planned course of action is morally acceptable. In the relatively isolated setting of a general practitioner's surgery (office) or in a patient's home, an apparent consensus decision may hide what is in fact an endorsement of a clinician's decision by a patient or family who feels pressured to agree and who does not have access to an advocacy service that may

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be available in a hospital. Alternatively, apparent consensus may be achieved when a clinician accedes to a family's demands for a particular treatment because of a fear of legal action or complaint. It is the ability to identify the moral difficulties, elicit the values of all concerned, empower individuals to articulate their views, and generate a consensus that is morally acceptable that the ethics consultant brings to clinical cases and that will be of benefit in primary care.

There are practical and organizational problems in developing clinical ethics support in primary care. The diverse geographical spread of patients and health professionals, the varied employment and professional structures that govern the different groups of health professionals that come together to provide care in the community setting, and the absence of a clear institutional and academic support system for the ethics consultant or committee all create barriers to the provision of ethics support. Problems associated with expanding ethics consultation into areas away from University hospitals or large service provider units have been identified in other settings such as rural hospitals[31] or community mental health services.[32] Solutions include developing stronger links between primary care and academic ethics departments and developing partnerships with existing ethics consultation services in local secondary care institutions. The ''hub and spoke'' model described by MacRae may be particularly appropriate for a primary care setting.[33] The logistical problem of providing rapid access to an ethics consultant in a dispersed community of small healthcare units may mean that the balance between education and case consultation will be different for ethics consultants in primary care. The practical challenges for ethics support and consultation in primary care require creative solutions, but such challenges are not insurmountable.

A more fundamental challenge to ethics consultation, whether it develops as an integral part of the primary care system or as an outreach service from a local secondary care institution, is the methodology of the case consultation itself. Agich has criticized the common approaches to ethics case consultation that are described in the clinical ethics literature (applied ethics, casuistry, principlism, and conflict resolution) as not capturing the distinctive essence of case consultation.[34] These approaches acknowledge the importance of context in clinical ethics by emphasizing the need to establish the facts of the case, but miss the deeper contextual importance of the social structures that give ethical meaning to the case. Using the traditional approaches, the only difference between case consultation in primary and secondary care would be that the facts of the case will be different. However, the social phenomenological approach suggested by Agich requires an engagement with patient care that recognizes the social structures that give ethical meaning to the case. It is the experience of those involved in the case, and not simply the facts of the case, that are important. Using this approach to ethics consultation in primary care, the social context of primary care discussed earlier cannot be ignored. In this context, the experience of healthcare for both patients and health professionals is fundamentally different from the experience of healthcare in a secondary care setting.

Conclusion

The vast majority of patient contacts occur in primary care, but to date this area of healthcare provision has had little or no access to clinical ethics support compared with the secondary and tertiary care sectors. The clinical ethics literature

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mainly focuses on the ethical problems arising in hospital care; hence, the needs of patients and health professionals in primary care for advice on the ethical difficulties they face are not being met. There is a great opportunity for ethics consultants to develop support services in primary care, but we cannot assume that models that are successful in secondary care will simply transfer across to primary care. There are both practical and methodological issues to address. The literature and empirical data on ethical decisionmaking in primary care suggest that the social context of primary care may influence both the nature and frequency of the ethical issues that arise and the approach to resolving these issues in clinical practice.

In this paper, I have characterized primary care and secondary care as two distinct, complementary, but contrasting models of patient care. This is in some sense a false distinction in that there is a significant overlap in the two models of care. Some secondary care services, for example, areas of pediatrics and psychiatry, dealing with long-term conditions or clinical genetics services, will share many of the features that I have suggested characterize primary care. However, as a practicing primary care physician who has also spent several years working in a secondary care respiratory unit, I would argue that these broad distinctions are still valid. This is particularly relevant for a discussion of ethics consultation, because the major focus of such work in secondary care, at least as described in the literature, appears to be in the area of high technology medicine, often in an intensive care setting. Ethics consultants who seek to offer support and advice in a primary care setting need to engage with the social structures that inform the identification of ethical issues in primary care and venture beyond moral theory and case analysis. In doing so they will have the opportunity to influence a much broader spectrum of patient care than is their current experience, a situation that, I submit, will benefit patients, health professionals, and ethics consultants themselves.

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