



CHAPTER 16

Developing Rural Ethics Networks

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ABSTRACT

Rural ethics networks are a tool that small, rural health care institutions can join in order to share ideas, explore questions with peers, and gain educational opportunities and support. Because there are few existing rural ethics networks, the development of new networks might help many hospitals or clinics that currently lack health care ethics resources in their workplaces. Health care institutions in rural geographical areas are often challenged with limited finances and overworked staff, which may make it difficult for those working on institutional ethics committees or providing ethics consultation to access ongoing education and development opportunities. This chapter will discuss various ethics network models that are currently available, including academic, government and independently-based networks, as well as informal networks. This chapter will also describe how an interested professional might begin building a new rural ethics network to meet rural health care needs.

INTRODUCTION

There are approximately 5708 registered hospitals in the United States, 1997 of which are community hospitals located in rural areas.¹ This means that approximately 37% of the nation's hospitals are considered rural. The American Hospital Association (AHA) defines a rural hospital, in general, as a large or small hospital that is located outside a metropolitan statistical area. A small hospital is defined as one having less than 150 beds; many rural hospitals have less than 150 beds.²

Ethics issues of a clinical and administrative nature cross over all health care environments, including rural and small institutions. Illness, and the ethics conflicts associated with it, occur no matter where we live. Rural areas require supportive professionals who appreciate and understand this context. Rural health care also requires ethics resources that may include networks of rural practitioners who communicate about their struggles with ethical issues, as well as practitioners who sit on the ethics committees and/or provide clinical health care ethics consultation.² Networking can be formal or informal. Formal networking might include inviting a trained ethicist to visit a rural institution's ethics committee to hold training sessions for committee members, or contracting an ethicist to provide ongoing training and/or consultation. Informal networking can include phone or e-mail contact with an outlying ethics consultant, or discussing issues with other local institutional ethics committee members.

Limited Ethics Resources

Many small, rural health care institutions (hospitals, nursing homes, and outreach clinics) are not affiliated with colleges or universities, where they might have access to scholarly resources or individuals trained in health care ethics.³ It might also be true that many small and rural institutions do not need a full-time ethicist on site, but rather would benefit from an ethicist who serves several institutions part-time through some form of health care ethics network. Limited financial and educational resources can be enhanced when several rural institutions work together. An ethics network can provide not only clinical ethicists, but also resources related to health policy, research, legal updates, committee education, and peer feedback.

Benefits of Rural Ethics Networks

There are important reasons for rural institutions to create networks, because rural health care ethics issues are often unique from those experienced by their urban counterparts. Ethics committee members and others interested in rural ethics could benefit from the opportunity to participate in the network, sharing a common rural understanding, perspective, and lived experience. As committee members, we feel more at home when others immediately understand the rural dynamics shaping the presentations of common challenges. The benefits of rural ethics networks are listed in Box 16.1.

BOX 16.1

BENEFITS OF RURAL ETHICS NETWORKS

- Access to health care ethics consultant(s)
- Collegial support
- Ethics committee member interaction and sharing of ideas
- Specific educational programs to meet the needs of small and rural institutions
- Opportunities to share research ideas and activities

A major benefit of rural ethics networks is that members are colleagues and professionals who all live and work in rural settings. Therefore, each has a greater understanding of the unique rural challenges and what kinds of solutions for ethics issues are most fitting for rural care situations. Cook and Hoas wrote, “Merely transplanting urban models, guidelines, standards, and training requirements into resource-limited rural health care scenes appear(s) to be inadequate. Identifying resources, disseminating materials, and developing linkages among similarly sized institutions could be useful interventions.”⁴ Providers can improve the rural health care experience by recognizing the unique attributes of the rural context, and seeking ethics network support from within as well as without individual health care facilities.⁵

TYPES OF RURAL ETHICS NETWORKS

There are several types of rural health care ethics networks in place throughout the United States and Canada today, listed in Box 16.2.

BOX 16.2**TYPES OF HEALTH CARE ETHICS NETWORKS**

- Academic-based networks with academic funding
- Academic-based networks with membership funding
- Government-sponsored networks
- Independent-based networks with independent funding
- Informal rural networks

Again, networks may be formal or informal, depending on the needs of those groups or individuals who make up the general group. Membership also depends on the individuals representing the various institutions, such as physicians, nurses, allied health care providers, and the like. The structures and purpose of the various networks differ, but there are several general types of rural networks.

Academic-Based Ethics Networks with Academic-Based Funding

Academic-based and -funded networks are those that are both facilitated and funded by a sponsoring academic institution. The Illinois Healthcare Ethics Committee Forum, based at the University of Illinois at Chicago Medical Center, is one example of such a network that provides useful resources to small and rural health care institutions. This network was developed in 2003 to assist institutions throughout the state of Illinois. There are 194 hospitals in Illinois, 88 of which are classified as small, rural, or both.⁶ The ethics committee membership focuses on members specifically, and not just the ethics consultant, as not all hospitals have an ethics-consulting service or department. However, even small and rural institutions must have some form of ethics committee or mechanism to address medical ethical issues, in order to meet basic patient rights and ethics standards as specified by The Joint Commission.

In order to successfully develop an ethics network of any kind, a dedicated, committed, and institution-supported leader must carefully plan the development of a network with as many rural facility professionals as possible. An early step in the development process includes surveying potential users of the network.

Preparation for the Illinois Healthcare Ethics Committee Forum began with a survey sent to 88 small and rural hospitals, including critical access hospitals, as listed by the Illinois Hospital Association (IHA). The surveys were addressed to the institutional risk manager, because most institutions have a defined person for this role. If the manager was not a member of the hospital's ethics committee, they were asked to pass the survey on to the appropriate contact. The survey described a future health care ethics committee network, in which members would be able to share ideas, experiences, JCAHO insights, and educational topics via a Web-based discussion board. Survey questions asked hospitals about the organization of their institutional ethics committee, how often the committee met, what responsibilities members had, and what kinds of resources were available. Survey participants were asked if they would be interested in joining a statewide network and, if so, if they would be willing to pay a fee for this service. The survey in Figure 16.1 was used to better understand the level of interest in a statewide network.

Of the 88 surveys sent out to small and rural Illinois hospitals, 51 responses were returned, a 58% return rate. All 51 indicated that their committee work included policy review, case review, and/or education. Twelve of the 51 would not be willing or able to pay any fee for membership to an ethics network, but the remaining 39 stated that they would be willing to pay \$25-50 for an annual membership. All but two of the respondents said that they would find membership in a statewide ethics network helpful.

After receiving positive feedback from the original surveys, work began with the University of Illinois Information Services support staff to build our virtual online forum discussion board Web site. Within six months following the survey, the University of Illinois at Chicago Medical Center launched the Illinois Healthcare Ethics Committee Forum. The forum was advertised via e-mail and letters sent out again to the Illinois Hospital Association's small and rural hospitals. The forum was also easily accessed via the Medical Center's Clinical Ethics Consult Service home page, where individuals could sign up for the secured discussion site. This forum is now offered free of charge as a service of the University of Illinois Medical Center. Within three months the forum had 23 members, and five years later there are over 175 members

FIGURE 16.1

SAMPLE ETHICS COMMITTEE SURVEY

- Does your institution have an Ethics Committee? Yes No
- If no, please explain: _____
- If yes, what professional classifications make up the committee membership? (Circle all that apply)
 MD RN Social Worker Clergy
 Respiratory Therapy Administrator Lawyer
 Other: _____
- How many members are on your Ethics Committee? _____
- How often does your committee meet? (Circle one)
 Monthly Bi-monthly Quarterly
 Annually Other: _____
- What activities does your Ethics Committee do? (Circle all that apply)
 Policy review/revision Case review
 Education Other: _____
- Do your committee members provide clinical ethics case consultations?
 Yes No Other: _____
- What ethics resources are available to your committee?

- Would it be helpful to your committee to participate in an informal network of ethics committees to share ideas and educational resources?
 Yes No
- Do you think your institution would be willing to pay a nominal fee (annually) to be included as a member of an Ethics Committee Network?
 Yes No
- If you answered yes to the question above, what fee range would be acceptable to your institution? (Circle one)
 \$25-\$50 \$50-\$100 \$150-\$200
- If such an Ethics Committee Network were available, would you be most likely to participate in: (Circle all that apply)
 Virtual Discussion Board (Internet-based) Annual Conference
 Face-to-Face meetings Other: _____

representing institutions throughout the state. The University of Illinois is committed to this resource and to the ongoing support of the virtual network.

Membership is not restricted to just members of small and rural institutions. All members have benefited from the varied experiences and expertise that we share online. In June 2004 the Illinois Healthcare Ethics Committee Forum held its first conference in central Illinois, with over 100 participants. The conference has become an annual event, and is an important opportunity for attendees to network face-to-face, to share experiences and ideas, and for those active in ethics committee work to conduct continuing education. The conference topics are member-driven, with most speakers coming from the membership, thus allowing for the forum to meet the specific needs of its members. For example, education might be available on the consultative process, for those institutions that may have less than five consultations per year; or a program might be given on home hospice care for rural locations where such services are challenging to obtain.

Academic-Based Ethics Networks with Membership Funding

A second type of health care ethics network is the academic- or university-based network, in which funding is provided directly by members. Here are examples from two well-established networks, both having been in operation for about 20 years.

The first network is the West Virginia Network of Ethics Committees (WVNEC), which began in 1988 as the West Virginia Network of Hospital Ethics Committees. There were 12 original members, and they raised start-up monies through conference registrations with the kind support of West Virginia University Health Sciences Center. The West Virginia Network of Ethics Committees expanded to include nursing homes, home care agencies, and hospices, in addition to hospitals. It currently has an institutional membership of 44 hospitals, 22 nursing homes, 5 home care agencies, 9 hospices, and 12 individual members. The network is governed by a Network Advisory Committee which represents the diversity of membership. The mission of the West Virginia Network of Ethics Committees is to promote ethical decision-making in both daily patient care and during quality end-of-life care,

by educating patients, families, professionals, and institutions about ethical and legal issues. In addition to serving as a resource for ethical decision-making for all West Virginians, the West Virginia Network assists hospitals, nursing homes, hospices, and home health agencies to start or strengthen ethics committees and to develop knowledge and skills in palliative care. The services that this ethics network provides are summarized in Box 16.3.

BOX 16.3

EXAMPLE OF NETWORK SERVICES (WEST VIRGINIA NETWORK OF ETHICS COMMITTEES)

- Web site, wvethics.org, with a complete toolkit for ethics committees
- E-mail newsletters with information about ethical and legal issues
- Telephone consultations
- List-serve to keep members current on pending health care legislation
- Assistance in drafting policies on ethics-related issues
- Quarterly newsletter containing articles on current topics and other help as needed

These services keep network members connected, even when they are separated by significant distance.

The yearly membership dues are \$150 for institutions with annual gross revenues of less than \$500,000 per year; \$250 for those institutions with revenues from \$600,000 to \$5,000,000 per year; and \$350 for those institutions with revenues in excess of \$5,000,000. Individual membership is \$25 annually.

Another example of an academic-based network that has membership fees is the Midwest Ethics Committee Network. This network was started in 1987 for hospital ethics committees in Wisconsin as a way to meet, discuss policies, and discuss other health care ethics topics of interest, including topics relevant to the rural settings in which many institutions in Wisconsin are located. The Center for the Study of Bioethics at the

Medical College of Wisconsin provided leadership for this network, and sent the original membership invitations. There are currently 120 hospital members of the Midwest Ethics Committee Network, representing 1500 individuals. Institutional membership is available on a sliding scale membership fee based on institution size. Institutions with over 500 beds pay an annual membership fee of \$1,200, while those with less than 150 beds pay \$300 annually. Individual membership is \$75 per year. The Medical College of Wisconsin funds the Midwest Ethics Committee Network on a partial basis. A variety of network activities are available to members, including an online discussion board, a member newsletter, and frequent educational programs at locations throughout the state, including regional meetings.⁷

Government-Sponsored and -Funded Ethics Networks

Ethics Networks that are government-based and government-funded include those networks that are financed and run by some type of state-sponsored organization.

There is evidence that having some type of system-wide or location-driven network successfully helps provide needed ethics resources to practitioners and ethics committee members in small and rural locations.^{5,6} The Provincial Health Ethics Network from Alberta, Canada is an example of a government-based ethics network that serves the entire province of Alberta, including both urban and rural health care institutions. Most of this geographical area remains very rural, despite the large landmass it occupies. Activities sponsored by the network include an annual conference, distance-education offerings, and Web seminars and workshops.⁷

The Department of Veterans Affairs (VA), the largest integrated health care system in the United States, includes many rural hospitals and outpatient clinics across the country. All VA medical centers have ethics committees or programs to assist clinicians and administrators in addressing ethics issues. Local VA medical center ethics committees are linked to the VA's National Center for Health Care Ethics, based at the VA's national headquarters in Washington, DC. The Ethics Center provides many educational and consultation activities and resources to assist local VA ethics programs. The Center drafts position papers

regarding a wide range of clinical and organizational ethics issues that are relevant for all health care facilities. The wide variety of National Center for Health Care Ethics resources can be accessed through their Web site. The resources are useful for both VA and non-VA health care organizations.

Independently Based Ethics Networks with Independent Funding

Independently based networks are those which are organized by private institutions or groups that receive funding from various sources, in addition to providing resources to institutions on a fee-for-service basis.

The Kansas City Area Ethics Committee Consortium is an example of an independent network that provides support to ethics committees throughout the Kansas City region, which includes a large rural constituent. This consortium was formed in 1986, and provides ethics committee education, research, policy development assistance, and bi-monthly meetings. The consortium is a service of the Center for Practical Bioethics, which is a nonprofit, independent health care ethics center that is funded by a combination of membership dues and community and foundational support. Consortium membership is a benefit of organizational membership to the Center for Practical Bioethics. Two representatives of each member hospital's ethics committee attend consortium meetings, which are hosted by various institutions during the year. Consortium meetings are supplemented by Center staff assistance to member institutions with on-site visits, phone consultations, and consultation on any difficult health care ethics issues that may arise. The Center staff also provides support by chairing the ethics committees of member hospitals.

The Consortium hosts an online discussion forum that is moderated and administered by Center staff. Members may subscribe to this forum by request only. The forum provides members with a means of communicating about bioethical issues in real time without travel. Forum members also receive monthly "Ethics E-Alert" messages to provide links to news and events at the Center and elsewhere in the Kansas City area. In addition, the Center sponsors a long-term-care ethics committee consortium to assist institutions that may not have access to ethics consultation and educational resources.⁸

Informal Rural Ethics Networks

In addition to the more formal ethics networks, there are informal ways that rural health care institutions can interact in order to meet their individual needs. Ethics committee members can contact the ethics committees of other small and rural health care institutions by obtaining membership lists from state hospital associations. For a small fee, state hospital associations often offer membership lists with contact information that can be used to locate institutions of a similar size. Sending a letter to the ethics committee chairperson of an identified similar institution can start informal networking that may lead to valuable interactions.

Informal networks can also be started by looking into various rural health care resources available via the Internet. For example, The University of Montana in Missoula is host to the National Rural Bioethics Initiative (NRBI), which was established to “create a formal mechanism for sustained health care ethics-related research and program development in rural communities and rural health care settings.”⁹ NRBI research is funded by federal grants and foundations. This initiative is not a membership network, however. The initiative works with rural hospitals and other health agencies in the West through its research projects. Health care providers can contact the NRBI for resources and assistance.

Established organizations, such as state medical societies and regional health care organizations, may also assist in the ethics networking process. Such organizations may be able to provide financial support to get a network started, or technical support to develop a Web-based or online network for rural institutions. In states with large rural populations, there are often local and state rural organizations related to health care, such as public health departments. Additionally, state universities may have important departments and research initiatives in place, related to rural health care, that could be helpful in organizing a specific network. It only takes one person with an interest to get a network started.

Many rural health care ethics networks are successful, allowing members from small and rural institutions to ask questions, share information, and communicate with resource members from both academic and non-academic institutions. However, we must now go the next step and produce

research through organizing scholarly work on the issues that small and rural institutions find interesting or challenging in their unique settings.

BUILDING A RURAL ETHICS NETWORK

Careful planning is important when building a rural ethics network. Important planning steps are suggested in Box 16.4.

BOX 16.4

GETTING AN ETHICS NETWORK STARTED

- Determine a sponsoring institution that is willing to house and support the initial efforts (state hospital, long-term home care and/or hospice association, medical or nursing society, major hospital in the area, university, etc.)
- Enlist a dedicated network leader and organizer
- Organize focus groups to brainstorm a network outline or plan
- Conduct a needs assessment of your state or region
- Host an initial planning meeting (either via conference call, an in-person meeting, or video conference)
- Prioritize the meeting based on initial planning meeting data
- Utilize resources from existing rural networks and resources
- Provide ongoing network assessment and evaluation
- Update the network as needed based on assessment and evaluations

It is very important to research the resources available in one's area, if any, and what resources are important and needed for all potential network members. Focus groups including individuals from sample rural institutions may be useful for brainstorming ideas about how a potential network could, or should operate in the particular rural area. From the brainstorming session(s), a network outline describing its purpose and activities can be established to further guide development. Then, a network model can be used to decide what type of funding, as well as other resources, will be needed to get the network running. E-mail is an efficient way to communicate with various potential network members. Preliminary Internet searches are also very useful as prospective members do background research regarding the rural ethics resources currently available in the area.

These steps are vital to the success of a rural ethics network. A well-thought-out plan, supported by feedback from focus groups and needs assessments, will reduce the likelihood for unnecessary spending, and will increase the likelihood for efficient and helpful network resources. Similarly, ongoing review and updating of the network will ensure the continual improvement of its programs.

Implementation of the Network

Once professionals have established an overall network outline and plan of action, implementation will begin. This process will take time and dedication, as members begin to interact and the network grows. Ongoing assessment and evaluation of network operations, goals, member interactions, and possible network projects are extremely important. Reviewing assessments and evaluations will allow the network to continuously evolve to meet the needs of the network membership.

CONCLUSION

Ethics issues in health care cut across all types of health care institutions, including those located in small and/or rural areas throughout the country. It is often the case that both the financial and professional resources that would assist small and rural institutions in solving problems relating to health care ethics are limited. Rural ethics networks can be a useful way to share health care ethics resources—both financial and professional—to optimally serve network members.

With the use of the Internet and Web-based discussion boards, small and rural institutions can network in ways that were impossible in past years. The exchange of information among network members can be extremely useful, as many of the ethics issues that rural institutions face are often similar in nature.

This chapter has described several types of networks, and given examples of how such networks can be developed and built into a useful resource for members. Health care providers in rural areas have an opportunity to improve ethics management by employing similar networks within and without their own institutions.

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