

Ethics of rural health care

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Accepted 6 February 2001

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Abstract

One quarter of the US population live in areas designated as rural. Delivery of rural health care can be difficult with unique challenges including limited access to specialists such as oncologists. The Rural Cancer Outreach Program is an alliance between an academic medical center and five rural hospitals. Due to the presence of this program, the appropriate use of narcotics for chronic pain has increased, the number of breast conserving surgeries has more than doubled and accrual to clinical trials has gone from zero to nine over the survey period. An increase in adjuvant chemotherapy has been noted. The rural hospitals and the academic center have seen a positive financial impact. The most prominent ethical issues focus on justice, especially access to

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health care, privacy, confidentiality, medical competency, and the blurring of personal and profession boundaries in small communities. As medical care has become more complex with an increasing number of ethical issues intertwined, the rural hospitals have begun to develop mechanisms to provide help in difficult situations. The academic center has provided expertise and continued education for staff, both individually and within groups, regarding ethical dilemmas. © 2001 Elsevier Science Ireland Ltd. All rights reserved.

Keywords: Care of the poor; Cost analysis; Medically under-served; Rural; Strategic alliances

1. Introduction

One quarter of the US population lives in areas designated as rural, or fewer than 2500 people per town boundary, and frontier, or fewer than 6.6 people per square mile [1]. The geographical and socioeconomic features of rural America present unique challenges to delivery of health care resources, especially delivery of oncology care.

Rural patient health is often poorer than urban or suburban patient health. The long distances make some types of care difficult. There is increasing evidence that high volume produces high quality cancer care [2,3] and many rural hospitals will always have low volume.

This article will explore the ethical issues related to rural health care, particularly oncology care. It will describe the rural cancer outreach program of the Massey Cancer Center (MCC) including a clinical and financial analysis of the program; the ethics of the program; applicability to other settings; and what we have learned in 10 years of creating access to care.

2. Program description: The Rural Cancer Outreach Program (RCOP)

The rural cancer outreach started as a 'strategic alliance' [4] between academic centers and rural non-profit hospitals. The goal was to establish a model of care that would provide state of the art care in rural areas, increase the access to care, generate services and revenue for both the rural and academic center, train health care professionals [5], and serve as a laboratory for intervention. (Table 1).

The RCOP has grown from one program in 1988 to five programs operating at five rural hospitals. Briefly, the majority of cancer care is provided at the rural hospital. A team of two–three oncologists and two nurse practitioners or nurse clinical specialists travel to each site weekly. While there, they see new consultations and patients under treatment. They work with primary care doctors at the rural sites who have expressed an interest in care of cancer patients; this typically includes two–three surgeons and two–four primary care internists or family physicians. Nurses

from the rural site come to the academic center for specialized cancer nursing, then receive annual updates. Many of the rural nurses have become certified in oncology nursing.

The program is administered by the Massey Cancer Center of the Medical College of Virginia, Virginia Commonwealth University, and each of the rural hospitals. Support for this program comes from the Commonwealth of Virginia.

3. Program analysis

3.1. Impact of the program on the clinical care provided

We have analyzed three important index conditions in our first two rural hospitals [6]. We chose these conditions because there was documented wide variation in practice, and poor medical outcomes if optimal process was not followed (Table 2). It was difficult to

Table 1
Goals of the rural cancer outreach program

Goal	Comment
Establish a model of care for rural Virginia	Virginia is typical rural US state
Deliver state of the art care in rural areas	See what care could be delivered at the rural site, what should be centralized
Increase access to clinical trials	Allow access to new drugs; increase accrual to clinical trials for the academic center
Train health care professionals	Help recruit and retain primary care and specialist physicians and nurses for the rural area. Provide a specialty service that makes rural practice more attractive
Link academic and rural hospitals in strategic alliance	Make regional policy, not hospital against hospital, to solve problems of indigent care.
Help finances of both hospital partners	Help support unprofitable small rural hospitals.
Serve as a entry point for community based interventions in prevention	Use the program for tobacco and nutrition interventions if desired by rural community.

Table 2

Index condition	Level before RCOP	Level after RCOP
Morphine use in chronic pain	0	+ 500%
Breast conserving therapy	<20%	60%
Clinical trial accrual	0	9
Adjuvant therapy for early breast cancer	Unknown. Probably high for affluent patients who could travel, low for the poor	Offered to all patients regardless of ability to pay

analyze the type of care because the volume of any one condition, e.g. use of adjuvant chemotherapy in Stage I–III breast cancer, was always low and usually less than ten cases per year. However, the importance of high quality care to those individuals is as important as in other settings. There is often reluctance to analyze care patterns if it is likely to show less than optimal care; for instance, a hospital that reports excess mortality from routine myocardial infarction may find that patients avoid that hospital for all cardiac care, especially troublesome for a small hospital that depends on retaining a large percentage of its market for survival. Also, there is often no financing available to support an in depth look at practice patterns and survival or recurrence.

The use of morphine for cancer pain was studied in one hospital. In the preceding 3 years before RCOP, there had been almost no morphine prescribed; within 2 years the amount of oral and intravenous morphine increased by over 500%. In addition, the use of meperidine declined. Breast conservation, considered the desired treatment for early stage breast cancer, had been rarely used before RCOP. By the 3rd year of operation at our first hospital, over 60% of patients were routinely treated with breast conservation. In addition, before the RCOP, all breast cancer patients were not routinely offered adjuvant treatment, because many could not see an oncologist due to distance or cost. In other studies, the referral of patients to a medical oncologist — rather than treatment by a surgeon alone — was significantly correlated with the likelihood of receiving adjuvant chemotherapy [7]. Clinical trial accrual to Cancer and Leukemia Group B (CALGB), National Surgical Adjuvant Breast and Bowel Program (NSABP) and other trials increased from essential zero to 9% of eligible patients. This compares favorably with the 2% national average in the US.

3.2. *Impact of the program on health care professional recruitment and retention*

The RCOP has been successful in helping to recruit and retain good physicians to rural areas. Physicians commonly mention the increased academic linkage

and ease of referral to the academic center. These rural doctors have noted that the concentration of complex cancer care in the hands of a few local doctors rather than many has allowed them to increase their expertise. There has also been continued centralization of some complex procedures such as radiation and leukemia treatment that are not feasible to perform at a rural center.

4. *Economic analysis*

Pre- and post-RCOP financial data were collected on 1745 cancer patients treated at the participating centers, two rural community hospitals, and MCC. The main outcome measures were costs (estimated reimbursement from all sources), revenues, contribution margins, and profit (or loss) of the program.

Key results are shown in Table 3, modified from the full report in the *Journal of Rural Health* [8].

The RCOP had a positive financial impact on the rural and academic medical center hospitals. The RCOP was associated with an increased number of referrals of 330% more cancer patients and 9% more other medical/surgical patients. The MCC had increased receipts of 6.2%. The rural hospitals each had over a million dollars in new charges and over \$500 000 US new profit each year. In total, the receipts for both centers increased by 137%. Most of this additional income was from ‘ancillary’ services such as increased use of the computerized axial tomography (CAT) or magnetic resonance imaging (MRI) scan, laboratory, and pharmacy. All patients were treated regardless of ability to pay, and the program generated sufficient profit to allow increased indigent care.

The net annual cost per patient fell from \$10 233 to \$3862 (– 62%) associated with more use of outpatient services, more efficient use of resources, and the shift to a less expensive locus of care. The cost for each rural patient admitted to MCV fell by 40%, compared to only an 2% decrease for all other cancer patients consistent with other programs that have increased coordination among providers [9].

5. Other programs

Similar results of improved clinical care process, equal or better patient outcomes and cost savings have been reported from the Manitoba Cancer Outreach Program, but final results have not yet been published. The Manitoba Cancer Research and Treatment Program was started in 1984 with similar goals [10]. It works on a similar model of consultation with the academic center, then all the care is delivered in one of six regional centers. Insurance is not an issue in Manitoba since there is a single universal payer. However, there are limited funds for cancer and dollars that can be saved by off loading to a regional center preserve dollars for research. Distance is even more problematic, with some centers 8 h by train, impassible by cars, and air transport too costly. Key rural primary care doctors and surgeons are identified, and given an initial training program followed by yearly updates. All protocols are specified in a central care plan, and the central hub audits dictations from the rural centers. Similar clinical results have been obtained, with excellent clinical care and less overall cost to the province [11]. (personal communication, Harvey Schipper 1999)

6. Applicability to other settings

We have not identified other similar programs that have published their clinical and economic results. The closest is the Centre Bernard Lyon that has shown good adoption of clinical practice guidelines and better clinical practice [12,13]. This program should be applicable to other centers that serve rural, dispersed populations. The main problems have been sustaining the medical innovation part of the program, and not 'burning out' the doctors and nurses who must travel the distance. The continued travel can be a major problem for health professionals.

7. Ethical issues in rural health care

The challenge is to provide high quality, affordable, accessible care for all. In the US, the absence of a single payer system allows exclusion of whole segments of the population. Combined with the dispersed poor population in rural areas, these issues represent significant obstacles to delivery of care. In Virginia, one third of the population is rural and most of these people are medically underserved for both primary and specialty care. The rural population has more federal Medicare and state Medicaid health insurance coverage with a low rate of reimbursement compared to most insurance, so rural hospitals and providers have less income than urban centers. 'Negative marketing' or locating services in affluent areas so that the poor do not have access is widespread.

The ethical issues most prominent in rural health care include justice issues, especially those involving access to and delivery of health care, related issues of medical competency, confidentiality and privacy issues, and conflicts of interest related to blurring of personal and professional boundaries. Finally, institutional ethics committees at rural hospitals are evolving, but may not have the necessary elements of expertise that are more accessible in urban centers.

7.1. Justice issues: access to and delivery of health care

The principle of justice calls for equitable distribution of health care resources, meaning that health care is distributed according to need rather than to the ability of a person to obtain it. Challenges to this principle in the rural health care setting include geographical and financial barriers. In some rural communities health care may be hours away. Nonmetro and frontier areas possess far less physician coverage than more urbanized areas even after controlling for population size. For example, in 1988, the ratio of primary care physicians per 100 000 persons for re-

Table 3
Impact of RCOP on rural and academic programs

	Pre-RCOP ^a	Post-RCOP ^b	Change (%)
Cancer patients from RCOP areas seen at MCC	173	743	330%
All patients from RCOP areas seen at MCC	6958	7572	9%
Estimated receipts, MCC	\$1 770 256	1 879 542	6.2%
Estimated receipts, RCOP	NA	\$2 314 516	—
Total estimated receipts	\$1 770 256	\$4 194 058	137%
Net annual cost per patient in the system	\$10 233	\$3862	—62%
Inpatient admission, MCC	\$12 268	\$7370	—40%

^a Represents average values of 1988 and 1989 financial data.

^b Represents average values of 1992 and 1993 financial data.

mote rural areas was 38.2; for the more inclusive nonmetro areas it was 51.3. In comparison, metro areas had a ratio of 95.9 [14,15].

This problem will be compounded as more independent community hospitals close their doors due to the lack of funding. The poor and elderly without access to transportation may receive little to no health care. The traffic and complexity of urban centers may intimidate those who have always lived in rural areas.

Financial barriers are similar to those experienced by the poor urban population. The community, however, may actually be a positive factor in overcoming these barriers. In a review of these issues, Purtilo and Sorrell remarked that in times of hardship, rural community members often help those of their community who are most financially strapped [16]. Among those community members are the physicians, who are also 'expected' to contribute their services and advocacy for the patient. Physicians are part of the community, and "the high probability that the physician will see a rejected patient at the drug store, Lions Club dinner, or next PTA meeting makes saying 'no' practically impossible" [17]. This situation may create a tremendous conflict of interest between the physicians' allegiance to their community and their hospital, which may not have the financial resources to provide care for indigent members of the community.

Improved access to oncology care is at the heart of our rural cancer outreach program. Oncology care in the rural setting is equivalent, or sometimes better, in terms of convenience, than that in the academic medical center. The most important aspect of the program is improving financial and geographic access to subspecialty care and consultation. Transportation is provided for patients who have daily radiation treatments. Although we cannot impact direct costs of the patients' oncology care, reducing out-of-pocket spending, which is significant, appears to be of great assistance to many of the patients. Finally, by providing care close to home, we hope to offer comfort and a greater sense of security to patients who are frightened or feel threatened by the diagnosis of cancer and the therapy they must endure.

7.2. Competency of medical care

Several issues surrounding competency of medical care exist in the rural setting, and some are particular to our rural outreach oncology setting. The first concerns competency to provide specialty care. Many rural areas have few primary care providers, and no specialists. There is increasing evidence that high volume produces high quality and many rural hospitals will always have low volume [3]. Physicians may feel forced to provide care, including procedures which

they perform infrequently or are beyond their level of expertise, especially if the closest large medical center is 3–4 h away. Physician assistants, nurse practitioners and other nursing personnel may also provide care beyond their level of expertise, with minimal supervision, to meet the health care needs of the rural population.

One of our primary goals was to surmount this problem by traveling 1–2 h to several rural areas to provide oncology expertise in the form of clinics in which we see new and returning patients on a bi-weekly basis. During the clinic appointment, the medical and radiation oncologists and nurse practitioners perform ongoing management of established patients, plan diagnostic and therapeutic interventions for new patients, and counsel patients regarding palliative care and end of life issues. We also educate the hospital oncology nursing staff, many of whom have become certified in oncology nursing. These specialized nurses see patients every day and administer chemotherapy and other treatments such as transfusions and intravenous fluids, and perform limited patent assessments thus trouble shooting problems experienced by the oncology patients.

Problems that can occur in this setting include are lack of direct supervision on a daily basis, lack of continuity of care, and problems related to handling and communicating medical information between the outreach sites and the cancer center.

Direct supervision by a specialist is obviously impossible 2 h away. We work closely with the primary care physicians in the community and the patients continue to see them regularly after diagnosis. The community physicians are most often the first to see and evaluate patients having problems, and will then often call one of the oncology physicians to discuss the case. If a patient is having a specific problem that must be handled by a specialist, such as a complicated neutropenic fever, or spinal cord compression, the patient usually must be transported to our medical center. However, the patient may often be stabilized and kept at the rural hospital if the primary care physician has the support of the oncologists and other members of the medical center faculty.

Continuity of care is an important concept in the patient–clinician relationship. Unfortunately, we are not always able to provide direct continuity of care to our oncology patients because of time and schedule constraints. We do the best we can by maintaining a constant pool of physicians and nurses designated for each site, detailed patient summaries and clinic visits, so that the next physician will know what the treatment plan and previous problems are, and frequent use of phone calls to patients we know are having problems.

Handling and communication of patient information involves confidentiality issues described below,

and also involves management of large volumes of information from multiple sites, which is extremely challenging. Some information is critical, and elaborate systems are in place to assure that the information is noted and recorded by the site nurses and the cancer center nurse practitioners, and that the oncology physicians are made aware of any critical values, such as abnormal CT scans or blood tests. Ongoing quality assessment is in place to assure impeccable data management, to avoid missing critical information.

7.3. Confidentiality and privacy

The proximity in which patients and health care workers live and work in rural communities makes it much more likely that physicians and other health care workers will know their patients personally and socially, which creates significant challenges to maintaining respect for confidentiality and patient privacy. A 1993 survey of 510 general and family physicians in Kansas revealed that 46% of respondents practicing in a community of less than 5000 were likely to have more than 5% of patients who were family members or friends of the physician or staff, significantly more than the 13% of respondents from communities of more than 20 000. fourteen percent of the physicians in the communities of less than 5000 also reported that in more than 5% of cases medical information is passed through the physician or staff to an outside party who knows the patient in question [18].

Purtillo and Sorrell describe a patient who is found to have genital herpes during a routine prenatal visit. The patient pleads with the physician not to enter the information in her chart: her sister-in-law is the physician's receptionist, the county public health clerk to which this transmissible disease should be reported is her cousin; other relatives work at the hospital where she will deliver; "virtually everybody in the situation is either a relative, friend or foe" [16].

In an instance reported by Roberts et al., a patient drove 6 h to an urban center for help with his substance abuse problems. He told the attending physician that he couldn't go to his community clinic because his sister worked there, and he was afraid she would tell the whole family. The patient's subsequent non-compliance with the program was at least partially blamed on the burdensome long distance drive to the urban facility [17].

We have had several patients in our rural oncology clinics that have expressed unwillingness to be treated at the facility, because their privacy might be jeopardized. The waiting rooms of these clinics are often crowded with people who are friends, neighbors and relatives. Because it is a specialty clinic only for patients with hematologic or oncologic problems, it is

not difficult for one to know another's general diagnosis. Diagnostic tests are performed, interpreted and transcribed by patients' relatives and acquaintances. The patients are given chemotherapy in one large room and on any given day, they may find themselves sitting next to a neighbor, the local florist, or a distant cousin. Several of the nurses have found themselves treating old friends, teachers, neighbors and relatives. This may sometimes be a comfort to the patient, but may also be embarrassing or uncomfortable for both the patient and nurse.

In our rural outreach practice, we must exchange information about patients frequently by phone and often by fax and by email over the Internet. None of these communication devices are entirely secure, especially the email system, but they are necessary in communicating important patient information in a timely and efficient manner.

Safeguarding confidentiality in such circumstances is important; the Kansas physicians reported several measures they took to do so, some of which could potentially compromise patient care, the physician's integrity or even legally endanger the physician, such as in the case of misrepresenting or omitting certain details on insurance forms, and omitting required notification of local public health officials. Other measures taken included speaking with office personnel regarding the importance of confidentiality of a specific patient, omitting or misrepresenting certain details for the official medical record and recording the importance of confidentiality in the chart [15].

Our outreach site staff are aware of the sensitive nature of our patients' conditions and maintain a high level of awareness regarding privacy and confidentiality. Simple measures such as keeping telephone conversations and reports out of hearing distance from the waiting room and patient rooms as well as ongoing discussions regarding confidentiality between nursing staff and outreach staff are highly effective. The nursing and secretarial staff maintains a high level of professionalism and respect for patients, and in particular, confidentiality, which sets the tone for the rest of the staff.

7.4. Institutional ethics committees

In response to the mounting complexity and number of clinical ethical issues encountered in healthcare, institutional ethics committees are developing in rural and urban hospitals. Some have the specific goals of developing and overseeing hospital policies, to respond to the requirements of the JCAHO and similar organizations, and others have multiple goals, including the former as well as addressing day-to-day dilemmas that arise in the course of patient care. They are as heterogeneous in their compositions as in

their goals and missions, some composed of physicians and administrators, others representatives from multiple divisions of the hospital, such as nursing, pastoral care, and even from the community. Their members have various levels of ethics knowledge and expertise. Some have support from local institutions that have established ethics committees and considerable expertise. Others have members who have taken additional training in bioethics at community or university programs.

The hospital ethics committee can be a tremendous source of knowledge and support for physicians and other health care providers confronted by the dilemmas listed above. It is critical that these committees have the expertise and influence to support and uphold behavior and policy based on ethical principles.

The development of such committees has been described as occurring in three stages: emergence of a local expert, educating the ethics committee and developing a body of knowledge, and expansion of the ethics activity into policy development and consultation [19].

In our rural cancer outreach programs, we have offered the expertise of our established and experienced hospital ethics committee and its members, as well as persuaded them to identify interested individuals for further training by the Richmond Community Bioethics Consortium. We have also given several lectures and held discussions related to ethical issues in the care of oncology patients to the nursing and medical staff. We will continue to support them in any way possible to guarantee ethical treatment of their patients and employees.

8. Conclusions

There are distinct and novel ethical issues in providing rural health care. Two groups have shown that rural cancer outreach (a structured alliance of a cancer center and rural hospitals and providers) works well clinically and economically. In addition, rural cancer outreach is ethical because it is distributive and just.

Reviewers

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Acknowledgements

We gratefully acknowledge grant support from the Jessie Ball duPont Fund, 225 Water Street, Jacksonville, Florida, USA

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Biographies

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Mary Helen Hackney, M.D., is the director of Rural Cancer Outreach Program and travels regularly to

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Tom Smith, M.D., is recognized nationally and internationally for his papers on health services research. He is currently the director of the ASCO curriculum on palliative care and has focused his research on palliative care topics. He is a Project on Death in America Scholar.