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ETHICS IN COMMUNITY CARE

Ethical Considerations in Rural Health Care: A Pilot Study of Clinicians in Alaska and New Mexico

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ABSTRACT: To investigate differences in the experiences of rural versus non-rural clinicians, we surveyed caregivers in New Mexico and Alaska regarding ethical aspects of care provision. Consistent with past literature, rural compared to non-rural clinicians perceived patients as having less access to health care resources. They reported more interaction with patients and less awkwardness in relationships with their patients outside of work. Rural clinicians also reported their patients expressed more concern about knowing them in both personal and professional roles, had more concerns over confidentiality, and experienced more embarrassment concerning stigmatizing illnesses. Ethical issues and implications of these results for providing care in rural areas are discussed.

KEY WORDS: rural; ethics; health care; confidentiality; stigma.

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INTRODUCTION

Disparities in the health and health care of rural residents represent a significant concern for our country (Ricketts, 1999; 2000; Rural Information Center Health Service, 2003). Depression and alcoholism, once perceived as “city problems,” are now experienced at higher rates in rural than urban areas (Wagenfeld, Murray, Mohatt, & DeBruyn, 1997), and suicide rates in rural areas have surpassed urban rates in some regions. Sequellae of depression are intensified by greater rural economic fragility (Shelton & Frank, 1995). Also, rural compared to non-rural residents have higher rates of chronic illnesses and life-threatening conditions, such as cancer, heart disease, diabetes, and arthritis (Thurston-Hicks, Paine, & Hollifield, 1998).

Coupled with the significant mental and physical health needs of rural residents is the reality that rural health care services are insufficient to meet existing needs (Ricketts, 1999; Rural Information Center Health Service, 2003; Rural Policy Research Institute, 2003). Most (73%) mental health resource shortages occur in rural areas (DeLeon, Wakefield, Schultz, Williams, & VandenBos, 1989). For example, although 10% of rural residents need psychiatric care, only 2–5% are actually treated (Flax, Ivens, Wagenfeld, & Weiss, 1978). Travel times are longer for rural than urban residents, a significant barrier to care, particularly for elders and children (Roberts et al., 2001). Compounding this is the reality that elders and children, who require more services, live in greater numbers in rural than urban areas (Geyman, Hart, Norris, Coombs, & Lishner, 2000).

Although health needs and limitations in health care delivery in rural U.S. have received some attention, awareness about ethical aspects of rural care has rarely been raised. This neglect is worrisome given early empirical work suggesting rural providers face ethical challenges relatively uncommon to urban providers (Bushy & Rauh, 1991; Glusker, 1989; Niemira, 1988; Roberts, Battaglia, & Epstein, 1999; Roberts, Battaglia, Smithpeter, & Epstein, 1999; Roberts et al., 2001). Rural practitioners are more likely than urban clinicians to know and interact with their patients in non-professional roles within their communities (Mutel & Donham, 1983; Purtilo & Sorrell, 1986; Ullom-Minnich & Kallail, 1993). Similarly, safeguarding rural patients’ confidentiality becomes a challenge when everyone in a community knows who went to a clinic on a given day or when clinic staff are related to community members who receive care.

These observations suggest that systematic inquiry is needed to understand how care is provided in rural settings and how rural caregivers respond to ethical issues that emerge in providing physical and mental health care. A literature search in 2001 using the key terms "ethics" and "rural health care" revealed only five articles, only one published after 1992. Another search using the terms "ethics and "rural health providers" yielded another five articles, all focusing on the shortage of practitioners in rural areas or use of telemedicine. The paucity of empirical data about the challenges of providing ethically sound care in rural communities clearly indicates the potential value of more inquiry.

To begin to address this need, we surveyed care providers in Alaska and New Mexico regarding ethical issues involved in health care delivery in rural areas of the United States. We focused on five primary challenges faced by rural providers: patient access to health care, patient confidentiality, health care decision-making, patient-caregiver relationships, and issues surrounding stigmatizing illnesses.

METHOD

Participants

We gathered data from two large rural states, New Mexico and Alaska. The New Mexico sample included all health caregivers at 43 community-based, primary care centers contracting with the New Mexico Department of Health. Of 228 surveyed in November 1998, 120 (53%) returned completed questionnaires. In Alaska, we sampled all care providers at 28 of the 58 comprehensive, not-for-profit mental health clinics. These clinics were located outside of Juneau, Anchorage, and Fairbanks, the three largest cities in Alaska. Of 86 providers surveyed, 41 (48%) returned completed questionnaires.

Respondents had a mean age of 45 years in both states and 55% were female in New Mexico and 39% female in Alaska. Responding providers were 63% White, non-Hispanic and 22% Hispanic in New Mexico and 88% White and 7% Alaska Native in Alaska. In New Mexico, 42% were physicians, 17% physician assistants, and 32% registered nurses; in Alaska, 71% were master's level counselors and 12% doctoral level psychologists. Respondents averaged 12 years (7 rural) of overall practice experience in New Mexico and 13 years (7 rural) in Alaska.

Survey Instrument

A preliminary survey instrument was developed to begin a program to study health care issues with ethical relevance and interest to rural caregivers. The survey included multiple measures concerning: (1) health care resources and access to care; (2) confidentiality of health care; (3) caregiver-patient relationships; (4) care for stigmatizing illnesses; and (5) values and attitudes in delivering health care. We also asked about the caregivers' work characteristics (e.g., years in practice, years in rural practice, community size) and personal characteristics (e.g., how long they had lived in a rural setting, age, gender). The core survey included 57 items, rated on scales ranging from *strongly disagree* (1) to *strongly agree* (7).

To organize the 57 items into conceptual categories and reduce them to a smaller set of measures, we performed a series of iterative confirmatory factor analyses on subsets of items that were conceptually related *a priori*. Results produced nine composite scales: (a) available resources for health care; (b) concerns regarding access to health care; (c) concerns about cost of health care; (d) patient embarrassment regarding stigmatizing illnesses; (e) caregiver embarrassment regarding stigmatizing illnesses; (f) avoidance of health care due to embarrassment; (g) caregiver and patient relationship; (h) caregiver attitude toward patient decision-making; and, (i) awkwardness of overlapping relations. The scales produced a mean Cronbach's α of 0.80 (range 0.66–0.98). Ten other items did not load onto any factor and were used as individual indicators.

Procedures

Surveys were mailed to potential respondents in New Mexico and Alaska in November 1998. The study was approved by the University of New Mexico institutional review board and the administration of the State of Alaska, Department of Health and Social Services, and return of a survey served as consent to participate. Two follow-up mailings were sent at 3-week intervals to increase response rates.

RESULTS

Five repeated measures MANOVAs were conducted using measure (3–6 items or composite scores depending on the construct) (WS) × state (New Mexico versus Alaska) (BS) × Community Size (≤ 2500 versus >2500) (BS) as IV's, and (1) patient access to health care; (2) patient confidentiality; (3) health care decision-making; (4) patient–caregiver relationship; and (5) reactions to being treated for stigmatizing illnesses as DV's. Table 1 summarizes all results.

Access to Health Care

Analyses for three composite scales and three items that assessed clinicians' perceptions of patients' access to care and availability of resources revealed a main effect for Measure, $F(5,144) = 4.51$, $p < 0.001$. Caregivers agreed most that patients have concerns about the cost of health care and agreed least that patients know where to get health care. These extreme means differed significantly from each other and from the other access measures, which did not differ significantly.

An interaction of measure × state was also detected, $F(5,144) = 5.82$; $p < .0001$, due to state differences on two items. New Mexican caregivers agreed more than Alaskans that patients were concerned about cost of health care (M = 5.72 vs. 4.55; Cohen's d = .63), and Alaskans agreed more than New Mexicans that not a lot of caregivers were available for their patients to see ($M = 5.04$ vs. 4.62; $d = .25$). A community size main effect, $F(1,\ 148) = 16.28$; $p < .0001$, revealed that clinicians in smaller communities agreed more that access was a problem ($M = 4.84$ vs. 4.38; $d = .29$).

Patient Confidentiality

Analyses for three items assessing confidentiality issues revealed a main effect for Measure, $F(2,\ 156) = 149.79, p < .0001$. Clinicians' rated the importance of maintaining patient confidentiality very high. They were neutral that patient concern about confidentiality reduced patients' willingness to talk openly or that patients had expressed concern about confidentiality. However, widely differing views across clinicians were found –51% agreed that patients expressed concern about confidentiality and 48% agreed that concern about confidentiality reduced patients' willingness to talk openly.

A main effect for community size showed that caregivers from smaller compared to larger communities agreed more with the statements about confidentiality ($M = 5.48$ vs. 4.77; $d = .49$), $F(1,157) = 42.81$, $p < .0001$. The main effect of community size was qualified by a measure × community size interaction, $F(2,156) = 3.43$, $p < .04$. Clinicians in smaller compared to larger communities agreed more that confidentiality is important to them ($M = 6.91$ vs. 6.68; $d = .42$), although all clinicians rated confidentiality as highly important. Caregivers in smaller communities were more likely to indicate that concerns about confidentiality reduced patients' willingness to talk with them ($M = 4.77$ vs. 3.61; $d = .85$), and clinicians in smaller communities were more likely to report that patients expressed concerns about confidentiality to them ($M = 4.77$ vs. 4.01; $d = .43$). Finally, a measure × state interaction was due to Alaskan caregivers agreeing more than New Mexican caregivers that their patients expressed concern about confidentiality to them ($M = 4.83$ vs. 3.96; $d = .47$), $F(2,156) = 4.32$, $p < .02$.

TABLE 1 Clinicians' Perceptions by Community Size and State

Composite Scales and Individual Indicators	*Alaska Community Size*			*New Mexico Community Size*		
	<2,500 (n = 13)	*≥ 2,501 (n = 26)*		*< 2,500 (n = 53)*	*≥ 2,501 (n = 60)*	
	Mean (SD)[1]	*Mean (SD)*[1]	*d*[3]	*Mean (SD)*[1]	*Mean (SD)*[1]	*d*[3]
Health care access						
My patients have concerns about the cost of health care. (Factor C; $\alpha = 0.69$)	4.73 (1.80)[4]	4.37 (1.76)[4,5]	0.20	5.55 (1.59)[4]	5.89 (1.23)[4,5]	−0.24
There are [not] a lot of different caregivers my patients can see if they have health problems.[2]	5.46 (1.81)	5.00 (1.50)	0.28	4.62 (1.69)	4.25 (1.59)	0.23
My patients have concerns regarding access to health care. (Factor 8; $\alpha = 0.78$)	4.27 (1.55)	4.09 (1.34)	0.15	5.07 (1.38)	4.41 (1.21)*	0.51
My patients have a hard time getting good health care.	5.08 (1.38)	4.19 (1.60)**	0.60	4.45 (1.82)	4.43 (1.76)	0.01
My patients lack available resources for health care. (Factor A; $\alpha = .66$)	5.04 (0.99)	4.19 (1.24)**	0.76	4.93 (0.92)	4.00 (1.23)*	0.86
If my patients really need health care, they know where to get it.	4.54 (1.90)	3.88 (1.77)	0.38	4.36 (1.48)	3.88 (1.77)**	0.29

Patient confidentiality						
Maintaining confidentiality regarding my patients' health care is very important to me.	7.00 (0.00)	6.59 (0.69)*	0.83	6.81 (0.48)	6.78 (0.52)	0.06
My patients have expressed concern to me about the confidentiality of information about themselves.	5.07 (1.77)	4.59 (1.76)	0.27	4.47 (1.58)	3.43 (1.91)*	0.60
Their concern about confidentiality reduces my patients' willingness to talk openly with me.	4.86 (1.70)	3.22 (1.31)*	1.09	4.68 (2.06)	4.00 (2.12)*	0.32
Decision-making with patients						
I never pressure my patients in their health care decisions.	4.69 (1.89)	4.59 (1.74)	0.06	4.81 (1.49)	4.50 (1.42)**	0.21
Helping my patients with decision-making is important to me. (Factor H; α = 0.76)	3.12 (1.10)	3.15 (0.96)	–0.03	3.74 (0.90)	3.45 (0.88)**	0.33
I make all of the decisions about my patients' health care.	1.54 (0.88)	1.70 (1.35)	–0.14	2.66 (1.31)	2.39 (1.19)	–0.22
Relationship with patients						
My patients and I have a good relationship.(Factor G; α = 0.81)	5.19 (0.83)	5.10 (0.69)	0.12	5.48 (0.80)	5.21 (0.78)	0.34
I often interact with my patients outside of the clinic.	5.23 (1.79)	4.30 (1.59)*	0.55	4.25 (1.95)	3.89(1.71)*	0.47
Overlapping personal and professional relationships with my patients feel awkward. (Factor I; α = 0.80)	3.54 (1.20)	4.32 (1.43)**	–0.67	2.93 (1.40)	3.32 (1.35)**	–0.29

TABLE 1 *(Continued)*

Composite Scales and Individual Indicators	*Alaska Community Size*			*New Mexico Community Size*		
	<2,500 (n = 13)	*≥ 2,501 (n = 26)*		*<2,500 (n = 53)*	*≥ 2,501 (n = 60)*	
	Mean (SD)[1]	*Mean (SD)*[1]	d[3]	*Mean (SD)*[1]	*Mean (SD)*[1]	d[3]
My patients have expressed concern to me about knowing me in my personal role and professional role.	3.62 (1.98)	2.85 (1.17)**	0.51	2.49 (1.37)	2.34 (1.36)	0.11
Caregiver vs. Patient Embarrassment						
My patients avoid health care because they are embarrassed. (Factor F; $\alpha = 0.81$)	4.05 (1.81)	3.51 (1.37)	0.33	3.52 (1.39)	3.30 (1.21)	0.17
It is embarrassing to my patients to talk to me about stigmatizing illnesses. (Factor D; $\alpha = 0.93$)	3.31 (1.53)	3.19 (1.43)	0.08	3.80 (1.61)	3.02 (1.39)*	0.52
It is embarrassing to me to talk to my patients about stigmatizing illness. (Factor E; $\alpha = 0.98$)	1.17 (0.36)	1.09 (0.20)	0.29	1.39 (0.67)	1.49 (1.14)	−0.11

[1] Responses to all items were on a scale from *strongly disagree* (1) to *strongly agree* (7).
[2] Item was reverse-scaled.
[3] Cohen's d is an effect size that is the standardized mean difference.
[4] Differences between means within any column of .78 or more are significantly different by Fisher's LSD at: $p < .05$.
[5] Community size differences within each state are significantly different by Fisher's LSD at: * $p \leq .05$; ** $p \leq .10$.

Health Care Decision-Making

Analyses for the composite scale and two items assessing health care decision-making revealed a main effect for Measure, $F(2, 154) = 80.07$, $p < .0001$. Clinicians mildly agreed that they never pressure patients in their health care decisions, slightly disagreed that helping patients with decision-making was important, and strongly disagreed that they make all the decisions about their patients' care ($M = 2.07$). A main effect for state, $F(1,155) = 6.77$, $p = .01$, showed that Alaskan caregivers disagreed more on these measures overall ($M = 3.13$ vs. 3.59; $d = .48$). No community size effects were found.

Patient-Caregiver Relationship

Analyses for the two composite scales and two individual items examining the relationship between patient and caregiver revealed a main effect for Measure, $F(3, 151) = 87.76$, $p < .0001$. Caregivers believed they had good relationships with patients, were neutral about whether they often interacted with patients outside work, mildly disagreed that overlapping relationships with patients felt awkward to them, and disagreed that patients expressed concern about knowing them in both personal and professional roles.

A main effect for State showed that Alaskan clinicians more agreed with the measures than those from New Mexico ($M = 4.27$ vs. 3.68; $d = .79$), $F(1,153) = 17.72, p < .0001$. A marginally significant Community Size main effect showed those in smaller compared to larger communities agreed more with the relationship measures ($M = 4.09$ vs. 3.85; $d = .27$), $F(1,153) = 2.80, p < .10$ Main effects were qualified by a measure × community Size interaction, $F(3,151) = 4.20$, $p < .01$. This was mainly due to clinicians in smaller compared to larger communities agreeing more that they interacted with their patients outside work ($M = 4.74$ vs. 3.84; $d = .66$), but they also more disagreed that overlapping relationships with patients felt awkward ($M = 3.23$ vs. 3.82; $d = .36$). Finally, caregivers in smaller communities in Alaska (but not New Mexico) agreed more that patients expressed concern about knowing them in both personal and professional roles ($M = 3.62$ vs. 2.85; $d = .51$).

Reactions to Stigmatizing Illnesses

Analyses for the three composite scales assessing aspects of stigma revealed a main effect for Measure, $F(2,149) = 144.69$, $p < .0001$.

Caregivers weakly disagreed that their patients avoided health care because of embarrassment or were embarrassed to talk to caregivers about stigmatizing illnesses, and they strongly disagreed that it was embarrassing for them to talk to patients about stigmatizing problems. A measure × state interaction, $F(2,149) = 3.34$, $p < .04$, showed that caregivers in New Mexico disagreed more than those in Alaska that patients avoided health care due to embarrassment ($M = 3.41$ vs 3.78; $d = 0.26$); but caregivers in Alaska disagreed more that it was embarrassing to them to discuss stigmatizing illnesses with their patients ($M = 1.13$ vs 1.44; $d = .34$).

A reduced model MANOVA conducted only on the two measures referring to patients showed a main effect for community size, which indicated that clinicians in smaller compared to larger communities agreed more overall that patients avoided care due to embarrassment and that patients were embarrassed to talk with caregivers about stigmatizing illnesses, $F(1,152) = 14.96$, $p < .03$ ($M = 3.67$ vs. 3.25; $d = .29$).

DISCUSSION

Caregivers in smaller compared to larger communities more strongly report the lack of available *health care resources*. Some significant differences emerged by state, with New Mexico clinicians expressing more concern by patients regarding cost of care and Alaskan clinicians expressing greater limitations in the number of caregivers. Across both states, however, caregivers in smaller communities report that their patients know where to obtain care more than larger community caregivers, probably because scarce providers are more salient in rural and frontier communities. Clarity of treatment options, however limited, may be an interesting and previously unrecognized strength in rural communities.

Findings related to *confidentiality* support the hypothesis that safeguarding patient information is particularly challenging in rural settings. Clinicians everywhere value confidentiality of their patients highly, but clinicians in smaller communities indicate greater adverse impact of patient confidentiality concerns. This is reflected in rural clinicians perceiving patients as less willing to talk openly because of confidentiality concerns and as expressing more concerns to their caregivers about confidentiality. These results affirm anecdotal reports (Purtilo & Sorrell, 1986; Roberts et al., 2001) and replicate findings of others (Ullom-Minnich & Kallail, 1993), suggesting that heightened challenges in rural areas of protecting patient privacy should receive greater recognition in the health services and ethics literatures.

Regarding *decision-making* and *patient-caregiver relationships,* caregivers in smaller communities and larger communities perceive themselves to be equally involved in *decision-making* with patients. This does not vary by community size, although it does by state, with Alaskan caregivers more strongly disagreeing that they “pressure” and “help” patients in their decision-making and make “all decisions” for patients. Clinicians in smaller communities more commonly report interacting with patients outside of the clinic, although they also report feeling less awkward about such dual relationships than peers in larger areas. In general clinicians indicate that patients express little concern about knowing their caregivers in both personal and professional roles, but those in Alaska report more such concern from their patients. Overall, it appears that overlapping personal and professional roles are perceived and handled differently and perhaps more adaptively in rural than non-rural areas. This fits with the observation that the culture of rural life differs from urban life (Conger & Elder, 1994), in part, perhaps, due to stronger bonds among people through family, church, and community relationships. These “natural supports” are believed to be great strengths in the rural community (Kane & Ennis, 1996). However, given our findings, the possibility that overlapping roles are experienced differently by clinicians and by patients deserves further inquiry.

Examination of *stigma* and embarrassment in the context of caregiver-patient relationships confirm that rural clinicians provide care under different constraints than those in non-rural areas. Caregivers in smaller communities more often indicate that patients avoid health care because they are embarrassed and report that it is more embarrassing for patients to talk to their caregiver about stigmatizing illnesses than do clinicians in larger communities. In light of the high prevalence and, in some instances, rapidly increasing rates of stigmatized illnesses and problems (such as suicide, substance abuse, and violence), this is an important finding that warrants replication with more rigorous measures (Mulder et al., 2000; Robertson, Sloboda, Boyd, Beatty, & Kozel, 1997; Rost, 1998). Avoidance of health care because of feeling stigmatized may represent a barrier to care in rural communities that may have widespread public health implications.

Several limitations of this study must be kept in mind. For example, the samples were not representative of all clinicians practicing in

Alaska and New Mexico but were samples of convenience. The manner of operationalizing rural vs. non-rural differences was limited to community population size, and other ways of contrasting community sizes may prove additionally informative. Finally, differences between clinicians in Alaska and New Mexico may not reflect disparities between states but instead may reflect the fact that the two samples did not have equivalent training and background. These limitations notwithstanding, this study contributes to the emerging literature on rural health through its focus on ethical aspects of care provision from the perspective of clinicians who reside in two predominantly rural states, Alaska and New Mexico. Results indicate that small communities possess distinct features, clinically and ethically, and hint that constructive adaptations in smaller communities need to be better understood: This work serves as an invitation for further investigation of neglected ethical issues that are involved in providing health care to over 60 million people in rural areas of our country.

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