

A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem

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OBJECTIVES: To determine whether outcomes have changed over time for a managed, systematic approach to advance care planning (ACP).

DESIGN: Retrospective comparison of medical record and death certificate data of adults who died over a 7-month period in 2007/08 with those of adults who died over an 11-month period in 1995/96.

SETTING: All healthcare organizations in La Crosse County, Wisconsin.

PARTICIPANTS: Five hundred forty adults who died in 1995/96 and 400 adults who died in 2007/08.

INTERVENTION: A systematic ACP approach, Respecting Choices, collaboratively implemented in 1993 and continuously improved in subsequent years.

MEASUREMENTS: Demographic and cause-of-death data were collected from death certificates. Type and content of any advance directive (AD), existence and content of Physician Orders for Life-Sustaining Treatment, and medical treatment provided at the location of death in the last 30 days of life were abstracted from the medical record.

RESULTS: The recent data show a significantly greater prevalence of ADs (90% vs 85%, $P = .02$) and of availability of these directives in the medical record at the time of death (99.4% vs 95.2%, $P < .001$) than the data collected over 10 years ago. The new data suggest that quality efforts have improved the prevalence, clarity, and specificity of ADs.

CONCLUSION: A system for ACP can be managed in a geographic region so that, at the time of death, almost all adults have an advance care plan that is specific and available and treatment is consistent with their plan. *J Am Geriatr Soc* 58:1249–1255, 2010.

Key words: advance care planning; advance directive; end of life; ethics

In 2008, the Department of Health and Human Services (HHS) issued a report to the U.S. Congress called *Advance Directives and Advance Care Planning*.¹ This report concluded that the use of advance directives (ADs) and the attempts to promote advance care planning (ACP) have largely failed. A number of other articles have supported this conclusion.^{2,3} Mere completion of legal documents, such as a living will or even a power of attorney for health care (POAHC), and most efforts to promote them are not associated with markedly better care at the end of life.

This report to Congress also identified two approaches that have demonstrated success: Respecting Choices (RC) and the Physician Orders for Life-Sustaining Treatment (POLST) paradigm. Data about RC's success were first reported in 1998 as the first La Crosse Advance Directive Study (LADS I).⁴ LADS I was a retrospective study that reviewed medical records and death certificates of 540 adult decedents in La Crosse County, Wisconsin, from March 1995 to April 1996. LADS I found that, at the time of death, 85% of all adult decedents had an AD, 95% of these ADs were in the patient's medical record at the healthcare organization providing care at the time of death, and in 98% of the cases, the instructions regarding cardiopulmonary resuscitation (CPR) and hospitalization in the AD were consistent with the treatments provided near the time of death. These findings were and remain markedly different from other reports about the prevalence, availability, and utility of ADs.^{5–9}

RC, fully implemented in 1993, began as, and remains, a collaborative effort of the La Crosse, Wisconsin, healthcare organizations. These healthcare organizations have worked to develop a system in which six goals are part of routine care:¹⁰ (1) adult patients are invited to understand, to reflect on, and to discuss plans for future healthcare relevant to their stage of illness; (2) adult patients are

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provided competent assistance by trained nonphysicians in the planning process; (3) written plans (however documented) are accurate, as specific as possible, and understandable to all stakeholders; (4) written plans are stored, transferred, and retrievable wherever the patient is being treated; (5) plans are updated and become more specific as illnesses progress; and (6) plans are reviewed and honored at the right time.^{11–13}

To achieve these goals in the La Crosse region, an ACP microsystem has been organized, and this system is subject to continuous quality improvement. A clinical microsystem can be defined as an organized group of people who work to provide a specific service to a defined population of patients.¹⁴ An ACP microsystem, then, organizes a group of people to elicit, understand, document, and honor a patient's preferences about future medical care.

A long list of improvements has been undertaken in La Crosse since 1993, but three important improvements have been introduced since the data were collected for LADS I.

- In 1997, the healthcare organizations in La Crosse decided to implement the POLST paradigm regionwide, including in all of La Crosse County, being the first place outside of Oregon to do so. The POLST paradigm is designed to convert the preferences of a patient whose death is not unexpected into specific, relevant medical orders on a standardized order sheet that is honored in all care settings.^{15,16}
- In 1998, a user-friendly, clinically specific, state statute-compliant document called the *La Crosse POAHC*¹⁷ was developed to replace the Wisconsin statutory document previously in use. This document was designed to be easier to read and understand, provided tips about how to make specific decisions (such as how to best pick an effective healthcare agent), provided more guidance about important instructions that were relevant even to a healthy adult, and explained how to send the completed document to the individual's healthcare provider.
- Finally, in 2002, one of the community's healthcare systems developed a unique application in its electronic medical record (EMR) that launches all routine ACP practices from a single summary page. For example, this application stores AD documents electronically according to type and allows physicians to dictate notes about important care plans under the paragraph heading "Advance Directive Section." These dictated notes range from "the patient has decided to be a full code" to "the patient has decided to take a palliative approach to treatment and wishes no treatment to sustain life." Any provider in this system can find these notes and any AD documents within 5 to 10 seconds of opening the patient's EMR.

This report compares data recently collected in LADS II with data collected and published more than 10 years ago in LADS I. The goal is to determine whether the "success" of RC in La Crosse, Wisconsin, as identified in the HHS report to Congress, has been sustained or improved. More specifically, the goals are to determine whether the high rate of prevalence, availability, and utility of advance care plans found in LADS I has been sustained and whether the prevalence, availability, and specificity of advance care plans are

better after the major improvement efforts described above, including implementation of the POLST paradigm.

METHODS

After approval of the LADS II research protocol by the Gunderson Clinic and Franciscan Skemp institutional review boards, a retrospective review of the medical record and death certificate data of adults who died under the care of any of the participating healthcare organizations any time from September 1, 2007, to March 31, 2008, in La Crosse County, Wisconsin, was conducted. LADS II was designed to study adult deaths in the same geographic location as—and using methods as similar as possible to those used in—LADS I.

Study Setting and Population

LADS II was conducted in La Crosse County, Wisconsin, a county with a mixed urban and rural population. In 2005, the county had a population of 110,000,¹⁸ up from approximately 102,430¹⁹ at the time LADS I was conducted.

All decedents aged 18 and older who resided in La Crosse County, Wisconsin, for at least 6 months before their death and who were mentally capable at some point during the previous 15 years were included in the study. Exclusion of a decedent was based on the researchers' judgment after review of the patient's medical record.

All emergency department deaths, as well as deaths of adults in the community who were not admitted as patients to a healthcare organization, were reviewed to determine whether adequate time was available for healthcare professionals to review the patient's preferences before death. For example, decedents who were pronounced dead at an auto accident, were found dead in their home, or were dead upon arrival were excluded from the study. These eligibility criteria were the same as in LADS I, with the exception that LADS I decedents had to be mentally capable at some point in the previous 10 years. These (10 and 15 years) time frames were established based on the period when ADs were legally recognized in Wisconsin. Before this time, creating an AD was not a realistic expectation for any patient.

All healthcare facilities in the county participated in LADS II: two nonuniversity, nonprofit teaching hospitals; seven nonprofit, Medicare-approved, long-term care facilities; two nonprofit home health agencies with hospice programs; and a county health management organization. All facilities approved the researchers' access to the medical records of all patients who died under their care during the study period. Two long-term care facilities that had been excluded from LADS I because of lack of funding to support research personnel to collect data in those two facilities were included in LADS II.

All of the healthcare organizations in La Crosse County are using the RC ACP system. RC uses an integrated, organized approach to ACP that uses standardized patient education materials and documents; medical records processes, policies, and practices; and trained nonphysician facilitators in collaboration with treating doctors. These various components are used in a coordinated manner to assist patients and their families to create informed advance plans, to document these plans in a uniform manner, to make sure that these plans are available to a treating

physician when needed, and to ensure that treatment orders are written in a manner consistent with a patient's preferences. This system depends on measuring outcomes and quality to constantly improve each element of the system.^{10–13}

Data Collection

Two research assistants trained in the study protocol by the principal investigators collected data. The principal investigators audited the data periodically for accuracy and consistency. Any inconsistencies identified during data collection or entry required a second review of the data sources by the principal investigators, but no formal reliability assessment was conducted. Questions about data interpretation were discussed and resolved in regular meetings between the research assistants and the principal investigators.

In LADS I, researchers were allowed to directly review all death certificates at the county offices, but in LADS II, it was necessary to send a list of study decedent identifiers to the State of Wisconsin. In turn, the state provided a compact disc containing data from those decedents' death certificates, including date of birth, date of death, sex, location of death, marital status, ZIP code of residence, highest year of education completed, immediate cause of death, and any other relevant conditions. The State of Wisconsin provided the total number of La Crosse County residents who died in La Crosse County in LADS II based on their review of their statistics.

As in LADS I, in LADS II, causes of death were grouped into four categories: terminal, chronic, sudden, and no underlying disease. Terminal causes included cancers, human immunodeficiency virus infection, and acquired immunodeficiency syndrome. Chronic causes were other progressive, incurable illnesses that led to death over many months or years. Sudden causes were cases in which no previous disease existed and that led to death rapidly. The no underlying disease category included trauma or self-inflicted injury as the cause of death.

Data collected from the medical records included information about the presence, type, and content of the ADs, as well as the presence of a POLST form, its respective orders, and who was involved in the creation of the form. All types of signed documents and dictated or written notes documenting a patient's preferences were considered to be ADs. The same data were collected in LADS I, with the exception of data about the POLST form, which had not been in use during the earlier study period.

As in LADS I, medical interventions, such as resuscitation efforts, intubation, ventilator support, antibiotics, feeding tubes, and surgeries, occurring within the last 30 days of life were recorded. Information about changes in code status within the last 30 days of life and code status at time of death was also captured.

Data were collected on standardized forms. Each data collection form for a single decedent was assigned an identification number to protect confidentiality.

Analysis

All data were entered into a database and analyzed using SAS, version 9.2 (SAS Institute, Inc., Cary, NC). Univariate analyses of categorical variables were performed using chi-

square tests. If at least 25% of cells had expected frequencies fewer than 5, the Fisher exact test was used in place of the chi-square test. Analyses of continuous variables over two classes, such as age between LADS I and II, were performed using two-tailed *t*-tests. If the sample data indicated that the population data might not have followed the normal distribution, as when comparing education level between LADS I and II, the Wilcoxon rank sum test was used in place of the *t*-test. $P < .05$ was considered significant.

Consistency between patient preferences (documented in ADs or POLSTs) and treatment provided was determined by comparing the dates on the document with the dates of treatment in the last 30 days of life. Documents with no dates were excluded from the consistency analysis. When inconsistency was determined, one of the principal investigators (BJH) reviewed the medical record.

RESULTS

Demographics

Four hundred four of 519 (78%) adult decedents were identified as eligible for LADS II. Four of these, all of whom had ADs, were subsequently excluded because insufficient medical information was available for analysis. In comparison, 540 of 707 (83%) adult decedents were included in LADS I.

LADS I and II decedents were similar in terms of age and sex, but there were differences in education, cause of death, and location of death (Table 1). Decedents in LADS I and II had the same median education level (12th grade), but a higher proportion in LADS I had an 8th-grade education (25% vs 15%), and a higher proportion in LADS II had a 12th-grade education (48% vs 34%). In LADS I, more decedents died suddenly (14% vs 7%), and fewer decedents died from chronic causes (58% vs 65%). The two studies also differed in location of death, but when inpatient hospice deaths were excluded from the analysis (inpatient

Table 1. Characteristics of La Crosse Advance Directive Study (LADS) I (N = 540) and LADS II (N = 400) Decedents

Characteristic	LADS I	LADS II	P-Value
Age, mean (range)	80 (20–103)	80 (36–108)	.12
Female, n (%)	292 (54)	220 (55)	.58
Education, mean/median, years	11/12	12/12	.001
Cause of death, n (%)			
Chronic	313 (58)	259 (65.0)	
Terminal	146 (27)	106 (26.5)	
Sudden	76 (14)	29 (7.0)	.007
No underlying disease	5 (1)	6 (1.5)	
Location of death, n (%)			
Home	76 (14)	56 (14)	
Hospital	197 (36)	120 (30)	
Inpatient hospice	0 (0)	40 (10)	<.001*
Long-term care facility	267 (50)	184 (46)	

* When inpatient hospice deaths were excluded from analysis (inpatient hospice was not available during LADS I), the difference in location of death was not significant ($P = .57$).

hospice was not available during LADS I), location of death was not statistically different ($P = .57$).

Prevalence and Type of Written Plans

The prevalence of ADs was significantly higher in LADS II than in LADS I (90% vs 85%, $P = .02$), and these ADs were significantly more available in the decedent's medical record at the location of death (99.4% vs 95%, $P < .001$) (Table 2).

Of the LADS II decedents who had ADs, a significantly higher percentage (90% vs 77%, $P < .001$) had POAHC documents than in LADS I. It was also determined that, in LADS II, all but two of the POAHC documents were La Crosse POAHCs, unlike in LADS I, in which all the POAHC documents were Wisconsin statutory documents.²⁰ Living wills or other instructive ADs were equally prevalent in LADS II and LADS I (8% vs 10%, $P = .41$), but there were significantly more dictated advance care plans in LADS II than in LADS I (33% vs 13%, $P < .001$). When considering all forms of ADs, the ADs in LADS II were created a median of 3.8 years (range 0–21 years) before death, compared with 1.3 years (range 0–13.6 years; $P < .001$) in LADS I (Table 2).

In addition to ADs, 268 (67%) of LADS II decedents had a completed POLST form at the time of death. For 264 (98.5%) of these decedents, these forms were found in their medical record at the organization providing care at the time of death. The POLST documents, which typically are created closer to the time of death than ADs, were created a median of 4.3 months (range 0–114 months) before death. LADS II decedents had an AD or a POLST form at the time of death 96% (384/400) of the time. One hundred sixteen decedents had an AD but no POLST.

Specificity and Consistency

The relationship between advance care plans and medical treatments from both studies were examined. Taking into

account all ADs and POLST forms, decedents in LADS II were more likely than those in LADS I to have documented specific preferences about CPR (93% (372/400) vs 63% (339/540), $P < .001$) and about hospitalization (65% (260/400) vs 15% (83/540), $P < .001$).

Overall, consistency between preferences about CPR and hospitalization and medical decisions at the end of life in LADS II was not statistically different from in LADS I (Table 3). In LADS I, it was found that preferences regarding CPR and hospitalization were consistent with treatment in 98% (530/539) of the cases; in LADS II, these preferences were consistent with treatment decisions in 99.5% (380/382) of cases ($P = .14$).

There was better consistency in LADS II when preferences not to hospitalize were analyzed alone. In LADS I, the request not to be hospitalized for acute care was not honored 16 times—eight times with no documented ethical or medical justification (e.g., ethical = the patient changed his mind but not his advance care plan; medical = the patient needed to be sent to a hospital for palliative reasons) for not doing so (8/37, 22%). In LADS II, there were 15 instances in which a patient was hospitalized despite the plan not to do so—twice with no documented ethical or medical justification for not doing so (2/151, 1%; $P < .001$).

In LADS II, there were no instances in which the decedent's CPR preferences were not followed; in LADS I there was one instance in which CPR was attempted on a decedent who clearly did not want it. In LADS II, 15 decedents requested CPR but did not have CPR attempted, and three decedents had preferences for no CPR but received resuscitation. In all 18 instances, a close review of the clinical record found that the treatment decisions adhered to the patient's known plans.

Table 2. Prevalence, Availability, and Creation Date of Advance Directives (ADs), La Crosse Advance Directive Study (LADS) I (N = 540) Versus LADS II (N = 400)

Advance Directive Status	LADS I	LADS II	P-Value
Decedents with ADs, n (%)	459 (85.0)	360 (90.0)	.02
Of these, ADs in medical record, n (%)	437 (95.2)	358 (99.4)	<.001
Type of AD, n (%)			
Power of attorney for health care	353 (77)	324 (90.0)	<.001
Living will	46 (10)	30 (8.0)	.41
Dictated note	60 (13)	120 (33.0)	<.001
POLST, n (%)	NA	268 (67.0)	NA
Of these, POLSTs in medical record, n (%)	NA	264 (98.5)	NA
Years from AD creation to death, oldest date used, median (range)	1.3 (0–13.6)*	3.8 (0–21)*	<.001
Months from POLST creation to death, median (range)	NA	4.3 (0–114)	NA

* 19 records in LADS I and 19 records in LADS II (1 AD and 18 Physician Orders for Life-Sustaining Treatment (POLST)) were not dated. NA = not available.

DISCUSSION

Data from LADS II show significantly greater prevalence, availability, and specificity of advance care plans than in LADS I. In addition, specific plans regarding hospitalization were more consistent with treatment in LADS II than in LADS I. This demonstrates that, after more than 10 years, not only have the results of LADS I been sustained, but significant improvements have also been made.

These findings stand in stark contrast to the claims by some authors that ADs have failed. This is not to suggest that the claims of these authors about the failure of ADs are wrong; rather, it is to note that these failures exist in places where sustained, systematic ACP approaches have not been attempted. According to one pair of critics, ADs would work only if five necessary conditions were met—conditions they contend are “nearly impossible” to achieve.³ The findings from this article show that it is possible to create and sustain an approach to ACP that meets all five of these conditions: (1) at the time of death, almost all of the decedents had an advance care plan (AD or POLST = 96%); (2) most plans had specific instructions such as CPR versus no CPR and no hospitalization; (3) these plans were written with sufficient clarity that clinicians and surrogates could use them in ongoing treatment decisions across sites of care; (4) almost all of the time, the plan was available to the healthcare professionals taking care of the patient near the

Table 3. Consistency of Patient Cardiopulmonary Resuscitation (CPR) and Hospitalization Preferences with Treatment Received*

Preference	LADS I (AD only)				LADS II (POLST)				LADS II (AD only)				
	Not Treated		Treated		Not Treated		Treated		Not Treated		Treated		
	Inconsistent	Treated	Inconsistent	Treated	Inconsistent	Treated	Inconsistent	Treated	Inconsistent	Treated	Inconsistent		
CPR preference, n													
No CPR	242	1	1	245	0	0	0	0	62	3	0	0	
CPR	7	1	ND	5	0	0	0	0	11	6	0	0	
Provider's choice†	85	3	ND	0	0	0	0	0	19	3	0	0	
No stated preference	100	1	UK	0	0	0	0	0	9	2	UK	0	
No hospitalization, n	21	16	8	136	15	2	2	15	0	0	0	0	
									P-Value‡				
									.498				

*Nineteen records in La Crosse Advance Directive Study (LADS) II (1 advance directive (AD) and 18 Physician Orders for Life-Sustaining Treatment (POLST)) were not dated. These documents could not be used in the analysis of consistency.

† P-value compares the proportion of inconsistent records between LADS I and LADS II.

‡ "Provider's Choice" is a preference documented in a La Crosse power of attorney for healthcare document. The preference means that a patient wants CPR attempted unless their treating physician has determined that the patient's health condition has become so critical that CPR has no reasonable chance of resulting in a prolonged survival if attempted. ND = consistency for these categories was not determined in LADS I.

time of death (99%); and (5) plans were almost always consistent with treatment (99.5%).

These conditions cannot be met by chance alone. To successfully meet these five conditions, an ACP microsystem must be developed. Like other successful microsystems in health care,¹⁴ an ACP microsystem needs to be designed, managed, and constantly improved.^{21,22} The quality improvements efforts in La Crosse have helped make the system work better.

Since the LADS I study, the La Crosse POAHC was introduced. This change was successful, as evidenced by a nearly complete shift in the type of POAHC used in the community. In LADS I, all POAHC documents were Wisconsin statutory documents. In LADS II, 99% of POAHCs were created using the La Crosse POAHC. This is especially notable because the La Crosse POAHC document is created in multiple settings, including attorneys' offices, outpatient clinics, hospitals, long-term care facilities, churches, and private homes. This change is also important because, in LADS II, the percentage of patients with known CPR preference is greater than what was found in LADS I (91% vs 63%). This increase is not surprising because the La Crosse POAHC document is designed to encourage the adult completing the document to think about and record a preference about CPR.

LADS II results also showed that implementation of the POLST paradigm was highly effective; 67% of decedents had a completed POLST form, the form was almost always in the place where the decedent died, and the POLST orders analyzed were nearly always consistent with the treatment provided. In fact, because it is common practice for local hospice programs to destroy any patient records in the home of a hospice patient after death, and because a copy is not always put in the permanent medical record, it is likely that the prevalence of the POLST form is underreported here. Most importantly, use of the POLST paradigm has increased the specificity of plans. For example, LADS II patients preferred no hospitalization six times more often than LADS I patients (164 of 400 vs 37 of 540).

It is also noteworthy that the active POLST form was created closer to the time of death (4.3 months) than the existing AD (3.8 years). Because the POLST form consists of medical orders most appropriate for patients with a short life expectancy (≤ 1 year), it is reassuring that the active POLST form was completed approximately 4 months before death. These findings suggest that, in this ACP system, planning is an ongoing process, plans become more specific as patients' illness progress, and plans are converted into medical orders that can be followed even as the patient changes settings of care. These findings are particularly important because patient preferences change over time,²³ and these changes often are not communicated between settings of care.^{24,25}

The EMR system enhancement at one of the healthcare systems, whereby providers can dictate and quickly retrieve notes about patients' end-of-life treatment decisions, appears well used and represents an improvement since LADS I. In LADS II, dictated notes were found for 33% of decedents with an AD, versus 13% in LADS I. This finding suggests that a well-designed EMR can help make ACP an ongoing, dynamic process, and not only will physicians engage in such discussions with patients about their value and

goals for future care, but also, when an effective EMR is in place, they will document these plans.

It was somewhat surprising that the subjects from LADS I and II differed in cause of death and education level, but improvements in acute care management and access to education might explain these differences. A smaller percentage of decedents in LADS II died of sudden causes and a greater percentage of chronic illness. This difference may reflect improvements in acute care management since LADS I that allow patients with diseases of the heart and brain to survive initial events only to die later of chronic conditions. The higher proportion of decedents with 8th-grade education in LADS I and higher proportion with 12th-grade education in LADS II probably reflects greater access to a high school education beginning in the 1930s.²⁶ It is unlikely that these differences affected the overall findings.

This study has several limitations. First, unlike in LADS I, direct access to the death certificates of everyone who died in La Crosse County during the study period was not available in LADS II. It is possible that a few eligible deaths were missed, although the number is probably small because the number of deaths captured is in keeping with what could be expected in a population of this size in 7 months (the study period). Second, given that this is a retrospective review of deaths and that the potential effects of system changes were being evaluated, that the differences between LADS I and II might be due to other unknown variables cannot be excluded. Third, retrospectively determining whether a patient's plans were honored in the last weeks of life is complex. What the family believed or what the health professional believed in these cases is unknown. Although the method of determining consistency may lead to differences of opinion in some cases, it is likely that a patient's preferences were ignored or overridden in only an extremely small set of cases. Finally, the population of La Crosse County is largely white, and two large integrated community health systems provide all physician and hospital care. It is not clear how generalizable these findings are to communities with more-diverse populations and more-fragmented healthcare delivery systems.

CONCLUSION

The results of this study suggest that, when an ACP system is designed and improved over time, it is possible to achieve a high prevalence of advance care plans, these plans can be available to any provider in any setting of care, and these plans can be specific enough to assist with clinical decisions. When these factors are achieved, it is possible to achieve a high rate of consistency between advance care plans and the treatment decisions made for the patient. Other systematic ACP approaches have shown similar success in other places.^{27–29}

This study provides additional support to the conclusion of the HHS report to the U.S. Congress—RC and the POLST paradigm are effective programs for ACP—and it suggests that combining the two programs may result in greater effectiveness.

Implementing such an ACP system is challenging. It requires resources and a redesign of the systems found in most places in the United States. Creating such a system needs not only a sustained commitment of resources, but also sustained leadership. Ultimately, what needs to be cre-

ated is a healthcare culture in which knowing and honoring a patient's preferences is given a priority similar to knowing and documenting: a patient's allergies to medications, what medications a patient is taking, and what medical problems a patient has. These are challenging, but not impossible, improvements to make. If a high value is truly put on knowing and honoring patient's preferences, an effective ACP system can be realized.

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Conflict of Interest: BJH and JGG are employees of the Gundersen Lutheran Medical Foundation, a not-for-profit organization dedicated to medical education and research that owns the copyrighted materials known as RC referred to in this article and sells these materials and the related training. BJH is a coauthor of the RC professional training materials and is entitled to a small royalty if and when a net profit is made on these materials. BLR has no competing financial interests.

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