

Research Methodology for Life Care Planners

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Introduction

Why are we, as clinical practitioners, interested in research aimed at validating the process of Life Care Planning? There are multiple answers. Through research we can improve the process, raise standards, help answer ethical questions and resolve ethical dilemmas. Perhaps most importantly we protect the patient's access to life enhancing care through this very useful Case Management tool. Ensuring the future of Life Care Planning is essential to protecting the catastrophically injured patient's access to quality of life enhancing care through visionary case management practices. In light of the recent challenges presented by the Daubert rulings, the future of Life Care Planning as a forensic tool is dependent upon validating the Life Care Planning process in the eyes of the court (Countiss & Deutsch, 2002). We can do this through definitive research attesting to consistent methodology employed by Life Care Planning professionals that is reliable, valid and relevant to the individual patient's case. Because we intend to objectively validate the utility of Life Care Planning as a tool in case management, let's first consider the facets of reliability that are prerequisite to validation of Life Care Planning.

Issues Related To Reliability

Demonstrating the reliability of Life Care Planning as a case management tool is at the heart of validating Life Care Planning as a specialty area of practice. Reliability is comprised of the dependability and consistency of the Life Care Planning process to yield similar results under similar conditions. In other words, Life Care Plans (LCPs) are reproducible. If Life Care Planning is a reliable tool in Case Management and the provision of patient care, then the results of a given LCP can be consistently replicated. We can convincingly demonstrate reliability of Life Care Planning by appropriately designed research studies. First we need to discriminate between two aspects of reliability: intra-planner and inter-planner reliability (Bellini & Rumrill, 1999).

Intra-Planner Reliability

Intra-planner (a.k.a., Intra -rater, or Intra -observer) reliability provides internal consistency to the process much like "test-retest". Intra-planner reliability attests to the consistent

application of an individual Life Care Planner's processes and the reliability of the results of that process. Given similar circumstances, the process of developing the LCP recommendations and cost estimates are the same. Certainly, similar forms and procedures would be used for collecting the information needed for similar cases. But intra-planner reliability goes beyond that type consistency.

Because the LCP is a document that makes recommendations for case management and estimates the costs of those recommendations, it will produce similar recommendations and cost estimates given patients with similar disabilities and life circumstances. Differences between the individual patients, their families, and geographic locations would be appropriately noted as modifying factors in the comparisons. Example: The basis for establishing the skill level involved in the provision of care for a C-5 tetraplegic should remain consistent regardless of geographic location and irrespective of subsequent development of cost data. What is being validated is the basis for establishing need for care, level of care, and availability of care. Costs are incidental to these issues. It does not vary depending upon the geographic locale or any other predisposing factor for bias. The significance of inter-planner reliability is that a given Life Care Planner will produce the same LCP document whether it is produced in Indiana or California, whether it is produced as an Independent Medical Examination (IME) or as a forensic tool of the defense or plaintiff or even whether funding is available to implement the recommendations.

Inter-Planner Reliability

Inter-planner (a.k.a., Inter-rater, or Inter-observer) reliability provides external consistency to the process. Inter-planner reliability indicates that Life Care Planning is a standardized process, consistently applied by Life Care Planners across the country in a similar manner. Given similar client disabilities and circumstances, Life Care Planners, in general, present similar recommendations and cost estimates. Wide discrepancies do not occur between plans generated by different Life Care Planners for the same patient. Let's consider an example demonstrating these concepts.

What if Dr. Smith who always works for the plaintiff, always gets his cost estimates for custom modification of a vehicle to accommodate a wheelchair from Jaguar, Porsche, and Mercedes? Dr. Smith could show a tight range of costs, and his results would be consistent and dependable over time, for each and every LCP he develops. On the other hand, his colleague, Dr. Jones, only accepts defense work. Dr. Jones consistently gets his cost estimates from Bubba's Junkyard, Billy Bob's Pre-Owned Palace, and Honest Eddie's. [Note: Honest Eddie's motto is "We'll beat any deal or give it to you for free," so Dr. Jones always checks with him last.] Dr. Jones's results are also consistent and dependable over time, for each and every LCP he develops. However, reliability between the LCPs provided by Dr. Smith and Dr. Jones does not exist. The results vary depending upon which Life Care Planner writes the LCP!

Dependability and consistency in applying the Life Care Planning process will reliably yield similar results under similar conditions. While general reliability is necessary to establish validity, it is not entirely sufficient. Validity is case specific. A standard, "valid" life care plan for all people who are infected with HIV does not exist. Each LCP must be valid for the individual for whom it was developed. If Life Care Planning is a valid process, then a good LCP will accomplish its mission: one mission should be to "provide appropriate future care to meet individual client needs, to decrease the frequency and severity of medical complications for a particular patient, avoiding case management by crisis intervention, and improving the

patient's overall quality of life. Establishing the validity of the Life Care Planning process shows that the basic tenets of Life Care Planning are sound.

Issues Related To Validity

Validity has four major aspects: face validity, content validity, criterion-related validity and construct validity. These four aspects can be used as lenses through which to view validity. For validity to be established, evidence of each of the four aspects should be demonstrated (Bellini & Rumrill, 1999, Chap. 3).

Face Validity

Face validity in life care planning refers to whether the LCP "looks like" it appropriately details the disability-related needs of a given individual. Although face validity is not evidence of whether or not the LCP accurately presents an individual's needs, it is still important to Life Care Planners. Because the LCP is a tool for educating people about disability-related needs, if it does not appear to represent those needs accurately, then family members, judges, juries, insurance adjusters, etc. may not accept it as a useful instrument. The establishment of face validity speaks to the lay audience.

Content Validity

Content validity relates to whether the elements included in the LCP actually address all the disability-related needs of an individual with a particular disability and set of circumstances for enhancing their life across their life span. The specific LCP should address all of a particular patient's needs without providing for extraneous treatments. An annual urological exam would be an important part of the LCP for a person with a spinal cord injury, but not for an individual who has had her leg amputated. Furthermore, to find a meaningful and useful life, the patient's needs could reasonably be expected to extend beyond medical care. These needs may include vocational education and retraining. One approach to examining content validity is to have a group of recognized experts come to consensus about which items are most appropriate. Relating your recommendations to published treatment protocols and standards of care could help you to demonstrate the content validity of elements in your life care plan. An excellent reference is *Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals* issued by the Consortium for Spinal Cord Medicine (July 1999).

Criterion-Related Validity

Criterion-related validity is the gold standard of validity. Evidence of criterion-related validity is presented when a relationship exists between the LCP's recommendations and estimated costs and some outside measure, or criterion, relevant to those recommendations and estimated costs. There are three types of criterion-related validity: concurrent validity, predictive validity, and convergent and divergent validity.

Concurrent Validity

Concurrent validity refers to the relationship between elements of the LCP and objective findings available at the time the plan was developed, (concurrent "at the same time"). If the client fits the demographic profile and circumstances of individuals studied in *Aging With Spinal Cord Injuries* (Whiteneck, Charlifue, Gerhart, et al., 1993), it should be possible to demonstrate similarity between the LCP's recommendations and the recommendations made for the individuals in that published study. As medical research and education advance, the standards of practice for Life Care Planning must necessarily evolve to keep pace. Demonstrating concurrent validity shows that the specific LCP meets the current standards of practice and is not obsolete.

Predictive Validity

Predictive validity is of greatest interest to those utilizing the LCP for reserve setting, budgeting, or in a forensic setting. Demonstrated predictive validity answers these questions: 1) Do the recommendations and cost estimates accurately predict the services over time that will be needed by the individual for whom the plan was written, and at what cost? 2) If the LCP's recommendations are implemented in full, and the LCP predicts they will help reduce the incidence, frequency, severity, and duration of complications, will the research study demonstrate a difference from the occurrence of those complications in patients with similar injuries but without LCPs? 3) If projections of life expectancy are included in the LCP, are those projections accurate? Predictive validity examines the quality and quantity of follow-up on patients with whom LCPs have been completed. The goal is to re-examine these patients and update the plans later in time to establish predictive validity.

Convergent And Divergent Validity

Convergent and divergent validity are specific types of criterion-related validity. They could be addressing either concurrent or predictive variables. Essentially, if you have evidence that two things that should be similar to each other, are similar to each other (converge) you have evidence of convergent validity. Likewise, if two things that should be different from each other, actually are different from each other (diverge), you have evidence of divergent validity. Evidence of convergent validity is demonstrated when the recommendations in a LCP for an individual who has lower extremity paralysis are similar, in some ways, to those in a plan for an individual who has lower extremity amputation. On the other hand, the recommendations for an individual who has congestive heart failure would be expected to differ from those of an individual who has a hearing impairment. If the Life Care Plans for these two individuals are not different, then the divergent validity of the two plans is not demonstrated.

Construct Validity

Construct validity is the essential validity to establishing that the basic tenets of Life Care Planning are sound and are evolving contemporaneously with related health care fields. Construct validity might best be understood as theoretically related validity. Evidence of construct validity is presented when a theory or hypothesis predicts a particular finding, and the

results of an analytical study correspond to that prediction. Although Life Care Planning is not a theory per se, many of the underlying tenets of Life Care Planning could be considered theoretical propositions. For example, we operate under the assumption that the development and implementation of a good LCP will decrease the incidence of medical complications, and increase an individual's quality of life. To test that assumption, we could compare the rate of complications for people who have implemented a LCP with those who did not have a LCP. We could also interview individuals with implemented LCPs and individuals without such plans, and ask them questions about their quality of life.

Consideration of construct validity leads us to conclude that validation must be an ongoing process. There are many different aspects of validity most of which change with time. The large number of variables involved in LCP complicates the process of researching reliability and validity relative to Life Care Planning. The only solution is to reduce the number of variables in any given research project and increase the number of projects being conducted. No single study will conclusively validate Life Care Planning once and for all. Every research study provides another piece of evidence establishing Life Care Planning as a valid Case Management tool. We need to begin collecting elements that contribute to establishing the validity Life Care Planning's place in the management of the catastrophically injured patient's case.

Basic Scientific Research Methodology

Basic scientific research can be applied to achieve the goals of demonstrating the reliability, validity and relevancy of Life Care Planning as a tool for Case Management of the severely disabled patient. In order to do that, we need an understanding of scientific methodology.

Hypothesis-Driven Research

Basic scientific research is driven by the testing of hypotheses. The hypothesis is our best supposition of what we think is happening under a given set of circumstances. While the development of a working hypotheses is applicable to individual client assessment (Reid, 1997), and is employed in daily clinical practice, it can also be applicable to a larger field in general such as Life Care Planning. Each scientific study or experiment is designed to ask a particular question about the hypothesis. The results of each study or experiment have the potential to either lend support to the truth of the hypothesis or to disprove some challenge to the hypothesis. As the evidence in support of a hypothesis accrues, the hypothesis may become a well-accepted theory on how things work. This does not imply that Life Care Planning is a theory. It is certainly not a theory, but rather a very useful tool. So how might we develop hypotheses about Life Care Planning to test scientifically?

Traditionally, hypotheses develop from careful observations of a phenomenon or reviews of the published literature in an area leading to a rational assessment of the field. Once an idea is intellectually formed of how things might be working, then a research question can be posed to test whether the hypotheses is true. A scientific study sets forth specific aims and objectives to answer the research question. The specific aims define the response variable that will be recorded as the outcome of the investigation. In the instance of research for validation of Life Care Planning, the body of published literature is only now emerging. For a comprehensive anthology, see the appendix to the *Amicus Curiae Brief* (Countiss, 2002) and *The Bibliography of Life Care Planning and Related Publications* (Weed, Berens & Deutsch 2002), as well as

Hamilton's state of the science paper (1999). However, the issues arising from the U.S. Supreme Court ruling on *Daubert v. Merrill Dow* (1993) can serve to support rationale for scientific studies to validate the Life Care Planning process. The ruling has asked three important questions as to whether Life Care Planning, in all its aspects, are 1) reliable, 2) valid, and 3) relevant to each specific patient's case. Therefore, our hypothesis is that LCPs are indeed 1) reliable, 2) valid, and 3) relevant to each specific patient's case.

The Research Process

A single hypothesis can generate many research questions. Several research questions generated by this hypothesis are posited as instructive examples throughout this manuscript. In a research study, the research question is addressed by development of specific aims and the research objectives through which the specific aims are going to be accomplished. The specific aims specify the response variables to be analyzed. Next, the study protocols and procedures are developed. The protocols and procedures detail the methods to be employed to assure consistent collection of reliable data. After the data is gathered, it must be statistically analyzed. To be meaningful, the results must be interpreted in context of the current state of the profession and its future directions.

The Design Of Research Studies

The research process is captured within the overall design of the proposed study. Whatever the hypothesis, design the best possible study to disprove it. Results gathered in this manner have the strongest impact.

Research Study Designs

A major distinction in design can be made between descriptive and analytical study designs, (Bellini & Rumrill, 1999, Chap. 6). Descriptive studies are non-experimental or "cohort" studies, while Analytical studies test hypotheses. Descriptive studies gather data of interest about a certain population, a cohort. A cohort is a subpopulation of patients that share particular characteristics, e.g. HIV infection or hemiplegia. The outcome of a descriptive study might be a determination of the prevalence of disability within a certain population. After analyzing the results of a descriptive study statistically and making some inference about the meaning of the data, a hypothesis may be generated that can be tested analytically. In a cohort of insulin-resistant type II diabetics, the prevalence of hearing loss might be determined. The individual case report and case series are always descriptive studies, usually of a singular, interesting nature. These studies can provide a provocative observation justifying a larger, descriptive cohort study. Descriptive studies can inform the design process for analytical studies. A retrospective case review groups similar cases as cohorts and collects specific data about them. They can be either descriptive or analytical. An example of an analytical case review study would be the comparison of LCPs that were updated 5-7 years after implementation to determine the predictive validity of the initial LCP. Prospective longitudinal studies are more powerful than retrospective case reviews. They always test hypotheses by following a particular endpoint over time in a specially enrolled patient population. If in the descriptive study the prevalence of hearing loss in insulin-resistant type II diabetics were found to be very high, then some hypothesis of why that occurs might be put forward and test-

ed by experimental intervention in a prospective longitudinal study (Elwood, 1998, Chap. 2; Piantadosi, 1997, Chap. 4).

Statistical Design And Power Analysis

Importantly, statistical consultation should be a part of the study design process. Because the data must ultimately be analyzed statistically to be meaningful, it is extremely helpful to consult with a statistician in the design stage of the study. The final methods of analysis should be determined before data collection begins.

After the data collection has been completed, statistical analysis will indicate whether the outcome is significant. However, the qualitative parameters for deciding what is significant must be chosen before data collection begins. The level of the difference detected must be set very low to minimize the chance of identifying a false positive effect, known as a Type I error. A Type I error occurs when the difference detected in the study is accepted as a true result when it is not. Conventionally, the level of significance is set at $p < 0.05$, so that the probability of a Type I error is less than 5%. In contrast to the parameter for the Type I error rate, the parameter for the Type II error rate should be set very high. A Type II error occurs when no difference is detected, but a difference actually does exist, in other words a false negative is identified. The Type II error probability is frequently set as high as 80 - 90% (Bellini & Rumrill, 1999, Chap. 3; Friedman, Furberg, & DeMets, 1998, Chap. 7; Piantadosi, 1997, Chap. 4).

Statisticians can also help determine whether the proposed study is feasible. This is done by power analysis. "Power" refers to whether the study has the capability to detect a significant difference in the response variables given the levels set for the qualitative parameters discussed above. Power comes from the number (N) of participants included in the study and the magnitude of the effect of interest. If a sufficient number of cases are not available to power the study adequately, then it is not feasible to conduct the study because no meaningful results can be detected. The N required for the study to detect a difference can be calculated from the expected effect size and the expected variation in the data. If the effect size is small, or the variation large, then the N must be large. The circular question is "How can the effect size from a study that has not been completed be determined?" The answer is, that it cannot be determined, only estimated. Published reports of similar effects or preliminary studies, which are small studies that were not "powered" and may not have detected a difference in outcomes, can inform us about estimating the effect size and the range of variation in the effect (Bellini & Rumrill, 1999, Chap. 6; Friedman, Furberg, & DeMets, 1998, Chap. 7; Senn, 1997, Chaps. 4 & 13.).

Inclusion/Exclusion Criteria

Inclusion/exclusion criteria define the study's target population, (Bellini & Rumrill, 1999; Piantadosi, 1997, Chap. 8). The baseline characteristics considered by the study are described by the inclusion/exclusion criteria, including any baseline exams the study might deem important to control of potential extraneous confounding variables. A confounding variable, or bias, is some factor that accounts for an effect identified in the study, but masks a true effect. Some commonly identified confounding variables include baseline characteristics of the cohort such as gender, age, cultural background and socioeconomic level. Other confounding variables could be identified as pre-existing medical conditions with pathology similar to the pathology

of interest in the study age or with pathology that exacerbates the severity or progression of the pathology of interest in the study.

One way to control for confounding variables is to set the inclusion/exclusion criteria to limit their presence within the study population. It might be reasonable in a study on the effects on I.Q. of HIV-Associated Dementia (HAD) to exclude those patients with a pre-existing closed head trauma or cerebral stroke. In the same study, age might be limited to young adults aged 21-35 to control for the normal age effects on intellect seen in immature and geriatric populations. The inclusion/exclusion criteria serve as an assessment of eligibility, or checklist, for participant enrollment to the study.

Another way to control for confounding variables is to include the confound in the study population, but stratify the study by the levels of the confounding variable. Socioeconomic effects are commonly stratified by level of education achieved and earned income. Gender might be an interesting confound within the same study of HAD effects on intelligence, not because males and females have essentially different IQ's, but because the HIV disease state underlying the observed pathology may progress differently in males and females due to their intrinsically different immune systems. Stratifying for a confounding variable has the potential to identify important and sometimes unanticipated effects.

Stratification can also be used to test hypotheses. In an analytic retrospective case review study, the response variable, i.e. recommended level of nursing care for a C5 tetraplegic, may be stratified by some factor of interest to test a hypothesis. An example would be testing for intra-planner reliability by grouping the members of the cohort from a single practitioner's caseload according to whether they were referred for development of the LCP by defense or plaintiff counsel or for IME and comparing the mean response variables for the groups for differences. In this study the inclusion/exclusion criteria would be set to limit the population to a single Life Care Planner's caseload and to specifically include patients referred from all three sources.

Ethics In Research

As practitioners and researchers we have a responsibility to protect the research subject from potential harms including psychological harm. This responsibility includes preserving the privacy and confidentiality of the patient's information. Federal regulations aimed at assuring these safeguards govern research. Maintaining the security of the research data bank is a separate concern that only ethical research is conducted using the information in the data bank. The data should not be available for "junk" or unscrupulous scientific endeavors. Finally, the conduct of research carries with it the ethical mandate to make public the findings of the scientific study, (Bellini & Rumrill, 1999, Chap. 4; Brody, 1998; Dunn & Chadwick, 1999; Piantadosi, 1997, Chap. 3).

Privacy And Confidentiality

One way to assure the confidentiality of the patient's records is to remove the identifiers from the records. Alternatively the identifiers can be dissociated from the records and the key to the dissociation process kept under lock and key as privileged information. These safeguards notwithstanding, informed consent for the study should be obtained from the study's subjects as part of the eligibility of subjects for inclusion in the study unless institutional review board guidelines provide for an exemption or client participation in the study is unnecessary. Subjects, who are vulnerable to manipulation and abuse such as the very young or old,

the impoverished, the sick or disabled, etc., are owed special protection by medical researchers (Brody, 1998; Chaps. 2 & 6; Dunn & Chadwick, 1999, Chap. 6). By definition, all subjects involved in studies validating the Life Care Planning process are vulnerable and therefore owed special protection. The informed consent process informs the subject of the purpose of the study and the risks to the subject. The informed consent document requires the subject's acknowledgement and is important in assuring privacy and confidentiality to the study's research subjects.

Unscrupulous or junk science is never in the best interest of society as a whole. The data bank available within the many caseloads of Life Care Planners should only be available to competent, ethical researchers who will produce credible research studies. Academic institutions or private research foundations can function as gatekeepers in permitting access to data banks held in their trust for appropriately designed and executed research studies.

The Institutional Review Board (IRB) of the research conducting institution is charged with administering research according to the Federal regulations. Some types of research are exempt from Federal regulation; however, the exemption must be certified by the IRB. The IRB provides ethical review of research protocols and informed consent forms, primarily to assure the protection of the subjects, but also to assure quality control of the research itself. This process also essentially limits access to data banks to authorized researchers (Brody, 1998, Chap. 2; Dunn & Chadwick, 1999, Chap. 6; Piantadosi, 1997, Chaps. 3 & 4).

IRBs provide two other services. Administrative IRBs are established to review proposals for research, applications for grant funding to perform research and contractual arrangements to conduct research with the institution. Other IRBs exist to provide for the peer review process in publication of research study results.

Publication Of Results

Active pursuit of publication of results is ethically mandated. Whether the results of a study are negative or positive, the mandate holds. Research uses valuable societal resources and the information garnered is held to be public domain. If results are not published, then the study may be repeated needlessly by other researchers, thus wasting scarce research resources. The most wanton waste is the unavailability of the research resources to move the scientific knowledge base forward (Dunn & Chadwick, 1999, Chap. 7).

Methodology Of Data Collection

Protocols and procedures establish the reliability and reproducibility of the study's results. They set forth who will collect the data and how they will be trained. Have a written protocol for how data is collected, then follow the same procedure all the time. Do not be tempted to make "adjustments" to the protocol as the study proceeds even if better ways of operating are identified. Without adherence to the study's protocols and procedures, the data will be meaningless. Any change in the protocol invalidates the results because inconsistency in how they are attained destroys their dependability (Piantadosi, 1997, Chap. 4). The person collecting or analyzing the data should be "masked" or "blinded" to the identity of the groups being compared. Masking is an important aspect of data collection and analysis in experimental research so that the outcomes are not biased by the researcher's expectations (Friedman, et al., 1998, Chap.6). All the data must be collected in a dependably consistent manner by a blinded investigator to obtain a reliable answer to the study's research question.

Statistical Analysis And Inference

Data analysis is always done statistically. The research question and experimental design determine in advance of data collection how the data will be analyzed statistically. However the process cannot be entirely anticipated until the data is available for analysis. In the conventional comparative research design using parallel groups, initial statistical tests comparing the two primary groups of interest are made even if the groups are stratified by other factors such as gender or age. If an overall, or main, effect is detected between the main groups, then the subgroups can be tested post hoc to determine the exact location of the effect within the study population's strata. The limitation of this type of study design is that interaction between effects cannot be determined. This is a problem particularly if the effect in one subgroup runs counter to the overall, main effect of interest such that the effect in the subgroup negates the main effect. The factorial study design adjusts for this possibility by allowing statistical analysis for main effects as well as the interaction of effects (DeMuth, 1999).

From statistical analysis, inferences can be made about the results of the study, but to have meaning the results of the study should be interpreted in light of the current times and the state of the art and what it may mean for the future. If an effect is detected by the study, then the various possible explanations of the effect can be considered. Interpretation of why or how an effect may have occurred is an issue that can be covered within the Discussion section of the published report.

Reading and Interpreting The Life Care Planning Literature

Ultimately, the professional should be prepared to critically evaluate a study reported in the literature and apply that new knowledge to their professional practice and future investigative endeavors. The reader should read and interpret the published literature in the professional field to determine for his/herself what to take away from the reading rather than accepting *carte blanche* the conclusions presented by the research investigators.

The research concepts parameter presented in this text offer a foundation for developing a general appraisal. Some critical questions a reader might ask of a published report include: How does the research design, methodology and statistical analysis affect outcome? Has the study been powered appropriately? What is the period of observation? If comparisons between LCPs were made after 5 months and the updated LCPs were completely congruous with the original LCPs, the meaningfulness might be suspect. However, if the window of observation were extended to 5 years, and the same result obtained, it might be meaningful. Was the research protocol appropriate and was adherence to it stringent? How credible, ethical and moral is the investigator? Does this researcher hold reputable credentials and is the work supported by a research institution? Has the author addressed the points that a study needs to address? Elwood (1998, Chaps. 10-15) presents guidelines for critically evaluating and interpreting specific types of research studies.

The purpose of the published literature is to inform the public in general and future research efforts in particular. Therefore it is paramount that future investigators and readers are equipped to read the work and parse out for themselves the strengths and weaknesses of the research, to enable the specialty practice of life care planning to move forward into the future.

Developing A Research Study Proposal

Inexperience does not preclude a professional from entering the arena of scientific research. All investigators were once novices. In developing a research study proposal, seasoned mentors serve an important function for experienced as well as novice investigators. They can guide the researcher through the investigative process and give key direction. Sometimes the key direction is an introduction to the person who can help at a particular impasse. Sage mentoring is an indispensable resource to support the professional who embarks upon the scientific course of investigation.

A second essential resource to facilitate research efforts is data base accessibility. Access to larger caseloads may be obtained through research institutions such as The Foundation for Life Care Planning Research. This foundation's purpose is to help develop research proposals, provide opportunities for mentoring, and access to significant data bases. For the professional who is developing a research study proposal, The Foundation for Life Care Planning Research offers important support.

References

- Bellini, J. L. & Rumrill, P. D. (1999). Ethical issues (pp. 49-77); Research design, Chap. 4 (pp. 78-100); Chap. 6 (pp. 117-150) in *Research In Rehabilitation Counseling: A Guide to Design, Methodology, and Utilization*. Springfield, IL: Charles C. Thomas Publishing.
- Brody, B. A. (1998). Research on human subjects, Chap 2 (pp 31-54); Research involving vulnerable subjects, Chap. 6 (pp. 119-138) in *The Ethics of Biomedical Research*. New York: Oxford University Press.
- Consortium for Spinal Cord Medicine. (July 1999). *Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals: Paralyzed Veterans of America*.
- Countiss, R. N. (2002). Amicus curiae brief to the Court of Appeals for the Seventh District of Texas at Amarillo, In re Archer v. Warren. *Journal of Life Care Planning*, 1(1), 9-34.
- Countiss, R. N. & Deutsch, P. M. (2002., The Life Care Planner, the Judge and Mr. Daubert. *Journal of Life Care Planning*, 1(1), 35-43.
- Daubert v. Merrill Dow Pharmaceuticals, 509 U.S. 579 (1993),
- De Muth, J. E. (1999). *Basic Statistics and Pharmaceutical Statistical Applications*. New York: Marcel Dekker.
- Dunn, C. M. & Chadwick, G. (1999). Behavioral research issues, Chap 6 (pp. 73-78); Publication of study results, Chap 7 (pp. 79-89) in *Protecting Study Volunteers in Research: A Manual for Investigative Sites*. Boston: Center Watch.
- Elwood, M. J. (1998). Study designs which can demonstrate and test causation, Chap. 2 (pp. 14-36); Critical evaluation of research studies, Chaps. 10-15 (pp. 245-347) in *Critical Appraisal of Epidemiological Studies and Clinical Trials*. (2nd ed.). Oxford: Oxford University Press.
- Friedman, L. M., Furberg, C. D., & DeMets, D. L. (1998). Blindness, Chap 6. (pp. 82-93); Sample size, Chap. 7 (pp. 94-129) in *Fundamentals of Clinical Trials*. (3rd ed.). New York, Springer.
- Hamilton, G., (May 1999). Patient Adherence, Outcome Indicators & Measurement in Case Management Healthcare. *Council For Case Management Accountability, State of the Science Paper: Case Management Society of America*.

Piantadosi, S. (1997). Ethical considerations, Chap. 3 (pp 29-60); Clinical trials as experimental designs, Chap. 4 (pp. 61-105); Sample size and power, Chap. 7 (pp. 148-185); The study cohort, Chap. 8 (pp. 186-202); in *Clinical Trials: A Methodologic Perspective*. New York: John Wiley & Sons.

Reid, C. (1997). Rehabilitation Client Assessment. *Rehabilitation Education*, 11(3), 211-219.

Senn, S. (1997). Probability, bayes, p-values, test of hypotheses and confidence intervals, Chap. 4 (pp. 43-54); Determining the sample size, Chap. 13 (pp 169-185) in *Statistical Issues in Drug Development*. Chichester: John Wiley & Sons.

Weed, R., Berens, D., & Deutsch, P. M. (2002). The bibliography of life care planning and related publications. *Journal of Life Care Planning*, 1(1), 73-84.

Whiteneck, G., Charlifue, S., Gerhart, K., Lammertase, D, Manley, S., Menter, R., & Seedroff, K. (1993). *Aging With Spinal Cord Injuries*. New York: Demos Publications.
