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Reliability of Life Care Plans: A Comparison of Original and Updated Plans

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Abstract. This exploratory study examines the reliability of life care plans by comparing original and updated versions of 65 life care plans. The 65 anonymous participants, with varying diagnoses and backgrounds, each had an original and updated life care plan developed for them. The time between the original life care plan and the updated plan ranged from one to five years with an average of 1.8 years. All life care plans were provided by two experienced and board certified life care planners who follow the established standards and procedures within the industry, and the samples chosen included all applicable cases within the five years preceding the time the study began in Spring 2002. The "Home/Facility Care" and "Routine Medical Care" subsections of the life care plans were compared by assigning current year (2002) costs to the projected needs and then analyzed using a Chi-square statistical analysis. These subsections were selected since virtually all cases had entries in these two areas. Results reveal the Chi-squares for Home/Facility Care and Routine Medical Care between the original and updated life care plans both were found not significant at the .05 level. These results provide further evidence of reliability over time of life care planning in the areas of Home/Facility Care and Routine Medical Care when using established procedures.

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To formulate an accurate depiction of an individual's current and future health care needs, a life care planner must integrate hundreds of pieces of information. This requires commitment to a consistent and unbiased process and reliance on fact, research, and expertise to formulate a plan that can predict future needs with accuracy and reliability. A life care plan (LCP) has been defined as "a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized, concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs" (combined definition, 1998, as cited in Weed, 1999, p. iii).

According to Deutsch (1994), the development of life care plans came as a response to multiple professional concerns. First, persons with disabilities and their families need a concise summary to plan for future needs. Second, a communication tool is needed with which all parties involved in a catastrophic injury case will be informed of these needs. Third, a planning approach in the field is needed rather than the traditional reactionary approach. Fourth, through the life care planning process, disabilities could be broken down into basic components to more carefully identify complex concerns. Finally, concerns specific to the person with a disability and their family, such as geographic location, preferences, and personal goals, need to be incorporated into a plan of care to ensure a realistic implementation. In response to these concerns, life care plans have become important tools in a number of different settings including complex disease management, establishing insurance reserves, worker's compensation case management, health insurance managed care, resolution of personal injury claims, and facilitating client and family understanding of the long-term costs and effects of injuries and illnesses (Weed, 1994). To meet the demands of preparing such a plan, certain skills provided by life care planning training programs, in combination with expertise in numerous areas are recommended. Brodwin and Mas (1999) outline 12 areas of expertise including medical aspects of disability, foundations of rehabilitation counseling, case management, psychosocial aspects of disability, behavioral interventions, preventative care, equipment and supplies, educational and vocational implications of disability, assessment and evaluation, community resources and services, rehabilitation facilities, and expert witness testimony. Similarly, the published life care planning model includes several subsections that should be addressed in a LCP in order to provide the most comprehensive plan possible. Subsections include:

projected evaluations,
therapeutic modalities,
diagnostic testing,
wheelchair needs, accessories, and maintenance,
aids for independent functioning,
orthotics,
home furnishings and accessories,
medications and supplies,
home/facility care,
routine medical care,
transportation,
health and strength maintenance,
architectural renovations,
potential complications,
aggressive treatment or surgical intervention,
orthopedic equipment needs,
and vocational planning (Weed, 1998).

It is from this knowledge foundation that life care planning professionals are able to make future projections and confer with multiple care providers to develop the most accurate care plan possible.

As the field of life care planning has become more defined through training programs, publication, and widespread use, a need for research that examines the reliability and validity of life care plans has emerged (Countiss & Deutsch, 2002). Although much research involving case management exists and numerous articles have been written on life care planning, little research has been conducted specifically to evaluate the reliability and validity of life care plans. Reliability is expected from a life care plan due to its influential role in the clients' future care management. Demonstrating reliability of life care plans also provides a foundation for establishing predictive validity. Due to the comprehensive and predictive nature of a LCP and the extreme variability of the population served (e.g., varying diagnoses, age differences, available support systems, treating professionals, etc.), it is a challenge to measure the reliability of a LCP (Deutsch, 2002). However, one study, by McCollom and Crane (2001), surveyed 10 clients with spinal cord injuries who had a life care plan developed for them several years prior to the study. The authors concluded that a clear consistency was found between projected and actual needs. In comparison, the study presented in this article measures LCP reliability by evaluating existing LCPs of clients who, for a variety of reasons, have had a second LCP written one to five years after the first plan was completed. These second LCPs were updated and revised versions of the original LCPs based on the status of the client and the interventions, services, and complications that arose following the original LCP. By comparing the two plans and determining what has been revised, a measurement of change can be generated which provides professionals with information regarding those areas of a LCP that likely are not subject to change and those areas that are sensitive to the passage of time.

The two major areas analyzed in this study include Home/Facility Care and Routine Medical Care. These areas were targeted for two reasons: a) they are common among virtually all LCPs and b) they comprise the bulk of the needs that can be tied to measurable data and costs in nearly every LCP. Based on a review of the literature, the following two hypotheses were formulated:

H1: There will be no significant difference between the Home/Facility Care costs of the original LCPs and the updated LCPs.

H2: There will be no significant difference between the Routine Medical Care costs of the original LCPs and the updated LCPs.

Method Participants

A total of 130 life care plans from 65 anonymous cases were obtained and analyzed. Each case had an original LCP (LCP 1) and an updated LCP (LCP 2). The diagnoses for the participants included a wide range of traumatic as well as chronic medical conditions such as acquired brain injury, spinal cord injury, birth defect, and pain syndromes. There were 44 males and 21 females of various ethnic backgrounds. Ages of participants ranged from 2 to 75 with an average age of 28 years. The years between LCP 1 and updated LCP 2 were one to five with an average of 1.8 years. The LCPs were obtained from two experienced and certified life care planners in private practice, both of whom maintain a policy of strict adherence to published life care planning processes, procedures, and standards. Due to the limited number of cases available, all LCPs that fit the criteria were included in the study. To maintain anonymity to the researcher, all LCPs were purged of names and replaced with case numbers. The study methodology was submitted to the Institutional Review Board (IRB) of Georgia State University for approval of human subject's research. Approval was obtained before the study was initiated.

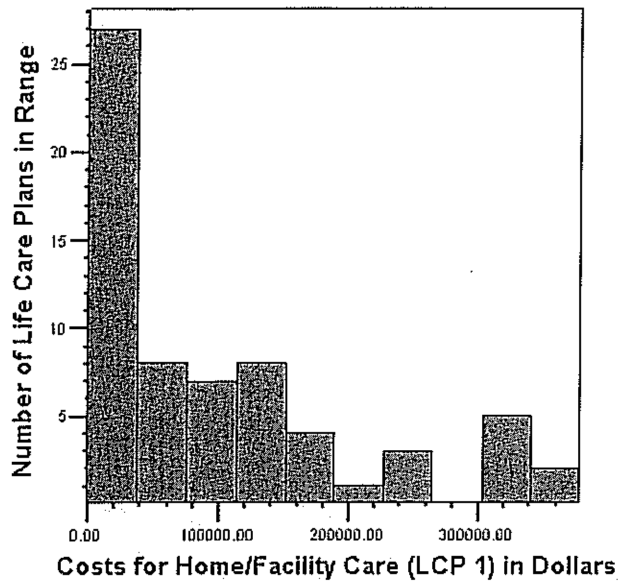
Procedure

Once all LCPs were reviewed, the projected needs outlined in the Home/Facility Care and Routine Medical Care subsections were extracted from each. A master list of all projected needs was generated and costs were assigned to the needs. The costs were obtained from a database of current health care costs from one specific region in the southeast United States during one specific time frame (2002). By using a consistent economic reference, all plans shared a common denominator with which they could be compared. As an example, the need for a home health aide was included in several LCPs and an hourly rate for home health aide was determined from the database. Once all needs were assigned a cost, each LCP was again evaluated. If a LCP recommended a home health aide five days a week for three hours a day, 15 hours were multiplied by the cost from the database and then multiplied by the number of weeks per year the client was to receive the service. Finally, a total cost per year for the home health aide recommendation was determined. This methodology was followed for each recommendation in the Home/Facility Care and Routine Medical Care subsections until a complete list of annual costs for the two subsections was obtained. The costs were then totaled to create an overall annual cost for the subsection comprising the variables "Home/Facility Care Costs #1", "Home/Facility Care Costs #2", "Routine Medical Care Costs #1" and "Routine Medical Care Costs #2".

While executing the aforementioned method, a number of challenges became apparent. First, many recommendations were presented as a range rather than a specific number. For example, follow-up visits with a neurologist were recommended four to six times per year. For the purposes of data analysis, recommendations were averaged in each case. The entry for neurologist visits from the above example was then recorded as "five times per year." Second, some of the recommendations were reported as less frequent than annually. For example, if a MRI was recommended once every one to two years, it was averaged on a yearly basis that equates to .66 MRIs per year. As each LCP is a unique plan that is tailored to the individual, other challenges materialized. Often, life care plans make recommendations for time periods such as "from age 20-30, age 31-55 and age 56 to life expectancy." For this study, one specific time frame was chosen so that data analysis was consistent across all plans. The time frame in the study was determined to be the first year immediately following the updated LCP regardless of when the original LCP was created because some recommendations would have been concluded before the second plan was completed. As such, recommendations which were "one time only" (i.e. urology consult-one time only) were included in the annual calculations only if the recommendation was to occur in the first year following the second LCP. This eliminated the concern that certain recommendations in the first plan may have been completed before the second plan was developed thereby creating an inaccurate discrepancy in the cost between plans. Finally, many LCPs offer multiple options within a subsection. For example, within the Home/Facility Care subsection, Option #1 commonly relates to the client being cared for at home and Option #2 for the client to be cared for in a long-term care facility. Statistical problems with averaging or totaling these different options, and the fact that some plans did not include both options, consequently led to the decision to consider only Option #1 in this analysis. With these procedural problems addressed, the data corresponding to the previously identified variables was analyzed using the Statistical Package for the Social Sciences (SPSS) and Excel. Three researchers, to ensure accuracy, performed the data extraction and data entry.

Results

Data points for the dependent variables did not fall into a normal distribution. Consequently, parametric tests such as analysis of variance, *t*-test, and repeated measures could not be used. Figure 1 and 2 demonstrates this lack of normal distribution with the example of Home/Facility and Routine Medical Care for the original life care plans (LCP 1). In particular, the distributions for each of the variables were skewed to the left, indicating that the majority of costs fell in lower cost portions of the distribution rather than the higher cost ends. For this reason, the Chi-Square "goodness of fit" test is the most appropriate means of ana-



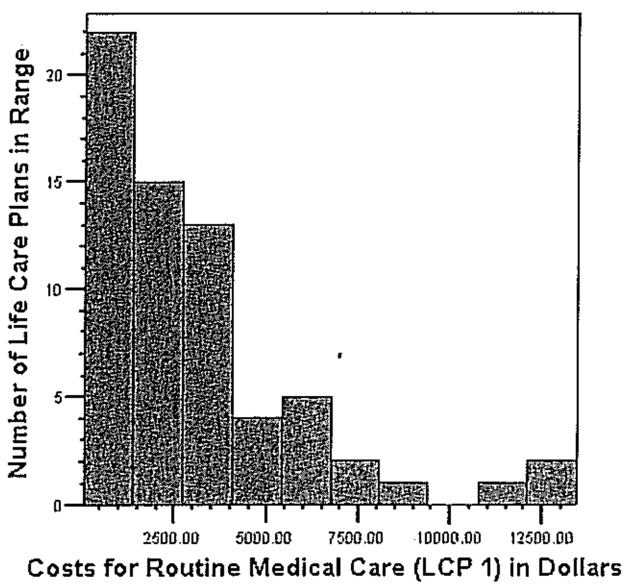


Figure 1. Distribution of actual costs for Home/Facility Care in ranges for original life care plans (LCP 1).
Figure 2. Distribution of actual costs for Routine Medical Care in ranges for original life care plans (LCP 1).

lyzing data that do not meet the normal distribution criteria. This test compares distributions and determines significant differences between the distributions. Costs were categorized into 10 "bins" according to frequency and these were then analyzed. It was necessary to use these 10 categories due to the large range of the variables as well as the fact that absolute zeros were present in two of these ranges (see Table 1). The Chi-Square for Home/Facility Care variances between LCP 1 and LCP 2 was not significant at the .05 level (Chi-Square = .85, df = 9, $p > .05$). The Chi-Square for Routine Medical Care variances between LCP 1 and LCP 2 also was not significant at the .05 level (Chi-Square = 5.04, df = 9, $p > .05$). The critical value for both hypotheses was set at 16.919. These data indicate that differences between original and updated LCPs are not significant.

Table 1
Means, Standard Deviations, and Minimum and Maximum Values of Routine Medical Care and Home/Facility Care Costs for Original and Updated Life Care Plans (in dollars)

Variable	Minimum	Maximum	*M*	*SD*
Home/Facility Care (LCP 1)	.00	378870.00	101059.60	105137.57
Home/Facility Care (LCP 2)	.00	365512.00	104645.50	102713.20
Routine Medical Care (LCP 1)	80.50	13429.00	3212.75	2913.67
Routine Medical Care (LCP 2)	215.00	16795.00	3566.89	3354.20

Discussion

Any number of complications or technological advances, which are relatively impossible to predict and plan for, may affect a client's prescribed needs and components of the LCP. Some degree of change, therefore, is entirely probable. However, an overall reliability is expected from a life care plan due to the large psychosocial, medical, and financial investments entrusted in the plan. The results of this study indicate that, for the two subsections analyzed, life care plan needs are resistant to the effects of time and therefore reliably predictive. Although projections made by the life care planner cannot be specifically validated by this study, projections remained consistent even after one or more years had passed. In order to specifically validate LCP plan entries, the various recommendations relied upon would be subject to further research design and analysis across multiple Life Care Planners. However, it is clear from these data comparisons of LCP 1 and LCP 2 that agreement on entries infers that over time recommendations were appropriate. It is also clear that the results of this study alone do not imply the reliability of all life care plans, especially for uncertified professionals or those who fail to use established procedures; however, the study can be a springboard from which more research can be conducted. Another interesting finding is that total costs for the subsections Home/Facility Care and Routine Medical Care tend to fall in the less expensive direction of the distributions. This finding supports the proposition that life care plans are "needs" driven rather than "cost driven" with a tendency toward conservative estimates of expenditures as opposed to liberal or inflated costs.

One limitation of the study is that there were only two life care planners providing cases for review. Additionally, both of the life care planners are considered experts in the field and may not be representative of all life care planners. Both assert that they remain consistent in their approach and committed to following published standards and methodology. Similar studies in the future will be more valuable if a larger sample of certified life care planners with varying levels of experience who also adhere to the published standards of practice participate. Future research should also include a large enough sample to evaluate plan reliability based on diagnoses, gender, and age, among other factors. Other studies may take a similar approach as this investigation but look at other subsections of the life care plan, particularly if enough samples can be identified for similar disabilities, gender, and to distinguish differences between children and adults.

Although a few of the updated life care plans in the study had marked variations from their original life care plans, these variations did not affect the overall results of the study. For future research, these cases could be investigated from a qualitative perspective to determine why these updated plans reflected greater change. Change may occur for any number of reasons such as the development of another medical condition, complications due to unforeseen events, failure to comply with the life care plan, changed physician recommendations, etc. Finally, a retrospective study to examine validity by determining what services were actually provided, what was needed, and what was projected would be valuable to determine recommendation validity.

This study underscores the effectiveness of future care forecasting where individual needs are identified and comprehensive treatment recommendations are documented when based on published models and procedures of life care planning. It appears that life care planners will benefit their clients by adopting a standardized approach to developing life care plans that is based on existing protocol designed for this specialized industry.

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