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Outcome Measurement in Life Care Planning: One Company's Approach

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Editor's Note: This article presents the concept of outcome measurement in life care planning and encourages others to develop and use standardized tools for evaluating quality and satisfaction. The survey instruments referenced in the article have not been peer-reviewed and only one of six questionnaires is printed in its entirety.

Abstract. *The purpose of this article is to identify and discuss the development of an outcome measurement system for the evaluation of the life care planning process. A literature review conducted by the authors did not reveal published standardized tools for evaluating life care planning services. In the authors' view, the importance of outcome data to substantiate the value of a service is important and one sample instrument used by the authors is offered as a model.*

Introduction

Outcome measurement is a process by which a professional or organization uses an evaluation tool to quantitatively measure customer satisfaction and identify benefits with services provided. It is this ongoing collection of feedback which promotes adjustment, evaluation, and fine tuning of the service that allows for service improvement.

The importance and value of outcome measurement has become most evident across all spectrums of professional organizations within the last decade (Matthews, 2000). A comprehensive literature review reveals that there is some method and level of outcome measurement, management, and evaluation in all professional sectors; most evident is the presence of outcome measurement systems in the health care industry. According to one source, "Outcome management increases the potential of organizations to achieve competitive leverage, quality patient care, and efficient operations through effectively collecting and interpreting information. This ability will become increasingly important in the future as the cost of care will certainly rise and the competition for revenues increase." (Matthews, 2000, p. 55).

Organizations use outcomes management, data collection tools, and data resources to gather precise information to be able to validate the importance of a particular service or program. Outcome measurement provides a wealth of knowledge that should ultimately feed valuable information back into the program or service in order to provide continuous improvement and increased effectiveness of the service or product. While outcome evaluation analyzes the effectiveness of an activity or process, it also can improve delivery mechanisms

by making them more efficient and less costly. Outcome evaluation is also a measurement tool which allows a user to identify strengths and weaknesses, produce data, and verify results. These data may then be used for public relations and promoting services. A professional might also employ the data to compare programs to decide which should be retained and to identify effective programs for duplication elsewhere.

It is important to recognize the value of the research, support, and organizational commitment required to plan and implement an effective outcomes management program. To facilitate progression towards an integrated outcomes information management system, one must be aware of emerging outcomes measurement; be proactive in integrating existing measurements with new measurements; and be sure that the information is precise, accurate, valid, and relevant to the organization's operations. In order for any business or organization to remain successful within our current high tech, information-seeking society, the business/organization must be able to clearly identify and document the value of the service or product which they provide.

Toward this end, the authors conducted a literature review and discovered that no standardized tool for businesses to evaluate life care plans was revealed. Two published studies indicated that life care plans are reliable over time when established procedures are followed (McCollom & Crane, 2001; Sutton, Deutsch, Weed & Berens, 2002). However, survey forms soliciting feedback from various people who may be involved in the life care planning process was not found.

Outcome Measurement and Rehabilitation

Rehabilitation nursing continues to evolve as a specialty practice within the nursing profession. In the authors' opinion, one particular role or niche that is a perfect match to the unique skills and knowledge of the rehabilitation nurse is that of the Rehabilitation Consultant/Life Care Planner. Rehabilitation nurses have traditionally played a fundamental role in identifying appropriate services and resources for individuals with disabilities and/or chronic illnesses. The identification of appropriate resources and coordination of care for the individual with a disability is paramount in facilitating an improved quality of life. Within all areas of health care, particularly within rehabilitation, the importance of tracking vital patient information for outcomes measurement continues to influence the delivery of care and services. The same should be true for the service of life care planning.

Within the specialized practice of life care planning, there is a definitive process which guides the development of the life care plan (LCP) and this process begins with general discussion regarding the nature of the disability or chronic illness of the individual for whom the LCP is intended. All pertinent medical, academic and/or vocational records are reviewed and incorporated within the LCP and a comprehensive evaluation of the individual's status according to NANDA (North American Nursing Diagnosis Association) approved nursing diagnoses is then completed. Communication (written and/or verbal) with all treating professionals is attempted in an effort to ascertain recommendations in relation to their area of specialty. The patient information and components of the life care plan are thoroughly evaluated to ensure focus on prevention of disability complications and outline expectations of disability management over the life span. Throughout the development of the life care plan, identifying the need for other professional evaluations and/or referrals for services, accessing equipment, and outlining appropriate costs contributes to greater quality and satisfaction. This comprehensive approach in preparation of the LCP yields benefit to the client, the recipient of

the LCP, and the rehabilitation professional. At the completion of the LCP process, the client is requested to complete the outcome measurement tool which accompanies the report and a self-addressed stamped envelope is included with the survey for the client's convenience in returning the form. In addition, the client is again contacted by telephone in an effort to determine if the LCP has met their needs. This provides additional opportunity for open discussion regarding questions or concerns in relation to the LCP.

Over the past six years, the authors have developed an outcome measurement system for evaluation of the life care planning process within their company. Consultants in the company use the system to elicit feedback from those for whom the life care plan was prepared and from third parties including the client's legal representative and insurance company. The outcome measurement system developed by the company is used to gather input on a regular basis through the use of customer satisfaction surveys, questionnaires, ongoing informal inquiry, and other forms of communication. The collection of this information is vital to evaluating and insuring that services are meeting the needs and expectations of clients and their families. Consumers have a definitive role in the planning, development, delivery, and evaluation of the services received and responses from the outcome surveys are incorporated into the authors' practice. The information obtained through the use of this process can be a prime consideration in the ongoing strategic planning process which guides any life care planning practice.

Based on the authors' experience, including preparation of 50-70 new LCPs annually, revision of an equal quantity, and preparation of petitions of care for special needs trusts, the outcome measurement surveys help to assess the effectiveness of LCPs, timeliness to complete LCPs, and overall satisfaction with the end product for it's intended purpose. Once the LCP is implemented and service coordination has been initiated, a survey is taken after six months to determine patient and/or family satisfaction with services provided. In addition, an annual satisfaction survey is taken on each case while services are being provided, duration of which varies from case to case. Currently, average utilization of services per case is 6 years with the longest case being 13 years.

As previously stated, a literature search revealed that there presently are no standardized outcome measurement systems available specifically for the life care planning process. As noted above, research reveals that studies have been done to measure the reliability of life care plan recommendations over time, with results showing that life care plans overall are reliable and accurate in outlining future care needs (McCollom & Crane, 2001; Sutton, Deutsch, Weed, & Berens, 2002). Questionnaires used by the authors are specifically designed to evaluate whether the life care planning process is meeting the needs of clients (defined here as the person with the disability). The advantages of questionnaires are that they can be non-threatening, completely anonymous, inexpensive to administer, and easy to compare and analyze. The disadvantage to questionnaires is that they can be impersonal and can be set aside and not returned. Additionally, the life care planner should be aware that questionnaires in and of themselves may present reliability problems, poor return rates, and accuracy problems in relying on self-reports. For these reasons, efforts should be made to minimize any potential effect of these problems on the results.

With the objective of the questionnaire to gather information to evaluate the strengths and weaknesses of the services provided, quantitative (ratings, rankings) and qualitative (written commentary) information is obtained. The results are then tabulated, included in a report for internal use to develop program recommendations, and shared with different groups including present and future clients.

Tips for the Life Care Planner

When developing a survey for outcomes measurement, life care planning professionals should be clear of what input is being requested and how that information will be utilized. This will provide focus on what information will be needed and will help determine what questions will be asked. Avoid wording that may influence the respondent to answer a certain way so as to avoid biased responses. Surveys need to include a brief explanation of the purpose of the questionnaire, clear explanation of how to complete the questionnaire, and directions about where and how to return the completed questionnaire. Avoid including too many questions as this may discourage potential respondents from completing the questionnaire. Checklists can lessen the time required to complete the survey but must be carefully phrased to elicit the information required. An example of one of the surveys used by the authors is included later in this article.

Purpose of an Outcome Measurement System for Life Care Planning

1. Provide opportunity for clients and families to communicate concerns.
2. Provide clients and families with comprehensive care and control over life care management experiences.
3. Ensure services provided are meeting the needs of all involved, including external parties, officers of the court, trustees and insurers.
4. Provide an opportunity for evaluation of the efficiency/effectiveness/progress performance through the eyes of its consumers.
5. Improve the quality of life for clients and families.
6. Communicate to internal staff, clients and families in a format that recognizes the value of input.
7. Encourage continued participation and incorporate outcome data in a strategic plan.
8. Monitor internal organization efficiency measures.

Survey Procedure Process

1. Surveys sent to the requester with the final copy of the LCP.
2. Surveys sent to families receiving case management or care coordination services on an annual basis.
3. Survey sent annually to the individual with the fiduciary responsibility.
4. Survey format and content reviewed annually for relevancy/need for addition/deletion of measurements based on input from staff and clients and families.
5. Organizational efficiency measures monitored quarterly to provide data for strategic planning.
6. Life care coordinator is responsible to communicate to administrative assistant the frequency of survey distribution based on acuity of clients and families, frequency of treatments, team meetings and identified family needs.
7. Progress measures documented for clients and families who receive services within program for six months or when approval from funding is secured on a semiannual basis.
8. Goals reviewed on a semiannual basis for active life care management cases; revised

goals are identified if indicated by documentation.

Evaluation of Completed Surveys

1. Returned surveys are reviewed and shared with the life care planning staff on a periodic basis.
2. Data from the surveys is analyzed utilizing the outcome measurement report tool.
3. Data from the organizational efficiency measures are analyzed utilizing the outcome measurement tool.
4. Corrective action plans are formulated as needed. Outcome data/corrective action plans are incorporated into strategic planning process.
6. Information is shared with consumers through publication of an annual report/newsletter.

Survey Examples

The authors have developed six different survey forms to measure satisfaction outcomes. Below is one full example of a survey as well as sample questions associated with the other surveys.

Survey #1, Family (full survey) (Reprinted with permission. Copyright retained by the authors.)

Favorable Unfavorable

Did goal setting at team meetings address relevant issues?

Did you have sufficient opportunities to participate in decision making of health care related issues of yourself/your family member?

Was you/your family member's quality of life improved?

Have team meetings and communication from life care planning coordination been timely?

Was the life care coordinator responsive to your needs?

Does the homecare program meet you/your family member's needs?

Do you view the services provided as increasing the independence/quality of life for you/your family member?

Does the life care coordinator provide sufficient opportunity for your suggestions?

Are your suggestions incorporated into you/your family member's program?

Thank you.

Comments:

The following are excerpts from other survey forms:

Survey #2, Life Care Plan
This survey requests information on performance in the area of life care planning. Some examples are:

- Was the report useful for settlement negotiation, trial and/or arbitration?
- Did the clinical referral to physician, therapists and/or academic personnel contribute to the preparation of your case?
- Did the report address future life care needs, costs and/or nursing practice issues required for litigation?

Survey #3, Settlement/Arbitration
This survey requests information on abilities to convey the essence of the client's health care needs. Some examples are:

- Was the life care plan assistive in defining the parameters of long term care needs?
- Did the life care plan clearly itemize future care and costs for the client?
- Was the life care plan easy to follow, thereby contributing to the presentation of the case?

Survey #4, Testimony
This survey requests information related to testimony in court, depositions, guardianship, orphan's court and specialized hearings. Some examples are:

- Presentation of life care plan and related information.
- Accessibility for preparation and testimony.
- Helpfulness during case preparation.

Survey #5, Families

- Was your child's and family's quality of life improved?
- Does the home care program meet your needs?

- Are your suggestions incorporated into your child's program?

Survey #6, Case Management/Life Care Coordinator Funders

- Are the Life Care Coordination reports useful for maintaining a clear understanding of case status and effectiveness of recommended services?
- Has communication regarding status of the case been provided in an ongoing timely manner?
- Has resource material/information regarding case services been provided when indicated?

Summary

In summary, it is the authors' view that any professional or organization should monitor the quality of their service or product through the use of an appropriate outcome measurement process/system. This article offers some initial suggestions which the authors believe address life care planning outcomes. Quality is an individual, subjective perception of a service or product, and attempts to assess and improve the quality of a service implies the ability to be able to identify quality and recognize variations in it. In order to remain successful and continue to thrive, it is again the authors' view that an organization should be able to collect, organize, analyze, and appropriately utilize information specific to their service. To quote from one source, "You can't equate information with knowledge. Information is simply a group of facts. Turn information into knowledge by analyzing the data, identifying patterns and relationships, and working to gain insight into what the information implies" (Alfaro-LeFevre, 1999, p. 156).

References

Alfaro-LeFevre, R. (1999). *Critical thinking in nursing*: *A practical approach*. Philadelphia, PA: W.B. Saunders Company.

Matthews, P. (2000). Planning for successful outcomes in the new millennium. *Topics in Health Information Management*, *20*(3), 55-66.

McCollom, P. & Crane, R. (2001). Life care plans: Accuracy over time. *The Case Manager*, *12*(3), 85-87.

Sutton, A.M., Deutsch, P.M., Weed, R.O., & Berens, D.E. (2002). Reliability of life care plans: A comparison of original and updated plans. *Journal of Life Care Planning*, *1*(3), 187-194. Reprinted in R. Weed (Ed.). (2004). *Life Care Planning and Case Management Handbook. (2nd ed.)*. Boca Raton, FL: CRC Press LLC.

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