

# Content Analysis of the Research Priorities in the *Journal of Life Care Planning* 2004-2017

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## Abstract

The *Journal of Life Care Planning* (JLCP) is considered the flagship journal for the publication of research related to life care planning. The journal provides a peer-review process that uses expert review to produce the highest quality of review. While the peer-review process encourages shared standards for the field of life care planning, a content analysis of the *Journal of Life Care Planning* can help identify areas of need in the field of life care planning. A content analysis of published work is a method of reviewing the content of a body of work for the purposes of gleaning information about trends. This analysis was conducted to better understand how trends in publication match the suggested research priorities developed through a process of life care planner consensus at the 2004 Life Care Planning Summit. Outcomes of this analysis suggest that the majority of publications in this journal focus on general research themes indicating: articles which are conceptual in nature; an emphasis on professionalization of the field; and an emphasis on the process of developing life care plans. Opportunities for future research directions are discussed.

*Keywords: Research, Content Analysis*

## Research in Life Care Planning

While life care planners have historically relied upon research conducted by others as a basis for life care plan foundation (McCullom, 2002), efforts are being made to encourage the life care planners themselves to produce independent research (Deutsch, et al., 2004; Owen, 2012). Several opportunities exist including a Foundation for Life Care Planning Research (FLCPR), which provides funding and support for those engaging in life care planning research. The *Journal of Life Care Planning* itself provides an outlet for individuals to publish research by having it reviewed by their peers for quality and accuracy. Also, annual conferences encourage presentation and discussion regarding the latest trends in the field and sharing of research and information. While these processes exist to encourage sharing and development of new ideas, it can sometimes be difficult to identify areas of research need in the field. As a result, life care planners have historically held Summits to gather and develop a consensus of opinions about the future directions of the field.

Life care planning Summits are international biennial gatherings of life care planners from various disciplines for the purpose of establishing future directions of the field based on input from planners themselves. As a part of the 2004

Summit, members developed a list of research priorities by levels of importance. Nine topics were agreed upon by the majority of planners in attendance: (1) Analyze life care plan validity and reliability; (2) Study of the percentage of plans that are implemented; (3) Assess the accuracy and durability of life care plans; (4) Analyze whether cost projections are sufficient; (5) Conduct longitudinal studies (e.g., aging and disability); (6) Identify specific clinical research related to life care planning recommendations (e.g., home supervision/DME); (7) Assess life expectancy accuracy; (8) Study the relationship of life care planning implementation to quality of life; and, (9) Evaluate the cost effectiveness of life care planners (Deutsch, et al., 2004). A complete list of suggested future studies is included in Table 1. For the purposes of this study, the author used these topics as a guide during the content analysis of the *Journal of Life Care Planning* to assess whether publication trends follow the areas of need identified at the 2004 Summit. Perhaps more importantly, identifying trends can provide a better understanding of what general areas of research are needed in the future.

## Methods

The author obtained electronic copies of every article published in the *Journal of Life Care Planning* from 2004 to 2017 (issues 3(3) to 15(4) inclusively). The author chose to start at journal edition 3(3) as this was the first edition published after the 2004 Life Care Planning Summit where the initial research priority topics were developed. A content analysis of each article was conducted using three metrics. The first criteria was levels of research (Bellini & Rumrill, 2009). Articles were categorized as either Primary (evaluator level), Secondary (practitioner level), and Tertiary (professional level). Owen (2012) summarizes the work of Bellini and Rumrill by describing primary research as involving “efforts that generate new knowledge and relate directly to the status/participation of people with disabilities in society” (p. 40). Secondary research “measures competencies, attitudes, and dispositions of services providers” (p. 40), while tertiary research focuses on “professional issues that are relevant to counselors and educators including ethical issues for practicing professionals” (p. 41). Frequencies of articles were measured by coding each article published within the period of interest with a number 1-3.

The author further categorized the articles as either conceptual, defined as not containing any data collection or

analysis; simple statistics, with descriptive statistical data reported as frequencies or quantities; or, complex statistics, employing advanced methodologies and uses of statistical tools. Conceptual articles share information without generating empirical data. Examples include comprehensive literature reviews, sharing expertise about a specific disability population, a treatment, or a process of practice. A second type of research collects empirical data and is often done by way of a survey methods. This data is most often reported in terms of frequency counts, and other measures of central tendency. This type of research is used to gather information about a specific sample but may not be generalized to a larger population. In other words, it may only be useful in describing the group being studied and cannot be inferred that all similar participants will produce similar results. The third type of research is referred to here as complex statistics. This type includes studies that put greater emphasis on more advanced methodologies or use statistical tools (e.g. structural equation modeling) to analyze empirical data. Using these tools, results can be collected from a small group and, using mathematical probability calculations, claims can be made about a much larger group. An example of this would be measuring a small group of amputee patients to infer some information about *all* amputee patients.

In this study, each article was read and assigned a code number based on its designated category. Articles not using any data or were given a number one (1). Articles using simple statistics like frequencies were given a number two (2) and articles using more advanced statistics were given a number three (3). The amount of each number was then summed to provide frequency data on the number of articles of each type were present in the journal.

Finally, a content analysis of research topic categories published in the *Journal of Life Care Planning* was completed. As noted, the 2004 life care planning Summit developed research priorities for the field by group consensus and prioritized them by level of importance.

In this study, instead of reviewing each article for a direct match, the research priorities from that consensus were coded and themed to better understand areas of research rather than specific topics. While a traditional content analysis typically develops themes from the content of the text, in this analysis, the goal was to compare the journal content to pre-established research topics. A traditional content analysis provides data on what research is present, but this method was employed to better understand what research is missing in the field and identify areas for future growth.

In order to categorize articles in the *Journal of Life Care Planning* (JLCP), a coding schema was established to create categories of research. The outcomes of the consensus activity at the 2004 Summit are listed in column 1 of Table 1. Following the methods established by those attendees present at the Summit, six topics were agreed upon by the majority of attendees, followed by 27 topics that garnered a vote by a

minority of individuals present. Nine additional ideas were proposed at the Summit, but did not receive a majority vote. One established future priority did not fit as a research question and was therefore excluded from this review ("Establishment of a clearinghouse for life care planning research"). A total of 46 search topics were reviewed. Table 1 shows how the suggested research topics developed at the Summit fit into thematic areas used to compare research published in the *Journal of Life Care Planning*.

**Table 1**

*Research topics coded to fit into thematic categories established by 2004 Life Care Planning Summit*

### **Implementation and Outcome of Patients**

- \* Study of the percentage of plans that are implemented
- \* Study the relationship of life care plan implementation to quality of life.
- \*\* Assess patient compliance with a life care plan
- \*\* Investigate the outcome of children with cerebral palsy as a function of school therapy vs. private care.
- \*\* Assess the effect of case management on implementation and satisfaction with a life care plan.
- \*\* Development of a caregiver/family competency (patient understanding) assessment tool.
- \*\* Explore the relationship between finances/support and return to work?
- \*\*\* Impact of case manager, court, and/or family coordination on life care plan implementation.

### **Topics relating to specific disabilities or patient characteristics**

- \* Conduct longitudinal studies (e.g., aging and disability)
- \* Identify specific clinical research related to life care plan recommendations (e.g., home supervision/durable medical equipment).
- \*\* Identify basic standards of care by diagnosis
- \*\* Explore the relationship between date of injury, referral and discovery deadline (e.g., timeframe).

### **Topics relating to specific items or content of the plan, as well as provider treatments**

- \*\* Compare life care plan projections, demand, award and actual cost.
- \*\* Study the effects of client characteristics on the life care planning process.
- \*\* Identify the effects of advancing technology on life care planning.
- \*\* Study unpaid caregiver services over time.
- \*\* Define "least restrictive" research by state; in other words, how it is done and what it is called?
- \*\*\* Use of urgent care vs. emergency department services in a life care plan.

### **Topics relating to the creation process of plans, legal proceedings, and expert witnessing**

- \*\* Analyze the comprehension and detail of life care planners.
- \*\* Analyze the frequency of updates (especially pediatric plans).
- \*\* Assess the cost of care by diagnosis.
- \*\* Evaluate referral reasons for life care plans.
- \*\*\* Impact/importance of family wishes (and cultural beliefs) on the life care planning.

### **Topics of the efficacy of plans, including reliability studies, meaning assessing the outcomes of the plans or planning process**

- \* Analyze life care plan validity and reliability.
- \* Assess life expectancy accuracy.
- \* Evaluate the cost effectiveness of life care planners.
- \* Assess the accuracy and durability of life care plans.
- \* Analyze whether cost projections are sufficient.
- \*\* Explore the relationship between geographic location and cultural diversity of life care planners and clients.
- \*\* Compare LCP and treatment provider recommendations
- \*\* Explore the relationship between referral source, purpose of a life care plan, and outcome.
- \*\* Research the impact of life care plans on case resolution.
- \*\* Explore the impact of the life care plan to decision making by the trier of fact; in other words, did the life care plan assist in this process?
- \*\*\* Impact of the funding source on life care plan totals (e.g., Workers' Compensation vs. "other").
- \*\*\* Comparison of plaintiff vs. defense life care plan reviews.
- \*\*\* Demographic information on life care plan use (national and international).

### **Professionalization, including scope of practice, certification, accreditation, ethics and standards of practice**

- \*\* Conduct quality outcome comparisons between certified and non-certified providers.
- \*\* Specify "Top 5" reasons a certified life care planner vs. non-certified life care planner is/would be disqualified
- \*\* Analyze adherence to life care planning standards
- \*\* Identify life care plan report formats (including research).
- \*\* Explore the relationship/effect of certification on job satisfaction.
- \*\* Assess the role of the life care planner.
- \*\*\* Outcome of mentoring vs. non-mentoring on life care plan quality.
- \*\*\* Ethical dilemmas in life care plan.
- \*\*\* Clarification of scope of practice.
- \* - indicates majority view; \*\* indicates Minority view; \*\*\* indicates research ideas that were proposed, and discussed,

but did not receive a vote for inclusion in the top five priorities (by any group). These indicate the level of agreement that life care planners view each topic as important to future research. In other words, a single asterisk (\*) means most people agree that the topic is important, while three asterisks (\*\*\*) mean that the topic was suggested and discussed but did not garner enough support to be considered important to the majority of life care planners in attendance.

The six categories described above include: (1) implementation of life care plans or outcomes of evaluatees; and (2) topics relating to specific disabilities or evaluatee characteristics; (3) topics relating to specific items or content of the plan, as well as provider treatments; (4) topics relating to the creation process of plans, legal proceedings, and expert witnessing; (5) topics of the efficacy of plans, including reliability studies, meaning assessing the outcomes of the plans or planning process; and (6) professionalization, including scope of practice, certification, accreditation, ethics and standards of practice. The coding schema can be seen in Table 1.

### **Literature Analysis**

The author downloaded all available journal editions from the International Academy of Life Care Planning (IALCP) website. Using a Microsoft Excel spreadsheet, each article title was copied from the index on the International Association of Rehabilitation Professionals (IARP) website and then articles were read to be coded into the three-category metrics of interest: level of research; type of research; and category of research based on the aforementioned research themes.

### **Exclusionary Criteria**

Some publications in the journals may be important to the general knowledge of the field but are not considered research and excluded from review. Examples of such include awards or recognitions, book reviews, editorials, and short summaries of events. Comprehensive reviews of Summits and Symposia were included, but some of the short summaries that did not include a detailed description of outcomes were omitted. Also, Summit proceedings were sometimes republished but were only counted once toward the total number of articles.

### **Results**

#### **Level of Research**

Of the 214 articles, 34 (16%) were considered Primary research topics about evaluatees or recipients of life care plans. Examples included a study of Quality of Life issues for individuals with spinal cord injuries (Salmons, 2008) and long-term neurobehavioral characteristics after brain injury (Witol, Sander, Seel, & Kreutzer, 2006). There were 24 (11%) articles identified in the Secondary level of research. A notable example of this was an article evaluating life care

plans based on an agency’s use of Standards of Practice (Nunez & Carruthers, 2011). Finally, 156 (73%) articles were found to fit as Tertiary level research. Examples included a comparison of life care planning Standards of Practice (Gamez, Johnson, & Stanjduhar, 2017) and all of the Ethics Interface articles such as Mitchell (2017). See Figure 1.

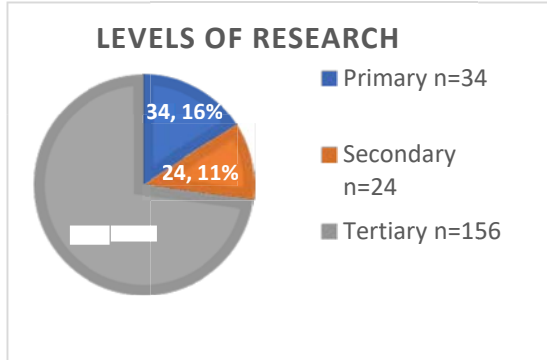


Figure 1.

**Type of Research**

In the conceptual category, there were 185 articles (86%). The majority of articles in this category were comprehensive literature reviews. In the descriptive category there were 17 (8%) articles that included frequency or quantity data. Examples include a survey of physical therapists (Marini, Luckett, Miller, & Blanco, 2009) that included percentage data regarding the opinions of professionals about certain conditions, and a qualitative exploration of special needs adoptions (Buckles & Pomeranz, 2017). In the last category, 12 (6%) articles included advanced methodology or statistical tools. For example, Krause and Saunders (2010) used a logistical regression to analyze household income and risk of mortality. See figure 2.

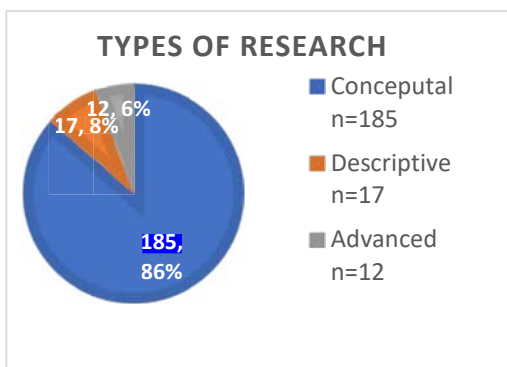


Figure 2.

**Categories of Research**

There were three (1%) studies that fell into the implementation of plans. Rutherford-Owen and Marini’s 2012 study of attendant care use is an example of implementation. There were 33 (15%) studies found relating to evaluatee characteristics or disabilities. An example is Nguyen-Finn, Lopez, and Alaniz’ (2013) article on

cardiovascular disease in evaluatees with spinal cord injury. Busch (2017) is an example of studies relating to specific items included in life care plans and 43 (20%) articles were relating to items in life care plans. There were 52 articles (24%) describing the development process of life care plans, legal proceedings, or issues related to expert witness practices, of which Field, et al. (2008) is an example. Six (3%) articles were found relating to efficacy studies of life care planning or plans. An example of efficacy studies would be Rutherford-Owen and Thomas’ (2012) study, comparing national costing information approaches to that of the life care plan. Finally, articles involving the professionalization of the field such as scope of practice, certification, accreditation, and standards contributed 77 (36%) of the articles reviewed. Regular publication of the Summit proceedings involving Consensus Statements about the state of the field were included in the last category, as well as regular publications on ethical practice. While the number of summit proceedings skew the results of the last column upward, they do not overshadow the lower numbers in other areas. Figures 3 and 4 show the number of topics or articles in the respective themes.

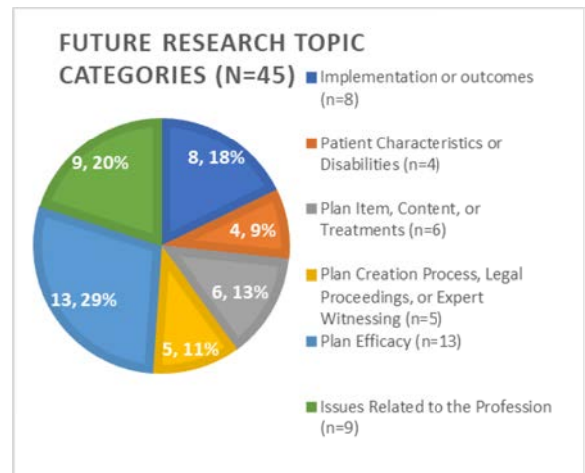


Figure 3.

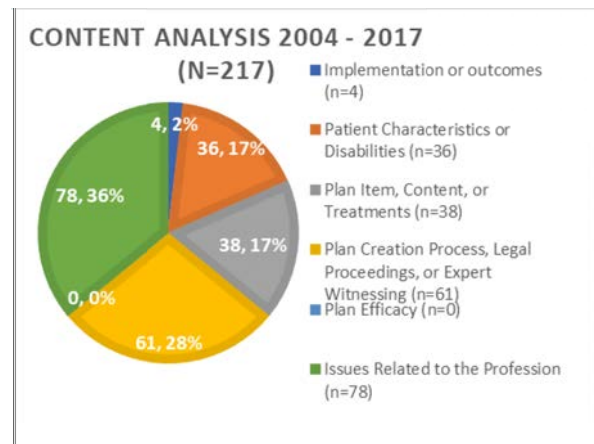


Figure 4.

## Discussion

Prior to a discussion of findings, there are a few caveats to consider. First, life care planning is relatively new and all findings should be considered within that context. The origins of life care planning are generally attributed to the work of Dr. Paul Deutsch in a 1981 publication, *Damages in Tort Action* (Weed & Berens, 2012). Given the hundreds of years of general medical research, the sophistication of research in new fields takes time. The forthcoming discussion is intended to be an opportunity to build on the existing research base and not to claim life care planning should be more developed than it is.

Second, just as the backgrounds of life care planners can be considerably diverse, coming from counseling, nursing, or other areas of medicine, the publication practices of planners may be equally diverse. This analysis includes only one journal out of many where life care planners may publish.

Lastly, the *Standards of Practice in Life Care Planning* (International Academy of Life Care Planners, 2015, p. 5), Consensus Statements created by life care planners (Deutsch, et al., 2004), and the Code of Ethics of life care planning (International Academy of Life Care Planners, 2015, p. 12) state that life care planners are required to participate in research at some level. Specific research requirements of various disciplines can be found in Owen (2012). The amount of research that individual life care planners contribute to is open for debate. While it may be realistic for some life care planners to spend time analyzing data, others may contribute by facilitating the research efforts of others in order to strengthen the profession. On any level, the contributions to the field are invaluable and facilitate progress for the profession.

Findings of this content analysis revealed that the majority of articles were tertiary in nature, with a focus on professional issues. This indicates that in order for life care planning to be an evidenced-based science, more study of evaluatees will be necessary. However, the numbers of tertiary research are not surprising considering that in the field, there is an emphasis on building a knowledge base concerned with collecting accurate information about treatments and costs. More research on implementation or settlement figures (also identified as research priorities at the 2004 Summit) could contribute to efforts in the areas of primary and secondary research.

Second, regarding the type of research, there is a heavy emphasis on conceptual writings. This is no surprise, considering that the field of life care planning consists of practitioners with a variety of backgrounds. Life care planning requires a thorough understanding of perspectives to justify recommendations from planners, as well as other providers. These conceptual articles provide important detail about the legitimacy of certain recommendations or treatments included in life care plans. This style of research also can be a good source of systematic reviews of literature

to bring together data from other research sources. While this is a possibility, some articles rely on the expertise foundation of the authors. This should not be considered a limitation, but rather a necessity of the field to share information based on the expertise of diverse professionals.

However, research including more descriptive statistics can provide objective measurement in a way that conceptual articles cannot. The benefit of such research is that data collected on a smaller sample can be inferred onto a larger population providing a richer understanding of the area of interest based on mathematical probabilities. One of the challenges with this type of research is that the strength of the research relies more heavily on research methodology than on area of expertise, which means that authors must have greater skill in survey development, data collection and statistical analysis. Even more challenging is the use of advanced methodologies and statistical tools. Many training programs emphasize practice over research, leaving life care planners with a need to build additional skills in this area.

Third, this content analysis did not seek to answer whether the specific research topics established by the life care planners present at the 2004 Summit were completed and published in the *Journal of Life Care Planning*. What was done was to see if 'like' topics are being addressed while assessing the level of sophistication of studies. Results confirm opinions suggested by other authors who stated, "there has been disappointingly little growth in the knowledge base regarding such private-sector phenomena as the validity of life care planning as a rehabilitation service" (Rumrill and Bellini, 2017, p. 287). Given their analysis, it is apparently known both within and outside of life care planning that if research is to meet the needs of the profession, the complexity of research needs to move closer to the complexity of the lives of evaluatees and the profession.

This analysis identified a relatively low number of efficacy and implementation studies. The relative age of the profession is still fairly young and it is not surprising that there is a significant number of studies about professionalization. These studies are essential to establishing the profession as a source for high quality care planning in the larger health and legal domains. Studies about the specific items of life care plans and the process of developing them are also essential to establish the reliability and validity of life care planning methodology. What is missing are answers to the big question, do life care plans actually do what they set out to do? In other words, studies about the contribution that a life care plan makes to settlement or award outcomes can establish a greater understanding of the provision of resources to evaluatees. Studies comparing other forms of long-term care plans or discharge papers of evaluatees can quantitatively provide empirical evidence of the benefit to individuals who receive life care plans.

It should be emphasized here that the efforts of some researchers are providing significant contributions to these

areas. Despite ongoing areas of need in research, the field is growing. By identifying areas of need, solutions can be developed to encourage more research and greater participation by individuals and practitioners alike, as well as attract talent from a larger pool of incoming professionals. As some of the forefathers of the field now enter retirement, opportunities for advancement in the area of research can be undertaken by a new generation.

### Notable opportunities

While the efforts of many have added great value to the field, some challenges remain. In an editorial in *The Rehabilitation Professional*, Dr. Scott Smith questioned the present state of scholarship in the field of private rehabilitation (Smith, 2017). He notes some specific challenges regarding personal practice priorities, a recent merger of accrediting bodies for training programs, weariness of academic writing, and misunderstandings of the need for publishing. While these opinions were not specifically intended for life care planners, many of the same training, accreditation, and scholarship challenges affect this field as well. However, despite these challenges, some notable efforts have been made that contribute greatly to opportunities to create and participate in the creation of research in life care planning.

A Foundation of Life Care Planning and Research (FLCPR) was established and continues to promote the availability of research support (<http://www.flcpr.org/index.html>). The primary purpose of the foundation is “life care planning validation studies and rehabilitation research” (Foundation for Life Care Planning Research, 2015) and it has done so for many articles for the *Journal of Life Care Planning* and other journals. The *Journal of Life Care Planning* itself provides a peer-review outlet for the proliferation of ideas in the field. It can be easy to take for granted the peer-review process, but for those who wish to produce a product that can pass the test of excellence, having other experts review their work is a great privilege.

The point that Smith (2017) was making is that individuals in the field have worked to develop organizational structures over time that enhance the field, provide opportunities for generations to come, but require input from the whole of the profession. Just as a healthy democracy depends on the votes of all of its citizens, the growth of a profession requires input from all of its members. As a committed reader, one may not foresee a career of writing and publishing, but participating and encouraging research in your practice can greatly contribute to the efforts of researchers.

One noteworthy example of this is the self-evaluative tools used by a practice to provide feedback to fine-tune service provisions (Patterson, Murphy, & Masterson, 2004). These data were primarily used for a single life care planning group, but it was published and shared to demonstrate how simple evaluatee satisfaction surveys can provide valuable data on implementations of life care plans, quality of life

improvements, or the outcomes of settlement or arbitration.

In addition to present examples in the life care planning literature on efforts to bolster research efforts, Rumrill and Bellini (2017) provide an excellent discussion in their text on methods for research design and strategies. The reader is directed to their text for a full discussion, but several highlights are worth mentioning. Qualitative methodologies are improving and providing a greater understanding of evaluatee experience, which is a much-needed addition to understanding life care planning from a person-centered perspective. From a quantitative perspective, advanced data analytic techniques such as a path analysis and structural equation modeling can contribute to theory-driven research and increase credibility of the methodological foundations of the practice. For example, using observed variables such as quality of life or the acquisition of resources can provide evidence for the latent variables of the needs-based approach of a life care plan to demonstrate how a robust methodology improves patient outcomes. This contributes to reliability studies already in the literature. Other statistical tools include hierarchical linear modeling to contribute to an understanding of the demographic or cultural difference among life care plan recipients, longitudinal studies to contribute to long-term outcomes of people with disabilities or illness, and non-parametric tools can be used with small sample sizes to estimate population data.

Perhaps the single greatest opportunity for current and future researchers is the list of research topics outlined at the 2004 Summit. For those who are interested in studying life care planning, these questions can be a starting point for moving the field forward. In many ways, there is acknowledgement of the need for studies of how the life care plan is used by evaluatees as a guide for future care, as well as to establish the reliability and validity of the life care plans themselves.

Finally, the discussion of conducting research in life care planning would not be complete without an appeal to the Standards of Practice of the profession. Standard IV.2.3 states that the life care planner “uses specialized skills including, but not limited to, the ability to research, critically analyze data, manage and interpret large volumes of information, [and] attend to details...” (International Academy of Life Care Planners, 2015). While this and other standards specifically refer to the consumption of available research or conducting cost research, the same skills apply for developing and conducting formalized research for publication. The process of conducting formal research can be intimidating, however it is this author’s opinion that the experience and skill of life care planners positions them well for creating or collaborating on advanced research projects. Conducting research can be viewed as an exercise in confidence and acknowledging the strengths already possessed, rather than an undertaking of a new academic endeavor.

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