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Practice Challenges Identified by Life Care Planners in the United States

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Abstract

A survey was conducted in October 2017 to identify current issues and needs faced by life care planners practicing in the United States. Life care planning practitioners were asked to identify the three biggest practice challenges they faced in their practice in the past 12 months. Data were analyzed using NVivo 11 to identify eight essential themes among the participants. These themes were: (1) collaboration for recommendations (2) business challenges (3) evolution of field of life care planning (4) referral constraints (5) attorney concerns (6) future care costs (7) case development and (8) legal proceedings. The authors further explore these themes and discuss the implications of each for life care planners. The findings of this research are contrasted to the survey data collected of Canadian life care planners in April 2017.

Practice Challenges Identified by Life Care Planners in the United States

In 2017, Fisher and Wilkins examined life care planning practice challenges faced by Canadian life care planners. By surveying 31 Canadian life care planners, six thematic practice challenges emerged as follows: (1) collaboration for recommendations (2) practice challenges (3) research and training (4) referral constraints (5) attendant care and (6) future care costs. The authors further explored these themes and discussed the implications of each for life care planners. These themes were discussed in Fisher and Wilkins (2017) and the reader is referred to this publication for discussion of these themes. The current study replicates this line of questioning, but with American life care planners. As such, a brief history of life care planning in the United States is undertaken.

Life Care Planning

The term "life care plan" was introduced in the early 1980s by Drs. Paul Deutsch and Fred Raffa in the publication *Damages in Tort Actions* and in 1985, the classic *Guide to Rehabilitation* introduced the rehabilitation community to the life care plan (McCollom & Weed, 2002). Life care planning developed in response to a number of multiple professional concerns including:

1) Persons with disabilities and their families need a concise summary to plan for future needs;
2) A communication tool is needed with which all parties involved in a catastrophic injury case will be informed of these needs;
3) A planning approach in the field is needed, rather than the traditional reactionary approach;
4) Disabilities could be broken down into basic components to more carefully identify complex concerns;
5) Concerns specific to the person with the 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 (Weed & Berens, 2010, p. 834).

Following the introduction of the life care plan to the rehabilitation community, one of the first life care planning educational conferences was held in 1986 and in that same year the first peer-reviewed rehabilitation journal article on life care planning was published in the *Journal of Private Sector Rehabilitation* (McCollom & Weed, 2002). By 1992, a comprehensive life care planning curriculum had been developed, comprised of eight training seminars lasting two and one-half days each, which was followed by the introduction of a certification in life care planning in 1996 (McCollom & Weed, 2002). By 1996, the first professional association specific to life care planning was also formed which evolved into the International Academy of Life Care Planners (McCollom & Weed, 2002). A series of life care planning summits was launched in 2000 and continued through the most recent one held in 2017.

Life care plans have been successfully used in various public and private sector venues where it is necessary to predict future care needs and costs (McCollom & Weed, 2002). Life care plans have been utilized for over thirty years in personal injury cases, workers' compensation, insurance reserve setting, estate planning, mediation, discharge planning, long-term managed care, geriatric services implementation, and various other disability-related specialty programs, such as the vaccine injury fund and Medicare (Countiss & Deutsch, 2002; Weed & Berens, 2010). Life care plans also serve as financial planning tools to allocate necessary funds for future medical and rehabilitation services. There are currently several programs of life care planning studies, a peer-reviewed journal, the *Journal of Life Care Planning*, a Code of Ethics and Standards of Practice, and a life care planning professional organization, the IALCP within the professional organization, the International Association of Rehabilitation Professionals (IARP). A 2003 study of accredited graduate rehabilitation counseling

programs revealed that 66% of CORE accredited schools surveyed addressed the topic of life care planning in their curricula (Marini, Isom, & Reid, 2004). The 2008 Council on Rehabilitation Education (CORE) accreditation manual identified life care planning as a required knowledge area (Weed & Berens, 2010).

Neulicht, Riddick-Grisham and Goodrich (2010) conducted a role and function study involving 293 life care planners. In this sample, 44.59% identified as licensed or certified in nursing, while 45% were licensed/ certified in rehabilitation counseling. In this sample of 293 life care planners, 44.59% of life care planners identified nursing as their primary field of practice, while 36.94% reported rehabilitation counseling and 13.51% reported "other". The most commonly held certifications included Certified Life Care Planner (74.30%), Certified Case Manager (40.99%), Certified Rehabilitation Counselor (34.23%) and Certified Nurse Life Care Planner (10.81%).

Since 1996, the professional designation of Certified Life Care Planner (CLCP) has existed and is currently regulated by the International Commission on Health Care Certification (ICHCC). As of May 2019, there were 893 individuals who are designated Certified Life Care Planners (ICHCC, 2019). Canadian life care planners have their own designation (CCLCP), which has existed since 2005.

Methodology

A qualitative methodology was utilized to investigate the main research question: *What are the 3 biggest life care planning practice challenges you have faced in the last 12 months?* According to Koch, Niesz, and Wilkins (2017) qualitative research enables researchers to gain an "understanding of participants' own views, perspectives, thoughts, feelings and experiences" (p. 186) by those who are most affected by the phenomenon being researched. For this reason, current individuals practicing life care planning in the United States were surveyed. Response counts were also analyzed for demographic variables and are reported in Table 1 below.

Participants

In October 2017, the International Association of Life Care Planners (IARP) hosted their annual conference in St. Louis, Missouri. This conference was attended by 270 individuals. At this conference, attendees were made aware of the research project and some chose to participate on-site. Following the meeting, a link to the survey was sent to all subscribers of the International Academy of Life Care Planners section of IARP. The survey consisted of two entries: *1) Please list educational/ professional credentials and 2) What are the 3 biggest life care planning practice challenges you have faced in the last 12 months?* Anonymous responses were collected from October 18, 2017 until October 29, 2017 and reminders for participation were sent through the IALCP list serve on October 23, 2017 and October 27, 2017. During the data collection period, 65 participants viewed the document and 55 responded. Of the 55 responses, three were eliminated due to not meeting the parameters of the survey questions.

Of the 52 responses analyzed, 49 (94%) reported their credentials. Educationally, 61% of respondents who reported educational credentials possessed a nursing degree (BSN [n=14], RN degree [n=15] or DNP [n=1]), 41% of respondents possessed a master's degree (n=20), and 12% possessed a PhD (n=6). Regarding certifications 73% possessed a CLCP designation (n=36), 39% (n=19) possessed a CRC and 33% (n=16) possessed a CCM. Other credentials reported included FIALCP (n=4), CNLCP (n=4) among others. It is noted that some individuals possessed multiple credentials. Respondent information is outlined in Table 1 below.

Table 1
Demographic Characteristics (n=49)

Education	
Nursing Degree	30 (61%)
BSN	14 (29%)
RN	15 (31%)
DNP	1 (2%)
Master's Degree	20 (41%)
Ph.D.	6 (12%)
Certification	
CLCP	36 (73%)
CRC	19 (39%)
CCM	16 (33%)

Data Analysis Procedures

NVivo 11, a software program for qualitative data analysis, was used to assist with content organization, as well as coding and themes from the 52 respondents. Initially, the researcher read through all of the responses from participants to get a sense of the whole. A total of 145 responses derived from the participants were entered into NVivo and these responses were then grouped into 12 nodes. Each comment was reread within the context of the node to ensure it was correctly categorized. Peer debriefing was then conducted to further review the nodes. The 12 nodes were then further regrouped to isolate eight essential themes.

Results

Based upon the qualitative data analysis described above, eight essential themes emerged from the data collected from life care planners in the United States: (1) collaboration for recommendations; (2) business challenges; (3) evolution of field of life care planning; (4) referral constraints; (5) attorney concerns; (6) future care costs; (7) case development; (8) legal proceedings. Each of the eight themes is discussed below, including specific comments

made by life care planners within each theme.

Collaboration for Recommendations

In this sample, life care planners frequently identified the challenge of difficulty collaborating with the evaluee's treatment team. Specific difficulties noted by life care planners included getting a doctor to understand a more probable than not standard, refusal by treating team members to collaborate, inadequate responses from treaters, and getting an opinion from a doctor during plan preparation stage only to have that opinion change during sworn testimony. Also within the theme of collaboration, life care planners noted difficulty working with unprepared or poorly qualified experts and getting vendors to respond in a timely manner. Also noted was difficulty getting age reductions where applicable based on co-morbid diagnoses and disability criteria.

Business Challenges

The second identified theme pertained to business practices for life care planners. Many life care planners expressed difficulty with juggling multiple and changing deadlines within and between their cases. Life care planners also faced challenges in managing their practices when workflow is inconsistent. This occurrence was documented by many life care planners who may have too much work for them to complete individually, yet expressed concern about hiring and training staff members and maintaining enough work to keep these individuals employed. The practice of subcontracting work was identified by several respondents as a method by which their practice exists. Other practice issues identified included marketing, proofreading, growing a practice, understanding the legal aspects of business structures and getting paid. The cost of doing business was another area of concern for respondents including the cost of purchasing peer-reviewed journals, office technology, software/ data management programs and purchasing professional legal and accounting services for the practice. A concern in this area included lengthy depositions and trials that were becoming more common. Within the realm of depositions, another concern was expressed about facing challenges about the validity and usefulness of the CLCP credential.

Evolution of Field of Life Care Planning

The third theme identified involved life care planners' concerns about how the field of life care plan is evolving. Specifically, individuals expressed concern about the fracturing of the field by the entrance of physician life care planners. Responses reflected a theme of concern that some life care planners are not following established guidelines including life care planning Standards of Practices (International Association of Rehabilitation Professionals, 2015) and Consensus and Majority Statements (Johnson, Pomeranz & Stetten, 2018). Responses in this area included observed inconsistencies in how life care planners provide evidence to support life care plan recommendations, life care planners working outside of their area of expertise/ scope of practice, lack of understanding of proper methodology, and failing to disclose costing data sources, any of which threatens the perceived validity of life care planning practice.

Referral Constraints

The fourth theme that developed from U.S. life care planners involved referral constraints. Specific concerns included difficulty of preparing a work product within a limited timeframe, with several life care planners mentioning attorneys delaying referral even though their services were retained months/ weeks before the receipt of records needed to commence work. In addition to working within the parameters of a quick turnaround time, many life care planners identified challenges including juggling deadlines, declining work due to time demands and time constraints placed by evaluees.

Attorney Concerns

The fifth theme that emerged in the data collection was that of working with attorneys or legal professionals. The challenge of educating new attorneys about the processes and methodology of life care planning was identified. Attorneys requesting that reports be prepared based upon specific cost data sources from collateral sources (e.g., Medicare) or non-database costing was also identified. Working with attorneys who do not obtain or send the life care planner the requested medical records was also identified as a common barrier. Reviewing reports prepared by economists was also mentioned. Having limitations on access to the evaluee during the life care plan preparation process was noted by several life care planners, while others mentioned attorneys limiting their follow up with evaluees after case resolution. Other respondents mentioned a barrier to include "attorney issues", "over-needy attorneys" and getting cooperation from attorneys and insurance companies.

Future Care Costs

The sixth theme that life care planners identified included challenges in costing. In these responses, the vocabulary used pertaining to this concept included "pricing", "charges" and/or "costs". Concerns included finding/ obtaining accurate pricing for surgeries, hospitalizations, unique treatment protocols, attendant care, facility/ long-term residential facilities, spinal cord stimulators, intrathecal pumps, disk replacements and amputations. Additional mention was made about difficulty in determining estimated cost for architectural renovations, without an individual assessment being performed. For life care planners who obtain costing data, many expressed concerns about how to determine the accuracy of the prices located. Similarly, concerns were expressed about costing inconsistencies between databases versus actual costs.

Several life care planners expressed concerns about obtaining pricing data when facilities or offices do not want to give out this data. Coding was also identified as a barrier by multiple life care planners, both in determining the correct code to be used by healthcare professionals and determining the number of current procedural terminology (CPT) codes to be used. Several life care planners mentioned difficulty in obtaining hospital/ facility fees as some institutions have individuals trained to research this data to be made available to life care planners, while other institutions do not have such a person.

Case Development

A seventh theme that emerged from the research involved case-specific concerns. These included concerns about how to determine attendant care hours and household services hours. Another concern was expressed about how to find specialized services such as life skills instruction, coaches or mentors to work with persons with disability in the community, particularly for individuals with acquired brain injury. Concerns about working with challenging family members was noted. Determining the duration of a service was noted as was how to determine transplant follow-up needs. Finding good medical treatment when patients reside in small cities was noted in this area. How to establish a foundation of a life care plan from resources was noted as was how to determine life expectancy.

Legal Proceedings

The eighth theme that emerged in this research pertained to legal proceedings. Several life care planners expressed concern about motions to exclude testimony. Life care planners expressed concern about collateral source challenges including the Affordable Care Act, particularly the unpredictability of the legislation's fate. Also noted in this area was the adversarial nature of other rehabilitation counselors or life care planners on the case.

Limitations

It is noted that participation in this research was voluntary and responses were only collected for a period of approximately 30 days. Respondents were notified of the research through IARP's fall 2017 conference as well as notification posted on the IARP/ IALCP list serve, thus likely limiting responses to members of IARP.

Instead of using a quantitative approach to "verify causal relationships between variables" (Maxwell, 1996), the researchers utilized a qualitative inquiry to "learn from the participants themselves how they experience particular phenomena or systems and how they understand these experiences" (Niesz, Koch, Davenport, Rumrill, & Wilkins, 2019). As Brantlinger, Jimenez, Klingner, Pugach, & Richardson (2005) explains:

> Qualitative research is not done for purposes of generalization but rather to produce evidence based on the exploration of specific contexts and particular individuals. It is expected that readers will see similarities to their situations and judge the relevance of the information produced to their own circumstances. (p. 203)

This study can be seen as having the same potential limitation in respect to transferability as other qualitative research studies may have (Koch, Niesz, Wilkins, & 2017). It is felt, that further quantitative research should be undertaken to measure the impact of these variables and to overcome the limitation of transferability.

Discussion and Implications

The concerns identified in this research were consistent with the themes identified in similar research conducted with Canadian life care planners (Fisher & Wilkins, 2017). In that research, 31 life care planners in Canada were surveyed and asked the same question as was asked in this research, that is: *What are the 3 biggest life care planning practice challenges you have faced in the last 12 months?* From this research, six essential themes were revealed and they were (See Table 2): (1) collaboration for recommendations; (2) practice challenges; (3) research and training; (4) referral constraints; (5) attendant care; and (6) future care costs. When this research was replicated in the United States, 52 life care planners responded noting eight essential themes which were: (1) collaboration for recommendations; (2) business challenges; (3) evolution of field of life care planning; (4) referral constraints; (5) attorney concerns; (6) future care costs; (7) case development; (8) legal proceedings.

Table 2
Practice Challenge Thematic Responses

Canadian Responses – **6 Essential Themes (N=31)**	United States Responses- **8 Essential Themes (N=52)**
Collaboration for Recommendations	Collaboration for Recommendations
Practice Challenges	Business Challenges
Research and Training	Evolution of Life Care Planning
Referral Constraints	Referral Constraints
Attendant Care	Attorney Concerns
Future Care Costs	Future Care Costs
	Case Development
	Legal Proceedings

As noted above, several themes in practice challenges were similarly identified by both Canadian and U.S. life care planners. These practice challenges will be discussed below, along with recommendations for further research in these areas.

Collaboration

Virtually all guiding documents in the field of life care planning identify collaboration as important to the life care plan methodology (Gamez, Johnson & Stajduhar, 2017; International Academy of Life Care Planners, 2015). Life

care planners in both the United States and Canada pursue this process in their practice. However, in both samples, life care planners reported difficulty getting involved parties to collaborate. Respondents in the U.S. based research indicated difficulty with scheduling consultation with and getting recommendations/ feedback from treatment team members in the life care plan development process. Canadian responders noted difficulty accessing treatment team members, dealing with conflicting opinions, and difficulties determining the weight to attribute to various opinions. The consistency of these responses suggests that life care planners in general experience difficulty getting collaboration from healthcare professionals in developing plans. As all life care planners are encouraged to collaborate with team members, continuing attempts for collaboration with documentation of refusal by treatment team members is recommended (Weed & Berens, 2018). The reader is directed to Shahanasarian (2017) for recommendations for dealing with collaboration with treatment team members. Additional discussion of this process through professional conferences and Summit proceedings is also recommended, as this theme was consistently identified as challenging to those attempting to follow standard life care planning methodology which encourages treatment team collaboration.

Future Care Costs

A second theme that was similar between both U.S. and Canadian life care planners included the challenge of costing items contained in the life care plan. Canadian respondents reported future care cost challenges to include difficulty obtaining costs and providing realistic costs when family members are currently providing support. Respondents in the United States reported barriers to finding/ obtaining accurate pricing for items contained in the life care plan as well as determining the accuracy of costing data obtained and the coding necessary to obtain costs for item/ services to be included in the plan. For resources in understanding coding procedures, the reader is directed to Albee, Gamez and Johnson (2017), Busch (2017), Holakiewicz and Pacheco (2012) and Weed and Berens (2018). Discussion of these challenges and resources for dealing with this are also regularly offered through life care planning conference sessions.

Practice Challenges

In the Canadian research, the theme of practice challenges emerged from the responses, including: limited Canadian-based life care planning literature, different methodologies/ approaches to life care planning and limited mentorship and networking opportunities. In the United States sample, practice challenges also emerged and they included structuring work with an inconsistent work flow, as well as business-related concerns about marketing, business structure, practice growth, costs of operating a business and collections. One possible explanation for the difference in the business practice challenges between the sample of Canadian life care planners and the U.S. life care planners is the difference in duration of the life care planning communities in Canada and the United States. It is unknown why U.S. based life care planners expressed specific concerns about operational challenges, while this was not reported in the Canadian sample. This is an area of suggested future research.

Whereas in the U.S. research, an essential theme of attorney concerns emerged, in the Canadian research, concerns about attorney expectations did not rise to a level of an essential theme. Nevertheless, in both groups of life care planners surveyed, life care planners acknowledged both practice-based barriers (i.e., barriers in actual life care plan preparation) and business-based challenges (i.e., operating a business as a life care planner). Life care planning resources for dealing with practice challenges include the IARP/ IALCP conference sessions. Additional resources can be found through IARP's mentoring program, the details of which can be found at https://connect.rehabpro.org/ mentoring/overview.

Case Development/ Attendant Care

A similar theme that emerged between the two samples included case development barriers. In the United States, these included concerns about how to determine attendant care hours and household services hours. This similar theme emerged in the Canadian research where respondents noted challenges in determining the need for home care versus facility care and determining the amount of attendant care required. In the United States research, additional case development challenges identified included finding specialized services such as life skills, coaches or mentors; dealing with challenging family members; identifying services in small cities; determining post-transplant needs and life expectancy opinions and when to end service provision.

For current resources in assessing the need for determining attendant care needs, the reader is directed to Crowley (2018), Maranan and Rose (2017) and Weed and Berens (2018). For resources on identifying services in rural areas, the reader is referred to the University of Montana's Research and Training Center on Disability in Rural Communities (rtc.ruralinstitute.umt.edu). For discussion of estimating life expectancy within the field of life care planning, the reader is referred to Krause and Saunders (2010) as well as the *Journal of Life Care Planning*, volume 12, issue 1, which contained multiple articles discussing this topic.

Dissimilar Themes

Evolution of the field of life care planning. In the United States sample, respondents were more focused on a perceived deviation from accepted life care planning methodology than were responders in the Canadian sample.

This is not entirely surprising given that as a field, life care planning in the United States has been in existence longer than it has in Canada. For example, the CLCP designated emerged in 1996 whereas the Canadian certification (CCLCP) first emerged in 2005 (Fisher & Wilkins, 2017). In this United States research, life care planners expressed concerns about physician life care planners who deviate from methodology, whereas no responders in the Canadian samples noted this concern. Additionally, in the United States sample, respondents noted concerns about challenges to admissibility of life care planner testimony in legal settings. This was not detected in the Canadian research sample. Finally, in the Canadian sample, respondents reported limited opportunities for life care planning training and development which was not detected in the U.S. sample.

It is incumbent upon all life care planners who wish to practice in this rehabilitation subspecialty to understand proper methodology which has been established through over 30 years of research and publication in such texts as *Guide to Rehabilitation* (Deutsch & Sawyer, 1985, 2003), *Life Care Planning and Case Management Handbook* (Weed & Berens, 2018), *Consensus and Majority Statements* (Johnson, Pomeranz & Stetten, 2018) and *IARP Standards of Practice for Life Care Planners* (IARP, 2015). For non-physician life care planners who wish to increase their knowledge of standards of practice for physician life care planners, the reader is directed to publications through the American Academy of Physician Life Care Planners (http://aaplcp.org/Education/Publications.aspx). Additionally, training materials offered through IARP, such as the webinar *20 Red Flags in a Life Care Plan/ Life Care Plan Review* (https://www.pathlms.com/iarp) may be helpful when reviewing life care plans for adherence to established methodology.

Conclusion

The goal of this research was to identify life care planning practice challenges faced by life care planners in the United States by asking the research question: *What are the 3 biggest life care planning practice challenges you have faced in the last 12 months?* In part, this research replicated research conducted by Fisher and Wilkins (2017), which surveyed 31 Canadian life care planners with six essential themes emerging including: (1) collaboration for recommendations; (2) practice challenges; (3) research and training; (4) referral constraints; (5) attendant care; and (6) future care costs.

In this research, 52 life care planners in the United States responded to the research question above and as a result, their resources noted the following eight essential themes: (1) collaboration for recommendations (2) business challenges (3) evolution of field of life care planning (4) referral constraints (5) attorney concerns (6) future care costs (7) case development and (8) legal proceedings. The concerns expressed in these samples of life care planners provide opportunities for future research and training as life care planners in two countries expressed multiple overlapping concerns.

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