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Challenges and Practice Issues Faced by Canadian Life Care Planners

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Abstract

A survey was conducted to identify current issues and needs that Canadian life care planners face in their practices. Thirty-one Canadian health care professionals were asked to identify the three biggest challenges or practices they had faced in their practice in the last year. Data was analyzed using NVivo 11 to identify six essential themes among the participants. The six essential themes were found to be: (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 explore these themes and discuss the implications of each for life care planners.

Challenges and Practice Issues Faced by Canadian Life Care Planners

As the number of life care planners practitioners has grown, the need for greater specificity of information required in the life care plan and increased complexity of referrals has also grown (Neulicht, Riddick-Grisham & Goodrich, 2010). Practitioners are seeking specific training and networking opportunities to address the additional challenges they are facing in their practice. Unfortunately, there is limited published literature regarding the challenges Canadian practitioners experience. A survey was conducted in 2009 by Neulicht et al. on the practices of life care planners. Of the 293 respondents, most were U.S. practitioners, with survey results representing only eight (2.7%) Canadian practitioners (Neulicht, Riddick-Grisham & Goodrich, 2010). The majority of respondents (81.5%) identified nursing or rehabilitation counseling as their primary field of practice; whereas in Canada the primary health care profession practicing in life care planning are occupational therapists. The goal of this study was to identify and explore common challenges that Canadian practitioners experience and offer an analysis to address these common challenges.

Life Care Planning in Canada

As life care plans are more frequently being used and there are many more experienced practitioners in the field, health care professionals are now looking to refine their skills and assessment methodologies in order to prepare more defensible life care plans. According to the International Association of Rehabilitation Professionals (2017), a life care plan is 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 care needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs.

While in the United States (U.S.) the term *life care plan* is used almost exclusively, in Canada, it remains just as common to also use the terms cost of *future care assessment* and *future care cost assessment*. The Supreme Court of Canada first outlined the basic principles for future care claims in 1978 based upon three cases known as *the trilogy*: Andrews v. Grand & Toy Alberta Ltd., Thornton v. School District No. 57 (Prince George) et al., and Arnold v. Teno (1978) (Klinger, Baptiste & Adams, 2004). The court identified that injured persons are entitled to a standard of care that can be justified as fair, and that is reasonably required to return them as closely back to the position they would have been had the injury not occurred. (Klinger, Baptiste & Adams, 2004). In the British Columbia case of Milina v. Bartsch (1985), Madam Justice McLachlin stated, "the award for cost of care should reflect what the evidence establishes is reasonably necessary to preserve the plaintiff's health." (McLachlin in Milina v. Bartsch (1985), 49 B.C.L.R. (2d) 33 (S.C.) at p.84)

In Canada, occupational therapists (OTs) are the primary health care professionals who complete life care plans. This is different than in the U.S. where the majority of life care plan practitioners are nurses and rehabilitation counselors (Neulicht, Riddick-Grisham & Goodrich, 2010). In Canada, occupational therapists have assisted plaintiff and defense lawyers in determining costs of future care awards for several decades. The occupational therapy literature first identified the role of the occupational therapist as an expert witness in 1987 (Harris, Henry, Green, & Dodson, 1994). Other allied health care disciplines have increasingly joined the life care planning field in Canada, including vocational rehabilitation counselors, nurses, and physiotherapists.

As the U.S. population is over 300 million (United States Census Bureau, 2017), as compared to Canada's population of approximately 36 million, it stands to reason that there are many more practitioners working in the life care planning field in the U.S. as compared to Canada. While neither country requires a specific certification to work in the life care planning field, the majority of life care planners working in the U.S. hold the designation Certified Life Care Planner (CLCP). This is a certification that has existed since 1996 and is currently regulated by the International Commission on Health Care Certification (ICHCC). The ICHCC began offering a specific designation as a Canadian Certified Life Care Planner (CCLCP) in 2005, with the first CCLCPs obtaining the designation in 2016 (V. May, personal

communication, July 3, 2017).

The ICHCC website identifies a total of 826 registered CLCPs in the world, with 41 CLCPs working in Canada. In addition, there are 147 practitioners with the specific Canadian designation, CCLCP (ICHCC, 2017). However, these numbers do not reflect the significant number of occupational therapists, and other healthcare practitioners working in the life care planning field in Canada without a CLCP or CCLCP designation. The Canadian Association of Occupational Therapists has not published statistics on the number of OTs in Canada who are life care planners (J. Lapointe, personal communication, July 4, 2017); however, it is well known that this number continues to grow.

Despite the growing number of life care planners in Canada, published literature in life care planning that is specific to Canadian practice and the Canadian legal system is limited. In the last two decades, there have been only a small number of articles published related to life care planning (Fischer, 2004; Harris, Henry, Green & Dodson, 1994; Klinger, Baptiste, Adams, 2004). The purpose of this study is to fill the void and identify issues/needs that are specific to Canadian life care planners.

Methodology

A qualitative methodology was utilized to investigate the main research question: What are the biggest challenges or practice issues faced by Canadian life care planners? According to Koch, Niesz, & Wilkins (2017), qualitative research is particularly useful in gaining an "understanding of participants' own views, perspectives, thoughts, feelings and experiences" by those that are most affected by the phenomenon being researched. For this reason, Canadian life care planners were surveyed.

Participants

In April 2017, 55 Canadian health care professionals practicing in the life care planning field attended a two-day course designed to enhance their skills and maximize the defensibility of their life care plans. During that two-day conference, which was held in Toronto, Ontario, individuals were asked to complete a single question survey aimed at identifying the most common practice issues and challenges they have recently faced in the industry.

Survey participants were pooled from a number of provinces across Canada including Ontario, British Columbia, Newfoundland, Nova Scotia, and Alberta; with the majority (75%) being from Ontario. There were healthcare practitioners with varied backgrounds including occupational therapy, physiotherapy, kinesiology, nursing, vocational rehabilitation, chiropractic, and social work; with the majority (64%) having an occupational therapy background.

Participants in the survey were informed by the first author of the purpose of the data collection and that all data would be collected anonymously with results to be published in the *Journal of Life Care Planning*. Participation in the survey was voluntary and not conducted as part of the training program. Of the 55 attendees, 31 chose to participate. Participants were asked the following question: *"What are the 3 biggest challenges or practice issues you have faced in your life care planning practice in the last 12 months?"*

Data Analysis Procedures

NVivo 11, a software program for qualitative data analysis, was utilized to assist with content organization, as well as coding and themes from the thirty-one participants. Initially, the researcher read over all of the responses given from participants to get a sense of the whole. A total of 81 responses derived from the participants were entered into NVivo, and these responses were then grouped into 16 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 16 nodes were then further regrouped to isolate six essential themes. This process involved grouping nodes together according to conceptual similarities, and providing each cluster with a descriptive label. The six essential themes were found to be: (1) Collaboration for Recommendations; (2) Practice Challenges; (3) Research and Training; (4) Referral Constraints; (5) Attendant Care; and (6) Future Care Costs. These themes will be further explained, and participants' responses shared in the following section.

Essential Themes

Collaboration for Recommendations

As life care planners address all aspects of a disability across a wide range of practice areas, they should, when available, collaborate with other medical professionals to establish a solid foundation for the resulting life care plan (American Association of Nurse Life Care Planners, 2015; International Academy of Life Care Planners, 2015; Johnson, 2015). Issues with this collaboration for their recommendations was found to be a common theme among all the survey participants. Participants reported collaboration issues to include:

Lack of access to medical professionals for evaluee-specific information.

Without having access to physicians to clarify a vague or uncertain prognosis, there can be uncertain medical foundation for the life care plan. In addition, not having the opportunity to consult with treatment practitioners involved in the evaluee's care limits gathering information that is often of assistance to determine the individual's future treatment needs.

Addressing conflicting opinions.

There may be conflicting opinions identified by the life care planner among other experts retained on the case. The life care planner may also not agree with opinions from some of the treatment practitioners from whom they have sought

information and opinions. Addressing these conflicts poses a challenge when ultimately making care recommendations within the life care plan.

Determining how much weight to place on various sources of data.

The life care planner relies on information from various sources to determine the client's life long needs. This often includes the life care planner's own assessment of findings, as well as information and opinions from medical experts and treatment practitioners. Amalgamating information and opinions from a variety of sources to arrive at final recommendations can be challenging.

Addressing pre-existing medical conditions.

Life care planners are required to consider pre-existing health and functional issues that the client was experiencing prior to the accident or event for which the life care plan is being prepared. When pre-accident and post-accident health and functional issues are interconnected, it can be challenging to differentiate between the two, and subsequently make specific recommendations relevant to the subject accident or event.

Practice Challenges

Practice challenges were found to be a common theme among all of the participants. Survey participants reported practice challenge issues to include: limited Canadian-based life care planning literature, different methodologies/ approaches to life care planning and limited mentorship and networking opportunities.

Limited Canadian-based life care planning literature.

Life care planners must be knowledgeable regarding the healthcare and legal systems in which a evaluee resides in order to produce a relevant and accurate life care plan. A significant amount of the life care planning literature is based on the U.S. healthcare and legal systems. However, healthcare and legal systems are different in the U.S. as compared to Canada. For Canadian residents, recommendations must abide by the Canada Health Act, as well as identify and consider any provincial healthcare funding sources available. Precedent setting judgments in Canada also influence practice and the content of life care plans, as they determine what are considered acceptable cost of future care items to include in the plan.

Different methodologies/approaches to life care planning.

There are similarities and differences in the methodologies applied by Canadian practitioners. The commonality is universal acceptance of the importance of relying on medical prognosis as a foundation for cost of future care recommendations. One of the major differences in methodology among Canadian practitioners is that some practitioners rely almost exclusively on data and opinions obtained from medical experts and treatment practitioners to identify future care needs; while other practitioners incorporate their own assessment findings, in addition to relying on opinions from other practitioners. Both approaches comply with the *Standards of Practice for Life Care Planners* (IARP, 2015), provided the life care planner stays within his or her scope of practice for their health care discipline.

According to IARP's *Standards of Practice* (2015), the life care planner is expected to assess the need for further evaluations or expert opinions. This indicates, for example, that when there is limited information available to reliably determine the evaluee's needs in a specific area of the plan, the life care planner may choose to conduct their own additional assessment. Provided the life care planner remains within their scope of expertise for their healthcare discipline, such information can be relied upon to identify an evaluee's needs (IARP, 2015). For example, an occupational therapist who determines there is a lack of information on file related to the evaluee's ability to carry out homemaking activities, may choose to conduct an Activities of Daily Living assessment to determine those needs.

Limited mentorship and networking opportunities.

Many practitioners identified limited opportunity to discuss critical issues affecting the life care planning field in the province or territory in which they practice, as well as limited opportunity to solicit advice from colleagues regarding case-specific issues. The International Association of Rehabilitation Professionals (IARP) provides opportunities for all life care planners to post questions on a forum to other practitioners. IARP has a Canadian Chapter currently with 85 members (IARP, 2017). Another venue is the annual IARP/ISLCP conference which hosts a discussion group specifically for Canadians to discuss issues affecting practice in their country and regions (E. Cowitz, personal communication, June 27, 2017).

While many American professional associations have websites which routinely publish information on life care planning (Johnson & Weed, 2013), this is less common in Canada. Life Care Planning Summits have been held biennially since 2000. The Life Care Planning Summit is

> . . . attended by representatives from professional organizations and training programs, researchers, practitioners, and support service providers to explore the current state and future directions of the specialty practice of life care planning. Although the process of life care planning and standards of practice have been established, consensus and unity in the field is a developmental process. Through Summits, participants have the opportunity to examine life care planning issues, contribute to the resolution of these issues, and be involved in the continued evolution of the field (Johnson, 2015, p.21).

To date, the Summit has been held 10 times, conducted once in Canada (Johnson, 2015). The most recent Summit was held earlier this year, and of the 107 participants, there were no Canadians in attendance (L. Woodard, personal communication, July 21, 2017).

Research and Training

Survey participants reported research and training issues to include: remaining abreast of legal judgments that affect practice, limited availability and/or access to accepted treatment protocols, and limited availability of continuing education opportunities for experienced practitioners.

Remaining abreast of legal judgments that affect practice.

As life care planners practice within the context of a legal framework, it is essential to remain abreast of precedent setting judgments to ensure that the content of their plans is appropriate and relevant. Canadian practitioners identified difficulty maintaining an up-to-date knowledge base regarding case judgments impacting life care planning practice.

Limited availability and/or access to accepted treatment protocols.

As life care plans are prepared for individuals with chronic conditions, recommendations are often made for long-term or lifetime access to various treatments and supports. Practitioners identified the challenge of finding and gaining access to treatment guidelines, particularly information related to long-term pain management. The concern is that, without availability or access to such information, frequency and duration of treatment recommendations in the life care plan may not be reliable, and may instead either over-provide or under-provide as to the evaluee's actual needs. While life care planners frequently rely on treatment practitioners for such information, treatment practitioners tend to focus more on the evaluee's short-term, rather than long-term treatment needs. Therefore, relying on only this source of information can make it difficult to determine an evaluee's long term needs.

Limited availability of continuing education opportunities for experienced practitioners.

Once practitioners have the basic foundational skills to practice and have gained experience, they are often retained for involvement in more complex cases. Seasoned practitioners identified difficulty in finding valuable and relevant Canadian-based opportunities to meet their continuing educational needs.

Referral Constraints

Survey participants reported referral constraint issues to include time pressures and budgetary issues.

Time pressures.

Practitioners identified frustration regarding unrealistic deadlines from referral sources for completion of life care plans, given the scope of work required. This is particularly problematic when further information is required regarding prognosis, and there is not enough time allowed for consultation with medical experts.

Budgetary issues.

Practitioners identified pressure from some referral sources to provide reports on a limited budget, making it difficult to provide as comprehensive a report as deemed necessary. Some referral sources request a condensed life care plan that is limited in scope and does not comply with the accepted definition of a life care plan in accordance with the *Standards of Practice* (IARP, 2015).

Attendant Care

Survey participants who practice in Ontario reported a major challenge to practice as addressing attendant care issues, including determining the need for home care versus facility care and determining the amount of attendant care required.

Determining the need for home care versus facility care.

An often cited issue in the life care planning literature is determining and providing rationale as to the need for home care or facility care as this is often the most costly item within the plan. This issue was also identified by survey participants.

Determining the amount of attendant care required.

Survey respondents identified a challenge with determining the amount of attendant care required. They identified multiple factors requiring consideration including: type of assistance, level of assistance, nightly supervision requirements, live-in versus live-out caregiver arrangements, and agencies available in the individual's region.

Survey results identified some life care planners as having difficulty explaining to stakeholders when there is a difference between attendant care hours determined for accident benefits (i.e. compensation) purposes as opposed to those for tort purposes.

In all provinces and territories in Canada, injured individuals are eligible for accident benefits regardless of which party is at fault for the accident. Specifically, in Ontario, an occupational therapist or registered nurse conducts an *assessment of attendant care needs* to determine the amount of accident benefits compensation. In Ontario, this is referred to as the Statutory Accident Benefits Schedule (SABS). This is separate from the personal care attendant needs assessment conducted as part of the life care plan for tort purposes.

In determining attendant care benefits (SABS), a form is completed estimating hours required for direct care as well as supervision and support functions the evaluee requires, including those either being currently provided by a personal care attendant and/or family/other non-paid individuals. (Financial Services Commission of Ontario, 2017). These hours are used to determine the injured individual's monthly care benefits allowance by the insurance company. The SABS has prescribed limitations with respect to what costs can be recovered. (Financial Services Commission of Ontario, 2017). Hours are multiplied by rates that do not reflect actual market value cost of services.

For tort purposes, the life care planner determines how many actual hours of paid personal care attendant services

the evaluee requires on a long-term basis. While information from the assessment of attendant care needs form is considered when determining the amount of paid attendant care hours to include in the life care plan, this is only one source of information considered by the life care planner. Therefore, it stands to reason that personal care attendant hours calculated for the purpose of determining accident benefits compensation versus tort purposes should not necessarily be expected to be equivalent. (C. Bierbrier, personal communication June 28, 2017). When determining the number of personal care attendant hours an evaluee requires on a long-term basis, it is important for the life care planner to focus on those activities the individual is unable to do for themselves as opposed to what they have others doing for them. Other factors include determining the level of support required for maintaining the evaluee's safety, as well as considering the medical prognosis identifying any changes in function anticipated over time. These factors, combined with research of the actual market value cost of services, allows for accurate determination of personal care attendant hours to include in the life care plan. Having an understanding of how to articulate the methodology and rationale used to calculate personal care attendant hours for accident benefits compensation versus for tort purposes may assist life care planners in better explaining to stakeholders any perceived discrepancy that exists.

Future Care Costs

Survey participants reported future care cost challenges to include difficulty obtaining costs and providing realistic costs when family members are currently providing support.

Difficulty obtaining costs.

Life care planning practitioners identified reluctance of some service providers to offer quotes for services such as yard work without having had the opportunity to view the property. Some practitioners also identified difficulty obtaining the rates for assessment or treatment sessions.

Providing realistic costs when family members are currently providing support.

When an evaluee is assessed, in some cases, family members are currently providing needed support. When services are not in place at the time of assessment, some life care planners find it difficult to identify an alternate scenario for the life care plan involving paid attendant care and homemaking support.

Discussion and Implications

This research was conducted to identify perceived practice challenges that Canadian life care planners face in their practices. The results highlight the importance of uniting as a group to problem solve similar issues being encountered by a significant number of Canadian practitioners in the industry. Survey results may also be helpful for educators in the life care planning field to design curricula that meet Canadian practitioners' current educational needs. Results may also help promote discussion of the most relevant issues to Canadians at life care planning conferences. Finally, issues raised highlight the importance of developing further practice guidelines. The study has also yielded results that other researchers can further explore in the future including replicating this study with life care planning professionals in other countries.

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