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Purpose and Objectives

The Journal of Life Care Planning publishes refereed education and research materials relevant to the practice and processes of life care planning. The specific objectives of the Journal are as follows:

- Publish materials which will add to the growing literature base of the practice of life care planning.
- Provide the professional field with information regarding events and developments important to the practice of life care planning.
- Provide a forum for the debate and discussion of practice issues.
- Promote professional practice by addressing issues relevant to certification, ethics, standards of practice and research methodologies.
- Promote advanced practice through the publication of preapproved continuing education feature articles.

Publication Guidelines

Journal of Life Care Planningl (JLCP) is a quarterly publication of the International Association of Rehabilitation Professionals (IARP). The articles are written with the rehabilitation professional in mind. Articles are suggested for, but not limited to, the following tracks: case management, rehabilitation education, ethics, vocational rehabilitation, disability management, forensic/life care planning, and practice management.

Author(s) should follow the 7th edition of the *Publication Manual of the American Psychological Association*. Articles should be in Microsoft Word format, using Times Roman font, and be double-spaced. Do not use the tab key or spaces to align text. Only one space should follow any punctuation. Do not include additional spaces at the end of the paragraph.

Tables need not be camera ready since they are reset to match the style of the journal. Tables should be located at the end of the document. Graphs, photographs, and figures should be included as separate files and be in a graphic format, e.g., JPG, TIF, BMP, PNG. Indicate correct location of tables and figures in text, enclosed in angle brackets.

Authors should use acceptable language, which respects individuals.

Abstracts of no more than 250 words each should be included. The abstract should include a brief summary of the content of the article. Author notes should conform to current APA 7th edition format.

The name and mailing address of the lead author should be provided to Editor in order that a complimentary copy of the journal can be sent in appreciation.

The articles are reviewed by the Editor and by members of the *JLCP* editorial board. There is no guaranteed publication date for an accepted article. Articles should be sent to the Managing Editor as an email attachment.

Upon review, an article is either accepted or rejected. Accepted articles often require editing for spelling and grammar. These are done without contacting the au thors. Authors will be contacted, however, if there are questions about the meaning of the content or if significant changes are needed to syntax. Articles are generally published in the order received.

Editor's Message

Aaron Mertes Phd, CRC, CLCP, IPEC, PCLC

Part of editorial duties are reading submissioning when they come from authors, then sometimes suggesting revisions. Sometimes there are several rounds of this as we help authors prepare their best work to be shared publicly. When I get the author's final product, I read it again before sending it off for review. When it comes back from peer review, there is more time spent with each article as comments are read and often transferred into a single file for authors to work with. Then when revisions come back from the author, I read the article again to ensure that changes were made or authors justify their decisions. Finally, I transform each article into what is close to final format before it is sent of to the printer.

I explain this process for two reasons. First, when people wonder about the rigor of peer review, now you know a little more about it. There are checks and re-checks throughout the process to make sure that authors maintain the integrity of their work and that their peers make meaningful contributions to the betterment of the article. Second, by the time an article is in front of you, reader, I feel a familiarity and pride that is perhaps only second to the authors themselves. I feel like I've invested significant time into it and am proud to put it in front of you. I'm privileged to have a front-row seat to the growth of the field.

This quarter we have an incredibly insightful article finding costs for attendant care in a life care plan. It reads like a tutorial that can provide a reader with a road map to many of the important issues related to finding these costs, from establishing the type of care needed to deciding the adequate size of a sample based on statistical probabilities to reporting that data with adequate foundation. This will likely be of great use to life care planners moving forward as a guide for finding their own costs for this part of a life care plan.

Next is a discussion on collateral sources. With collateral source rules differing across the country and in various jurisdictions, this article gives important contextualization to the differences in who is responding to this issue in different ways. For those working across state lines, it can be an especially helpful resource to understand how their life care plan may be interpreted in different ways in different places.

After this is an exploratory study on the impact of medical marijuana use on patients with chronic pain. This qualitative study provides readers with a great deal of patient perspectives on several topics from cost to social support to accessibility to quality of life to prior opioid use and how marijuana is different.

I don't expect that readers will labor over these articles the way that the authors did or in the way that I did as I edited. However, some of these may just be read intimately as other life care planners learn to apply the concepts within. If you do choose not only to read and inform yourself, but also to transform your own practices, don't be surprised if what starts as increasing familiarity finishes with pride in your own investment in yourself. These articles are worth the read and you will likely be better for it.

IARP INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

IARP Education Annual Report: A Year-In-Review

Dear IARP Members:

IARP's education committee continues to be committed to providing quality content and continuing education credits to our membership. We recognize that we all practice in a variety of settings and come from a variety of disciplines. As such, each member has differing needs for education to maintain their licensure and credentialing status. Our goal is to provide educational opportunities through conferences (virtual and in person) and via Webinars and special education programs (summer series, etc.)

We kicked off 2022 with a webinar entitled: Introduction to the Foundation for Life Care Planning and Rehabilitation Research.

Additionally, the ELearn committee is already underway with reviewing and scheduling additional webinars beyond May 2022. Check out our upcoming webinars below:

- March 9, 2022 @ 11:00 a.m. (CT)-Medical Cannabis 101 (Michael McKenzie, MD)
- April 21, 2022 @ 12:00 p.m. (CT)-Diversification: Adding Life Care Management to your Practice (Shanna Huber and Jennifer Crowley)
- May 5, 2022 @ 12:00 p.m. (CT)-Topic TBD (James McNeil, MD)

Don't forget we have a ton of content in our ELearn Library of webinars that have been provided this year (and years past). Some of the highlights of these are listed below. Click on the link to access the ELearn Library

- Bone Anchored Prosthetics-Eliminating the Socket
- SSVE Core Elements & Best Practices
- From the Clients Perspective
- Executive Function Coaching

https://www.pathlms.com/iarp

Julie Sawyer Little, MS, OT/L, CRC, CLCP, F-ABVE

Attendant Care Survey Methodology (ACSM): Introducing a Costing Model Attendant Care Survey Methodology (ACSM)

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Abstract

When attendant care costs are included in a life care plan, they can be the costliest item. No methodology has been introduced to teach the life care planner how to gather, report, and defend attendant cost data validly and reliably. The Attendant Care Survey Methodology (ACSM) is such a method. Created on survey research methods applicable globally, it provides life care planners with the foundation to collect and include attendant care cost data. This article introduces the ACSM's five phases and 12 steps not only theoretically, but also as applied and replicated by each author across the country in multiple surveys since early 2020. This initial article is the first in a trilogy of how to use the ACSM for attendant care costs. Anticipated future publications focus on data analysis and interpretation as well as how repeat surveys (e.g., annually) can provide important longitudinal cost data.

Keywords: Survey Research Methods, Attendant Care Cost Research, Caregiver Services Costs, Life Care Planning Research, Personal Care Assistant Cost Survey, Home Health Aide Cost Survey, Certified Nursing Aide Cost Survey, Licensed Practical Nurse Cost Survey, Registered Nurse Cost Survey

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Attendant Care Survey Methodology (ACSM): Introducing a Costing Model

Having the availability and accessibility of resources, including the provision of attendant care, is foundational for quality of life for individuals with disabilities (Boswell et al., 1998). When attendant care or caregiver costs are projected as part of a life care plan, they are often the costliest item (Fischer, 2007; Pomeranz et al., 2006; Rutherford Owen & Marini, 2012; Rutherford Owen & Thomas, 2012).

Due to the cost of recommended services, particularly attendant care, life care planners bear the responsibility of explaining recommendations and any discrepancies contained within the life care plan as it relates to what the client currently receives (Rutherford Owen & Marini, 2012). Particularly for attendant care, a thorough explanation is likely required with focus on what level of care is necessary and how the level of care was determined (Holakiewicz, 2006). Pomeranz et al. (2006), indicate the skill level of the attendant care provider impacts on the overall cost of services.

Costing and related consensus statements in the field (Johnson et al., 2018) call for life care planners to:

- understand the definition of reliability and consistently practice in such a manner (# 5)
- research . . . costs (# 54)
- use protocols for cost research (# 69)
- apply protocols for using local versus national resources (# 71)
- identify costs in life care plans that are verifiable from appropriately referenced sources; geographically specific when appropriate and available; non-discounted/market rate; more than one cost estimate, when appropriate (# 85)
- gather geographically relevant and representative prices (# 70)
- develop individualized plans (# 45)
- understand and explain research in life care plans (# 79)

Furthermore, current practice standards (International Academy of Life Care Planners, 2015) call for life care planners to:

- [follow] a consistent method for . . . projecting costs.
- [develop and use] written documentation tools for . . . cost projections.
- [develop] recommendations for content of the life care plan cost projections for each evaluee and a method for validating inclusion or exclusion of content (p. 9).
- the life care planner uses a consistent, valid and reliable method to research, data collection, analysis, and planning

Also,(Apuna-Grummer & Howland, 2013) cite standards about the inclusion of:

- caregiving resources, patterns, cost, and duration (p. 985).

- supportive documentation of cost sources (p. 1436).
- costs . . . appropriate for the locality of the evaluee or [are] taken from discounted prices or private buying groups (p. 1436).
- three or more costs . . . , if possible (p. 1508)

Lastly, the American Academy of Physician Life Care Planners (2022) # 4 states:

- physician life care planners describe the methodology used to perform all calculations, so as to make their cost analyses independently replicable/disprovable.

Maniha and Watson (2019) provide the Area Cost Analysis Request Form that includes checklist items for obtaining home health aide (HHA), licensed professional nurse (LPN), and registered nurse (RN) care cost data collection in a life care plan. Absent from the literature, standards, or cost collection forms or checklists, however, is a method to assist the life care planner to obtain valid, reliable, and defensible costs for local attendant care services. Until now. The purpose of this research was to use existing small sample survey techniques, adapt them to the collection of local attendant cost data, and demonstrate how a sample size of three contacts (n=3) that are part of current practice may, in some instances, be indefensible by comparison to the method proposed in this article.

Defining: Attendant Care, Survey, and Methodology

The Attendant Care Survey Methodology (ACSM) introduced in this article comes from three distinct terms: 1) Attendant Care, 2) Survey, and 3) Methodology. To grasp ACSM, the life care planner must understand the different definitional and theoretical components that make up the model.

Attendant Care

Attendant care is a term that is well defined in the life care planning and occupational literature. Covalle (2004) describes an attendant as someone who "provides a service to another, a helper, or assistant. This assistance can be in the form of supervision, hands-on assistance with personal care, and stand-by assistance during ambulation, skilled nursing services, and so on." (p. 15). Pomeranz et al. (2006) posits that other attendant services include: transfers, safety precautions, household cleaning and maintenance, driving to and from appointments, running errands, minor home repair and yard maintenance, leisure activities, and employment assistance and that those providing services may be skilled or unskilled workers; these attendants may be licensed or unlicensed and have no formal training. Litvak (1987) with the World Institute on Disability defines the lesser skilled personal attendant care services as "tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society as a whole" (p. 155). While evaluating the needs of an individual with a spinal cord injury (SCI), Harvey et al. (1992) reported additional elements such as age, sex, severity, place of treatment, and resources must be taken into consideration when assessing costs.

For purposes of this research, in Table 1 we identify four types of attendant care with occupational definitions provided by the U.S. Department of Labor, Bureau of Labor Statistics (2021a, 2021b, 2021c, 2021d).

Table 1

Types and Descriptions of Attendant Care

Type	Credentialed	Description
Home Health/ Personal Care Aides (HHA)	N	monitor the condition of people with disabilities or chronic illnesses and help them with daily living activities. They often help older adults who need assistance. Under the direction of a nurse or other healthcare practitioner, home health aides may be allowed to give a client medication or to check the client's vital signs. (2021a)
Certified Nursing Assistants/Aides (CNA)	Y	provide basic care and help patients with activities of daily living. (2021c)
Licensed Practical Nurses (LPN)	Y	provide basic nursing care. (2021b)
Registered Nurses (RN)	Y	provide and coordinate patient care and educate patients and the public about various health conditions. (2021d)

Source: Bureau of Labor Statistics, *Occupational Outlook Handbook*, www.bls.gov/ooh

Like Matryoshka dolls, these attendant care levels are nestled according to scope of practice, level of responsibility, education, and credentialing (if the specialty is credentialed at all in a particular jurisdiction). These professional specialties can also be delimited according to what a credentialing board in any jurisdiction allows within each respective scope of practice. For example, HHA who are often not credentialed or receive just employer-specific training, may be called companions or personal care attendants in some jurisdictions and may have basic hands-off or only standby assist duties but not engage in direct patient medical care. We recognize that definitions of attendant care may vary geographically. Therefore, we encourage life care planners to understand the distinction of the different levels of attendant care within the region they survey and to consequently apply those relevant definitions and standards to their ACSM research in collecting cost data.

Survey

The American Statistical Association (n.d.) defines a survey as "a method of gathering information from a sample of individuals" (p. 2). Fink (2017) expands the definition by stating that surveys are highly used because they are a fundamental method of getting "information directly from people" (p. 1) and notes that "sometimes surveys are combined with other sources of information. This is particularly true for evaluations . . . " (p. 5). Specifically, survey methods become essential tools for collecting attendant care cost data using standardization to help ensure data quality if the tool is used correctly.

This article is not a primer on survey research. Yet, survey research is the foundation that drives the development, application, and outcomes of the ACSM. The survey research sources in the references to this article provide excellent contemporary volumes on the topic for life care planners who need more details about survey research methods.

In this article, we describe the ACSM adapted from a 12-step process typically used by life care planners coming from the rehabilitation counseling profession (Barros-Bailey, 2012a, 2012b, 2012c, 2020a, 2020b; Barros-Bailey & Heitzman, 2014; Barros-Bailey & Karman, 2014). The process details the 12 steps over five phases of survey research, which are themselves fundamentally based upon the survey research methods promoted by the American Association of Public Opinion Research (AAPOR). The AAPOR survey methods are often the theoretical and practical framework used in private and public sectors and in the academic literature (Fink, 2017; Fowler, 2014). Consequently, the approach used by the ACSM is deeply grounded within the foundation and pillars of survey research methods as applied in different disciplines and private, public, and nonprofit sectors internationally.

Methodology

Merriam-Webster defines methodology as: 1) "a body of methods, rules, and postulates employed by a discipline, particular procedure, or set of procedures" (Merriam-Webster.com dictionary, n.d.). Consistent with this definition, we propose the ACSM as a new method, rule, or practice within the standards of practice of life care planners in cases where attendant care services will likely be a considerable cost of the life care plan. This dictionary holds a second definition that is also pertinent to life care planning: "the analysis of the principles or procedures of inquiry in a particular field" (Merriam-Webster.com dictionary, n.d.). For those life care planners performing a peer review of another professional's life care plan, we propose using the ACSM as a method to replicate principles and procedures used to arrive at the attendant care costs included in the life care plan under review as collected from local sources in the individualized assessment advanced by life care planning standards and methodological tenets.

Describing the ACSM

The five phases (and 12 steps) of the ACSM follow. Within each phase and step, we describe the theoretical and conceptual elements. Then, we bring the method down to the level of the practitioner, not the academic theoretician, by describing how the phase or step was applied by these researchers in using the ACSM across 10 jurisdictions throughout the country. Each of the steps below demonstrates how we conceptualized and operationalized the steps in Phase I.

Step 1: Identify Research Questions

Research questions are often very straightforward, either for practitioners performing research or those reading survey research, so much that the research questions are often missed. Research questions are merely what the life care planner wants to know once the data is gathered and analyzed. For attendant care costing, the research question(s) can be very narrow or broad such as:

- What is the cost for in-home personal care assistants within the X area for Y hours of daily care?
- What is the cost of in-home 24/7 attendant care at the nursing assistant level within the X zip codes?
- What is the cost of assisted living for an individual with X age in the X area?

Take any general question you have about attendant care, and it will drive how you will go about your data collection. Consequently, such queries form your research question(s). Survey research can have a single research question, or a variety of questions. Based on what data needs you have for the case(s) you evaluate, you decide the overall purpose of the survey and the research questions.

How We Used Step 1 in our Surveys.

For maximum opportunity to examine the data across the different scopes of attendant care practice and for purposes of this research that spanned across a variety of geographical jurisdictions, our survey question for each of our sample surveys was as follows:

- What is the cost of in-home private pay attendant care at all levels within an average commuting distance of X zip code?

Step 2: Developing Survey Questions (Items)

Survey questions (called items in the research literature) are what you use to collect the information that, once analyzed, will culminate to answer your research question(s). Therefore, survey questions are those distinct inquiries on the questionnaire (called the survey instrument). Fink (2017) outlines various precepts of how to develop such items:

- Check for biases and avoid biased words and phrases.
- Each item has just one concept.
- Each question is concrete, not ambiguous.
- Each question needs to be meaningful to respondents.
- Use caution when asking for personal information.
- Use standard language rules (grammar, spelling, and syntax).

Importantly, do not ask a lot of questions (more than 5), and do not ask questions that do not directly solicit needed information. Generally, items for survey questions should be written at the 6th to 8th grade levels (Fink, 2017). Fink (2017) states that, "Most surveys produce statistical data, but others may include open-ended questions that need interpretation . . . " (p. xvi.). That is, survey items could be closed- or open-ended. Closed-ended questions have very specific answers that are typically dichotomous (yes/no) or have a limited set of answers (costs per attendant care category) and produce quantitative data. An example is, "Do you provide staffing for 24-hour live-in attendant care services?" Open-ended questions are typically narrative and result in qualitative data. An example of an open-ended question is, "How does the work performed by the home health aide and certified nurse's aide differ in this area?" The response is not a simple yes or no that can be quantified and counted, but can be anything that will have to be analyzed for common themes when all the responses are brought together.

How We Used Step 2 in our Surveys.

In the ACMS instrument, the items are between the Flesch-Kincaid Grade Levels of 4.7 and 9.2 grade level due to the nature of the survey and the level of knowledge of the subject assumed to be possessed by most respondents. Specifically, we asked the following questions:

1. 1. Do you provide private/self-pay attendant care services at X level(s)?
2. If not, who would you recommend I contact in this area?
3. What are the hourly costs for [HHA, CNA, LPN, RN] care?

We also inquired about the minimum level hours of care, cost for minimum and longer durations, and live-in or 24-hour care rates for each of the attendant care levels. The researchers found that a comments section on the instrument helps to quickly write notes and then summarize them on a response rate table. In addition, the ease of questionnaire format for the interviewer may be helpful, such as an electronic form that collects the data into a spreadsheet to avoid human error in transferring data from the collection instrument to the data analysis.

Step 3: Training the Interviewer(s)

The life care planner can get every step of the ACSM correct and perfect, but if the person collecting the data is not trained on proper data collection methodology, the quality of the data collection is questionable and the validity of the survey results could be compromised. Therefore, the training of the attendant researcher is vital for accurate (valid) and consistent (reliable) data to be collected.

It is common in survey research for the survey developer not to be the data collector. It is also not unusual in life care planning for the life care planner to develop the details of needed cost research, the instrument, and the sampling frame, and have a colleague, assistant, or researcher make the actual calls to collect the data itself. The same approach was used with the surveys performed using the ACSM.

The person collecting the data should know and understand the reason for each of the questions on the instrument, as well as the lingo used within attendant care for the geographical area covered by the survey. Maniha and Watson (2019) provide some tips to life care planners collecting information by telephone and email. Consistent with their recommendations and the literature, the interviewer should be friendly and conversant, and not robotic, automated, hesitant, aggressive, or verbose. The data collector is respectful of the respondent's time and person. Interviewers should not lead the respondents in their answers to avoid introducing bias into the data results, but ask the question and record the response, providing answers to clarifying questions as needed. The interviewer should want to make the calls and be interested in the data collected to understand when and how to make clarifying follow up questions to draw out responses. Interviewers should record responses on the survey instrument immediately, including any comments offered by respondents that may not have been answers to specific instrument items but may provide additional contextual data. Importantly, if data collectors who are different from the survey designer encounter odd, varied, unusual, or unexpected responses, the interviewer should contact the survey developer before proceeding with further contacts.

How We Used Step 3 in our Surveys.

The data collectors in our research using the ACSM instrument are all trained life care planners ranging from recent entrants into the field to those with nearly three decades of practice. The principal investigator was the main trainer for the other researchers, developed the survey instrument template, and provided training and answered questions about methods and procedures. Training involved video conferencing sessions followed by emails or other contacts to answer clarifying questions. Given the researcher's experiences implementing the ACSM over multiple geographical areas, the following recommendations are offered:

1. Be clear about your research question before beginning the calling task – do you want to know about HHA, LPN, or other rates, or all of them?
2. Be thoroughly familiar with the instrument and procedures before making the first call.
3. Know the terminology for the different kinds of attendant care levels in the areas where the survey is conducted.
4. Think through possible answers/explanations regarding the nature of your call before picking up the phone; ensure your respondent understands the need to obtain the attendant care information.
5. Everyone has a different conversation style and cadence, so sometimes it takes a few calls to develop a personal style that works
6. Follow the lead of the respondent as some provide the information quickly and matter-of-factly, and others see it as a marketing opportunity.
7. When collecting data in an area where the language, culture, or norms are different, it is important to have an interviewer who is fluent in that language and understands how individuals with disabilities or the elderly may be cared for in that group when collecting the cost data.
8. Block off a portion of the day to get into the flow of the task.

Step 4: Selecting the Population: The Sampling Frame; Step 5: Taking a Census vs. Sample; and Step 6: Deciding on Probabilistic vs. Non-probabilistic Sampling.

Steps 4-6 are typically singled out as distinct stages of the survey research because of the importance and examination of completing each steps separately. Together, Steps 4-6 compose the cluster of activities necessary to develop the list of all potential contacts to drive the decision of how many entities will be contacted.

The sampling frame is the starting list of all potential attendant care sources to contact. Fowler (2014) identified three important components of the sampling frame: comprehensiveness, probability of selection, and efficiency. The entries in the sampling frame list all the potential sources to contact within a designated geographic area. The entirety of all potential sources within the designated area is called a population or universe. To develop the list, you first need to determine the geographical area the survey covers. Generally, we recommend establishing the average commuting distance from the location you consider to be at the epicenter of the survey, such as the evaluee's residential or pertinent zip code. There are a variety of sources that allow you to determine the average commuting distance or time as collected by government data (Burd et al., 2021; U.S. Census Bureau, 2021). Once you have determined the epicenter zip code and the radius from it that represents the geographic area, other online tools allow you to select zip codes within the radius of what is considered a reasonable commute for someone who might be providing in-home attendant care. Based on the particulars of a case, however, other methods of selecting the geographical area may be more applicable. The geographic area, however, becomes the first decision the life care planner needs to make to determine who should be called.

Selecting potential sources to contact within the designated area becomes the next activity in the development of the sampling frame. In some government areas, attendant care agencies are highly controlled and the licensing and enforcing entity will likely have a list of the organizations credentialed to provide attendant care services. This government entity can serve as an initial source for the development of each entry into the sampling frame. In the United States, Medicare also provides a source of finding home health agencies by zip code: https://www.medicare.gov/homehealthcompare/search.html. Depending on whether or how attendant care is regulated in the geographical area considered, confirming or expanding the sampling frame with potential entries from other sources (e.g., search engine results) is recommended. At this stage of the ACSM process, it is better to have a more expansive list that may include sources culled by the data collection process than to miss potentially important cost sources that should have been included on the list. The reason for the first two questions of the ACSM questionnaire is to – conceptually – apply a snowball effect thereby using contacts for the agencies on the sampling frame that do not provide care within the parameters needed (e.g., private pay) to suggest appropriate agencies in the community that may otherwise have been missed when the life care planner constructed the sampling frame.

Depending on the length of the sampling frame, the life care planner must decide whether to contact all entries on the list or just some of them. Therefore, the life care planner must decide whether to conduct a census (call all entries on the list), or a sample (call some entries on the list). This decision depends on the time and resources available to make the calls and analyze the data. There is nothing wrong with taking a sample to infer the characteristics of the population. Indeed, we would rather a phlebotomist take a sample of our blood to determine its type rather than drain all our blood to arrive at the same conclusion.

The same concept is true with taking samples in survey research. The method that is used to select a sample is either probabilistic (random) or non-probabilistic (non-random). If you do not call the entire sampling frame, you must decide how you are going to go about selecting who to call so each entry on the list has an equal opportunity to be contacted. Imagine a life care planner has a list of 100 alphabetizing sources in the sampling frame, but only has time to call 35 of them. If the life care planner starts with the first entry on the alphabetical list and makes phone calls through the 35th source, the remainder of the list from number 36 through 100 would never have a chance of being called. This approach is considered non-probabilistic (non-random). For another example, assume the life care planner only contacts attendant care agencies who advertise on indeed.com for caregivers. Again, this is considered non-probabilistic sampling as not all employers advertise openings on that platform and there may be something about those employers who choose not to do so that might contort the measure of costs if only such agencies were included. Consequently, the results of such a survey may be biased based on who is left out from being contacted. How the collected information accurately (validly) represents the population or universe of potential contacts (or the N=100) becomes questionable under either of these examples.

On the other hand, if the life care planner uses a random number generator tool, such as is available in some spreadsheet software programs or online, and creates a list of random numbers that allow the interviewer to skip back and forth along the entries until 35 are called, then each of the 100 entries has an equal chance to be contacted. This use of a randomized approach to calling a sample is probabilistic or random sampling. Probabilistic sampling is the most robust method of sampling. If the life care planner is conducting a sample rather than a census, it is important that the life care planner vie for a simple random sample because of the statistical strength that it provides to the outcome of the survey. If someone else has the same list of N=100 sources on their sampling frame and also randomly calls 35 entries, the probability of their outcome being close to that of the original survey is greater than if both surveyors conducted non-random sampling.

How do you decide how many entries to contact? There are several online or software-based sample size calculators that help guide the life care planner (e.g., Excel, Qualtrics, SurveyMonkey). Ultimately, the life care planner must feel confident the sample size will result in data that can be relied upon more probable than not. Continuing with our example, if n=35 random calls were made out of a sampling frame of N=100, using a sample size calculator, the life care planner would have 80% confidence that the true cost of care for that sample was within a 9% margin of error. However, if the life care planner had only randomly called n=3 within the same N=100 population, at an 80% confidence level, the margin of error increases substantially to 45%. It is no wonder there could be substantial cost differences between life care planners collecting attendant care information on the same case and in the same area if each only obtains three sample cost estimates.

How We Used Step 4, Step 5, and Step 6 in our Surveys.

The ACSM we used in a variety of 10 communities throughout the United States, including one territory, resulted in both census and sampling surveys. Barros-Bailey and Brown (2022) cover an extensive description of the data analysis and technical concepts, rules, and application of ACSM data collection and presentation by life care planners based on a detailed analysis of the data collected in the surveys performed by the authors.

For Step 4, the sampling frame in each case was first determined by selecting the main zip code that served as the epicenter of the analysis. Next, we determined the reasonable commuting distance for the identified epicenter. Third, we selected all the other zip codes that were within the reasonable commuting distance. Once the geographical parameters were identified, we developed the sampling frame starting with local, regional, or national government sources within the geographical parameters and added in all potential sources for private pay attendant care services, even if there was a question whether a particular type of organization might provide such service because the first question of the instrument was designed to cull out irrelevant contacts. Not all jurisdictions regulate attendant care services; therefore, reliance on government sources as the main stimulus for the development of the sampling frame was shifted to secondary sources like search engines and a greater reliance on the snowball sampling question of the instrument in some areas contacted, particularly in more rural settings. Also, the ACSM sampling frame developer who is from a geographical area may be aware of attendant care service providers that do not emerge from government or other sources.

For Step 5, whether a census or sample was taken was contingent on the size of the sampling frame and the resources available to the particular life care planner to cover the time and cost of data collection. Therefore, as identified in Phase III, some ACSMs took a census and others took a sample. The snowball method allowed for adding to the sampling frame in several jurisdictions. In all instances, when a sample was taken as recommended in Step 6, the life care planner performed a simple random sample.

Step 7: Constructing and Testing the Instrument

In this last step of the Design Survey phase, the life care planner brings together all the concepts and decisions made in Steps 1-6 into an instrument used for data collection.

How We Used Step 7 in our Surveys.

Figure 1 has a sample instrument that we used for our ACSM research across the country. It contains all the Phase I elements in Steps 1-6: research questions; items; instructions to guide interviewers; numbers sampling frame with detailed cells including space for answers per type of attendant care and duration of that care; space for the relevant zip codes within a reasonable commuting distance or designated geographical area; and the random number list for those instances where taking a sample instead of completing a census is required.

This instrument detail is excellent to collect annual data for a geographical area where a life care planner may develop a variety of life care plans that require attendant care at any level. Instead of calling n=3 sources every time a life care plan in developed in the area, we recommended performing a complete ACSM survey for all attendant care levels, which will also allow the life care planner to have a better understanding of how rates change in the area from year to year, thereby performing the ACSM longitudinally with actual, not inferred, data. Although all levels of attendant care were included in the instrument and data collection used by the ACSM researchers, if only one level of attendant care is required, the instrument could be modified accordingly.

Note that the survey instrument had previously been piloted by the lead author for data collection over different years and geographical areas; therefore, formal piloting was not performed for the purposes of this project as the instrument had not changed.

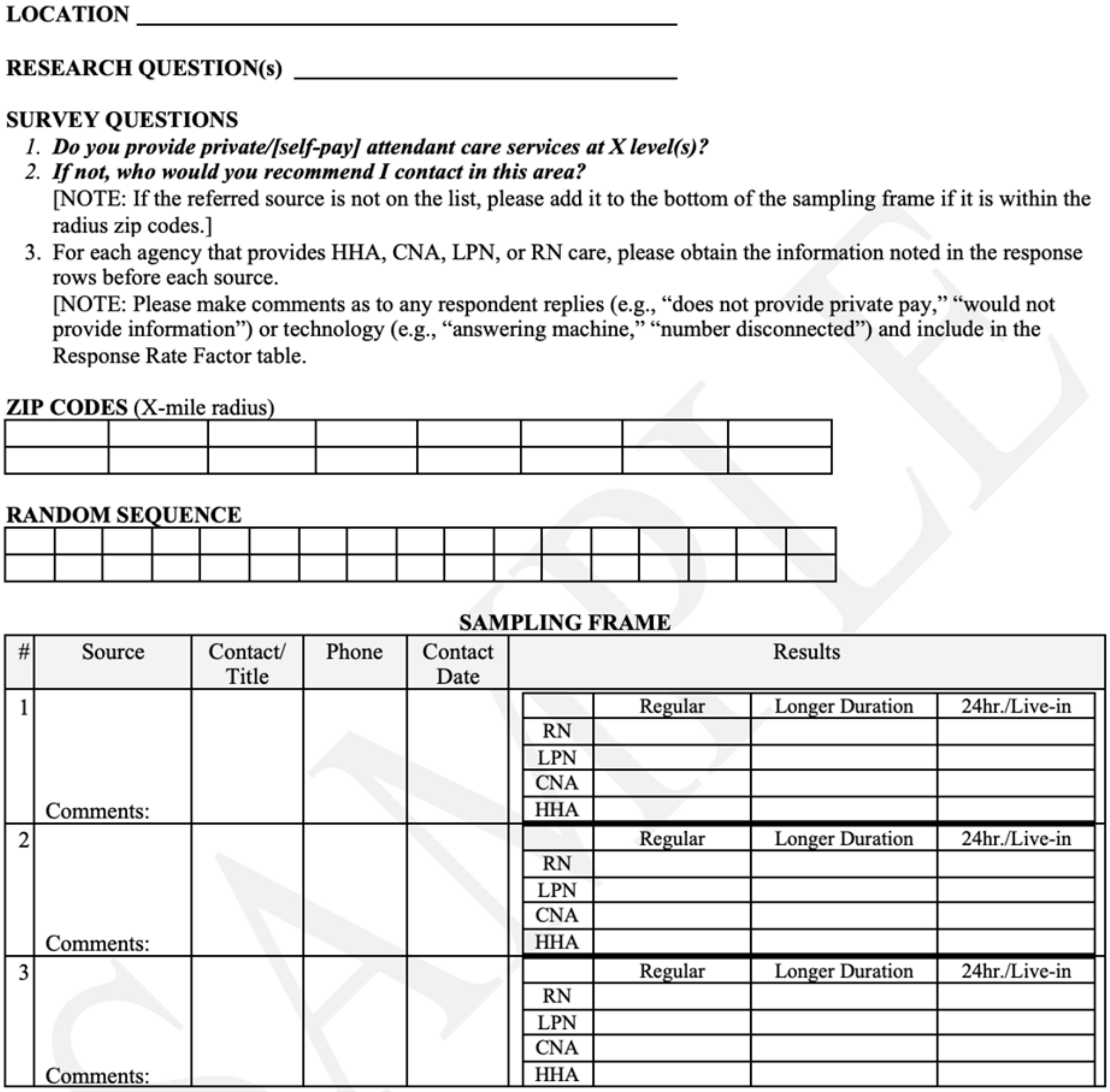
Phase II: Data Collection

Step 8: Collecting and Preparing the Data

There are different ways – called modes in research – to collect data from individuals using an instrument: face-to-face (such as on-site interviews), telephonically, surface mail, online, or through a combination of these modes. An advantage outlined by Fink (2017) of

Figure 1

Attendant Care Survey Instrument



LOCATION ____

RESEARCH QUESTION(s) ______________________________

SURVEY QUESTIONS

1. ***Do you provide private/[self-pay] attendant care services at X level(s)?***
2. ***If not, who would you recommend I contact in this area?***
   [NOTE: If the referred source is not on the list, please add it to the bottom of the sampling frame if it is within the radius zip codes.]
3. For each agency that provides HHA, CNA, LPN, or RN care, please obtain the information noted in the response rows before each source.
   [NOTE: Please make comments as to any respondent replies (e.g., "does not provide private pay," "would not provide information") or technology (e.g., "answering machine," "number disconnected") and include in the Response Rate Factor table.

ZIP CODES (X-mile radius)

RANDOM SEQUENCE

SAMPLING FRAME

#	Source	Contact/ Title	Phone	Contact Date	Results			
1						Regular	Longer Duration	24hr./Live-in
					RN			
					LPN			
					CNA			
	Comments:				HHA			
2						Regular	Longer Duration	24hr./Live-in
					RN			
					LPN			
					CNA			
	Comments:				HHA			
3						Regular	Longer Duration	24hr./Live-in
					RN			
					LPN			
					CNA			
	Comments:				HHA			

Source: Mary Barros-Bailey, PhD, CRC, CLCP, Intermountain Vocational Services, Inc., ©2022 (used with permission) telephonic interviews is that “answers can be explored with respondents” (p. 15). Another advantage identified by Fink is that telephonic surveys assist respondents with unfamiliar words. Contextual details are also more easily gathered through telephonic contacts than through surface mail or online surveys. Using the telephone is not as time and resource intensive as on-site interviews.

Fowler emphasizes seven points of importance in the data collection process:

1. brief introduction;
2. impress the importance of the respondent’s participation;
3. be flexible;
4. be alone and in a quiet location;
5. ask everyone the same questions and in order as questions appear on the ACSM;
6. follow instructions provided by the survey developer;
7. ensure that ethical standards of confidentiality will be adhered to, within the limits of the law.

Research on call-backs on surveys suggest that a quarter to a third of those who did not respond at the time of the first contact, will respond at the time of follow up (Fowler, 2014). Therefore, as long as not too much time has lapsed between calls (more than a week or two), it may be advantageous to call back some of the non-respondents to obtain a more comprehensive set of cost data. In our experience, it was important to follow the same method with each ACSM survey to ensure accuracy and to follow the simple random sample sequence to maintain the integrity of the research.

How We Used Step 8 in our Surveys.

In practice, gathering cost data through telephone calls is a common mode of information collection used by life care planners for other items in the life care plan. Because of its many advantages, its familiarity with life care planners, its relatively low cost to implement, and its efficiency, telephone was the primary data collection mode that was easily adapted to the ACSM. The instrument was provided in a Word file to interviewers into which they placed collected responses. Our interviewers recommended that a life care planner should be ready to make multiple calls and recalls to obtain the needed data. The data was cleaned for non-responses and integrated into a spreadsheet program by the second author.

Phase III: Data Analysis and Summary

In Phase III, there are two steps, although they can take the majority of the time to perform, particularly if large volumes of data are collected. The first (Step 9) is the analysis of the collected data and Step 10 is summarizing the data in a form that is understandable to the reader.

Step 9: Analyzing Qualitative and Quantitative Data

Because the majority of the data collected in ACSM surveys is quantitative, the life care planner must know the correct way to prepare and analyze it. Determining and implementing data analysis rules are vital for consistency and standardization of the data analysis. Apply data analysis rules that make sense to the type of data collected and the type of survey conducted – some of these rules might be governed by the geographic area where the ACSM is performed. If there are ranges provided, the life care planner obtains the average of that range from each respondent before analyzing all the answers together to determine such descriptive statistics as averages (means), midpoints (medians), highs and lows (ranges), differences between groups (e.g., HHAs v. RNs) or the amount of services provided (minimum number of daily hour rate v. longer duration), etc.

Depending on what you want to know, you may have open-ended questions that have narrative responses you cannot express in numbers, but need to determine themes in the data. For example, you might want to know what the requirements are for live-in aides. The kind of responses you collect are narrative (qualitative) in nature and require a different kind of analysis to identify themes. A variety of content analysis tools exist for coding such data and analyzing it, although this kind of data is not typically going to be collected in ACSM surveys.

How We Used Step 9 in our Surveys. For the ACSM surveys performed by the researchers in 2020-2021 the kind of data collected was almost exclusively quantitative. A set of data analysis rules were developed so there was the same rule applied to each of the surveys. The data analysis rules the researchers used for attendant care rate/time categories were as follows:

1. Base Rate: Agencies that require X amount of hours as a minimum for service. This is typically the highest range and was found to typically range from 1-4 hours. The rule the researchers used was three or less hours for the base rate.

2. Negotiated Rate: The breaking point where the agency applies what is typically a lower rate, with a threshold typically found at the 8- to 12-hour mark. The researchers used the 4- to 12-hour range as the negotiated rate.

3. Live In Rate: This is the rate that agencies typically charge for services over 12 hours and can include up to 24/7 care, or an all-day rate.

While most agencies responded with the cost/time falling into the data analysis rules, a rarely minority had different ways to charge and were considered outliers that need to be reported differently. A few agencies charged per visit, not per hour. For example, if 32 organizations charge per hour and 3 charge per visit, the first group's descriptive statistics needs to be analyzed and then that of the second group because the unit of analysis between both is different (hours v. per visit). It does not mean the data from the 3 that charge per visit should be excluded, just reported as outlier data. The same is true for the rare agency that charges differently for weekday and weekend rates.

Likewise, most home care providers across the country offer a per-hour break after the first visit. This minimum number of hours at a higher rate typically ranged from 2-4, after which there was a drop in rate, although not all respondents had such a breaking point.

Because of the variability between different sources, the data analysis rule we applied was three hours as a common metric between all surveys, although applying the ACSM at only one geographic area, there may be greater homogeneity as to where the minimum number of hours ends and the break in hourly rate at the next level begins. Life care planners may need to make a data analysis rule for their data analysis of where to make that break. There are numerous online free descriptive statistics tools that allow such data to be quickly analyzed, although spreadsheet software can also provide similar analytical tools. More detail regarding data analysis and understanding the numbers derived from the ACSM data analysis phase and steps is in development (Barros-Bailey & Brown, 2022).

Step 10: Summarizing the Data

Results of ACSM surveys can be summarized narratively, numerically, or graphically. Life care plan reports are typically narrative and tabular (Barros-Bailey, 2012c). Fowler (2014) describes the response rate as “simply the number of people who completed the survey divided by the number of eligible people (or units) sampled” (p. 43). Calculating response rates are parts of the data summary as the culling or snowball process during the calls may result in a different final population list than the starting sampling frame. Therefore, if your initial sampling frame started with N=100 and you decided to do a simple random sample and call 35, it could be that a number of those called had disconnected numbers, did not provide attendant care for private pay, or did not otherwise fit the criteria of your desired population (e.g., did not offer private pay attendant care services). Therefore, some of the entries on the initial list may be culled from the sampling frame, so that the number that is divided by 35 calls may not be the initial N=100, but could be a smaller group – or larger if additional contacts were found through the snowball sampling question. For more information about response rates, see articles and free calculators at the AAPOR website (American Association of Public Opinion Research, 2016).

How We Used Step 10 in our Surveys. The results of the ACSM were calculated by each surveyor with the second author applying the data analysis rules and checking the results against those of the surveyor. Having someone double-check the calculations provided checks and balances to potential human errors in calculations. In our research, rates of response varied widely with some greater than 80% and, in one area, only one agency out of 30 providing the data (although the interviewer had obtained a very high response rate in another region of the country); likely due to culture norms in the area affecting how society provides care for the elderly and individuals with disabilities in that society. Each interviewer summarized the results of their survey into a response rate calculator as displayed in Figure 2.

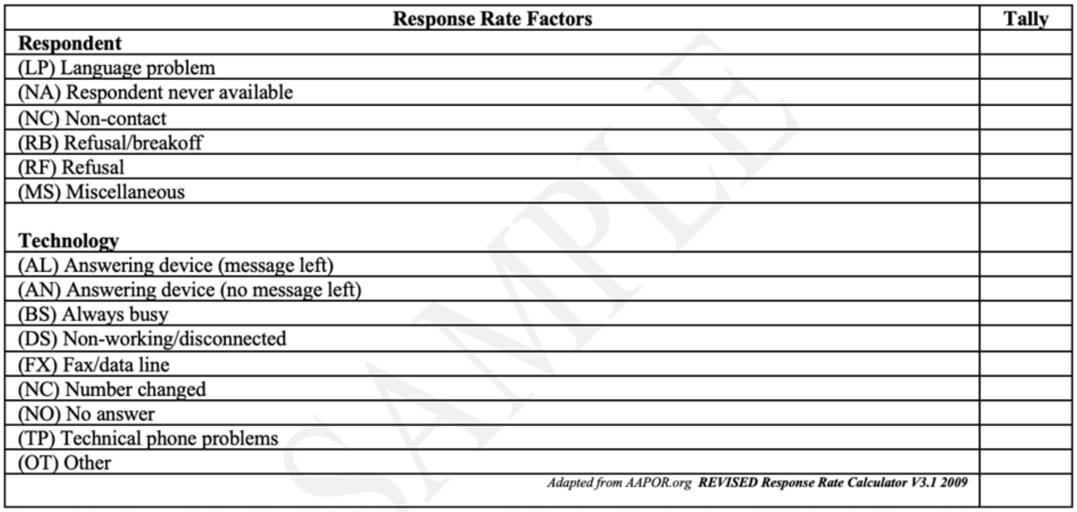
One interviewer recommended modifying the response rate calculator to include a category for messages taken that may require follow up.

Phase IV: Reporting the Survey Results

Phase IV has only one step – #11 Reporting the Data.

Figure 2

Response Rate Factors



Response Rate Factors	Tally
Respondent	
(LP) Language problem	
(NA) Respondent never available	
(NC) Non-contact	
(RB) Refusal/breakoff	
(RF) Refusal	
(MS) Miscellaneous	
Technology	
(AL) Answering device (message left)	
(AN) Answering device (no message left)	
(BS) Always busy	
(DS) Non-working/disconnected	
(FX) Fax/data line	
(NC) Number changed	
(NO) No answer	
(TP) Technical phone problems	
(OT) Other	
Adapted from AAPOR.org ***REVISED Response Rate Calculator V3.1 2009***	

Source: Mary Barros-Bailey, PhD, CRC, CLCP, Intermountain Vocational Services, Inc., ©2022 (used with permission)

Step 11: Reporting the Data

The life care planner must decide how to describe the ACSM data in oral or written reporting to convey the greatest understanding and also be consistent with life care planning standards as well as research ethics. These professional demands can seem at odds, but they are not. The ACSM adheres to American Association of Public Opinion Research (2016) and Council of American Survey Research Organizations (2019) ethical standards, as well as Protection of Human Subjects (2020) for the protection of human subjects. There has to be a process in reporting the data whereby there is the opportunity of protecting confidential data from the source providing it as well as being transparent with the research results.

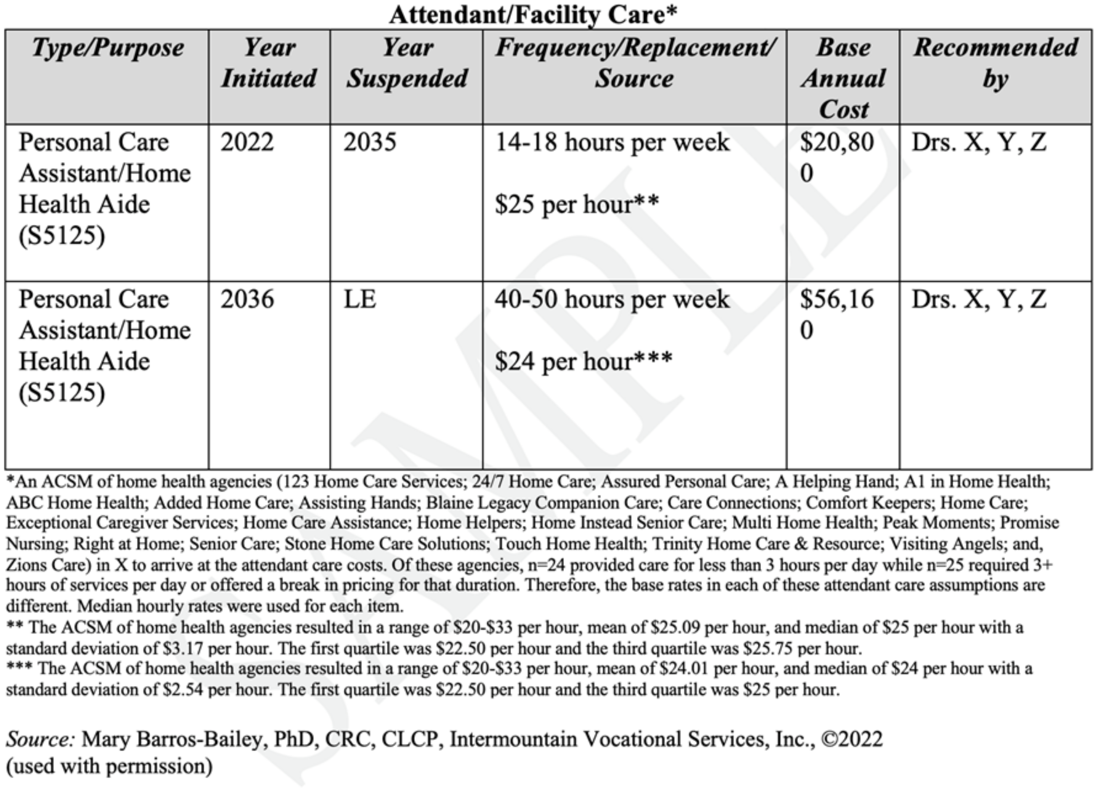
Ultimately, results of the survey are intellectual property of the life care planner that can be applied to various individual life care plans. The best way to secure confidentiality of this data is to not directly associate each data point with each source, but list the data through descriptive statistics and provide sufficient information so that the survey ACSM can be replicated.

How We Used Step 10 in our Surveys.

The data for each survey performed by the authors was summarized in tabular format, although when applied to an actual case, the cost data was integrated mainly into the tabular part of the report. For reporting of the data in a life care plan, the life care planner can be compliant with the various professional demands in many ways. One possible reporting method that allows for agreement with research ethics and life care planning transparency is illustrated in Figure 3.

Figure 3

Life Care Plan Tabular



Attendant/Facility Care*

Type/Purpose	*Year Initiated*	*Year Suspended*	*Frequency/Replacement/ Source*	*Base Annual Cost*	*Recommended by*
Personal Care Assistant/Home Health Aide (S5125)	2022	2035	14-18 hours per week $25 per hour**	$20,800	Drs. X, Y, Z
Personal Care Assistant/Home Health Aide (S5125)	2036	LE	40-50 hours per week $24 per hour***	$56,160	Drs. X, Y, Z

*An ACSM of home health agencies (123 Home Care Services; 24/7 Home Care; Assured Personal Care; A Helping Hand; A1 in Home Health; ABC Home Health; Added Home Care; Assisting Hands; Blaine Legacy Companion Care; Care Connections; Comfort Keepers; Home Care; Exceptional Caregiver Services; Home Care Assistance; Home Helpers; Home Instead Senior Care; Multi Home Health; Peak Moments; Promise Nursing; Right at Home; Senior Care; Stone Home Care Solutions; Touch Home Health; Trinity Home Care & Resource; Visiting Angels; and, Zions Care) in X to arrive at the attendant care costs. Of these agencies, n=24 provided care for less than 3 hours per day while n=25 required 3+ hours of services per day or offered a break in pricing for that duration. Therefore, the base rates in each of these attendant care assumptions are different. Median hourly rates were used for each item.

** The ACSM of home health agencies resulted in a range of $20-$33 per hour, mean of $25.09 per hour, and median of $25 per hour with a standard deviation of $3.17 per hour. The first quartile was $22.50 per hour and the third quartile was $25.75 per hour.

*** The ACSM of home health agencies resulted in a range of $20-$33 per hour, mean of $24.01 per hour, and median of $24 per hour with a standard deviation of $2.54 per hour. The first quartile was $22.50 per hour and the third quartile was $25 per hour.

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Phase V: Data Integration

The last phase (V) has the last step (12): Data Integration.

Step 12: Data Integration

The ACSM is primary data because it is collected directly by the life care planner. There may be secondary data sources (those collected by others and provided to or researched by the life care planner) for attendant care. Examples are bills for attendant care being provided, surveys by government or private entities, etc. In this last step, the life care planner uses professional judgment to compare their primary data collected with these secondary data sources and decide whether these additional cost sources are relevant.

How We Used Step 12 in our Surveys.

This last step of the ACSM is as independent in its application as the individualized life care plan evaluation demands. Therefore, the authors defer to each life care planner's judgment to the relevance of data integration with other attendant care sources. Regardless, the ACSM cost data should integrate with the assessed needs of the individual for such care.

General Findings of Applying the ACSM, And Potential Implications

In performing multiple ACSM surveys across the country, we had some general findings about attendant care:

- Availability of the range of attendant care services varies drastically between geographic areas. In some areas, some agencies provide personnel only at the paraprofessional or the skilled level, whereas in other areas it was common to have agencies provide personnel at both levels. Most agencies only offering paraprofessional services referred to these employees as "nonmedical" personnel while calling skilled service providers, perhaps provided by other attendant care agencies, as "medical" personnel.
- In some locations, the HHA and CNA rates were vastly different, and in other locations, there was not a distinction between either the rates for each level of care or the duties of non-credentialed and credentialed paraprofessional staff.
- Some states during the course of the research passed legislation limiting attendant care services to only be performed by CNAs.
- Skilled attendant care services for private pay (e.g., LPNs, RNs) were substantially less available than paraprofessional services (e.g., HHAs, CNAs).
- Some attendant care agencies that are found nationwide may be franchised, with different rates based on what a particular market can bear – most agencies are willing to provide their rates, and a few from the same agency may not be.
- The time the interviewer spends with agencies offers an opportunity to educate the public about life care planning as well as exchange information about community resources and gather more information about available local resources.
- A secondary gain for life care planners who provide primary care is that the information collected promotes a better understanding of the resources in the community, thus, making life care planners valuable resources for their clients/patients.
- The ACSM can be used for any high priced item to provide a very accurate collection of costs.
- Live-in care services, their definitions, requirements, and scrutiny under labor laws are undergoing many changes and vary drastically from state to state in their availability.
- The availability of 24/7 care services may vary widely between geographic areas, and these services may become increasingly regulated due to considering anything over 40 hours as time-and-a-half pay.

Overall, we found that there are vast changes occurring in attendant care and their associated costs, particularly as it involves 24/7 services. It is important to consider the nature of caregiving, attendant care, and domestic service workers' roles as they are likely to change with new laws being considered and implemented. For example, throughout the period of our research, there have been legislative actions introduced in Congress that could impact life care plan costs for live-in or 24/7 care. Since 2019, both houses of Congress have attempted passing The Domestic Workers Bill of Rights Act (2019a, 2019b, 2021). The proposed bill has the potential of affecting the rights of domestic workers (i.e., home health, personal care aides) and how their jobs are carried out. The U.S. Department of Labor provides insight to the laws that support live-in domestic services workers through the Live-in Domestic Service Workers under the Fair Labor Standards Act of 1938 (FLSA). An employee that does not meet the definition of a live-in domestic service worker must be paid at least the federal minimum wage and overtime pay for over 40 hours worked within one workweek (U.S. Department of Labor, Wage and Hour Division, n.d.). At the writing of this article, there are 10 states (California, Connecticut, Hawaii, Illinois, Massachusetts, Nevada, New Mexico, New York, Oregon, Virginia) and 2 major cities (Philadelphia, Seattle) that have passed similar Domestic Workers Bill of Rights measures and protections (Gillibrand, 2021; National Domestic Workers Alliance, 2021). Virginia passed the most recent domestic worker legislation in early 2021 (National Domestic Workers Alliance, 2021; Virginia Human Rights Act, 2021). Consideration for how laws impact caregiver roles should be ongoing and updated as home health services are used in life care planning assumptions. As discovered in our research, some home health agencies are increasingly aware of the trends for protection of domestic long-term attendant care workers and are considering their service charges accordingly.

Future Research

The ACSM as presented in this article is a cross-sectional survey of attendant care rates collected at a particular point in time. Because the life care planner can gather the same type of data year after year in some geographic locations of practice, the practitioner has the opportunity to update the data on a regular basis and see how it changes between periods of collection. Analyzing the trends between data collection over time is called longitudinal research and can provide input into long-term costing considerations of a life care plan where attendant care will be needed over someone's life expectancy or over long periods of their life. The authors have performed the ACSM longitudinally and will publish the data in a supplemental publication (Barros-Bailey et al., 2022), which will also explore potential impacts of the pandemic on the results of the surveys. In addition, for life care planners who do not have any background in basic research methodology principles, we realize that some of the data analysis introduced as part of the ACSM may seem a bit overwhelming. Therefore, a supplemental publication is forthcoming using the data collected in our surveys as examples of how to analyze and represent the ACSM data (Barros-Bailey & Brown, 2022).

Lastly, there are obvious different kinds of attendant care beyond those provided by agencies. The ACSM can be applied to collecting data from group home, assisted living facilities, or other sources.

Conclusions

During the course of the research performed in the ACSM, between the authors involved in this research, the application of these results of our studies resulted in over $100,000,000 of attendant care cost opinions and recommendations and in cases where attendant care typically resulted in about 70% of the entire cost of the life care plan. Of all costs included in a life care plan, when attendant care is needed, it is typically the highest lifetime value category. While past literature has focused on how to come up with the recommendations, we failed to find a methodology to assist the life care planner in defending their opinion. The ACSM is such a method.

Using the ACSM for all items in a life care plan would be time and resource prohibitive and is not recommended. Traditional methods of costing, defensible databases, or emerging costing tools (e.g., CostingHelper) developed with similar principles of research, sampling, and descriptive statistics will continue to push the envelope of professional practice in the life care planning field.

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Collateral Source Rule Approaches and its Implications for Usual, Customary and Reasonable Pricing

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Abstract

The Collateral Source Rule is a legal doctrine that holds if an injured party receives some compensation for his injuries from a source wholly independent of the tortfeasor, such payment should not be deducted from the damages which the plaintiff would otherwise collect from the tortfeasor. This longstanding rule in civil procedure has been recently challenged in courts and state legislatures throughout the United States in the presentation of evidence regarding past and future medical expenses. As healthcare costing has become increasing complex, some courts have allowed evidence to be presented to the jury about reduction in plaintiff's medical expenses based upon amounts paid by third party vendors. As such, life care planners have experienced the impact of the various approaches by state courts when presenting testimony about future medical expenses contained in the life care plan. This article discusses the current approaches by state courts in the United States and the implications collateral source rule approaches may have on the work of life care planners.

A person who is injured by another's negligence may recover damages from the other person for all past, present and prospective harm (*Singh v. Larry Fowler Trucking, Inc.*, 2012). In this recovery process, a plaintiff may recover two types of damages: economic (or pecuniary) damages and non-economic (or personal) damages (2012). Economic damages include past medical expenses, future medical expenses, lost wages, and lost earning potential. Included in the prospective harm for which damages may be recovered is the reasonable cost of the medical services that will probably be incurred because of the lingering effects of the injuries caused by the negligent person (2012). The measure of damages generally recoverable is "the amount which will compensate for all the harm, losses and damages proximately caused" by the tort.

To sustain an award of future medical expenses, the claimant must present evidence to show there is a reasonable probability the medical expenses will be incurred and the reasonable costs of such care (*Columbia Med. Ctr of Las Colinas v. Bush*, 2003; *Ibrahim v. Young*, 2008). Medical expenses are the costs of doctors' services, hospital services, medicines, medical supplies and medical tests and any other charges for medical services.

The payment is the fair and reasonable value of such medical expenses. A life care plan is a useful tool in forecasting future medical expenses. A life care plan is defined:

> The 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 needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs." (International Academy of Life Care Planners, 2015, p. 5)

Inherent in the definition of a life care plan is the concept of costs for healthcare and related services.

For decades in the United States, the reasonableness of the medical costs was rarely disputed in litigation. Life care planners involved in litigation may have had different opinions about what was contained in the plan, but the reasonableness of the cost was typically not discussed. A review of 13 years (1991 through 2003) of The Neurolaw Letter (HDI Publishers 1991-2003), a monthly publication devoted to attorneys and professionals who provide services to survivors of brain injury and spinal cord injury found fewer than a dozen articles discussing life care planning in general and no articles discussing the usual, customary or reasonableness of medical costs. In fact, in 1999, life care planner Robert Voogt wrote "A dollar amount can easily be assigned to physician visits, in-home healthcare, medication, therapy, equipment and surgeries," (Voogt, 1999, p. 5) implying that assignment of cost could be easily performed.

Following the 1993 United States Supreme Court landmark decision in (*Daubert v. Merrell Dow Pharmaceuticals*, 1993), critical attention was drawn to the methodology the life care planner employed in preparing the plan. Litigants fought over issues of the life care planner's qualifications (*Kent Village Associates Joint Venture v. Smith*, 1995; *Norwest Bank, NA v. Federal Kemper Life Ins. Co.*, 2000) and competency to testify; hearsay (*Gourley v. Nebraska Methodist Health System*, 2003; *Tornatore v. Cohen*, 2018); whether a specific service was reasonable or even necessary; if the plaintiff needed 24-hour care and if so, whether that care should be provided by a family member, home health agency or privately hired worker; or whether licensed practical nurses were needed to perform intermittent catheterization or tube feeding (Deutsch, 2011). However, the question of the reasonableness of the medical cost estimates, the medical coding system, or medical database relied upon was rarely raised.

However, this all changed in 2011 when the California Supreme Court decided the case of *Howell v. Hamilton Meats & Provisions, Inc.* (2011). In the Howell case, the Court held that a plaintiff could only recover damages based upon the discounted amount paid by the insurance company, rather than the amount charged by the provider, as the plaintiff never incurred the economic damages equivalent to the charged amount. After the Howell decision, assignment of costs to healthcare services included in the life care plan was no longer considered to be an easy task and in courts throughout the United States, the issue of life care planning costing became a topic for argument.

Collateral Source Rule

In 1854, the United States Supreme Court first recognized what is now known as the Collateral Source Rule in *The Propeller Monticello v. Mollison* (1854), which involved a collision between two vessels. The collateral source rule precludes a defendant from presenting evidence that an injured plaintiff's medical expenses have been paid by an independent source. Because the individual plaintiff procures insurance at their expense, in a transaction that in no ways involves the defendant party, historically courts deemed that any proceeds from an insurance policy received by a plaintiff were collateral" to any recovery from the wrongdoer, hence the term "collateral source rule".

Normally, of course, in an action for damages in tort, the fact that the plaintiff has received payments from a collateral source, other than the defendant, is not admissible in evidence and does not reduce or mitigate the defendant's liability (*Fye v. Kennedy*, 1998). While the rule may effectively allow a plaintiff to receive a double recovery:

> [t]he collateral source rule expresses a policy judgment in favor of encouraging citizens to purchase and maintain insurance for personal injuries and for other eventualities. The theory behind the collateral source rule is that a wrongdoer should not have the benefit of insurance independently procured by the injured party and to which the wrongdoer was not privy (*Brown v. Am. Transfer & Storage Co.*, 1980).

In the late 1980's and 1990's, a major piece of the tort reform movement centered on attacking the collateral source rule. Defendants, manufacturers and insurance companies argued that plaintiffs should not recover for incurred or to be incurred medical expenses covered by third parties such as private insurance or Medicare/Medicaid. States began enacting legislation to eliminate recovery for medical expenses paid or payable by private insurance (NJ Rev Stat § 2A:15-97, 2013). By 2007, it was noted that 44 of the 50 states had taken legislative steps to limit the collateral source rule (Zorogastua, 2007). In 2011, the California Supreme Court decided the case of *Howell v. Hamilton Meats & Provisions, Inc.* In Howell, the California Supreme Court wrote, "The collateral source rule precludes certain deductions against otherwise recoverable damages, but does not expand the scope of economic damages to include expenses the plaintiff never incurred" (Howell v. Hamilton Meats & Provisions, Inc., p. 548) (*Howell v. Hamilton Meats & Provisions, Inc.*, 2011, p. 548).

As of 2021, there is no consensus among state courts. State courts have taken essentially four approaches of whether to admit undiscounted medical bills into evidence when the bills have been satisfied for less. These are (1) the "actual amount paid" approach, which allows into evidence only the actual amount paid for medical care; (2) the "benefit of the bargain" approach, which allows the undiscounted medical bills into evidence if the plaintiff paid meaningful consideration for the insurance or other collateral source from which payment was made (3) the "reasonable value" approach, which allows admission of undiscounted medical bills without restriction as at least evidence of the medical services' value (*Dedmon v. Steelman*, 2017; *Weston v. Akhappy Time LLC*, 2019); and (4) a hybrid approach. However, the vast majority of states adhere to the "reasonable value" approach. Table 1 below outlines the four primary approaches state courts are currently taking along with states where the approach is followed as of the time that this manuscript was prepared. Not all 50 states are included in this chart.

Table 1

Four Approaches to Collateral Source Rule

Approach	**Basis for Calculation**	**States Currently Following Approach**
Actual Amount Paid	Only the actual amount paid for medical care is allowed in evidence	California New York Pennsylvania Michigan Texas Idaho
Benefit of the Bargain	Undiscounted medical bills if plaintiff paid for insurance or other collateral source from which payment was made	Delaware Louisiana
Reasonable Value	Undiscounted medical bills without restriction	Alaska Virginia Hawaii Illinois Kansas Montana Kentucky Oregon South Dakota West Virginia Wisconsin Tennessee Massachusetts Arizona Arkansas Colorado Maine Maryland
Hybrid	Plaintiffs submit full, undiscounted medical bills and defendants submit evidence that the plaintiff's medical providers accepted less than the full bills (without mention of insurance)	Ohio Missouri Indiana

The "Actual Amount Paid" Approach

Howell v. Hamilton Meats & Provisions, Inc. (2011), provides an excellent example of the actual amount paid approach. In *Howell*, the issue presented was whether an injured plaintiff whose medical expenses were paid through private health insurance could recover as economic damages the amount billed by the medical provider, or were they limited to the actual amount paid by the insurer? The California Supreme Court ruled a plaintiff could not recover as economic damages more than the discounted amount paid by the private insurer. The Court reasoned:

> Because they do not represent an economic loss for the plaintiff, they are not recoverable in the first instance. The collateral source rule precludes certain deductions against otherwise recoverable damages, but does not expand the scope of economic damages to include expenses the plaintiff never incurred. The rule that a plaintiff's expenses, to be recoverable, must be both incurred and reasonable accords, as well, with our damages statutes. 'Damages must, in all cases, be reasonable (Civil Code, § 3359)....' But if the plaintiff negotiates a discount and thereby receives services for less than might reasonably be charged, the plaintiff has not suffered a pecuniary loss or other detriment in the greater amount and therefore cannot recover damages for that amount (Civil Code, §§ 3281, 3282). The same rule applies when a collateral source, such as the plaintiff's health insurer, has obtained a discount for its payments on the plaintiff's behalf.

The Court concluded that plaintiff's recovery was limited to the discounted value of the medical expenses. The Court did acknowledge that a tortfeasor who injured an individual insured under a managed care insurance policy would pay less than if the injured person was uninsured.

As of the writing of this article, it is noted that six states have adopted the actual amount paid approach. These states include California, New York, Pennsylvania, Michigan, Texas and Idaho.

The "Benefit of the Bargain" Approach

A few states have adopted an alternative sometimes called the "benefit of the bargain" approach.

Under the benefit of the bargain approach, the plaintiff who has purchased insurance is assumed to have paid for the "negotiated rate differential" as much as for the actual cash payments made by the insurer to medical care providers. However, plaintiffs who did not pay for the benefit of discounted rates and write-offs (e.g., beneficiaries of Medicare and Medicaid) may not introduce their undiscounted billings. In these cases, the court "treat[s] the amount paid by Medicare [or Medicaid] as dispositive of the reasonable value of healthcare provider services" (*Bozeman v. State*, 2004; *Stayton v. Delaware Health Corporation*, 2015; *Weston v. Akhappy Time LLC*, 2019).

As of the writing of this article, it is noted that two states have adopted the benefit of the bargain approach. These states include Delaware and Louisiana.

The "Reasonable Value" Approach

The reasonable value approach allows the admission of undiscounted medical bills without restriction, as evidence of medical services' value. Courts following this approach "adhere to the traditional collateral source rule, as outlined in Section 920A of the Restatement (Second) of Torts § 920A (American Law Institute, 1977). that tortfeasors should be responsible for all the damage they cause and that plaintiffs, not tortfeasors, should benefit from any negotiated discount" (*Weston v. Akhappy Time LLC*, 2019, p. 1026).

Some of these courts emphasize that because the value of medical services is a fact-intensive question, juries should receive all relevant evidence, including undiscounted medical bills. An example is *Arthur v. Catour*, (2005). In this case, all of plaintiff's bill were paid by health insurance. Defendant moved for partial summary judgment, seeking to limit plaintiff's claim for medical expenses to the amount paid rather than the amount billed. The Illinois Supreme Court rejected defendant's argument, upheld the collateral source rule, and determined Plaintiff could present to the jury the amount that her healthcare providers initially billed for services rendered.

The Tennessee Supreme Court decision in *Dedmon v. Steelman* (2017)is illustrative of this approach. In this case, defendants filed a motion to limit plaintiff's recovery for past medical expenses to those amounts actually accepted by medical providers. The Tennessee Supreme Court reviewed the approaches taken by courts throughout the United States and rejected abrogating the collateral source rule, holding:

> All of the alternative common-law approaches have the effect of undermining the collateral source rule and the significant public policies it continues to serve. A decision to depart from the established precedent of the collateral source rule would have to be supported by the firm belief that justice dictates a different path. None of the common-law alternatives to the collateral source rule give us such a firm belief.
>
> Importantly, we have no assurance that adoption of any of the alternative approaches would result in a more just and accurate assessment of the reasonable value of medical services received by plaintiffs in personal injury cases. The discounted amount of medical services does not necessarily, and in fact probably does not, reflect the true value of services rendered... A discounted rate, however, generally reflects the third-party payor's negotiating power and the fact that providers enjoy prompt payment, assured collectability...
>
> We also decline to alter existing law in Tennessee regarding the collateral source rule. Consequently, the Plaintiffs may submit evidence of Mrs. Dedmon's full, undiscounted medical bills as proof of her “reasonable medical expenses,” and the Defendants are precluded from submitting evidence of discounted rates for medical services accepted by medical providers as a result of Mrs. Dedmon's insurance. The Defendants remain free to submit any other competent evidence to rebut the Plaintiffs' proof on the reasonableness of Mrs. Dedmon's medical expenses, so long as the Defendants' proof does not contravene the collateral source rule.

In essence, the Dedmon Court decision reaffirmed the reasonable value approach whereby a plaintiff may recover the amount of the full (undiscounted) medical bill.

In deciding the case, the Dedmon Court acknowledged the increasing complexity of healthcare pricing, stating:

> During this same period since adoption of the rule, the pricing, payment, and reimbursement system for health care providers has become exponentially more complex. The rise of managed care organizations has distorted pricing for health care services, as the deep discounts demanded by the MCOs require providers to offset those discounts by charging higher prices to other patients. . . . As observed by the Court of Appeals below, all of these developments have caused “the issue of what constitutes a reasonable medical charge or expense [to become] the subject of increased litigation due to the increased involvement of government payors, the complexity of health care reimbursement provisions, financial pressures on hospitals, and the significance of medical expense recovery in personal injury litigation” (p.452).

As of the writing of this article, it is noted that 18 states continue to follow the reasonable value approach. These states include Alaska, Arkansas, Arizona, Colorado, Hawaii, Illinois, Kansas, Kentucky, Massachusetts, Maine, Maryland, Montana, Oregon, South Dakota, Tennessee, Virginia, West Virginia, and Wisconsin.

Hybrid Approach

A few courts that permit plaintiffs to recover their full, undiscounted medical bills use a "hybrid" method of presenting evidence of "reasonable value" to the jury. Using this method, plaintiffs may submit their full, undiscounted medical bills to establish the "reasonable value" of the medical services received. The defendants, however, may submit evidence that the plaintiff’s medical providers accepted less than the full bills to rebut the reasonableness of the full bills, so long as insurance is not mentioned (*Patient Protection and Affordable Care Act of 2010*, 2010; *Robinson v. Bates*, 2006). To date, Ohio, Indiana and Missouri have adopted this approach.

Future Medical Costs

While there has been a great deal of litigation activities around past medical expenses, there has been less about the admissibility of future medical expenses. Whether these expenses are contained in a life care plan or simply testified to by a healthcare provider, there is no reason to expect that future medical costs will be treated by the courts in a different manner from past medical expenses. A look at court decisions regarding reimbursement of past medical expenses will prove a reasonable roadmap as to where the courts will go in deciding the reasonableness of future medical costs contained in life care plans. The 2017 case *Cuevas v. Contra Costa County* is an example of a case where the court addressed the future costs included in a life care plan (*Cuevas v. Contar Costa County*, 2017).

In *Cuevas v. Contra Costa County* (2017), plaintiff disclosed a life care plan, in which the life care planner provided her opinion as to the kind of medical and rehabilitative care plaintiff would need for the rest of his life, along with the projected cost for each specific care item. Her plan was based on the recommendations of medical specialists who testified on plaintiff's behalf. As to future medical costs, the plan did not account for service discounts associated with Medi-Cal, even though plaintiff was currently receiving Medi-Cal benefits. Nor did it reflect negotiated discounts that would potentially be available under insurance procured through the Patient Protection and Affordable Care Act of 2010 (ACA). Instead, plaintiff's life care planner determined future costs for medical care by referencing a national database that reflected the average charges billed for each type of service.

Defendant's life care planner prepared life care plans based on services recommended by a defense pediatric neurologist. In contrast to plaintiff's life care plan, defendant's life plan reflected three alternate cost scenarios, including one in which plaintiff would continue to be covered by Medi-Cal; one in which plaintiff would procure private insurance under the Affordable Care Act; and one in which he would pay for his expenses out of pocket. With respect to the private pay scenario, defendant's life care planner did not rely on amounts billed by health care providers in calculating future medical expenses. Instead, she contacted local health care providers and asked them how much individuals without insurance are required to pay. These rates typically are less than what providers would state on a bill.

Defendant's life care planner's alternative plans reflected the wide variations that exist in medical charging practices. The Medi-Cal life care plan reflected reimbursement rates that were substantially lower than the rates paid by persons without insurance. For example, one category of expenses reflected a more than 60 percent difference between the private pay rate and the Medi-Cal rate. Within the three plans, she also took into consideration the free benefits that plaintiff was currently entitled to receive from the regional center and public school system.

Defendant's life care planner prepared a report comparing the costs for the services itemized in plaintiff's life care plan with the Medi-Cal payment rate for the same goods and services, revealing that the plaintiff's life care costs were substantially higher. For example, the cost for a wide variety of physician visits listed in plaintiff's plan were four to six times higher than the corresponding Medi-Cal rates.

In keeping with California's long judicial history (*Hanif v. Housing Auth. Of Yolo County*, 1988) of limiting reimbursement for medical expenses to that which was accepted by the provider, the Court ruled in defendant's favor and ruled defendant could introduce evidence of the effect of the Affordable Care Act. The Court (*Cuevas v. Contar Costa County*, 2017) instructed,

> For insured plaintiffs, the reasonable market or exchange value of medical services will not be the amount billed by a medical provider or hospital, but the 'amount paid pursuant to the reduced rate negotiated by the plaintiff's insurance company (p.179) . . . . [W]hile an injured plaintiff is entitled to recover the reasonable value of medical services that are reasonably certain to be necessary in the future, evidence of the full amount billed for past medical services cannot support an expert opinion on the reasonable value of future medical services (p.182).

For readers interested in an analysis of potential problems with projecting future costs based upon discounting pricing, the reader is referred to De Saint Phalle and Clay (2018), which discusses the methodologies of calculating future medical costs after the Cuevas decision.

Implications for Life Care Planning

Based upon the most recent life care planning role and function study (May & Moradi-Rekabdarkolaee, 2020) only 5 of 212 (2.36%) life care planners participating in the study held a juris doctorate. As early as 2015, Field et al. (2015) stated that legal decisions that impact the collateral source rule are outside the role and function of a life care planner. Nevertheless, life care planners must contend with the issues outlined above pertaining to collateral source approaches in the courts. To assist life care planners with these issues, it is recommended that life care planners consult life care planning guiding documents such as standards of practice (International Academy of Life Care Planners, 2015); read previously-published materials on the Collateral Source Rule (Field, Johnson, Choppa, & Fountaine, 2015)and usual, customary and reasonable pricing; inquire about previous court decisions related to life care planning issues; and understand the individual approach of the court where each life care plan is prepared.

Guidance from Life Care Planning Documents

Previously-published life care planning documents provide guidance to life care planners on methodological issues as well as collateral source issues. For example, the *Standards of Practice for Life Care Planners, 3rd edition* states that the life care planner "Develops recommendations for content of the life care plan cost projections for each evaluee and a method for validating inclusion or exclusion of content" (International Academy of Life Care Planners, 2015, p. 9). Some may argue that choosing what is included or excluded in a plan based upon a jurisdiction's collateral source approach is deviation from standard life care planning methodology. However, these authors contend that one's life care planning method, that is, record review, consultations with evaluees and healthcare professionals, development of a narrative and tables, and report dissemination will not change based upon collateral source jurisdictional differences. A similar assertion was made in 2015 by Field et al., who concluded, "Life care planners cannot know with reliability what the courts or legislative bodies may choose to do in the future; the traditional life care planning methodology remains the same" (p.7).

Rather, some of the data *allowed by the court* to be presented to the jury, and therefore included in the life care plan, may vary. As a result of jurisdictional differences, the same life care planner may include the full charge of a healthcare service in a life care plan that is venued in Delaware but only the adjusted amount in a life care plan venued in California. This is based upon the jurisdictional requirement as established by the court and does not amend the method by which the life care planner prepares their report and presents testimony.

In 2015, Johnson et al. noted that jurisdictional variations should be noted when considering collateral source rules in life care planning. Additionally, life care planning *Majority and Consensus Statements* (C. B. Johnson et al., 2018, p. 15) state: "Life Care Planners shall have knowledge of relevant laws and regulations as well as local and national care standards." It is recommended, therefore, that life care planners gain familiarity with various collateral source rule approaches by courts to understand what the court will or will not allow to be presented to the jury in terms of past and/or future medical expenses (Field, Johnson, & Choppa, 2015). Failure to do so may result in the life care plan being excluded.

Over six years ago, Johnson et al. (2015, p. 48) stated the following about collateral source rules in life care planning, “There is nothing in the *Standards of Practice* or *Consensus and Majority Statements* indicating we cannot provide a variety of information regarding costs and collateral sources if requested”. Based upon a review of current life care planning documents, the current authors conclude that years later, this statement holds true. For life care planners who work within litigated systems, consideration of the jurisdictional requirements governing admissibility of life care planning testimony must be undertaken.

Gain Education about Collateral Sources Rules within each Jurisdiction

Life care planners who prepare life care plans within litigation must follow the rule of the specific jurisdiction, regardless of their personal beliefs. However, it is certainly within the purview of the life care planner, at time of referral, to refuse to accept the referral if they conclude that inclusion, for example, of only the adjusted healthcare cost is not consistent with their life care planning process. For life care planners who work in various jurisdictions, gaining knowledge about jurisdictional requirements at the time of case referral is recommended. Just as life care planners are skilled in conducting consultation with healthcare professionals to discuss recommendations for future care included in the life care plan, it is recommended that life care planners ask relevant questions of referral sources about collateral source approaches in the case’s jurisdiction.

During the referral conversation, if the life care plan will be used in litigation, it is advisable that the life care planner gain an understanding of prior life care planning-related court opinions within that same venue. Looking to previously decided cases is a method by which the life care planner can obtain this education. An example of state court cases that limited recovery to the amount paid by insurance is seen below in *Markow v. Rosner* (2016) and *Madrigal v. United States* (2021).

In *Markow*, plaintiffs’ life-care planning expert, estimated that the amount billed for *Markow*’s future hospitalizations would be approximately $2 million. Based on her research, knowledge, and experience, plaintiff’s expert testified that the amount actually paid is usually 50 to 75 percent of the total amount billed. She also testified that with respect to one particular hospitalization, the cost was reimbursed at a much lower rate of 12.9 percent. The jury’s award of $1.3 million was approximately 65 percent of the estimated future billing amount of $2 million, or roughly halfway between the 50 to 75 percent reimbursement testified to by plaintiff’s life care planner.

The appellate court held:

> Substantial evidence supports the jury’s award. While [Plaintiff’s life care planner] acknowledged that in one instance a hospital accepted a reimbursement rate much lower than 50 to 75 percent, she also testified that reimbursement rates vary and that there is no one "across-the-board, set percentage." [Plaintiff’s life care planner] testified that she has been doing life care planning for almost seven years. In addition to her experience as a life-care planner, she has a bachelor’s degree in critical care nursing, and a master’s degree in business administration with a specialty in health care management; she is also a certified hemodialysis nurse and is licensed as both an R.N. and a public health nurse. The jury could reasonably find [her] testimony on the reimbursement rate to be credible. Ac-

> cordingly, we find that substantial evidence supports the jury's award of future economic damages (*Markow v. Rosner*, 2016, p. 1051).

Madrigal v. United States (2021) provides another illustration where both plaintiff and defense experts' approaches were rejected by a federal court applying California law. There, plaintiff's expert physicians unilaterally relied on their assignment of value of future medical treatment. On the other hand, defendant's expert in reasonable value analytics opined "on the fair market value" of Plaintiff's medical care. In reaching her conclusions, the expert applied a multiplier to data extracted from the Medicare Physician Fee Schedule Database, a comprehensive source of information on fees for medical services. The Court without much discussion rejected the testimony of plaintiff's physicians. With regard to the defense, the Court held:

> The Court finds [defense expert's] methodology to be more probative of the reasonable value of medical services but nevertheless problematic. While her methodology more nearly pinpoints the reasonable value, it concerns a singular "fair market value." The Court is not convinced that the relevant market for Plaintiff's treatment is precisely aligned with the market identified in [defense expert's] methodology. That is, [defense expert's] methodology encompasses those rates negotiated by payers who may have more bargaining power than Plaintiff. Accordingly, the Court does not adopt [defense expert's] conclusions but accords reasonable values for Plaintiff's medical services more closely tied to figures proffered by [defense expert's] (*Madrigal v. United States*, 2021).

In other states that have applied the reasonable value approach, the life care planner will need to determine what the reasonable undiscounted amount that will be charged by the provider of the service.

Understand Costing Concepts Relevant to Life Care Plan preparation

It is noted that a court's approach to the collateral source rule may affect not only the content of the items in the plan (e.g., the inclusion or exclusion of available community resources) but also the source of the cost data contained in the life care plan. It is likely the cost of the healthcare items will be the factor that will have the most variation among venues, as a result of differing collateral source rule approaches. That is, if the jurisdiction only allows for the jury to consider the allowable cost of a healthcare service, the court may only allow the life care planner to testify to such data sources.

Life care planning literature has extensively addressed the process of costing items contained in a life care plan. Life care planning Majority and Consensus Statements (C. Johnson et al., 2018, p. 17) state: "Life Care Planners shall gather geographically relevant & representative prices." Variation in how courts are handling the collateral source rule may impact how life care planners treat the word "representative". Historically in life care planning, the prevalent concept was that the life care plan would contain prices for items that an evaluee would reasonably expect to pay. However, with the current variation in collateral source approaches by courts, the *representative* price that may be presented by the life care planner may be dictated by the courts, rather than the life care planner. Again, *Majority and*

Consensus Statements (C. Johnson et al., 2018, p. 17) state that best life care planning practice includes obtaining "Non-discounted/market rate prices" (p.17). However, the life care planner may lose the ability to include the full charge of a medical office visit if they are preparing a life care plan in a venue that does not allow charges (i.e., non-discounted rates) to be introduced. Again, we argue that it is not a deviation from standard life care planning methodology to use the adjusted cost in certain jurisdictions, if that is what is required for the life care plan to be deemed admissible. This would involve, as (Field, Johnson, Choppa, & Fountaine, 2015, p. 8) described an additional step to identify collateral source offsets. This is similar to the concept expressed by Field, Johnson, and Choppa (2015) in a collateral source rule discussion when they stated, "Life Care Planners are permitted to provide useful information to the parties as requested" (p.48). Additionally, the Standards of Practice for Life Care Planners (3rd edition) (International Academy of Life Care Planners, 2015, p. 10) state that the life care planner who engages in forensic applications, "Acts as a consultant to legal proceedings related to determining care and needs and costs in the role of an impartial advisor to the court." Based upon a 2021 review of life care planning documents, there was nothing found that would preclude the life care planner from providing a variety of data points reflecting costs and collateral sources, if this is requested.

It is, therefore, incumbent upon the life care planner to understand the sources of healthcare costs and demonstrate the ability to adequately explain their approach to life care planning costing. Some life care planners utilize the usual, customary and reasonable (UCR) pricing when costing items contained in a life care plan. The concept of UCR has been adopted by the American Medical Association (2013) with the following definitions:

Usual: Fee usually charged for a given service to a private patient

Customary: Fee is within the range of usual fees currently charged by physicians with similar training and experience, for the same service within the geographic area

Reasonable: Fee meets above 2 criteria and is justifiable without regard to payments that have been discounted (American Medical Association, 2013).

It behooves the life care planner to understand and be able to clearly communicate the concept of UCR, a concept that has been previously published in life care planning literature (Busch, 2018; Maniha & Watson, 2019). A full discussion of UCR is beyond the scope of these article, but interested readers are referred to the Busch (2018) and Maniha and Watson (2019) for a complete discussion of the topic. If the life care planner possesses an understanding of charge vs. cost, paid vs. adjusted amounts, UCR and non-discounted cost, the life care planner should be well positioned to educate the parties involved of such concepts. For some life care planners who may be required by jurisdictional requirements to include "paid" amounts in the life care plan, explaining what the market rate amount was and how the adjusted amount was derived will likely assist the trier of fact when damages arguments are presented. The life care planner should also be prepared to discuss how an individual evaluee may not be afforded the same ability to adjust the amount charged for a medical good or service, as is customary for third party payors, whether private or public.

Proceed According to Jurisdictional Requirements

Once a life care planner has agreed to accept a referral for a life care plan for litigation and they have educated themselves on the collateral source rule approach within the venue where the plan will be developed, they must proceed accordingly. In a venue where the "actual amount paid" approach is controlling, life care plans developed within these states may expect that future medical costs included in the plan may reflect only adjusted amounts, rather than the charge amount. Such approach may require analysis of prior medical bills and adjustments made on previously incurred medical expenses. Again, a reader is referred to Busch (2018) for a complete explanation of the revenue cycle for this process.

In a venue where the "reasonable value" is the approach adopted by the courts, life care planners may include the actual charge, or the amount a physician or other provider actually billed, without consideration of adjustments or reimbursed amounts.

In a venue where the "benefit of the bargain" is the approach adopted, if the plaintiff paid for insurance, the amount included in the plan may only include undiscounted medical bills. If they did not pay for insurance, the amount included would likely be what is reasonable, taking into account what medical insurance would pay or what was actually paid.

In a venue where the hybrid approach is adopted, there may be multiple life care planners involved. While the plaintiff's life care planner may include full charge costing in the plan, it is likely the defendant-retained life care planner will include only what was paid in medical expenses or what is expected to be paid in the future. An example of this approach is reflected in the California case *Cuevas v. Contra Costa County* discussed above.

Conclusion

Over the last 30 years, courts throughout the United States have developed divergent approaches to collateral source rules that govern presentation of evidence to juries regarding damages. Four primary approaches have been developed which are: Reasonable Value; Benefit of the Bargain; Actual Amount Paid; and a Hybrid approach. Given the various approaches outlined above, the question becomes, what source should the planner utilize in determining the cost of the proposed treatment? Unfortunately, the Courts have not provided clear guidance to answer this question.

Familiarity with collateral source approaches by courts has historically not been an area of contention in life care planning. However, as courts have grown disparate in their approaches to the collateral source rule, life care planners have been asked to present life care planning data based upon the court's jurisdictional approach. A life care planner should understand the jurisdictional approach to the collateral source rule that affects life care plan development in order to properly comply with jurisdictional requirements.

As life care plans must be lifelong, flexible, and based upon current research and standards, so too must life care planning as a specialty practice be flexible and stay abreast of jurisdictional requirements in which we practice. As Field, Johnson, and Choppa (2015, p. 48)concluded about collateral source rule issues, "We are not making a statement about what is the "right" cost to use, or who should pay. The jury and/or judge will do that."

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Your hard work and expertise
result in a wonderfully comprehensive journal,
making our profession better with each edition.
Thank You!!

An Exploratory Study of Medical Marijuana's Impact on Patients with Chronic Pain Beyond an Individual's Level of Function: Implications for Life Care Planning

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Abstract

Studies examining the efficacy of medical marijuana show limited evidence of its therapeutic potential and narrowly focuses on how medical marijuana improves level of functioning and ignores other key aspects of health-related quality of life. As life care planners consider disability beyond level of function, this article provides considerations for medical marijuana as a potential treatment to improve quality of life. The purpose of this study was to examine the efficacy of medical marijuana beyond the level of functioning among individuals with chronic pain. A direct content analysis was used to examine semi-structured interviews about medical marijuana use and experiences among individuals with chronic pain. Five themes were analyzed within the data: health impact of medical marijuana, cost, quality of life, social support, and accessibility. Three subthemes emerged from the data that were not initially predicted in the direct content analysis: opioids and addiction, social media and travel. Participants experienced an improvement in quality of life because of medical marijuana, and described its use as an opioid replacement in treating chronic pain. Results from this study provide a context for life care planners when considering medical marijuana as a treatment option for individuals with disabilities living with chronic pain.

Keywords: medical marijuana, cannabis, chronic pain, opioids, quality of life, disability, life care planning

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Throughout history, marijuana has been used across countries for religious ceremonies, herbal remedies, symptom relief and recreational use (Lusk et al., 2015; Pagotto, 2006). Although its medicinal use is well documented, the pharmacology of marijuana was only recently described (Lusk et al., 2015). Recent reviews show that there is substantial evidence for the therapeutic effects of cannabis in treating epileptic seizures, patient-reported spasticity in multiple sclerosis, nausea and vomiting from chemotherapy (National Academies of Sciences, 2017; Stetten et al., 2020). Although there is interest in treating other conditions (e.g. sleep apnea, fibromyalgia, Tourette's, anxiety, depression, post-traumatic stress disorder, dementia, glaucoma, spasticity due to a spinal cord injury, Huntington's disease, and Parkinson's disease) there is limited evidence to support any therapeutic benefits from treatment using medical marijuana (National Academies of Sciences, 2017; Stetten et al., 2020).

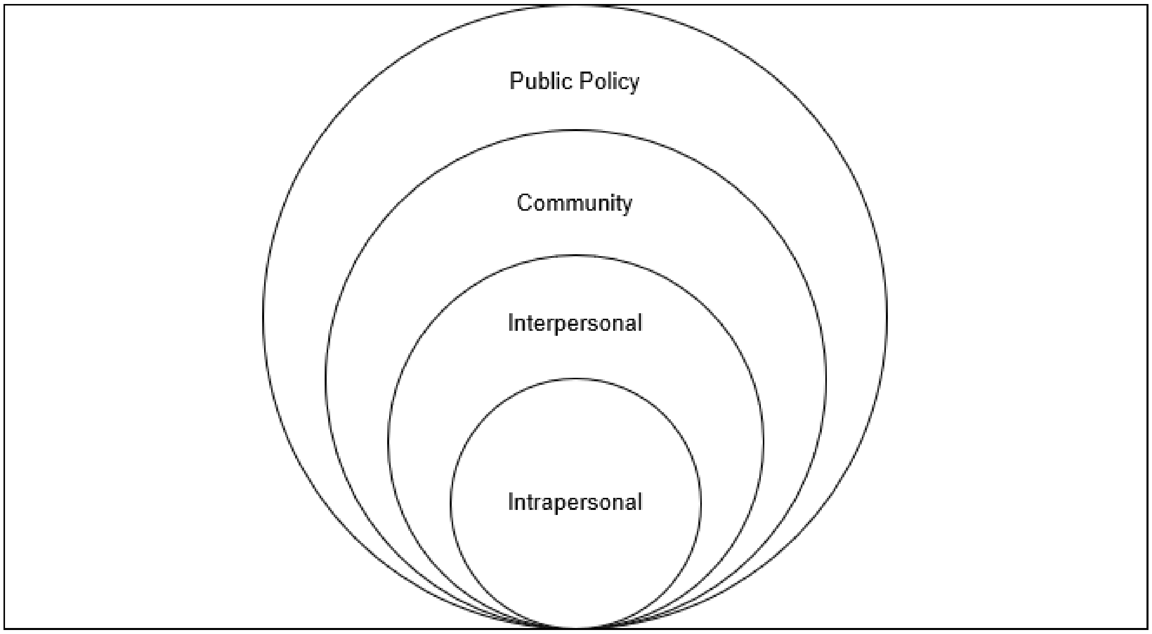
It is important to note that the majority of medical marijuana clinical trials and research narrowly focus on how medical marijuana improves level of functioning as opposed to activities of daily living and participation in society. This focus stems from the standard medical approach that views disability as a condition or problem within an individual's body that needs treatment in order to "fix the disability" (Goering, 2015). Examining the efficacy of medical marijuana beyond functioning is crucial to developing a broader scope of empirical evidence for medical marijuana which may be better captured through a theoretical lens.

The use of theory provides researchers and practitioners a larger picture of what is really going on with a health behavior or outcome (Rimer & Glanz, 2005). The Social Ecological Model (SEM) shows that "behavior both affects, and is affected by multiple levels of influence, and behavior both shapes, and is shaped by, the social environment" (Rimer & Glanz, 2005). Within the SEM there are four levels of influence on health behaviors and conditions: intrapersonal, interpersonal, community and public policy (Figure 1). The SEM can serve as a guide to understanding social and behavioral variables associated with people with disabilities and medical marijuana use. Using the SEM will allow the "interactions between and interdependence of factors within and across all levels" of using medical marijuana to be shown (Rimer & Glanz, 2005).

Although the SEM is commonly used within public health, the current canonical theory in disability research is based on the International Classification of Functioning, Disability and Health (ICF) Model. A scoping review and evidence synthesis by Berghs et al. (2016), specifically criticizes only using public health theories when creating interventions and examining behavior among people with disabilities. Within the review, some studies point out that public health professionals should only rely on the International Classification of Functioning, Disability and Health (ICF) Model, when working with people with disabilities (Berghs et al., 2016). The ICF is based on the biopsychosocial model that shows disability and functioning are outcomes of interactions between health conditions (biological) and contextual factors (psychological, social) (WHO, 2002). The ICF also identifies three separate levels of functioning: the body or body part (body function & structure), the whole person (activity) and the whole person in a social context (participation). This allows the ICF model to show that disability occurs within a range that is unique to each type of disability and individual, in turn holistically conceptualizing a person with a disability, going beyond the

Figure 1

Social Ecological Model



traditional medical model (Berghs et al., 2016; Institute of Medicine (US) Committee on Assessing Rehabilitation Science and Engineering, 1997; Jette, 2009; McDougall et al., 2010; Pomeranz & Shaw, 2007; WHO, 2002).

Life care planners utilize this well established, frequently published, international model of disability to guide their methodology. Just as life care planners regularly rely on published research, clinical practice guidelines, and professional standards, the ICF can serve as a valuable source for substantiating recommendations included within a life care plan. The ICF can provide a very useful framework for conceptualizing and explaining the process of life care planning. The ICF model is being utilized by a number of rehabilitation professionals demonstrating its broad range applicability to injuries and disabilities. Please refer to Pomeranz and Shaw (2007) Pomeranz and Shaw (2007) for detailed examples and applicability of the ICF model within the field of life care planning.

The purpose of this study was to conduct qualitative interviews using the ICF and SEM models in order to examine the efficacy of medical marijuana beyond level of functioning among individuals with chronic non-malignant pain in Florida. Ideally a study would look at all of the disabilities and health conditions that medical marijuana is approved to treat at the state level, but to make results generalizable across all disabilities this would require a significantly large sample size. Chronic pain was chosen as an area of focus as it is the most common cause of long-term disability and can occur alongside other diseases and health conditions (NIH, 2010, 2015). Consistent with the International Classification of Diseases 11, this type of pain is associated with a condition leading to persistent pain occurring for longer than three months (Treede et al., 2015).Along with being the most common cause of long-term disabilities (Glanz & Rimer, 2005), chronic pain was estimated to affect 20.4% of adults in the past three months in the United States (Zelaya et al., 2020).

Methods

A semi-structured interview guide based on the ICF and SEM model was used to capture the medical marijuana use experience among individuals with chronic nonmalignant pain. Interviews ranged from 24 to 61 minutes and took place over the phone while being recorded using Microsoft's Voice Recorder©. This study was approved by the Institutional Review Board at the study institution.

Theoretical Foundations

The SEM was specifically chosen for this study as ecological models lack specificity and does not establish variables that generalize across behaviors (Rimer & Glanz, 2005). Instead, ecological models are built off of five principles that can be generalized across different behaviors (figure 2). The intention of ecological models is instead to provide a framework for other theories to fit into. The ICF was chosen for this study as it is considered the gold standard within disability research but also because the ICF fills in the gaps from the SEM specificity limitation and provides generous detail about an individual's disability. The ICF model can show the range of disability that occurs in individuals with chronic pain and the SEM can show the social determinants surrounding medical marijuana.

Figure 2

Five Principles of Ecological Models

Principle 1: There are multiple levels of influence on health behaviors.
Principle 2: Environmental contexts are significant determinants of health behaviors.
Principle 3: Influences of behaviors interact across levels.
Principle 4. Ecological models should be behavior specific.
Principle 5: Multilevel interventions should be most effective in changing behaviors.

WHODAS 2.0

To incorporate questions using the ICF model, the World Health Organization (WHO) Disability Assessment Schedule (WHODAS 2.0) 12-item version was used. The WHODAS was developed using the ICF model as a conceptual framework (WHO, 2010). The ICF provides an individualized assessment of a person with a disability at an individual, environmental and societal level and "provides a definition for its operational assessment and defines disability as a decrement in each functioning domain" (WHO, 2010). The ICF is impractical in measuring health and disability across cultures, so the WHODAS 2.0 was developed to provide a standardized generic assessment tool to measure "health and disability at the population level or in clinical practice" (WHO, 2010). The WHODAS 2.0 is considered a generic assessment as it does not target a specific disease and allows for the comparison of disability due to different diseases (WHO, 2010). As the study recruited individuals with chronic nonmalignant pain that could be caused by numerous health conditions and disabilities, the WHODAS 2.0 was the ideal tool to use, as it is etiologically neutral [15].

The WHODAS 2.0 showcases the level of functioning in six domains: 1) Cognition – understanding and communicating, 2) Mobility – moving and getting around, 3) Self-care – attending to one's hygiene, dressing, eating and staying alone, 4) Getting along – interacting with other people, 5) Life activities – domestic responsibilities, leisure, work and school, and 6) Participation – joining in community activities, participating in society (WHO, 2010). Participants were asked to assess how difficult doing the following activities were in the past 30 day, with responses ranging from none = 0 to extreme or cannot do = 4. A license approval was given by WHO to use the WHODAS 2.0 in this study.

Social Ecological Model

Questions were developed using the SEM to show how using medical marijuana for chronic pain affected all aspects of an individual's life, in order to assess the impact medical marijuana usage has on quality of life. Questions at the intrapersonal level of the SEM assess how medical marijuana has affected the disability/health condition, medical marijuana cost, and the use of recreational marijuana and other prescriptions. Interpersonal level questions focus on how family and friends affected the choice to use medical marijuana and how those relationships changed because of medical marijuana. The relationship between physician and patient was also examined. Community and societal level questions center around the accessibility associated with acquiring medical marijuana. Overall, 12 questions were asked that encompassed the intrapersonal, interpersonal, community and societal levels of the SEM (Figure 3). Questions were assessed by public health experts (JP, AB, MH, AY) to ensure construct and face validity.

Recruitment

Participants were recruited using convenience sampling from medical marijuana dispensaries, tobacco shops and online through Florida specific Facebook© groups. Recruitment was performed using an advertisement flyer depicting the study information. No contact was made to specific individuals unless they expressed interest in the study over the phone or through email communications. Locations for recruitment were chosen to ensure that rural and urban areas were covered in the state of Florida. Facebook© specifically allowed recruitment to occur across the entire state. Interested participants were emailed an informed consent through Qualtrics. After informed consent had been received, the participants were contacted to conduct the interview. Following completion of the interview, individuals were mailed a $40.00 gift card for participation. Addresses given in order to send gift cards, showed that recruitment methods were successful in obtaining participants across the entire state. Only ten participants were recruited. Qualitative research methods also show that saturation is met at around 10 participants plus or minus two (Hennink & Kaiser, 2021).

Inclusion and Exclusion Criteria

To be included in the study, participants were (1) over the age of 18, (2) had a medical marijuana prescription and (3) had to be using the prescription for chronic nonmalignant pain. Participants were excluded from the study if (1) they did not meet the proper age range defined above in the inclusion criteria, (2) did not have a medical marijuana prescription from a certified physician, or (4) could not read and/or communicate in the English language.

Figure 3

Interview Questions Developed Using the Social Ecological Model

Intrapersonal Level

1. How has the use of medical marijuana effected your health condition (e.g. chronic pain)?
2. Do you use other substances in combination with your medical marijuana? (Probing questions: Recreational marijuana? Prescriptions? Over the counter medications/supplements?)
3. How much does medical marijuana cost you?
4. How long does the medical marijuana last before you need a refill?
5. How has medical marijuana affected your quality of life?*

Interpersonal Level

6. How did you go about seeking a medical marijuana prescription/recommendation? (Probing question: Or did your doctor prescribe it to you first?)
7. When your physician recommended medical marijuana did they give you any instructions on how to use it? (Probing questions: Dosage? How to use it? Where did you learn how to use it?)
8. How did your friends or family members feel about your decision to use medical marijuana? (Probing question: How did your choice to use medical marijuana effect any of your relationships with your friends or family members?)

Community and Societal Level

9. How accessible are the dispensaries where you currently live?
10. Tell me about your experience when you go to the dispensary. (Probing questions: How helpful were the staff? What type of information did they provide?)
11. How does having a medical marijuana prescription effect you in the workplace/recreation/daily activity? (Probing questions: Traveling out of state?)
12. How would you describe the process of obtaining a medical marijuana card? (Probing question: Did you experience any barriers (e.g. time, accessibility)).

*Question was asked at the end of the interview, not in the order listed above.

Inclusion and exclusion criteria was determined through self-report questions within the informed consent. Inclusion and exclusion criteria were also verified through interview questions.

Data Analysis

The WHODAS 2.0 data was scored based on the scoring instructions recommended by WHO (WHO, 2010). A direct content analysis was used to analyze the interview questions. This qualitative method was chosen because the process is more structured and interview questions were developed using the SEM (Hsieh & Shannon, 2005). The structure of the interview provides an initial coding scheme and relationship between codes, also known as deductive category application (Hsieh & Shannon, 2005). Initial coding categories for this direct content analysis are shown in Figure 4. Interviews were then coded into the predetermined categories, and any content that could not be placed into the original coding scheme were given a new code.

Figure 4

Initial Coding Themes

1. Health Impact of Medical Marijuana
2. Cost
3. Quality of Life
4. Social Support
5. Accessibility

Results

Ten interviews were completed for this study. The majority of the participants were male (n=6, 60%). Participant ages ranged from 31 to 66 years old. The majority of participants had obtained some type of secondary degree (Associate degree (n=3, 30%), Bachelor's degree (n=3, 30%)), with the remaining participants obtaining either some college credit (no degree), trade/technical/vocational experience, high school or GED. Only one participant did not finish high school or obtained a GED. More than half of the participants were currently married (n=6, 60%). The remaining participants were single (never married) (n=3, 30%) or cohabitating (n=1, 10%). The majority of participant's work status was paid work (n=4, 40%) or self-employed (n=3, 30%); followed by unemployed for health reasons (n=2, 20%) and retired (n=1, 10%). Participant demographics are shown in table 1.

Table 1

Demographics

Characteristics	**Frequency, n (%)**
Gender	
Female	4 (40)
Male	6 (60)
Age	
18-24	0 (0)
25-34	1 (10)
35-44	2 (20)
45-54	3 (30)
55-64	3 (30)
65-74	1 (10)
Education	
Some High School, No Diploma	1 (10)
High School or GED	1 (10)
Some College Credit, No Degree	1 (10)
Trade/Technical/Vocational	1 (10)
Associate Degree	3 (30)
Bachelor's Degree	3 (30)
Master's Degree	0 (0)

Continued on next page

Table 1 – continued from previous page

Characteristics	Frequency, n (%)
Marital Status	
Single, Never Married	3 (30)
Currently Married	6 (60)
Separated	0 (0)
Divorced	0 (0)
Widow	0 (0)
Cohabitating	1 (10)
Work Status	
Paid Work	4 (40)
Self-Employed	3 (30)
Student	0 (0)
Retired	1 (10)
Unemployed (Health Reasons)	2 (20)
Other	0 (0)

WHODAS 2.0

Participant's overall WHODAS 2.0 score ranged from five to 30 (M =15.1, SD=7.68) (Figure 5). A score of zero equates to having no disability and a score of 48 translates to being fully disabled. Each of the six domains show level of functional limitation with score ranging from 0 to 4 (None =0, Mild =1, Moderate =2, Severe =3, Extreme or Cannot Do =4). Domains that showed participants on average having none to mild functional limitation included Cognition (M=0.45, SD=0.49), Self-care of (M=0.55, SD=0.93), and Getting along (M=0.40, SD=0.52). Domains that showed participants on average having mild to moderate functional limitation included Participation (M= 1.70, SD=1.25) and Life activities (M=1.95, SD=1.04). Mobility had an average score of 2.5 (SD= 1.22), showing moderate to severe functional limitation among participants. Overall domain scoring summary are shown in Figure 7 and individual domain scores are shown in Table 2. The WHODAS 2.0 also asks how many days the difficulties were present across all domains. Answers ranged from five to 30 days with the average being 24 days (SD =8.75). Responses ranged from zero to 14 days (M=3.40, SD=4.59) when asked how many days they were totally unable to carry out usual activities or work because of any health condition. When asked how many days activity was reduced (not including days unable) because of any health condition, participants responded with zero to 30 days (M=7.20, SD =8.94).

Social Ecological Model

Interviews were coded into the predetermined themes depicted in Figure 4. After the qualitative analysis was completed, additional subthemes were added that did not fit into the original coding scheme (Table 3).

Health impact of medical marijuana

When asked how the use of medical marijuana has affected their health condition, all participants responded with a positive impact statement. First responses from participants

Figure 5

Overall WHODAS 2.0 Scoring Summary

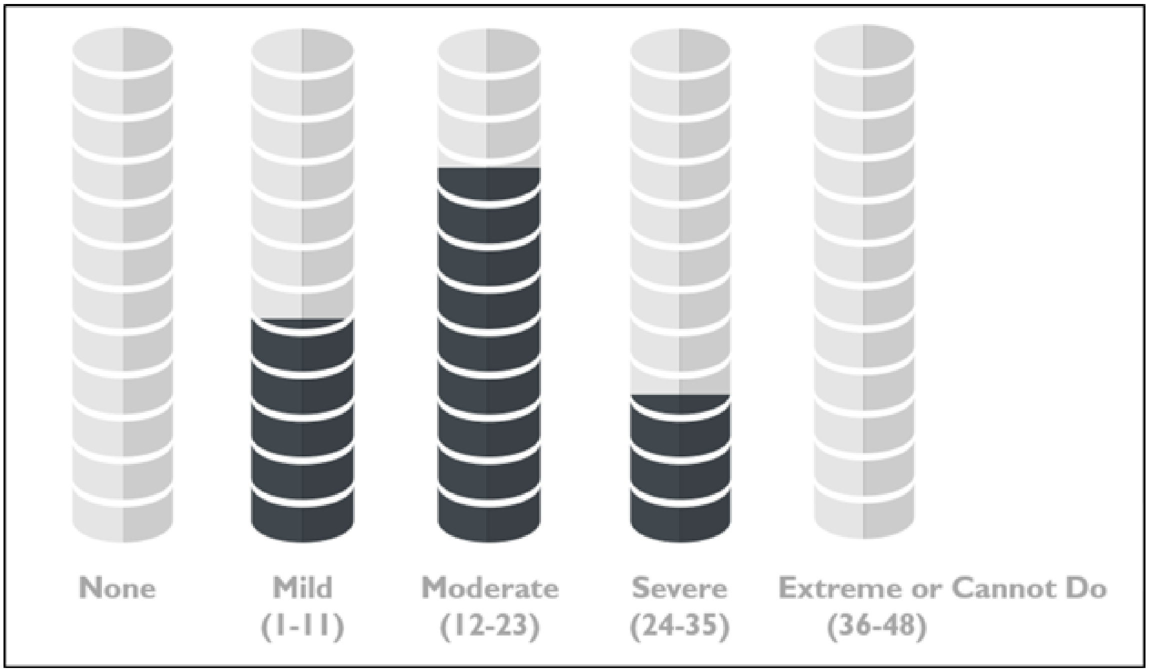


Figure 6

WHODAS 2.0 Domain Scoring Summary

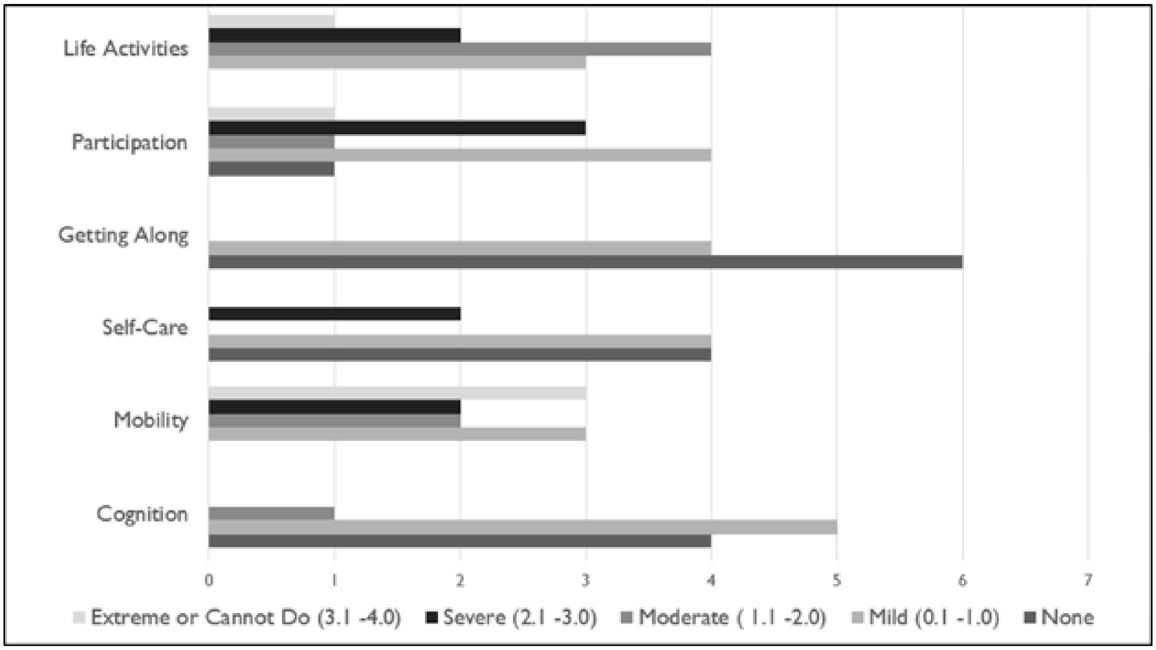


Table 2

Participant WHODAS 2.0 Scoring Results

	Overall WHODAS Score	Cognition Score	Mobility Score	Self-Care	Getting Along	Participation	Life Activities
Participant 1	8	0	2.5	0	0	0.5	1
Participant 2	17	0	3	1	0	2.5	2
Participant 3	5	0	1	0	0	0	1.5
Participant 4	18	1	4	0	1	1	2
Participant 5	16	0.5	2	0.5	0.5	2.5	2
Participant 6	30	0	4	3	0	4	4
Participant 7	17	0.5	3.5	0.5	0	1.5	2.5
Participant 8	6	0.5	0.5	0	0.5	1	0.5
Participant 9	12	1.5	1.5	0.5	0.5	1	1
Participant 10	22	0.5	3	0	1.5	3	3

Table 3

Final Themes and Subthemes of Direct Content Analysis

Themes	**Subthemes**
Health Impact of Medical Marijuana	Opioids/Addiction
Cost	
Quality of Life	
Social Support	Social Media
Accessibility	Travel

included superficial statements such as “Oh, amazing, it’s changed my life.” When asked to expand on how it had changed their life participants described experiences of increased function, weight loss and pain relief.

> “It’s enhanced my functionality.... Pretty much the reason I answered most of those questions [WHODAS 2.0] the way that I do is because I use medical marijuana.”
>
> “It’s changed my life... I’m able to eat better, I’m more socially active, I’m completely off of opiates.”
>
> “I went from always being able to walk with a cane to walking in a pair of boots with no cane. Inflammation was so bad I couldn’t hardly walk. To moving around looking like a normal person... I lost like almost 50 pounds.”
>
> “Well since I’ve been using it, I have lost weight, I feel a lot better, just overall a better person, it’s just everything”
>
> “I have lost weight, I feel a lot better, just overall better person, it’s just everything... I don’t think I can work without it.”

> "It helps with the pain in my neuropathy. It helps with the pain in my back. It helps me sleep. I have a terrible time sleeping. I'm a six hour a night guy, even with a CPAP and Ambien and medical marijuana... I don't sleep that much but when I do, I sleep very soundly, and I think the medical marijuana helps me get there."

Despite medical marijuana being described as extremely effective, some participants still used recreational marijuana. One reason for recreational use was the due to the inability to smoke cannabis. For example, one participant stated, "We don't have smokable flower available currently so of course I get my flower from other channels." Smoking cannabis results in feeling more immediate effects of the drug whereas other methods of consumption may take a considerable amount longer to feel the effects (Ashton, 2001). Other participants used recreational marijuana because medical marijuana wasn't fully relieving their symptoms or pain.

> "As far as the cannabis remedying the situation, it doesn't, but as far as treating and providing relief, it's excellent at that because when I have a situation where I'm getting spasms and I get these really bad knots, when I take it primarily something that's high in CBD or balanced equally, so if it's half CBD half THC, especially the vape pen"
>
> "The fact that we cannot grow our own, and eating is not the answer for me, because it's just tearing my throat up."

When asked about medical marijuana's effect, many participants also described that it helped them reduce the amount of prescriptions they have had to take daily.

> "They gave me a prescription for one 5mg pill evening. I cut them in half, so I actually use a two-and-a-half-gram pill to sleep with. And I've done that ever since I've been on it [medical marijuana] which has been years."
>
> "I actually still have most of those prescriptions... I think it was kind of like a safety net for me, but I don't need them... I'll maybe just get rid of them, yeah."
>
> "I originally got the recommendation, I was taking a lot of Advil, I was taking Advil three, four times a day. I was taking 10 Advils over the course of the day and I was really upsetting my stomach, and since I switched to the cannabis, I take Advil very sparingly.... if any way I try not to use any other medicines if I can, and just stick to the cannabis. If the pain is very high, like surgery pain has to be an opiate, that's the only thing that would cut through right after the surgery, but beyond that I try to stick to the cannabis."

Other participants expressed the desire to eventually be off all other medications besides medical marijuana.

> "My goal is to be off of those two also [current prescriptions]."
>
> "The reason I got on it was basically for the chronic pain and to get off the medications that were starting to affect my organs. I had the very early stages of kidney disease from taking opioids for 12 years."

Opioids and addiction

When asked about medical marijuana's impact almost all of the participants talked about opioids and addiction. A few participants sought out medical marijuana to avoid addiction that they saw in their families.

> "I just quit taking them, I was too young, and I just hated it. And there was addiction in my family, so I didn't want to go down that route."
>
> "Every doctor wants to prescribe opiates and I'm not down with that. I can't even collect disability because the disability lawyer won't touch me because the diagnosis is, you can treat your pain with opioids. . . . So, it is sit there and say I've refused opioids, in that case, I'm refusing treatment"
>
> "To know me, you'd know I don't drink alcohol and I don't take pills because it's killed all of my family. . . and I just can't go down that path."

Participants also described how medical marijuana helped them escape their own addiction to opioids.

> "I was addicted to opiates twice and taking them for chronic pain. I wouldn't say cannabis is better for you, but much less side effects, so that is a better option in my case." "My mom always took pills, but I didn't know why and now I know. For her thing it was like I have my addiction, you have yours. I'm like no, it's not the same."
>
> "I was on opiates for seven and a half years. . . and all kinds of other stuff, all of that shit weighing me all the time. To the point where people didn't even want to be around me."
>
> "So, for on a day-to-day basis, usually if I wouldn't have had medical marijuana, I would've had to relied on other things to help with the pain so I could still work. So, whereas before, the VA and doctors only wanted to give me pain pills, i.e. opiates, and I developed a pretty bad addiction with them. When I switched to medical marijuana, I was able to cut all those opiates out of my life. I don't have to take those any longer. I don't have to take any kind of narcotic. . . I think painkillers, one, I stay pretty tired, pretty slow. Whereas with the marijuana, I'm active. I'm upbeat. I'm happy. I also don't abuse the marijuana the way I did the pain pills. Towards the end, my addiction got pretty bad, and I didn't know how to take them properly."

Cost

When asked how much they spent on medical marijuana participants gave ranges of 200 to 1800 dollars per month. As it is federally illegal, health insurance will not cover any cost related to using medical marijuana (i.e. doctor appointments for medical marijuana, devices to use medical marijuana). Individuals are also required to pay cash for medical marijuana at the dispensaries in Florida.

> “Too much… It’s probably right around 200 a month, unlike my prescription medication, which was always free. So, I’ve had to cut back in other areas in order to afford the medical marijuana… I had to cut back on my grocery bill. That’s the only place I can cut back. I’m eating less in order to stay out of pain.”
>
> “It costs me about 4-500 dollars a month… I’ve had such chronic pain issues that I have to utilize that much, and it doesn’t get you high or anything, it just does the job it needs to do to take your pain away or put you to sleep. But it’s expensive, yes.”
>
> “I could spend $300 a month no problem. I wish it was a lot cheaper. Of course, if they let us grow it, it would be, but that’s still up in the air.”
>
> “Right now, in Florida it’s very expensive… I can easily be spending 100 a week…. In Florida you were allowed to have flower, I can grow my own, then I can make my medicine so much cheaper.”
>
> “Over 600 a month… I tend to run out of it too quickly, it’s very expensive, and it needs to be offered in stronger doses.” “I can spend anywhere from $1,500 to $1,800.”

Social Support

The majority of participants described their general practitioners (GP) as supportive in their use of medical marijuana.

> “I was interested in it years ago, thinking about it for my leg pain, and my current doctor was for it. We tried different medications for my knee pain and she wrote me a recommendation to the marijuana doctor, and ever since then, it’s been great… We tried other pain medication and it just wasn’t working, and I told her I was interested in doing it. When it became legal, we decided to go that route.”
>
> “My primary care physician, which I’ve had for over 15 years, has always known that I’ve medicated and she’s always, you know, and she can’t prescribe it because we’re not at the point we are now anyways and we’re not .... She’s always been like, "If that’s what helps you, then you do it." She knows the family history.”
>
> “I was the first paying patient that my doctor, my pain management doctor allowed to try it… And it was to the point where I could, we had tried every pill, 47 steroid injections, and she just couldn’t get it. I can’t shoot anymore steroids in you. Because of inflammation. I told her, there’s no other option, let me try medical marijuana and get on the CBD.”

Another participant described their GP as not being supportive in their use of medical marijuana but still open-minded in how it personally affects them.

> “My pain management doctor is not cannabis friendly, although he is interested in how it effects my day to day life and how it’s effecting me personally, he’s not a proponent of medical cannabis at this time.”

Another participant expressed fear in letting their GP know about their medical marijuana use.

> "My medical doctors don't know anything about it. I'm afraid to even mention it. I've heard of people telling their doctors that they are pursuing medical marijuana, and their doctors disowned them as patients."

When asked about their interactions with physicians that have undergone the required training in Florida to prescribe medical marijuana, participants described disappointment. Many felt that the medical marijuana doctors did not know a lot about marijuana and were in it more for the money.

> "They do, but it's just real vague and it's not out there like regular medication. It's basically, "Try this and see how this does, and X amount of times."
>
> "That's one thing I'm very disappointed about. The medical marijuana doctors, they aren't very good. I mean they don't tell you anything. They just say, "Yeah. Okay. You qualify. Here you go. Go get your license and be on your way." That's basically it."

The largest amount of social support for medical marijuana use came from family and friends.

> "I think I have about three or four friends on the train now, my mother has a card, even my best friend has a card. Cause once they saw me and how much better I was, they really wanted it. And they're were all non-utilizers, most of them. Everyone's fine with it, my daughters fine with it, she has no problem. My grandkids know it's my medicine, I teach them that."
>
> "I've had, for the most part, pretty good support. Me and my dad are not close, but he said he supported it and I'm closer to my wife's side, my in-laws, and they're all supportive, they think it's great. My son supports it, my wife supports it. The only thing she hates about it is it's just too dang expensive."
>
> "She's always been supportive of it. Most of my friends use it in some way, shape or form."

Participants also describe how some family and friends showed initial hesitation towards the use of medical marijuana, but when they saw how it had positively impacted them, they then came around to support their use of medical marijuana.

> "I have many that are really accepting of it and a few that are not very accepting of it... They're starting to come around a little bit more now that they see how it's changing my life."
>
> "Well, most of them aren't saying much about it. They're seeing the results and they're seeing that it's working. And they're going, "Hm, I guess marijuana isn't so bad after all."
>
> "I kind of opened their minds to it, especially my wife's Brazilian, and her family's from Brazil, so they have a completely different perspective with cannabis, just with the cartels and the violence that they deal with in their country... But after

> they see it here and I've brought my mother in law to the dispensary, they just see how professional, how clean the environment is, and how ... they're able to look at all the benefits because of the way it's presented. It's not presented with the stigmas and stereotypes of the past. Pretty much everybody, once they've seen the benefit, and because it's been recommended by a doctor, and my wife came with me to the appointment, so they know that it's beneficial and they haven't seen any decline in my activity or performance or personality, so at that point they've pretty much been okay with it."

The only negative reactions participants described were from friends and not from family members. A few participants also described how their medical marijuana use changed or ended a friendship.

> "Yeah. I have a friend at work that we used to be closer and he had a ... I think it was a drug or had alcohol abuse earlier in this life, and he was kind of ... We're still friends, we still work together, but we're not as close as we used to be since I started using it."

> "People that don't like it don't like it and if you tell them about it and it rubs them the wrong way, then you get attitude. I don't keep it a secret. I don't go out of my way to tell anybody, but I keep it a secret."

> "Everyone that said that wasn't my friend anymore."

Social Media

When participants discussed how medical marijuana doctors did not provide adequate information on how to use medical marijuana, they would use social media, specifically Facebook, to learn how to use various medical marijuana products. Some people even used these Facebook groups to figure out how to find a medical marijuana doctor.

> "I learned about the different clinics on Facebook."

> "There's quite a few marijuana Facebook groups that people education themselves. We're relying on self-education because doctors and the dispensaries are all freaking clueless."

> "There's a lot of people out there that have no clue and have no clue where to begin. If it wasn't for Facebook, I'm sure a lot of people would not know about it."

> "Researching, YouTube, Facebook, my buddy, my partner... And we just discovered together."

> "It was a Facebook group we're still a part of and we pass along tips and stuff like that."

> "Well, I was on Facebook and I ran into a post about Dr. X and that's who I went to."

> "There's no reference, it's like you can search internet and everything else, other than the social media sites that people talk about what worked for them, and try this, and try that, without the social media sites."

Social media also provided a network of social support for individuals outside traditional networks, such as family and friends.

Accessibility

Currently the majority of Florida's dispensaries are located in urban areas, specifically in bigger cities (i.e. Tampa, Miami). Participants that lived in these urban areas described dispensaries as being very accessible; "If I want to go to the one right up the road, I can get there in five minutes." Although more dispensaries are opening in Florida many participants described dispensary locations as a barrier.

> "The newest dispensary is a 90-mile round trip from my home... probably an hour and half to two hours." "The closest one is like 45 minutes away. That's very inconvenient for me."
>
> "A good, probably 20-minute ride to the closest dispensary, the best dispensary is about a 30-minute ride from me."
>
> "It's a two-hour one way, so it's a four hour to five-hour trip for me to go get it... it completely consumes a whole day."

To circumvent this barrier, many dispensaries offer delivery directly to an individual's home.

> "They're getting more accessible. Originally, I was having to have it delivered, but now within a month or so there's one right around the corner from me and then the one that I normally drive to is a 30-minute drive."

Participants also described their experiences at dispensaries as timely and pleasant, despite having to travel a considerable amount of time.

> "It's pretty efficient if you're already a patient. Basically, it's on you. You can call ahead, put in your order and when you get there it can be ready for you or your queued into the system. Then you just sit in the waiting room and you go in and you purchase your medicine."
>
> "I feel like I'm finding a reason to go just because the staff is really nice, so it's a pleasant experience. It's usually pretty quick and easy too... I really like what they do for veterans, so that's something that I'm very appreciative."
>
> "People are nice. They're friendly. You tell them what you want, and they get it. They ring it up, but you have to pay cash for it. Can't use a credit card."
>
> "Now the dispensaries are starting to do a group meeting once a month where people can come in and talk, and share stories, and ideas, or like maybe try this, maybe try that. So, it's getting better. Well, we crawled through this program, I mean crawled."

Dispensaries are also providing medical marijuana patients with the information that the doctors prescribing medical marijuana failed to give them.

> "Some are very knowledgeable and very helpful and then there are others that it seems like it's just a job for them and they don't care one way or the other."
>
> "I guess other than their lack of knowledge, it's always good. I go and get what I need and gave them all of my money and leave."

> "The doctor, not as much, but the dispensaries are really good about providing information, counseling some things when you get the product, and also they're willing to explain everything to you."

The largest complaint from participants was that the dispensaries tend to run out of stock. Participants expressed frustration as many times their preferred products were unavailable.

> "I've found that their inventory tends to run low a lot." "At first, it was difficult because there were so many people and they ran out of product a lot." "In general, it's pretty good. The only problem I run into is they always run out of stuff." "I always call ahead and ask if they have it. I'm not gonna drive 45 minutes on a "I wonder if they're gonna have it." "They're constantly out of stuff, though, every time you go, they're out of stuff, and you got to be down there right when their delivery gets there." "So, they run out of their stock quite frequently."

Individuals that were some of the first to sign up for the program described the process of obtaining their medical marijuana card as difficult and frustrating.

> "The state refused my photo the first time, they rejected it, which was a passport photo that was taken at the post office. They rejected it. I had to resubmit the application and a new photo and then it was approved after that. It took me every bit of four months."
>
> "Oh, mine was very tedious, like at the beginning. It took three months to get it. I had to fill out the application and mail it in, I had to mail a check or money order, I had to send two passport photos in... Well now you can pay online, they extract your driver's license photo, so you don't have to do anything with that, and you can complete everything online and sign and pay online. So, it's taking 10 sometimes only five days, and you're getting your temporary card in the email, then you can go to the dispensary"

Participants that started later in the program described it as more accessible as the process has been moved completely online; "That was easy. It was all online." Participants that initially had a difficult time later talked about how the process has changed and is more accessible; "I think it's even more accessible now than it was."

Travel

Participants were also asked how using medical marijuana affected them in their daily lives (i.e. running errands and going to work. A couple of participants discussed how they scheduled their errands around their medical marijuana use.

> "The thing there is when I use medical cannabis, I do not and will not drive."
>
> "It's not preventing me from doing anything. If I know I'm driving, I usually try not to take it just in case I should get pulled over for some reason."

Other participants discussed how it did not affect them at all, because they were using CBD and not THC cannabis products, so they were never "high."

> "It doesn't affect me at all... It's not like I don't know what I'm doing or what's going on. It's not like getting drunk. It's not like you're jumping into your car and you're wasted on wine or something."
>
> "It's absolutely getting me out of the house. And start working in my yard, and start working in the garden, and being able to go and do stuff... Absolutely just day and night, to being on opiates to going to medical marijuana. Absolutely. 100%. I'd lay around the house sometimes so depressed, and so wigged out from all the chemicals, I wouldn't even take showers for four or five days. Not even get out of my pajamas. Not even leave my house."

The use of medical marijuana had more of an impact on participants when it came to the workplace. A couple of participants considered it a non-issue.

> "It actually makes me feel safer because I illegally used cannabis for a few years, and I risked my job and . . . but I couldn't not do it, because I was in so much pain."
>
> "Well, at first, I was really wary about even letting them know about it, but then I found out that my company secretly started supporting it two years ago."

Many participants expressed fear of losing their job when thinking about having to tell coworkers and when having to look for another job.

> "I am afraid that they would judge me, even though I do an amazing job and they love me and I've been there. I don't want them to judge me on the fact that I have to use cannabis as my medicine... I don't want to lose my job."
>
> "Difficult, for sure. I mean, I still have the job I've had all along. So, with my current position it's a non-issue... But I'm in the process of looking for other jobs also, and that's something that's a concern of mine because I may need to go a month without the medicine so that I can possibly pass a test if that's necessary, especially with my degree, I'm sure at some point, unless things change, I'm gonna have to pass a test and pull off cannabis during that time period."
>
> "Well, some people I know it's affecting. They're having to hide it, or they're afraid their companies are going to let them go or fire them. My brother had trouble finding a job. He's got one now that didn't care. I have a buddy, he wants to get his medical marijuana card but won't get it because he's afraid they'll take his weapons away from him."

When asked about traveling out of state with medical marijuana, a couple of participants said they would travel with their medical marijuana, but not their recreational marijuana.

> "It's like American Express. I never leave home without it."
>
> "No, not right now because, I mean the product that I use, I'm not bringing flower, I vape but people think it's a vape cigarette, it doesn't smell, it has no marijuana odor at all. And the distillate doesn't smell, and I just put that in my suitcase. And check my bag."

Most participants said they would not travel with their medical marijuana in fear of getting into legal trouble.

> "I'd be terrified to step over the state line if I have marijuana with me. I don't know. A lot of people say they travel with it. You just take a chance I guess... I don't want to end up behind bars at my age."
>
> "I'm not going to take my medicine with me, I'll just have to wait until I get there and buy recreational marijuana there."
>
> "Well, I left it here. I didn't take it with me... I went to Pennsylvania. I wasn't sure whether they allowed medical marijuana, so I wasn't gonna have TSA find my vape pen and arrest me. I called the airport and asked them, and they said "Well, it depends on the TSA officer. You might get arrested." And I said yeah, okay."
>
> "I'm petrified to go out of state with my medical marijuana. I go to the casinos, I don't take it with me there, because it's illegal there... going from state to state with it is still illegal, and to use, I mean I've taken it, but I've been panicked the whole time that if I got in a wreck, or got pulled over, and it was found in my vehicle, what would happen to me... Well I would love to travel more if I could take my medicine with me."

Quality of life

Despite the barriers that the participants experienced personally, socially or within their communities, all the participants expressed how much medical marijuana has improved their quality of life and gave them relief from years of chronic pain. Quality of life can be defined as "an individual's or a group's perceived physical and mental health over time" (CDC, 2018).

> "My attitude is better. I still have some pain issues, but my wife says I'm not grumpy anymore, I tend to be in more of a happy mood. I think its mood elevation. I feel better, so my attitude is better. My pain levels during the day are diminished somewhat, are under control at least... When I was taking the pills and opiates, I was lethargic, I didn't want to move, I didn't want to do anything. At least now I want to do things. I want to go out and be active, I want to go out and walk. Unfortunately, I'm limited in how much of that I can do, but at least I have the will to walk and that's important."
>
> "It's affected my quality of life to where I wanted to work more."
>
> "I would cry almost to sleep, because the pain was unbearable... I guess I thought I was heading that direction [suicide], but the pot has actually helped me, and the stress has gone bye-bye. There's no stress in my life no more, very little."
>
> "It's enhanced it to where I don't have to rely on opiates to maintain the pain that I have. It makes me more functionable. It's also made me healthier in a way because as someone, who's always been overweight. I don't take medications for anything to maintain my current lifestyle. Nothing."
>
> "It's affected it in a positive way. My mood is much better, and the pain is subsided and I'm getting my sleep, which is really important to me."

> "Not everybody is that strong, because there's you know, years of chronic pain, what it does to you. I mean it really destroys you, it's horrible... I would never have gotten off chemicals if it hadn't been for medical marijuana. I would still be in pain management, eating two, 300 pills a month, killing my liver, killing my kidneys. Changed my life."
>
> "My overall state of life. My overall mood. The cannabis helps everything that I have wrong with me. Everything. I mean, it helps me in every aspect of my life. That's not an exaggeration."

Discussion

Results from the WHODAS 2. 0 revealed that individuals' overall level of functioning ranged from mild to severe impairment, with the majority of participants having moderate impairment (Figure 5 & Table 4). Across the six domains, impairment ranged from no impairment to extreme/cannot function (Table 5). Cognition scores ranged from none to moderate, with the majority of participants having none to mild cognitive impairment. Mobility scores ranged from mild to extreme/cannot do, with the majority having extreme impairment. Self-care ranged from none to severe, with the majority of having none to mild impairment. Getting along scores ranged from none to mild, with the majority having no impairment. Participation scores ranged from none to extreme/cannot do, with the majority having mild impairment. Life activity scores ranged from mild to extreme/cannot do, with the majority having moderate impairment. Overall mobility followed by life activities and participation had the greatest level of impairment. Results from the direct content analysis further corroborate the results from the WHODAS 2.0 as many participants described having limited mobility that affected them not only in their daily life activities but participating in other community and societal functions.

Table 4

Overall WHODAS 2.0 Scoring Summary

	None	Mild (1-11)	Moderate (12-23)	Severe (24-35)	Extreme or Cannot Do (36-48)
Number of Participants	0	3	5	2	0

Results from the direct content analysis revealed that medical marijuana use had a positive health outcome when used in the treatment of chronic pain. Participants described their use of medical marijuana as "life changing" as many personally found that medical marijuana was the only form of relief for their chronic pain. Although randomized control trials show that medical marijuana is limited in its therapeutic benefits, results from this study contradict those findings (National Academies of Sciences, 2017; Stetten et al., 2020). Along with chronic pain relief, participants described that medical marijuana helped them in treating other health conditions (e.g. depression, PTSD, spasticity, insomnia), albeit evidence from clinical trials. As medical marijuana is seen is being touted as a "miracle drug," these results could simply be the result of a placebo effect. As medical marijuana research among human participants is limited, these results could show the potential medical marijuana has

Table 5

WHODAS 2.0 Domain Scoring Summary

	None	Mild (0.1-1.0)	Moderate (1.1-2.0)	Severe (2.1-3.0)	Extreme or Cannot Do (3.1-4.0)
Cognition	4	5	1	0	0
Mobility	0	3	2	2	3
Self-Care	4	4	0	2	0
Getting Along	6	4	0	0	0
Participation	1	4	1	3	1
Life Activities	0	3	4	2	1

for treating other health conditions outside of epileptic seizures, patient-reported spasticity in multiple sclerosis, nausea and vomiting from chemotherapy (Stetten et al., 2020).

Along with finding relief from the pain many participants also found reprieve from their addiction to opioids. These results are specifically important as the US is currently facing an opioid epidemic. In 2016, opioids killed more than 42,000 individuals, with 40 percent of deaths being from prescription opioids alone (CDC, 2017). It is currently estimated that 2.1 million individuals suffer from an opioid use disorder (HHS, 2018). Research is beginning to show that as recreational and medical marijuana have been legalized, opioid related deaths, hospitalizations and overall use have significantly decreased (Boehnke et al., 2016; Livingston et al., 2017; Powell et al., 2018; Shi, 2017). With increased legalization also comes concerns as marijuana does have negative short and long-term side effects such as breathing problems (specifically from smoking marijuana), increased heart rate, Cannabinoid Hyperemesis Syndrome, temporary hallucinations, and paranoia, and the worsening of symptoms in patients with schizophrenia (NIDA, 2018)(NIDA, 2018). Despite these negative side effects, when comparing the side effects of cannabis to opioids, cannabis appears to be a safer method for treating chronic pain and could be seen as an appropriate harm reduction approach for opioids. Along with abstaining from opioids many participants also described being able to eliminate other types of medications, to where medical marijuana was their only prescription drug currently being used. A few participants used recreational marijuana in conjunction with medical marijuana, as they felt that the CBD alone did not treat their chronic pain.

Results also revealed that many participants personally sought out medical marijuana, despite their general practitioner (GP) not being cannabis friendly. Many described positive relationships with their GP's, and that they were supportive of them trying medical marijuana for treatment as no other forms of treatment were currently working. GP's that were described as not being cannabis friendly, even showed interest in the health outcomes of the patients as the pursued the use of medical marijuana. The largest form of support described from participants was from family and friends. Family members that showed initial hesitation, eventually fully supported participants when they saw how effective medical marijuana was at treating an individual's chronic pain. Participants talked about how the "stigma of marijuana was lifted" when their friends and family members saw how much it was improving their overall quality of life. According to the literature, social support has a significant impact on health outcomes. Therefore, the increased social support participant's experienced from family and friends, could be a reason that participants experienced health benefits outside the medical marijuana treatment of their chronic pain (Reblin & Uchino, 2008; Wang et al., 2003).

The largest barriers experienced by participants were the cost of medical marijuana, knowledge provided by medical marijuana physicians, dispensary locations and stock, and fear of traveling out of state. Participants spent anywhere from 200 to 1800 dollars a month on medical marijuana. Many described how they had to cut back on other things in their lives to be able to afford medical marijuana. Even though they had to cut out other things in their budget, participants deemed it worthwhile as the relief medical marijuana brought them was described as "priceless." Participants also expressed how they were disappointed in the medical marijuana physicians in Florida, as many of them could not give them general knowledge on medical marijuana or how to use it correctly at the time of their first appointments. Participants circumvented this barrier through their social networks. These networks consisted of family and friends, but mostly from individuals they met via social media, predominantly Facebook. They described Facebook as a place where individuals not only share their experiences on how medical marijuana has helped them but also a place to see what has worked and what products haven't worked for those with similar health conditions.

Participants also listed dispensaries as another place to find information on medical marijuana and how to use various products. Participants described an overall positive experience when discussing dispensaries, except when it came to the location of dispensaries and the overall number of products each dispensary had in stock. Many participants had to travel a fair distance (30 minutes to an hour) to dispensaries, as many are in large urban hubs. Dispensaries have begun to bypass this barrier to individuals by offering at home delivery for a small fee or for free. The only barrier dispensaries have been unable to address are that of the amount of stock they can hold at one time. Many participants complained on how the dispensaries were "always running out of stock." This barrier was elevated when participants had driven a long distance to return home without the product that worked best to treat their chronic pain. Finally, participants experienced a considerable barrier in accessibility, as marijuana is federally illegal, many participants were too afraid to travel out of state with medical marijuana.

Implications for Life Care Planning

As of February 2022, 37 states and the District of Columbia (DC) have legalized the use of medical marijuana (ProCon.org, 2022). According to Lusk and Rutherford Owen (2017), as states continue to legalize medical marijuana and evidence demonstrates the benefits of its use, further training is necessary in the advancement of life care planning. Additionally, due to the opioid epidemic, pain management plans should include alternatives to traditional pharmacologic options including medical marijuana (Albee & Penilton, 2019).

Results of this study reveal numerous implications for recommending medical marijuana within a life care plan. Each theme identified through the qualitative analysis reveal considerations for life care planners when developing their plans. Table 6 depicts the relationship between the themes identified within the results section above and their impact on the life care planning process. As evident in the table, participants reported many examples of how medical marijuana has positively impacted their functioning while managing pain.

Table 6

Linking Results to Life Care Planning Consideration‘

Theme	**Participant Example(s)**	**LCP Consideration**
Health Impact	"It's enhanced my functionality. . . " "I actually still have most of those prescriptions. . . I think it was kind of like a safety net for me, but I don't need them. . . I'll maybe just get rid of them, yeah."	Evaluations, Routine Future Medical Care, Vocational Implication, Recreation Recommendations, Attendant Care, Therapeutic Modalities, Medications
Cost	"It's probably right around 200 a month." "It costs me about 4-500 dollars a month. . . ." "Over 600 a month. . . "	Medications, Evaluations, Routine Future Medical Care
Quality of Life	"My attitude is better. I still have some pain issues, but my wife says I'm not grumpy anymore, I tend to be in more of a happy mood. I think its mood elevation. I feel better, so my attitude is better. . . . . . . When I was taking the pills and opiates, I was lethargic, I didn't want to move, I didn't want to do anything. "It's affected my quality of life to where I wanted to work more."	Therapeutic Modalities (individual/marriage/family counseling), Leisure/Recreation Activities, Evaluations, Routine Future Medical Care, Medications, Vocational Recommendations
Social Support	"I have that are really accepting of it and a few that are not very accepting of it . . . They're starting to come around a little bit more now that they see how it's changing my life." "There's quite a few marijuana Facebook groups that people education themselves. We're relying on self-education because doctors and the dispensaries are all freaking clueless."	Intake process, Education, Evaluations, Therapeutic Modalities (Group Therapy, (Family System Therapy), Vocational Implications, Recreation/Leisure Activities

Continued on next page

Table 6 – continued from previous page

Theme	**Participant Example(s)**	**LCP Consideration**
Accessibility	"They're getting more accessible. Originally, I was having to have it delivered, but now within a month or so there's one right around the corner from me and then the one that I normally drive to is a 30-minute drive."	Transportation, Medication Needs

Due to the multidimensionality and dynamic nature of the life care plan, any impact on individual's level of disability can affect other areas of a life care plan. Results of this study illustrated how several participants reported positive impacts on overall health due to medical marijuana and decreased opioid use. This included enhanced physical functioning, increased social engagement, ability to participate in more activities, better eating habits, and ability to explore vocational options. With changes in disability due to the positive impact of medical marijuana use, life care planners need to consider addressing multiple areas of the life care plan. These authors have provided potential areas that could change if medical marijuana was recommended within a life care plan (Table 6).

Previous literature on life care planning has focused on the potential and impact of medical marijuana as a treatment option for people with disability (Albee & Penilton, 2019; Lusk & Rutherford Owen, 2017). Although this article is the first to provide empirical evidence demonstrating the positive efficacy of medical marijuana and associated implications for life care planning, it should be noted that this study is exploratory in nature. Study findings demonstrate the importance of gaining knowledge about medical marijuana as a treatment option for people experiencing chronic pain and applying such knowledge to the process of life care planning. This applies to dialogue with clients during the intake process, communication with health care providers, and making recommendations within the life care plan.

Limitations

One limitation to the study is the sample size associated with the WHODAS data. The WHODAS can be used to describe the level of disability in a population and to validate the specific tool among a specific population. As this study was only looking for the level of disability and not to validate the tool among patients with chronic pain, a small sample size is appropriate. Another limitation with the small sample size of the study, is that is not considered generalizable. However, the concept of generalizability is not valid for qualitative research, but rather validity is captured through saturation (Hsieh & Shannon, 2005). Another limitation is that the sample was only taken from chronic pain patients living in Florida. It is possible that results might change depending on states due to regulations and the legalization of recreational marijuana. Finally, selection bias may have occurred within the sample. Many of the participants were strong advocates of medical marijuana that may have biased the results to show medical marijuana in a more positive light.

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Ethics Interface

Nancy Mitchel[1]
[1]Mitchell Disability Assessments

This column is the collaborative effort of Nancy Mitchell, Mary Barros-Bailey, Sherry Latham, Ann Neulicht, and Bobbi Dominick. The author is grateful for their editorial support, wisdom, and collective experience.

The column is meant to be an educational forum for life care planners. It is not designed to offer an authoritative opinion from the editor or editorial board of the Journal of Life Care Planning, the board of the International Academy of Life Care Planners, or the board of its parent organization, the International Association of Rehabilitation Professionals, nor is it designed to represent or replace official opinions from the certifying body of other organizations associated with the practice of life care planning.

Dilemma

I recently participated in a research project with several people, and we want to publish the findings in our professional journal. One of the senior members of the group thinks the authors should be listed alphabetically, but individual efforts varied greatly. I invested a lot of time in the project and my name falls at the end of the alphabet. Are there ethical standards that address this issue?

Response

There are many ways one may contribute to research and the publications of the findings, and some activities are far more time and labor intensive than others. Journals vary in their approach and publication protocol, so one needs to know the procedures of the particular journal. Certain journals may mandate an author's CRedIT (Contributor Roles Taxonomy), which allows for detailed information on each author's contributions. It is expected that all contributors will have reviewed and approved the submission for accuracy. Other journals require written confirmation that all authors take responsibility for the contents of the submitted work.

The ethical standards from all our professional codes emphasize justice, beneficence, and honesty. However, the Commission on Rehabilitation Counselor Certification. (2017) code of professional ethics for rehabilitation counselors addresses this issue directly; the exact standards are listed below but in summary it states this issue should be dealt with in advance and principal contributors should be listed first.

From the Commission on Rehabilitation Counselor Certification (CRCC) Code of professional ethics for rehabilitation counselors (Commission on Rehabilitation Counselor Certification, 2017)

I.2. Rights of Research Participants

- h. Agreement of Contributors. Rehabilitation counselors who conduct joint research establish agreements in advance regarding allocation of tasks, publication credit, and types of acknowledgment received, and incur an obligation to cooperate as agreed.

1.4. Research Publications and Presentations

- d. Contributor(s). Rehabilitation counselors give credit through joint authorship, acknowledgment, footnote statements, or other appropriate means to those who have contributed significantly to research or concept development in accordance with such contributions. Principal contributors are listed first and minor technical or professional contributions are acknowledged in notes or introductory statements

International Academy of Life Care Planning Standards of Practice (International Academy of Life Care Planners, 2015)

III. Standards of Performance

2 The life care planner shall practice in an ethical manner and follow the Code of Ethics of his or her respective professions, roles, certifications and credentials.

Measurement Criteria:

- a. Follows the Code of Ethics for his or her profession.
- b. Follows the Code of Ethics for his or her professional roles, certifications, and credentials.

From the CDMS Code of Professional Conduct (Certification of Disability Management Specialists Commission, 2019)

Preamble Certified Disability Management Specialists (certificants) recognize that their actions or inactions can either aid or hinder clients in achieving their objectives, and they accept this responsibility as part of their professional obligation. Certificants may be called upon to provide a variety of services and they are obligated to do so in a manner that is consistent with their education, formal training, and work experience. In providing services, certificants must demonstrate their adherence to certain standards. The CDMS Code of Professional Conduct (Code) has been designed to achieve these goals. . . .

The fundamental spirit of caring and respect with which the Code is written is based upon five principles of ethical behavior. These include autonomy, beneficence, nonmaleficence, justice, and fidelity, as defined below:

Autonomy: To honor the right to make individual decisions. Beneficence: To do good to others. Nonmaleficence: To do no harm to others. Justice: To act or treat justly or fairly. Fidelity: To adhere to fact or detail.

A code of professional conduct cannot guarantee ethical behavior. Moreover, a code of professional conduct cannot resolve all ethical issues or disputes or capture the richness of complexity involved in providing professional input within a moral community. Rather, a code of conduct sets forth values, ethical principles, and ethical standards to which professionals aspire and by which their actions can be judged. Disability management specialists' ethical behavior should result from their personal commitment to engage in ethical practice. The Code reflects the commitment of all disability managers to uphold the profession's values and to act ethically. Principles and rules of conduct must be applied by individuals of integrity who discern moral questions and, in good faith, seek to make reliable ethical judgments.

Rules of Professional Conduct Section 1 – Relationship with All Parties RPC 1.09 – Reports Certificants shall be accurate, honest, unbiased, and timely in reporting the results of their professional activities to appropriate third parties.

RPC 1.12 – Misconduct Certificants shall not engage in professional misconduct. It is professional misconduct if the certificant: c. engages in conduct involving dishonesty, fraud, deceit, or misrepresentation. . .

From ICHCC-Practice Standards and Guidelines (International Commission on Health Care Certification, 2020)

Principle 1 - Professional and Legal Standards ICHCC certificants shall behave in legal, ethical, and professional manner in the conduct of their profession, maintaining the integrity of the Code of the Professional Ethics and avoiding any behavior which would cause harm to other entities and/or individuals.

Rules of Professional Conduct:

> R1.4 ICHCC Certificants shall not engage in any acts or omission of a dishonest, deceitful, or fraudulent nature in the conduct of their professional activities.
>
> R1.5 ICHCC Certificants shall understand and abide by the Principles and Rules of Professional Conducts which are prescribed in the Code of Professional Ethics.
>
> R 1.6 ICHCC Certificants shall not advocate, sanction, participate in, and cause to be accomplished, otherwise carry out through another, or condone any act, which the ICHCC Certificants are prohibited from performing by the Code of Professional Ethics.
>
> R1.9 ICHCC Certificants shall not write, speak not act in ways that lead others to believe Certificants are officially representing the ICHCC unless such written permission has been granted by the ICHCC.

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- Publish materials which will add to the growing literature base of the practice of life care planning.
- Provide the professional field with information regarding events and developments important to the practice of life care planning.
- Provide a forum for the debate and discussion of practice issues.
- Promote professional practice by addressing issues relevant to certification, ethics, standards of practice and research methodologies.
- Promote advanced practice through the publication of preapproved continuing education feature articles.

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Submission of articles and manuscripts consistent with the objectives of the Journal are welcome. In the preparation of any submission to the *Journal*, please carefully consider the following:

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