

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, Care-giver 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

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 evaluatee 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 evaluatee 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/ Aides (HHA)	Personal Care			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 health-care practitioner, home health aides may be allowed to give a client medication or to check the client's vital signs. (2021a)
Certified tants/Aides (CNA)	Nursing	Assis-		Y	provide basic care and help patients with activities of daily living. (2021c)
Licensed (LPN)	Practical	Nurses		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, <i>Occupational Outlook Handbook</i> , 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 & Karmann, 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 evaluatee'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 is 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			
					HHA			
	Comments:							
2						Regular	Longer Duration	24hr./Live-in
					RN			
					LPN			
					CNA			
					HHA			
	Comments:							
3						Regular	Longer Duration	24hr./Live-in
					RN			
					LPN			
					CNA			
					HHA			
	Comments:							

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	
<i>Adapted from AAPOR.org REVISED Response Rate Calculator V3.1 2009</i>	

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.

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

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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