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Cultural Experiences and International Practices of Life Care Planners: Results of an Exploratory Research Study

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Abstract

An exploratory study of the multicultural and cross-cultural experiences of life care planners identifies common themes in the areas of communication, access/use of medical or other health systems, and the role of the family. Themes specific to other areas of multicultural or international practice were also identified. Implications for practice, professional development, and future research are discussed.

Keywords: Culture, Multicultural, International, Diversity, Life Care Planning

National and International Issues in Life Care Planning

For this research, culture was defined as "any unit of people in any society or region that share beliefs, lifestyles, ethnicity, or customs in common" (Barros-Bailey, 2017). Culture could be contained within national borders or extend internationally. This research sought to explore the issues of culture and international practice as well as themes for life care planners nationally and internationally.

Virtually nothing is known about how culture impacts life care planning practice, regardless of whether the plan was developed within or across national borders. In 2008, the Life Care Planning Summit considered a consensus item that stated, "… life care planners may utilize literature to become familiar with and update current knowledge on the evaluee's diagnosis, population, and cultural background" (Preston, Pomeranz, & Walker, 2008, p.56), but it does not appear to have been adopted (C. Johnson, personal communication, November 16, 2016). The updated *Standards of Practice for Life Care Planners* states, "The life care planner considers cultural and linguistic factors that may influence the assessment, development, and implementation of the plan" (IALCP, 2015, p.34). More recently, religious traditions and beliefs as cultural considerations for life care planners were addressed in the literature (Cosby, 2016). These general references to culture reflect the full extent of what was found (Barros-Bailey, 2017).

Life care planning practice internationally garners about the same lack of attention in the literature. Between the 2001 and 2009 *Life Care Planning Survey: Process, Methods, and Protocols* (Neulicht, et al., 2002; Neulicht, Riddick-Grisham, & Goodrich, 2010), a very subtle, but important, additional question was added to the questionnaire. In 2001, the researchers asked if the life care planner provide services at a local, regional, or national basis. By 2009, the questionnaire expanded the response options to include international services and found that over 11% of respondents developed life care plans internationally over the preceding five years (Neulicht et al., 2010). A cursory review of case law over the last two decades also found instances of life care plans developed for international locations, such as Mexico *(Banuelos v. Secretary of the Department of Health and Human Services, 1990; Martinez v. P.J.'s Lumber, Inc.,* 2009), Nicaragua *(Royal Caribbean Cruises, Ltd. v. Cox,* 2011*),* and the Philippines *(Aggarao v. Mol Ship Management Company, LTD*, 2012) to name a few.

Diversity of religion and ethnicity are but two examples of groups within the national or world population that are often considered when the topic of culture arises. With religious affiliation, the most recent data collected by the United States [U.S.] Census was in 2008. That year, the U.S. population was just over 304 million (U.S. Census, 2017c). That same year, the agency's *American Religious Identification Survey* estimated that of the 228 million adults in the country, 76% identified themselves as Christian belonging to more than 30 denominations; 4% identified themselves as Jewish, Muslim, Buddhist, Unitarian/Universalist, Hindu, Native American, Sikh, Wiccan, Pagan, Spiritualist, or other religions; about 15% identified as having no religion; while 5% refused to answer. Even accounting for those who did not report having a religion or who refused to answer, well over 60% of the entire U.S. population are thought to ascribe to a religious belief system; and this identity plays a part in the development of a life care plan. Understanding if or what impact someone's religious beliefs may have from the start of the evaluation to the final recommendations may impact the validity of the plan itself. Cosby (2016) cited some practical points to keep in mind when developing life care plans for individuals from various religious cultures.

Ethnicity is often the topic many people first affiliate with culture. Whether domestically or foreign born, the U.S. continues to growth ethnically more diverse with the Hispanic and Asian populations experiencing the fastest growth (U.S. Census, 2011). Between the decennial census in 2010 and to the writing of this article in the spring 2017, the population of the U.S. grew by nearly 16 million inhabitants, with a birth every 8 seconds, a death every 12 seconds, and an international migrant every 33 seconds (U. S. Census, 2017a).

Some of these migrants come to visit (called non-immigrants), and some come to stay (called immigrants). In either state of migration, diversity continues to describe the U.S. In 2016, the U. S. Department of State issued nearly

10.4 million non-immigrant visas, almost double the 5.8 million visas issued in 2009 (U. S. Department of State, 2017c). By continent and starting with the three highest country rates, the most non-immigrant visas were issued by the U.S. Department of State (2017c) to:

- Africa: South Africa, Nigeria, and Egypt
- Asia: India, China (mainland and Taiwan), and South Korea
- Europe: Russia, Poland, and Great Britain/Northern Ireland
- North America: Mexico, Jamaica, and Dominican Republic
- Oceania: Australia, New Zealand, and Tonga
- South America: Brazil, Colombia, and Argentina

On the other hand, immigrant visas to the U.S. in 2016 totaled nearly 618,000, up by 30% from a decade earlier (U. S. Department of State, 2017c). Again, by continent and the three highest country rates, in 2016 the U.S. Department of State (2017a) documented immigrants came from:

- Africa: Nigeria, Ethiopia, and Ghana
- Asia: China (mainland and Taiwan), Philippines, and India
- Europe: Ukraine, Albania, and Great Britain/Northern Ireland
- North America: Mexico, Dominican Republic, and Haiti
- Oceania: Australia, Fiji, and New Zealand
- South America: Colombia, Ecuador, and Peru

Either among the permanent or transitory population living in or migrating through the U.S., accidental events or incidences occur that could impact a single person or a cohort of individuals from any culture. With the accelerating diversity of the U.S., the probability that a life care planner will have increased multicultural or cross-cultural experiences in practice is likely. The numbers depicting the tremendous diversity of just two slices of the population (religion and ethnicity) clearly illustrate how under studied this topic is in the field of life care planning. It is time for the literature to start addressing the different facets, issues, and considerations of culture.

Purpose of the Study

The purpose of the study was to answer the question: What experiences have life care planners had with culture in life care planning services? This question was designed to collect data to understand some of the broad multicultural and international experiences of life care planners to contribute to the understanding, advancement, and practice of multicultural and cross-cultural considerations in the field.

Methodology

The question this research sought to examine is exploratory in nature because it seeks to study something we know little about. Exploratory research necessitates a qualitative research design (Marshall & Rossman, 2016) that empirically generates initial themes for areas of further study. Whereas quantitative data measures information with numbers, qualitative data measures it with words. For quantitative research to be meaningful, it must rest upon empirically-based themes that typically derive from qualitative research or theories.

Therefore, in spring 2016 an online qualitative survey was developed and disseminated through a variety of online professional listservs where life care planners typically participate including the Care Planner Network, American Association of Nurse Life Care Planners, and International Association of Rehabilitation Professionals/Life Care Planning Section. The purpose of the survey was to minimize respondent burden by collecting data in a brief five-minute survey administered over four weeks specific to the desired research question.

Instrumentation disclosed and informed respondents of their voluntary participation in the anonymous survey, and included three qualitative questions:

1. Over the last three years, please estimate the number of life care plans you completed in the following categories: Multicultural [definition provided], Cross-cultural [definition provided]
2. Please describe up to three differences that you found in developing life care plans where there were multicultural or cross-cultural considerations.
3. If you performed a life care plan cross-culturally, please identify in what country(ies) and/or subculture(s) within that country.

The instrument also collected demographic data about the respondent's credentials specific to life care planning, years of experience, and primary geographical region of practice.

Data Analysis Procedures

Coding of the qualitative data was the method of analysis for the responses received to the survey. Because most of the responses were short phrases or sentences, and not long narratives or paragraphs, there was no need to go beyond exploratory coding (Saldaña, 2009) to greater depths of first or second cycle coding. Themes easily emerging from the collected data and, in some themes, being repeated across the respondents.

Results

A total of 26 responses were received. While in quantitative research, a power analysis is used to estimate a sample size sufficient to ensure a degree of confidence in the data, in qualitative research the metric is data saturation (Glaser & Strauss, 1967) where additional data do not contribute more themes or information to the analysis. Therefore, sample size in qualitative research bases itself not on the *quantity* of the responses, but the *quality* and depth of those responses resulting in the repetition of concepts and themes based on a constant comparison coding of the narrative. Of all responses, 22 were complete in all sections of qualitative survey and analyzed, while four terminated the survey prematurely and were discarded from the data analysis. The respondents were experienced, with the largest

group having between 11-20 years of life care planning experience (40.90%), followed by 21-30 years of experience (27.27%). New entrants into life care planning, those with fewer than 10 years of experience, represented the third largest group of respondents (18.18%), while those with the most experience, (over 31 years) repreented the smallest group (13.65%).

Although the survey was disseminated to sources across multiple professions, including dissemination to life care planners outside the U.S., respondents were only U.S.-based. The largest group of respondents were from the South Atlantic and Mid-Atlantic region (n=4, 18.18% each), followed by the Midwest/West North Central, West South Central, and Mountain areas (n=3, 13.64% each). The last two areas of respondents were from the Midwest/East North Central and Pacific regions (n=2, 9.09% each). One respondent (4.54%) indicated being from an Other region rather than choosing the geographic selections on the survey (U.S., Canada, and Ireland), but did not specify from where. There were no respondents from New England, East South Central, U.S. Territories areas, or from outside the U.S.

With respect to credentials, the most common certification was that of the Certified Life Care Planner (n=13, 59.09%) held by half the respondents, followed by the Certified Nurse Life Care Planner (n=6, 27.27%). Two life care planners indicated the Certified Case Manager was their primary credential specific to life care planning (9.09%). Each of the following received a response (4.55%): CAPS, CDMS, CRRN, LNCC, and LNCPC. Totals do not add to 100% because some respondents held multiple credentials.

Content Analysis of the Data

Respondents identified developing 162 life care plans in the past three years (2013 to 2016) where the evaluee came from a different culture than the planner's and multicultural or cross-cultural issues were a consideration during the development of the life care plan. Those who provided life care planning services internationally during that period noted these to be in the following countries: Australia, Brazil, Cambodia, Costa Rica, Cuba, England/UK, Germany, Honduras, India, Italy, Japan, Laos, Mexico, Pakistan, Peru, Russia, and South Africa. Two respondents reported developing life care plans in the Caribbean, but did not specify the countries served.

The study clustered into three thematic categories: 1) common considerations whether the case was developed nationally or cross-culturally; 2) themes more prevalent in a multicultural environment; and 3) themes more prevalent in a cross-cultural environment. The respondents seemed to identify culture mainly from ethnic and religious perspectives.

Among Group Themes

The three areas that seemed as equally widespread nationally and internationally were: communication; access/use of medical, mental health, or related care; and the role of the family. Each of these three themes reached the level of data saturation.

Communication

More than half of the respondents identified communication issues as being the predominant multicultural consideration in life care planning. Many these respondents merely identified language differences as a barrier, while others provided greater detail as to how language affected communication and other considerations in the life care plan, (e.g., discussing bowel, bladder, or sexual issues). The more detailed responses identified language barriers affecting the evaluee's ability to access care or the "difficulty in expressing needs to [the] healthcare provider."

Access/Use of Medical, Mental Health, or Related Care

Access to the required or recommended services outlined in a life care plan was considered a common ground theme for those performing life care plans nationally or internationally. Comments mainly clustered in areas of healthcare being different in the evaluee's home country from what is considered mainstream in the U.S. Life care planners described evaluees using nontraditional medications or differing "attitudes toward medicine/aggressive treatment." With therapies, one life care planner cited the "role of alternative modalities" while another noted "religious components to therapeutic modalities." Use of recommended services stipulated in the life care plan was also noted as an area of difference. Some respondents reported a lack of or unwillingness to follow through on life care plan recommendations as a concern. With respect to durable medical equipment or assistive technology, particularly if there is a stigma associated with the item, the evaluee may not use the recommendation, or the item may not be available in the same form (or at all) in another country. How the evaluee or the family perceives mental health or psychological services may also affect the use of those services.

Role of the Family

Family support and care of the evaluee and input into the plan were identified about as frequently as the other two common themes relevant to multicultural and international issues in life care planning. Statements such as, "very strong family units" summarize the tone of the experiences of many life care planners. Differences in "attitudes toward family members caring for patient versus paid help" or the client having a "large family or caretakers and did not want outside help" were identified as areas of attention, while other respondents bluntly stated that the evaluee only wanted the family to provide care. The long-term care of the evaluee by family members as well as "geographic preferences of/for families" driving the decision-making for life care plans were areas for assessment.

Within Group Differences

Beyond the common themes among both multicultural and cross-cultural places of practice, there emerged distinctive themes within each area.

Multicultural Issues in Life Care Planning

Two other areas stood out as significant in multicultural situations: Housing and Other. Each of these areas did not reach data saturation.

Housing

The "pre-injury housing arrangement" was cited by one life care planner as an important area of assessment. Other life care planners were specific to a single cultural unit making statements like, "Hispanic multi-family homes."

Other

A variety of other single responses provided insight to a mix of themes ranging from attitudes to beliefs or affects. Sometimes the evaluee was described as "more dependent and passive." Other times, the level of the evaluee's education was posited as an area of concern. The cultural difference in the evaluee's expectations and coping style received mention by one life care planner; another respondent cited the "reverence for aged." Yet, other life care planners simply provided single-word responses such as "beliefs," "psychosocial," or "shame."

Cross-Cultural Issues in Life Care Planning

Cross-cultural experiences of life care planners were identified in the following thematic areas: Cost Resources, Society, Legal, Providers, and Referral Source Education. Data saturation was reached only in the Cost Resources theme.

Cost resource

The main consideration for those performing life care plans internationally was the practical ability to obtain costs for the life care plan items, particularly in societies where socialized medicine covered many recommendations. Also, identified as a challenge were "differing healthcare delivery systems," presumably presenting challenges to valuing or measuring the costs of the needed care.

Society

Overarching the international life care plan development is the understanding of community or societal priorities that may be different in a country of service than what may be the norm in the life care planner's home country.

Legal

Within a society, attention to the "laws of the particular country/nation" was noted by a life care planner as the most prominent issue in developing a life care plan in a cross-cultural setting. Another respondent succinctly stated, "differences in the legal gestalt affecting service provision." From a more practical standpoint, one respondent described the need to understand the legal mandates governing such practices as disclosure and informed consent, which is a common in practice in the U.S.

Providers

Research within the country of service can be challenged by the unfamiliarity of those providing care to the evaluee as to the purpose of a life care plan. Education of these providers as to life care planning as well as providing their care recommendations within the more-probable-than-not threshold was mentioned in the responses. Other respondents identified that the systems for delivery of care, such as therapies, were sometimes different or involved a variety of providers different from what the life care planner may be accustomed.

Referral source education

Lastly, educating the referral source about the need and value of a face-to-face evaluation and home visit as is common when providing life care planning services in the U.S. country was identified as an area of challenge.

Discussion and Implications

This introductory research exploring the multicultural and cross-cultural experiences of life care planners resulted in three main themes. In communication, life care planners need not only to make provisions to understand the evaluee's language, but also the intent of what is being communicated and its implications for the development and delivery of a valid life care plan. Training to help life care planners develop better and more effective methods of communication in a multicultural or international setting by educational or professional organizations could help increase life care planner competencies and resources in this regard.

Many respondents expressed concern about the evaluees' access to or use of recommended or alternate healthcare services, resources, or technology. Life care planners may need to learn how to navigate the divergence between the recommendations of the mainstream or consulting medical provider and the behaviors dictated by the evaluee's culture. This may determine the need for a creative approach to care to remain within the practitioner's standard of care, to avoid harm to the evaluee, but also respect the evaluee's culture and wishes.

Family was the third theme that arose consistently in both multicultural and cross-cultural life care planning areas. The predominant mention was the family's participation in the care of the evaluee, and often the rejection of care by a non-family member. Whether addressing attendant care, or other issues, considering the role of the family may become more significant in some cases, or in some countries. Awareness of the level of the family's role and involvement may provide insights to the life care planner. For multicultural life care planning, other considerations identified included evaluee housing, education, or societal attitudes.

Those recently developing life care plans cross-culturally identified by respondents as having been completed in the recent past appear to be developed in countries with very different legal, societal, and healthcare systems than exist in the U.S. Comparative literature that includes some legal and cultural differences in the development of life care plans in the U.S. and Canada has begun to appear in the literature (Phillips, 2016). Barros-Bailey (2017) recommends several competency topics that could be helpful to the life care planner, such as

understanding if the society is individualistic or collective. Whereas an evaluee from an individualistic society may respond favorably to life care plan recommendations with a goal of promoting independence, those from a collective society may not respond in the same way. Understanding someone's level of acculturation or enculturation may also be important as it may influence how much the individual identifies with his or her dominant cultural values and the appropriateness of the life care plan recommendations or the probability the advice would be implemented. Just like in the U.S. where it is important to understand the jurisdiction where the life care plan is being developed, this recommendation is no different if the venue is in a different country. A variety of authoritative resources exist that life care planners can use to obtain essential information about a country (e.g., World Bank, U.S. Central Intelligence Agency country reports, U.S. Department of State, embassies of the foreign government). Research regarding those main sources of societal, legal, health and other country profiles could be an important area for study.

In performing services in an international arena, the life care planner may need to take on a greater role as an educator. Those providing services to be incorporated into the life care plan may not know what it is or its purpose and contents, and may need to learn of its use as a tool in someone's current and future care. Referral sources may not always understand or appreciate the importance of adhering to the same evaluation tenets and principals of life care planning across borders as would be expected in the U.S., such as a face-to-face home visits with the evaluee in the country of ultimate residence. Lastly, life care planners reported that finding the sources for determining costs was a practical challenge when preparing a life care plan in another country. Obviously, life care plans are being regularly developed that include associated costs in the home country, and examining the resources used by those preparing the plans could benefit life care planners in the future who may be tasked with the same or similar assignment.

Future Research

Exploratory research is meant to start the discussion on a topic about which there is little known. Because the method requires a qualitative research design, the number of respondents is less of a concern than the quality of responses. In the areas that were common across both multicultural and cross-cultural life care planning practices, data saturation occurred. This was also the case in the cost areas of the international life care planning themes. Each of these themes that emerged intra- and inter-geographically merits substantially more detailed study. Greater depth in each of the themes would be best applied by the practitioner if tools, theories, or methods were offered.

Further, although a cursory review of case law revealed cross-cultural cases spanning a period of 20 years, an area for future research could be the examination of those cases as to the issues addressed by the courts, and resulting decisions.

Valuable to the development of any life care plan are reliable and valid resources. Research projects, directed by those life care planners who regularly work with evaluees in multicultural or cross-cultural environments, could develop a list of resources (e.g. evaluation instruments, costs). The rate of immigrant and non-immigrant mobility into the U.S. from Mexico, China, and India suggests these may be the countries to be researched first with respect to themes identified in this study.

This research was directed towards the life care planner's experience. Almost tacit in their description of those experiences was an underlying question as to the ethical dilemmas in these environments. Therefore, research about the ethical quandaries encountered by life care planners engaged in multicultural and cross-cultural practice along with resources to help the resolution of those dilemmas could enhance professional development of life care planners.

Lastly, methodological frameworks help us conceptualize a case and guide our clinical decision making. Caragonne (2016) developed the first known model for those working cross-culturally in life care planning involving nine stages. Further research on the application of her model, or the use of other new or existing content, process, or hybrid models, could engage the profession in making the issues of our experiences the stimulus for our innovation.

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