In search of lost leisure: the impact of caregiving on leisure travel

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Abstract:
One of the fastest growing market segments of the tourism industry over the last two decades is made up of consumers 55 years of age and older. As we enter the new millennium, over 50 million of these “mature adults” will find themselves on the edge of retirement, equipped with the freedom and financial means to travel, but restricted by a loved one who may become ill or disabled. The purpose of this study was to explore the impact of caregiving on the leisure travel behaviors of family caregivers and their care-recipients. Qualitative data collection and analysis methods were employed. In addition to identifying impediments (physical, social, emotional) to pursuing or maintaining leisure travel for caregivers of older adults, the qualitative analysis yielded other emergent themes such as changes in patterns and types of leisure travel, entitlement, resentment, and anger. Implications and recommendations for researchers and practitioners are included.

Keywords: Leisure travel; Family caregivers; Older adults; Barriers to travel

Article:

1. Introduction

According to the World Tourism Organization (2002), tourism is the world’s largest industry. Prior to September 11, 2001, the growth of the tourism industry had shown virtually no signs of slowing down. For the previous 16 years, international tourism experienced an average growth in revenues of approximately 9% a year. In 2000 alone, international tourism generated $476 billion (US dollars), coupled with an arrival of 698 million international visitors. On the domestic front, the Travel Industry Association of America (TIA) (2000) reported just under 1 billion domestic person-trips in the United States for the year 2000. About 75% of these trips were for pleasure, which indicates a strong market in leisure travel.

With the steady increase of baby boomers moving into retirement, leisure travel shows great potential for continued growth. According to the TIA (2001), in 2000 baby boomers produced the highest travel volume in the United States. This market generated 245 million trips, which was more than any other age group. On average baby boomers spent $479 per trip (excluding transportation to their destination), also more than any other age group. When traveling, approximately 60% of the boomers stayed in hotels and 25% used air travel as their mode of transportation.

Unfortunately, as they age, some baby boomers will find their leisure travel compromised. Additionally, this restriction to travel can be exacerbated by an inconsiderate society and an ignorant or apathetic travel industry. As we enter the new millennium, more than 50 million mature adults will find themselves perched on the edge of retirement, equipped with the freedom and financial means to travel, but restricted by a loved one who may become ill or disabled. Added family care responsibilities and dynamics will compromise these newfound caregivers’ ability to travel freely. Also, their free time and money may be redirected to the home care of an ill parent or spouse.

The National Family Caregivers Association (NFCA) (2000) estimated that 54 million individuals in the United States provide some sort of caregiving. The tourism industry has the potential to meet the needs of this largely
An untapped market of Americans with moderate changes in facilities and practices, plus heightened sensitivity of personnel. This article will address the growth in “mature travelers”, examine the influence of caregiving responsibilities on leisure travel, and discuss methods for providing safe and accessible travel opportunities to caregivers and their ill or disabled family members.

2. Background

2.1. Mature travelers

According to Cook, Yale, and Marqua (2002), one of the fastest growing market segments of the travel and tourism industry over the last two decades is made up of consumers 55 years of age and older. This market has been referred to as the “older market”, the “muppie market” (mature upscale post-professional), and the “mature market” (Allan, 1981; Lazer, 1985; Seelig, 1986).

The US Census Bureau reported that in 2000, there were more than 59 million Americans 55 years of age and older (US Census Bureau, 2000). In addition to the actual size of the mature market, mature adults are living longer. By the year 2030, adults over the age of 65 will number 70 million; twice the number of older adults living in 2000 (Administration on Aging, 2002). Due to its growing numbers, financial means, availability of time to travel, and its diversity, this group is a very attractive market for the United States travel industry.

According to Southwest Airlines, the mature traveler represented 19% of all travelers in the United States and spent an average of 4.9 nights away from home (excluding day trips) which was longer than any other age group. Mature travelers also accounted for the highest share of day trips, at 21%. Similarly, they spent more than any other age group in the United States on outdoor vacations, spending an average of $1300 on their last adventure travel trip. More than half of all mature travelers (52%) stayed in hotels or motels while on their trips, and 43% stay with family or friends. Mature travelers accounted for 32% of all travelers who visited historical sites or museums and also constituted 33% of all cultural travelers in the United States (TIA, 2000).

In addition to the sheer number of older adults that travel, the volume of their discretionary income is significant. The mature travel market spends 30% more than younger travelers and accounts for 80% of all vacation travels. According to Bandenelli, Davis, and Gustin (1991), mature travelers control over 75% of the United States’ disposable wealth. “Where do they spend this abundance of money and time? Research shows that when people retire, the number one thing they say they want to do is travel” (Supernaw, 1985; cited in Blazey, 1992, pp. 771–772).

2.2. People with disabilities as a travel market

As baby boomers age, however, they will experience activity limitations due to chronic health conditions. In 2000, approximately 26.1 % of adults aged 65–74 reported a limitation due to a chronic health condition, while 45.1 % of adults over the age of 75 reported similar limitations (Administration on Aging, 2002).

According to Burnett and Baker (2001), this segment is an untapped travel market. They stated:

Few consumer groups have greater potential and are more ignored than disabled [sic]. Consisting of 50 million individuals in the United States, with discretionary income of over $200 million, this largest of all minority groups has been viewed by many tourist businesses as a source of confusion, requiring extra expenditures on ramps, specially fitted rooms, and loss of prime parking (p. 4).

The Americans with Disabilities Act (ADA) of 1990 was designed to help public accommodations (hotels, restaurants, and other establishments providing goods and services), as well as public transportation, address some of the “confusion” referred to by Burnett and Baker. By using ADA guidelines and support for creating accessible facilities, services, and programs, minimum adaptations are often all that is required to serve this market of people with disabilities. Considering that the number of people with disabilities is expected to double in size by the year 2030 (Lach, 1999), this market segment could become active in the travel industry with the implementation of simple facility and service adaptations.
2.3. Family caregivers as a travel market

Many older adults have chosen to live with family members to accommodate their health and medical needs. In 2000, approximately 70% of older adults who were non-institutionalized reported living with a spouse or others (Administration on Aging, 2002). For those who have chronic health conditions, much of their long-term care is provided in the home by informal family caregivers—family members who provide unpaid care to loved ones. Estimates suggest that anywhere from 25 million (Arno, Levine, & Memmott, 1999) to 54 million (National Family Caregivers Association, 2000) individuals have been involved in some level of care for ill or disabled family members within the last year. The average age of family caregivers is 46 years, however, 12% of the caregivers are over the age of 65 themselves. Additionally, 40% of those providing care are also caring for children in the home (Administration on Aging, 1997). About 70–80% are women, 47% of whom are employed. Of those who were employed, 71% worked over 31 hours per week outside the home in addition to providing family care (NFCA, 1997). Therefore, the added responsibility of caregiving for a working adult who is approaching retirement age is a challenging burden for many.

The daily demands of caring for an ill or disabled family member take their toll on many family caregivers. Due to the stress of caregiving, many caregivers experience myriad physical and psychological disabling conditions (National Family Caregivers Association, 1998). For example, Marks (1996), as well as Gallant and Connell (1998) found that family caregiving negatively affected the caregivers’ own health status and behaviors. Similarly, Meshefedjian, McCusker, Bellavance, and Baumgarten (1998) identified depression as one of the major problems faced by family caregivers of individuals with Alzheimer’s disease. Perhaps most significant are the data that suggest that caregiver burden is related to early mortality. For example, research by Schulz and Beach (1999) identified that family caregivers who experience stress from caregiving are more likely to die earlier than non-caregivers or those not stressed.

2.4. Loss of leisure

In addition to physical and psychological consequences of caregiving, caregivers often compromise social aspects of their lives. Caregivers have described reductions in regular exercise, time for oneself, visiting friends and family, church and club activities, hobbies, relaxing, and time for leisure pursuits (e.g., Bedini & Guinan, 1996; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Silliman, 1993; Wilson, 1990). Additionally, in a national survey of family caregivers in the United States, loss of leisure was identified as one of the top three negative consequences to caregiving (NFCA, 1998).

One of the most missed leisure experiences reported seemed to be leisure travel. For example, Kleban, Brody, Schoonover, and Hoffman (1989) found caregivers reported that caregiving caused interference with vacation plans. Similarly, in a study by Chakrabarti, Kulhara, and Verma (1993), 30% of family caregivers actually abandoned planned leisure activities such as vacations. Additionally, 77% of the families stated that “...the care-recipient’s illness was using up their leisure time, leave, or holidays” (p. 174). Ory et al. (1999) noted that caregivers of individuals with dementia found themselves giving up their leisure, including vacations, because of caregiving responsibilities.

This loss and disruption in leisure travel can cause additional consequences for family caregivers. Lindgren (1996) found that caregivers of spouses with Parkinson’s disease experienced sorrow triggered by restricted social life, hobbies, future plans, and inability to travel. Similarly, Bedini and Guinan (1996) found that female caregivers felt particularly resentful for having to give up travel and vacation opportunities as a result of caregiving. Also, the Caregiver Strain Index (Robinson, 1983) has specific questions about travel loss as indicators of strain for this population.

2.5. Motivations and barriers to travel

Tourists are at the heart of the travel and tourism industry. If the industry continues to grow as projected, it is imperative that tourism professionals who are responsible for serving the tourists understand their needs and behaviors. Over the last several decades a significant amount of research has focused on understanding why individuals travel and how they reach specific travel decisions (e.g., Guinn, 1980; Hagan & Uysal, 1991;
McIntosh, 1980; Pearce, 1991; Plog, 1974; Ritchie, 1975; Schewe & Calantone, 1978; Zimmer, Brayley, & Searle, 1995). From this research, a number of motivations to travel have been identified such as the need for social interaction, rest and relaxation, challenge, escape from daily stresses, stimulation, education and learning, and to visit family and friends.

In addition to understanding why people choose to travel, it is important to know what factors may act as barriers and constraints to traveling. Some of the primary obstacles to travel are lack of time, poor health, disability, financial limitations, safety/security concerns, and a lack of information (Blazey, 1992; McGuire, Dottavio, & O'Leary, 1986). If the motivation to travel is strong enough, these barriers may be negotiated, yet these forces and the systems that drive them still have the potential to influence the means of travel as well as destination choices (Goeldner, Ritchie, & McIntosh, 2000).

3. Purpose
Considering the projected growth of the travel market for mature adults with and without disabilities, as well as the untapped market of family caregivers, the purpose of this study was to explore the impact of caregiving on the leisure travel behaviors of family caregivers and their care-recipients with disabilities. Specifically, this study sought to (a) explore the importance/significance of leisure travel for informal family caregivers and their care-recipients, (b) identify barriers and impediments preventing caregivers from pursuing leisure travel, and (c) offer suggestions for negotiating the barriers identified to caregivers and the travel industry.

4. Conceptual approach and method
The basis for this research study was an interpretative paradigm. Researchers (e.g., Bedini & Guinan, 1996; Henderson, 1991; Hood, 2003; Hutchinson, Loy, Kleiber, & Dattilo, 2003) have demonstrated the value of using interpretative paradigms to explore the relationships of leisure to describe the lives of under-represented populations. In-depth qualitative interviews were used to discover the meanings underlying the significance for leisure travel of caregivers. The guiding questions were designed to allow caregivers to talk about their lives and to provide the researchers with insights into the meanings of caregiving and its effects on leisure travel. Analytic induction allowed the conclusions and grounded theory to emerge from the data.

4.1. Subjects
Thirteen subjects were obtained using theoretical sampling method (Glaser & Strauss, 1967). Within qualitative approaches, theoretical sampling is a process of collecting a sample that will represent the concepts being studied (Denzin, 1978), and allows the researcher to “decide what data to collect next and where to find them in order for theory to emerge” (Henderson, 1991, p. 133). Initial respondents were solicited from churches, retirement homes, and local adult day centers in the Piedmont Triad area of North Carolina. These subjects recommended other individuals who met the delimiting criteria (adult, caring for adult family member in home without pay). Through this “snowball sampling” or “network” technique, identified subjects referred potential respondents to the researchers. Data collection was terminated at the point of saturation, whereby based on the procedures of theoretical sampling, no new information was generated from the sample and a broader picture of the meanings of leisure travel for caregivers was obtained. The focus of interpretive research is not to assume representation or to establish causality (Mason, 2002). Rather, it is to develop explanations and understanding of selected phenomena. Therefore, 13 subjects at saturation are acceptable.

4.2. Instrument
The data-gathering tool was an 11-item semi-structured interview guide designed by the researchers. The content of the questions was determined based on previous research and professional literature about travel and caregiver leisure. The instrument consisted of questions about the caregivers’ past and present leisure travel experiences (before and after caregiving began), their feelings about leisure travel, and suggestions they had to facilitate access to leisure travel for caregivers of older adults. Prompts for each question were prepared by the researchers to facilitate subjects’ responses if needed.
4.3 Procedures
Qualitative data collection and analysis methods were employed for this study. A trained interviewer conducted in-depth semi-structured face-to-face interviews to gather and analyze information about the specific questions identified above. Each interview, which ranged 30–40 min in length, was audio-taped and then transcribed verbatim into a written transcript. Data collection continued until saturation, or no new information or insights, were achieved.

4.4 Data analysis
Data were analyzed using constant comparison analysis (Glaser & Strauss, 1967) and analytic induction (Bruyn, 1966). Constant comparison involved reading and coding the data to reflect content related to leisure travel behavior of the respondents. Major themes about leisure travel of caregivers emerged and were recoded to reflect specific subthemes. Transcripts and notes were read and reread by the interviewer and two additional researchers to determine and confirm that categories fit the data and vice versa. Finally, analytic induction and professional literature were applied to help further interpret the emerging themes from the data.

Trustworthiness (Lincoln & Guba, 1985) (reliability/validity) was addressed in several ways. First, the interviews were read and analyzed by a trained interviewer, as well as the two primary researchers, to ensure objectivity and accuracy in interpreting the data. Additionally, using multiple readers allowed the re-searchers to develop reliability and dependability within the analyses. Second, all of the researchers kept notes from the interviews and of their weekly meetings during their data collection/analysis. Lastly, issues of objectivity and sensitivity were addressed by attempting to “increase our awareness and help us control intrusion of bias into the analysis while retaining sensitivity to what is being said in the data” (Strauss & Corbin, 1998, p. 43).

5. Results
A total of 13 caregivers were interviewed. The sample was 85% female and 83% European-American. Their education ranged from high school to a master’s degree. A third of the respondents were employed (n = 5), four were retired, and four were never employed. The majority (62%) were spousal caregivers while the remainder were children caring for their parents or parents-in-law. The length of time the respondent had been caregiving ranged 3–18 years with an average of 5 years. More than half of the subjects received no outside support (support groups, in-home care, or adult day care services) that allowed them respite (breaks) from caregiving. The care-recipients’ disabilities included cardiac problems, Alzheimer’s disease, Parkinson’s disease, arthritis, and mobility problems.

The primary focus of the interviews was to examine the significance of and impediments to pursuing or maintaining leisure travel for caregivers of older adults. Significance was explained by two emergent themes: patterns of leisure travel and issues of entitlement, resentment, and anger.

5.1 Changes in patterns and types of leisure travel
The majority of the respondents mentioned leisure travel as a substantial part of their personal leisure prior to becoming a caregiver. In fact, most of the caregivers stated that before taking on caregiving responsibilities they had maintained an active travel lifestyle, being “on the go pretty much”. Many noted that in the past they had traveled consistently throughout the year going on trips ranging from cruises and international travel to bus tours and day trips. One respondent noted that they (husband and wife who became caregivers) would “travel every year [to Europe, cruises]...It was truly wonderful”. Another respondent stated that they “traveled rather frequently, adventurously, and some-times on the spur of the moment”. The respondents indicated that since becoming caregivers their leisure now primarily consisted of activities in and near the home such as reading, walking, church activities, swimming, gardening, and spending time with family and friends. Few of the caregivers noted travel as a significant leisure activity in which they currently participated. One respondent caring for her mother with Alzheimer’s disease noted, “we like to travel ... now it is impossible”. When asked if her leisure travel had changed since becoming a caregiver, another woman stated, “oh, absolutely, I don’t get a chance to do it”.
Motivations to travel before becoming a caregiver ranged from pure personal leisure to traveling for education. One respondent who shares the caregiving responsibilities of her mother with her husband described their leisure travel before becoming a caregiver. She said they had, “wonderful vacation wherever we went, and we went...we traveled through Europe, we traveled, we took cruises, we just went wherever we wanted to go. We were free to go anywhere we wanted to go”. However, their travel since caregiving was limited to short day trips with the primary purpose to visit family. Another respondent caring for her husband with memory and mobility problems noted that since becoming a caregiver, “We have not been any place outside of our son’s in Roanoke and...we have only stayed overnight twice in four years. Most of the time we just do it in one day”.

Care-recipient travel was also a significant issue raised by the respondents. The majority of the respondents indicated that their care-recipients loved to travel before they became ill or disabled. One caregiver said that, prior to her husband’s disability, they “...would go on a lot of short trips with other friends that are retired...we went on cruises and went to visit relatives...we went of the senior citizen bus tours and ... stayed pretty much on the go”.

The relationship of the caregivers to their care-recipients seemed to be relevant to their perceptions of the changes to leisure travel. For spousal caregivers, this change seemed particularly important. For both the caregivers and their care-recipients, traveling together had been an important part of their life. Most of the spousal caregivers identified their spouse as being their travel “buddy” of choice. One caregiver said, “There are times when I wish I could just pile in the car and take off and go to some place I hadn’t been before...it makes a lot of difference if you can have your wife with you because when you are traveling alone, you can’t ... enjoy things as much as you can by having someone at your side”.

On the other hand, most of the caregivers who were children of care-recipients identified others (spouses, friends) as their preferred travel companions. As one daughter said, “Yes, I do take her [mother] sometimes, but then I just don’t want to go because I don’t have the freedom to do what I want to do when I’m on the trip ... I have friends that would travel and...my daughter would travel anywhere in the world”.

5.2. Old themes revisited: entitlement, resentment, and anger
Entitlement is how much an individual feels she or he deserves to have something in their life. Similar to previous studies (e.g., Bedini & Guinan, 1996), the respondents noted various levels of entitlement to their leisure. Some suggested that the loss of leisure travel was not a problem for them. A woman caring for her husband with Alzheimer’s disease stated, “[loss of leisure travel] doesn’t really bother me that much, I, ummm, enjoyed it when we did it, but I don’t desire it now”. Others indicated that they were disappointed but were coping with the loss of leisure travel. For example, a woman caring for her husband noted, “I miss it [travel], but, ah, better roll with the punches”.

Most of the respondents, however, identified resentment and anger with the changes and loss of leisure travel experienced as a result of caregiving responsibilities. For example, a woman caring for her mother with mobility problems stated:

... the fact that all of the sudden I’m tied to a person, or place, or a thing and I can’t come and go as I want. And I think, well, I’m free enough or young enough and healthy enough that I should have some freedom there. So, I’ll have to admit, I get real angry about it sometimes.

5.3. Impediments to travel
Analysis indicated that barriers to leisure travel for informal family caregivers fell into three distinct areas (physical, social, and emotional) within which minor themes emerged.

5.4. Physical obstacles
The primary physical obstacles to leisure travel included accessibility of facilities and services, time to prepare, mobility, and energy. Despite the changes mandated nationally by the ADA in 1990, accessibility of services
was still a barrier to travel for many of the caregivers. However, several noted that airlines, hotels, and cruise ships were both “good” and “bad” in providing accessible services. Although one caregiver noted, “the hotel rooms are very roomy”, most identified the aspects of lack of access in their experiences with accommodations. A caregiver whose mother has Alzheimer’s disease talked about a trip which she and her husband enjoyed but noted, “we’ve seen situations where the handicapped parking is right in front of the hotel ... handicapped access is around the side of the hotel at some distance and you see a ramp that comes right up to a revolving door”. Architectural barriers were more than the actual stairs and ramps, however. The same respondent spoke of the difficulty her mother would have accessing the rest room facilities on an airplane. She said,

...if we went on an airplane and had to take her to the bathroom ... I don’t even know how we could manage something like that. The airplane is just a little thing, the two of us would have to go into that little compartment and help her. It would just be impossible.

In particular, the time required to prepare for a trip or an outing was a problem for many caregivers and their care-recipients. They noted that some tours, e.g., did not allow for travelers who required more time to get ready. One woman noted that she and her husband with memory and mobility limitations used to go on bus tours with other seniors.

He [care-recipient] requires a lot of time in the morning to get up and get dressed ... most of the tours we have been on ... you have to be ready like at 8:00 in the morning for them, to go for breakfast or to get on the bus and what not. So that would leave us getting up probably at 3:00 or 4:00 in the morning.

She continued “...that’s another thing that’s held me back from trying to go on any kind of trip”.

Mobility limitations of the care-recipients were also identified often. For example, several respondents addressed walking slowly, “...he just doesn’t move quickly ... you know, he can’t hold up the bus”, or the strain of walking, “going upstairs, anything that puts a strain on a heart ... makes things difficult for her. So, that’s limited her ability to travel and enjoy some of the facilities that we go to”. Another concern discussed related to limitations in mobility with service provision. For example, one respondent caring for her husband with Parkinson’s disease mentioned the assignment of people with disabilities, particularly those with mobility difficulties, to upper floors of a hotel. She noted, “...they put them on the sixteenth or seventeenth floor, never stopping to think, if in the event of an emergency, elevators don’t run, they can’t get down”.

A last physical limitation identified was the loss of physical stamina and energy experienced by the care-recipients when they travel. A woman caring for her mother with Alzheimer’s and circulatory diseases stated, “As soon as we get out, she’s wiped out and she’s tired and she’s ready to go. She doesn’t have the energy to really get out and do anything”. Another woman who is a caregiver to both her parents who have multiple disabilities suggested that tour operators not plan, “...so much in a trip because I think they wear out very easily. Don’t have a lot of energy”.

5.5. Social obstacles
The social obstacles addressed by the respondents included importance (and in some cases lack thereof) of financial, family, and human service support. This sample was skewed in terms of economic status, therefore, we found little concern in regard to financial needs for most of these caregivers. The respondents did, however, discuss the importance of financial support. For example, several noted that their finances provided them opportunities. For example, one caregiver noted that money allowed them to “...hire responsible, reputable people to care for your charge if occasions came up for you to take a weekend or week away”, and that this ability made a big difference.

Lack of human support was a significant social barrier. For some, lack of support from family members posed a barrier to their leisure travel. For example, one respondent caring for her mother complained that her siblings “claim to have their own problems” and as a result will not take on any caregiving responsibilities for their
mother who has Alzheimer’s disease. The respondent stated, “I have siblings. It would be nice if they could come here and take care of her like we take care of her and allow us to travel”.

The most prominent theme that emerged within this area, however, dealt with the support of service providers. A significant limiting factor, somewhat related to accessibility, was the attitude and perceived skill level of the people within travel businesses when serving individuals with varying types of disabilities. According to research in the area of societal constraints for people with disabilities, negative attitudes of others is the most difficult barrier one can face (e.g., Devine & Dattilo, 2001; Oliver, 1989). A woman caring for her husband with Parkinson’s disease noted that society seems to look down on individuals with disabilities in public. She stated, “You always feel as though you are a second class citizen”. Another woman stated, “I would think that a little bit of human concern would be most appropriate”. One caregiver was concerned, in particular, because her care-recipient tended to make inappropriate remarks in public. She shared that when her care-recipient acted inappropriately in public, “…it’s not their [care-recipient] fault, they [service providers] don’t understand it”. She went on to suggest the providers should have “compassion for them [care-recipients]. I think someone doing it would have to be trained and understand…” She said that if she could wave a magic wand, she would make it so that she could travel with her husband and not fear being criticized, among other things.

Closely related to the negative attitudes of the service providers were the attitudes of other individuals on tours and in public places. A man caring for his mother-in-law with Alzheimer’s disease commented on how he wished others would offer his mother-in-law “the same compassion as if she had broken her leg. Some people are resentful about it”. Because of her limitations, he and his wife are not able to travel alone and must rely on short day trips with his mother-in-law. He finds this difficult, because it greatly restricts his and his wife’s leisure travel.

5.6. Emotional obstacles
The emotional obstacles identified by the respondents included fear of the unknown, loss of freedom, and loss of spontaneity. Minor themes arose within the area of fear of the unknown. Several respondents shared that they either avoided activities like group tours or participated with great trepidation because they never knew what their care-recipient might do (or might not do) nor how to deal with it if it happened. For example, one respondent whose husband had a stroke noted, “He was a very nice and kind person, but in this day and age you don’t walk up to little children and talk to them...or make inappropriate remarks that you can’t explain to anybody”. Another respondent noted that she took her husband who has cancer, heart, and mobility problems on a trip, “with my heart in my mouth, we made the trip...”.

Fear existed for caregivers regarding travel with their care-recipients, yet, fear was also often present when traveling without their care-recipient. Some respondents noted that even if they had the financial means to hire someone to care for their care-recipients, the burden of worry and fear of the unknown could keep them from traveling. One caregiver, when talking about traveling without his mother-in-law with Alzheimer’s disease, stated that “it was continually stressful ... it’s not like just going away and go on a vacation without any worries. It was a lot of worries”. The same respondent’s wife went on to say,

...even though we put my mother in an assisted living facility...it was constantly calling back and forth worrying if they would take good care of her and how she would feel, you know, the fact that I were leaving her. I make her understand it was not a permanent situation. So, we managed to have a good time; it was not a good vacation.

Another respondent with parents who have arthritis, heart, and emotional problems stated that, “I guess if you are doing leisure travel and you have elderly parents, no matter where you go, you still have the mental part, no matter where you are physically...”.

Leisure travel seemed to represent freedom and spontaneity, or traveling on the “spur of the moment” for many of the caregivers. With the responsibility of caring for a dependent loved one, however, several respondents
noted disappointment for the loss of spontaneity in their leisure pursuits. For example, a woman caring for her mother with Alzheimer’s disease shared that it is “...frustrating not to be able to do what I want to do when I want to do it...Up until I started taking care of her, whatever I wanted to do, I was able to do it. And now, everything that I do is based on her care”. Thus, when assuming caregiver responsibilities, many of the respondents felt that restriction of their leisure travel symbolized loss of freedom, as well as spontaneity. As a respondent who was caring for her mother with mobility problems stated,

...after a while when you’re a caregiver like I am ... it’s like I don’t want to go because I just don’t want to get her ready and take her everywhere I go ... Yes, I do take her sometimes, but then there are times I just don’t want to go because I don’t have the freedom to do what I want to do when I’m on a trip. I have to do what she’s capable of doing.

6. Conclusions
Several conclusions became evident from these results. First, leisure travel not only had been important to these respondents, but they also expressed a particular sense of loss for leisure travel after beginning caregiving. While many still traveled, their motivation changed from leisure to more functional purposes. Similarly, many of the spousal caregivers missed their spouse or “travel buddy” and thus were less enthusiastic about traveling without him or her. Finally, the respondents identified three areas of impediments to their leisure travel (physical, social, and emotional).

Their concerns in the three areas of barriers included new, and traditional concerns. Their physical barriers were not only architectural; they also dealt with pace of tours and trips. In addition to family issues, their social barriers included service providers in the tourism industry. Emotionally, many experienced fear of the unknown, not only when traveling with their care-recipients, but more often when traveling without their care-recipients.

More importantly, however, it seemed that the three areas of barriers were potentially hierarchical. Many of the respondents indicated that with the exception of finances, if they were able to negotiate the physical barriers to leisure travel, they might then be blocked by social barriers. Likewise, if they were able to negotiate physical and social barriers, the emotional barriers might prevent their leisure travel. For example, if not impeded by any physical or social obstacles, a caregiver might still feel uneasy about leaving his/her care-recipient to travel. More so, even if the caregiver actually traveled without the care-recipient, the emotional worry and concern for consequences upon return from their trip clearly negated the “leisure” in leisure travel.

7. Recommendations
Several recommendations exist for this study. For practitioners, the results suggest three areas of focus. First, physical accessibility should be re-examined, not only in terms of legal regulation, but more so in terms of actual functional access. According to Darcy and Daruwalla (1999), accessibility constraints can be categorized as the lack of (a) access to physical infrastructure needs, (b) accessible accommodations, (c) access at a destination to its attractions, and (d) availability of accurate information pertaining to accessibility. The caregivers in this study expressed frustration due to many of these types of constraints. Attempts have been made to remove many of these constraints; however, in many cases these efforts fell short of providing actual functional access. For example, many airports have revamped their walkways to accommodate individuals who use wheelchairs, yet check-in counters have not been modified and remain too high for such people to use.

Second, sensitivity training is needed to address the issues of attitudes (and ignorance) of some service providers in the various facets of the tourism and hospitality industries. Respondents noted that although they had good experiences with the sensitivity and knowledge level of some of the service providers with whom they interacted, they often encountered professionals who had little knowledge of, or sensitivity to the needs of older adults who had mobility, cognitive, or social limitations. Training programs that teach service providers how to anticipate, and meet the needs of people with disabilities would aid in providing more satisfying travel
experiences. A disability etiquette training program developed by American Airlines for all its airport customer contact staff is an example of such training.

Finally, tourism and hospitality professionals need to develop methods to decrease the worries and increase the quality of the travel experiences for caregivers. The results of this study suggested that the emotional barriers, particularly the worry of unknown events, caused significant stress for the caregivers and in some cases, curtailed their travel plans or aspirations. One example of how the industry can assist in this area is Marriott Corporation’s provision of respite opportunities for caregivers. If a caregiver is going on vacation, his/her care-recipient can receive short-term respite care at one of Marriott’s assisted-living and special needs facilities. Caregivers can be assured that their care-recipients will receive medical supervision and assistance with daily living needs by a trained staff, as well as socialization with other guests and residents of the property.

For researchers, future studies should include larger and more diverse samples, specifically with regard to financial means, disability type of the care-recipient, and cultural background. Additionally, researchers should explore the impact of worry on the travel decisions made by caregivers. Further study should also address the differences between caregivers who are spouses versus those who are caring for parents and the ways caregiving influences each of these groups’ travel behavior. Lastly, additional research is needed to determine how the tourism and hospitality industries can better serve the leisure travel needs of caregivers and their care-recipients.

References


